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Disability, Care, Postsocialism

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ФОНД
НАУЧНИ
ИЗСЛЕДВАНИЯ
МИНИСТЕРСТВО НА ОБРАЗОВАНИЕТО И НАУКАТА

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PREFACE

A preface to an issue titled *Disability, Care, Postsocialism* certainly runs the risk of falling into the sentimental register of absence, into the ambitious heroizing mode of catching up, or the metaphor of the slow but inevitable awakening that has acquired special charm in recent years – in general, it risks being seen as a natural, if not rather boring and familiar when it comes to the situation in Bulgaria, academic ethos.

In this particular case, though – when the focus is on living with disability – the stakes truly transcend any limited way in which they may be formulated. The cultivated – historically, affectively, materially – inability to address this subject in the Bulgarian context should indeed provoke debate and concern.

Internationally, the field to which the collective effort resulting in this issue belongs – namely disability studies and the directly related areas of care research, research on living with serious, chronic, or terminal illness, and ageing studies – has been developing, deepening, and becoming increasingly sophisticated for about half a century now. Conceptually, there are now several distinct waves within disability studies, there are conflicting paradigms as well as approaches based on different premises that constantly generate interesting debates and theoretical innovations. Institutionally, leading (and not only) universities have long had such courses, the subject of living with disability is also part of the curricula of medical specialties, and in addition to long-established academic journals in this field, new ones are emerging that attempt to reflect on living with disability beyond the so-called Global North. At the same time, narrative activism, if we can call it that – i.e., the tradition of activists, people with disabilities, people with mental health conditions, loved ones and carers sharing first-person stories in order to break up the total medical jurisdiction over their lived and embodied experience – is also a burgeoning genre that has indeed managed to contribute to a radical reconfiguration of identities, images, and attitudes. All this has naturally given an impetus to relevant legislative changes and led to the adoption of key international documents. The Bulgarian situation, however, continues to live its own parallel life, now and then appearing to officially 'align' itself to the new paradigms in this sphere by ratifying some of the documents in question. Bulgarians apparently still prefer denial – like the Soviet representative who was asked by a Western journalist during the 1980 Olympic games in Moscow whether the Soviet Union would participate in the Paralympic games and promptly replied: 'There are no invalids in the USSR!'[1] The Bulgarian collective imagination and epistemic resources, the material and affective environment which represent and integrate people living with disability in an adequate, inclusive, respectful way, have traditionally been scarce. And what is even more amazing is that this is so in the socio-political context of a country with a miserable healthcare system, missing social services – in terms of number, quality, and accessibility – an ageing population, deep inequalities, and daily encounters with poverty. In a country where the environment is inaccessible for people with mobility impairments, which prevents them from exercising basic rights, and where it was not until 2021 that Bulgarian Sign Language was recognized as a language in its own right (for comparison, the US has had a bilingual university with academic titles in American Sign Language for decades now).

It seems to us that these scientific tasks, which have been long since resolved or at least tabled for discussion in other countries, are yet to be addressed in Bulgaria. And it is not just a question of catching up from a provincial position or of conforming to scientific fashions, but of recognizing and promising attention to and analysis of the identities, practices, and experiences of individuals and groups that not only have real social and cultural significance, but ultimately indicate a common life place in which each one of us is quite likely to find ourselves sooner or later in our lives.

This issue – like every endeavour that from its very inception has been marked both by the guilt of being late and of the enthusiasm generated by the idea of ‘catching up’ – attempts to do many things at once, which always carries risks. It attempts to catch up at once in conceptual analysis, in reflection on specific policies, in a historical effort to offer an answer to the constantly renewed question, ‘Why are we like this?’, in the encouragement and inclusion of personal narratives. The historical section with interviews and the overall historical focus of the issue are reminders of the lost but, we believe, not irretrievable memory of attitudes, behaviours, and approaches towards bodily and social vulnerability.

We hope we have provided a space where the voices and perspectives of researchers and researched, of carers and care recipients, of experts and laypersons from different generations and with different social and academic experiences can meet. This issue has brought together the voices of oral historians, sociologists, bioethicists, biolaw specialists, and of the ‘traditional experts’ – social medicine professionals – to attack, at least a little, the segregation and silencing of disability, the stranglehold of the medical model, and the strict professionalization of social work in Bulgaria.

There are undoubtedly countless things that we have failed to do and which are expecting to be given a platform. It remains to be seen whether this will happen. But as the protagonist grimly notes at the end of Georgi Rupchev’s poem ‘Plastic Figure Factory’ (to our knowledge, the only[2] *honest* depiction of living with disability under socialism in Bulgarian literature): ‘Tomorrow is another day!’

Ina Dimitrova and Galina Goncharova

NOTES

[1] V. A. Fefelov, *V SSSR invalidov net!* [There are no invalids in the USSR] (London: Overseas Publications Interchange Ltd, 1989), cited in S. D. Phillips (2009) "There are no invalids in the USSR!": A Missing Soviet Chapter in the New Disability History, *Disability Studies Quarterly*, 29 (3), available at: https://dsq-sds.org/article/view/936/1111#endnote01 (accessed 31 July 2021). We leave the connection to the other even more famous phrase – 'There is no sex in the USSR!' – to the curious reader.

[2] 'Fabrika za plastmasovi chovecheta' in Bulgarian. The other is Mitko Gorchivkin's novel *Volya* (Will-power), but its approach and message are completely different and far more traditional than Rupchev's poem, which allows us to consider together the images of vocational rehabilitation as the leading form of social 'inclusion' of disabled people under socialism and the abundantly promised but completely blocked and stalling socialist future.

Teodor Mladenov

THE SOCIAL MODEL OF DISABILITY, THE INDEPENDENT LIVING, AND THE IDEA OF ‘CARE’

Introduction

Contemporary disability policies gravitate increasingly around two concepts – social model of disability and independent living, but the idea of ‘care’ continues to exercise influence, especially at the level of everyday practices, as well as in the approaches influenced by the ‘ethics of care’. For the last several decades, it is precisely the approaches of the social model and independent living that have transformed the political thinking and speaking about disability on national and international levels. Today, they are key both in Bulgaria and in the United Kingdom. They also play a central role in the UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by most countries in the world.

The social model and the independent living are concepts that have emerged and have been asserted as a result of disabled people’s activism and they are characterized by a strong mutual affinity. These ideas have motivated and guided the global movement of disabled people for equal rights and social inclusion, whose rise began at the end of the 1960s and which is still active at present. With the entry into force of the CRPD in 2008, the social model and the independent living found expression in the international legislation as well. They are often counterposed to the idea of ‘care’, which is associated with the traditional approach to disability whose characteristic features are paternalism and medicalization (see, for example, Hughes et al., 2005; Watson et al., 2004). In fact, the CRPD can be understood precisely as an attempt to substitute the paradigm of care with the paradigm of rights – the Convention is presented on the thematic webpage of the UN as:

> tak[ing] to a new height the movement from viewing persons with disabilities as ‘objects’ of charity, medical treatment and social protection towards viewing persons with disabilities as ‘subjects’ with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. (https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)

In this article, I will explore the meanings of the social model, the independent living and the idea of 'care', the significance of these concepts for contemporary disability policies, as well as the relationships between them. I will make recourse to the CRPD as a document that expresses the increasing global consensus regarding disability policies. The analysis of the way in which the social model and the independent living are reflected in the CRPD will help illuminate the role of these concepts in contemporary disability policies on the international level. I will also use the perspectives of the social model, independent living and care to explore the situation in Bulgaria that ratified the CRPD in 2012. This article is grounded in two decades of advocacy and analytical activity that have supported the change of disability policies on national and international levels towards affirming the social model and the independent living. This activity started in 2000, when I got involved for the first time in the work of the Center for Independent Living – Sofia.

The Social Model of Disability

The social model of disability is often regarded as the 'big idea' (Hasler, 1993, p. 280) of the disabled people's movement. One of the formulations that has founded the social model has been provided as early as in the middle of the 1970s by the members of the Union of the Physically Impaired against Segregation (UPIAS), a British organization of disabled people advocating for a radical change in the then dominant understandings and practices concerning disability:

> we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (UPIAS and the Disability Alliance, 1976, p. 14)

This definition has been amongst the most discussed, criticized and revised statements in the field of disability studies. It makes a sharp distinction between 'impairment' and 'disability' that has later been used to formulate the social model of disability in its influential British version (Oliver, 1996). In both formulations, the term 'impairment' refers to bodily differences and later its scope has been expanded to include mental and behavioural differences (see, for example, Beresford, 2005; Beresford et al., 2010). On its behalf, the term 'disability' denotes the restrictions imposed by society on people who have 'impairments'. From the perspective of the social model the problems faced by disabled people are not *caused* by their physical, mental or behavioural differences but by the way society is organized (Mladenov, 2010). This also means that the social model does not deny the value of medical intervention and medical 'care' but presupposes that medical procedures and technologies can only treat the 'impairments', whereas the treatment of *disability* requires other means and approaches.

The social model has exercised an immense impact on contemporary policies in the area of disability, whose most important expression is currently the UN Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is an international, legally binding instrument in the area of human rights that entered into force in 2008, reflecting nearly four decades of struggle of disabled people and their organizations for equality and social inclusion (Moriarity and Dew, 2011, p. 686). The States Parties that have ratified the document are required to amend their legislation in accordance with the provisions of the CRPD and to start to apply relevant policies. The CRPD has been ratified by most countries in the world, including by Bulgaria that ratified the Convention on 26 January 2012.

The CRPD states in its Preamble that 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'.[1] In this formulation, the CRPD accepts the distinction between 'impairment' and 'disability' asserted by the social model, but it also modifies this distinction by stating that the restrictions faced by disabled people result from the interaction between the 'impairment' and the barriers in the environment, rather than being directly caused by the barriers, as is the case in UPIAS's (1976) more radical formulation. However, the CRPD clearly focuses on the socially constructed barriers rather than on individual 'impairments'.

The other place in the document where the meaning of the term 'disability' is directly discussed, this time with reference to defining the term 'persons with disabilities', is Article 1: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'[2] Here the CRPD reproduces one more time the distinction between 'impairment' and 'disability' asserted by the social model of disability.

The Independent Living

The idea of the 'independent living' of disabled people emerged and developed in parallel with the social model of disability. Its roots are in the activism of the disabled Americans who founded the first Center for Independent Living in 1972 in Berkeley, California. In the 1980s, the idea was brought to Europe and the independent living philosophy grounded the development of the personal assistance and direct payments schemes in Sweden and the United Kingdom, and later in other European countries as well (Evans, 2002; Ratzka, 1993). In Bulgaria, the advocacy for independent living commenced with the founding of the Center for Independent Living – Sofia in 1995 by a group of disabled Bulgarians, on the initiative of Kapka Panayotova, who leads the organization to this day (https://cil.bg/en/about-us-en/).

At first sight, the idea of the 'independent living' of disabled people may seem strange and even counterintuitive, because the individual impairment often leads to dependence on additional support in the form of personal assistance, assistive devices, financial support, medical care, and so forth. Moreover, social scientists, especially the proponents of feminism, have asserted for decades that everyone, and not only disabled people, is interdependent, because everyone needs care, support, technologies, medical interventions, etc. (Watson et al., 2004). For example, Lennard Davis (2002, p. 31), one of the leading American disability studies scholars, has argued that: 'Impairment is the rule, and normalcy is the fantasy. Dependence is the reality, and independence grandiose thinking.' With this dramatic formulation, Davis (ibid., p. 30) wants to emphasize the universal nature of human interdependence:

> As the quadriplegic is incomplete without the motorized wheelchair and the controls manipulated by the mouth or tongue, so the citizen is incomplete without information technology, protective legislation, and globalized forms of security ordering and peace.

However, the independent living movement understands the idea of 'independence' differently than Davis. When Davis argues that 'independence [is] grandiose thinking', he uses the term 'independence' in the conventional way, to mean ability to cope alone, without external support, to be self-sufficient. However, from the perspective of the independent living movement, to be 'independent' does not mean to cope without support or to be self-sufficient but to have access to support that is organized in such a way so that the person who uses it has choice and control in his or her everyday life. On the homepage of the website of the Swedish Independent Living Institute – a leading research centre on independent living in Europe – we read the following definition:

> Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. (https://www.independentliving.org/indexen.html)

In other words, from the perspective of the independent living philosophy and movement, disabled people are independent when their interdependence is organized or socially constructed in such a way so that their opportunities to have choice and control in their everyday lives are equalized with the opportunities of non-disabled people. The idea of 'independent living' does not negate but accepts, presupposes and builds upon the idea of 'interdependence'. For example, if I can choose when to have breakfast and what to have for breakfast, I am independent in the sense intended by the independent living movement even if I need someone or something – a personal assistant or an assistive device – to help me with feeding. However, if my support is organized in such a way so that someone else – say, a home carer or a service provider – determines when to have breakfast or what to have for breakfast, then my independence is hindered by a social barrier. It is clear that to be able to choose my breakfast, I need to have something to eat in the first place, but often the very access to basic goods such as food, shelter and clothes depends on the opportunities to live independently. In turn, it is precisely the barriers to independent living that increase poverty and marginalization, depriving disabled people of basic goods.

The focus on the barriers to independent living suggests that the idea of independent living is directly linked to the social model of disability. Recall that the social model directs the attention towards the socially constructed barriers faced by disabled people and away from their individual 'impairments'. In the same way, the advocates of independent living explain the difficulty with living independently with the socially created and maintained barriers in the environment rather than with disabled people's individual 'impairments'. Therefore, 'the philosophy of the social model of disability underpins the aims of the independent living movement' (Jolly, 2009, p. 3).

There is influence in the opposite direction as well. The idea of independent living enriches the social model by emphasizing that it is not enough to remove the barriers to participation of disabled people in social life. What is also needed is to organize this participation in such a way so that disabled people have opportunities to exercise choice and control – in other words, social justice requires to combine structural-collectivist with liberal-individualist strategies in disability policy (Mladenov, 2012, p. 257). The impact of independent living on social model theorizing is highlighted by the British scholar Colin Barnes (2007, p. 349), who argues that '[d]isabled people's self-organization and the thinking behind the concept of independent living provided Mike Oliver (1981) with the inspiration for the development of the *social model of disability*'.

Independent living is also key for the CRPD, whose Preamble recognizes 'the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices'. Moreover, in its Article 19 titled 'Living independently and being included in the community', the CRPD affirms independent living as a universal human right and obliges its States Parties to take positive measures to ensure that it is exercised:

> States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment

> by persons with disabilities of this right and their full inclusion and participation in the community...

The meaning of Article 19 is further clarified in the General Comment No. 5 of the Committee on the Rights of Persons with Disabilities (2017, p. 1) that states:

> Independent living and inclusive life in the community are ideas that historically stemmed from persons with disabilities asserting control over the way they want to live by creating empowering forms of support such as personal assistance and requesting that community facilities be in line with universal design principles.

The Idea of 'Care'

Disability studies scholars and disability rights activists often consider the idea of 'care' as being in opposition to the social model and independent living. For disability activists – and particularly for the supporters of the independent living – the notion of 'care' summarizes the traditional approach to disability, in which disabled people are expected to play a passive role, submitting to the will of those who provide them with 'care' – relatives, medical doctors, service providers, charities. 'For many disabled people the concept "care" is both patronising and oppressive', state Oliver and Barnes (2012, p. 66). The reason for this is to be found in the historically established associations of this concept with the everyday ableism and the practices of charity, medicalization and paternalism in disability policy that oppress the object of care and empower and heroize its subject:

> This representation, and the language that sustains it, has the effect of promoting patronizing attitudes towards the recipients of care. They become 'takers' and 'burdens'; men, women and children who live their lives vicariously and at the expense of others. For every self-sacrificing martyr, there is a parasite benefiting from the charitable nature of a heroic carer. (Watson et al., 2004, pp. 335-336)

The Bulgarian language adds to these connotations the primary meaning of 'care' [*грижа*] in Bulgarian: 'Excitement of the soul, uneasiness [*притеснение*] associated with the thought of something; anxiety, worry [*безпокойство, тревога*]' (Institute for Bulgarian Language, https://ibl.bas.bg/rbe/lang/bg/грижа/). Care as uneasiness, anxiety and worry strengthens the meaning of care as encumbrance, burden and self-denial, and the perception of disability as a personal tragedy (Oliver, 1996, p. 32) instead of social oppression reinforces the disparagement of the disabled people subjected to 'care'. Assuming in advance that it is possible to use the word 'care' differently, I will identify this traditional understanding with the term 'paternalist care' – care in which the interests and desires of the care giver dominate, while the care receiver is deprived of opportunities for choice and control.

As a reaction, instead of talking about ‘care’, many disability activists and disability studies scholars prefer to talk about ‘assistance’ – a term that presupposes horizontal relationships between equal partners and negotiations based on informed consent. The concept of ‘personal assistance’ has been an important part of this terminological and conceptual shift.[3] Personal assistance is a key prerequisite for the independent living of disabled people (Ratzka, 2004). The European Network on Independent Living defines personal assistance in terms of relationships between employer and employee, which is in sharp contrast to the relationships between care giver and care receiver:

> Personal Assistance is a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance. (ENIL, n.d.: n.p.)

However, together with its patronizing, paternalist and ableist connotations, the idea of ‘care’ has also made a positive contribution to the social-political understanding of disability issues. The critical and analytical potential of the concept has been emphasized by the ‘ethics of care’ that has been developed and promoted by feminist philosophers such as Joan Tronto (1993) and Eva Kittay (1999; 2018). The ethics of care opposes (neo)liberal individualism, marketization and the work ethic, asserting the universal nature of the relations of interdependence, as well as their intrinsic worth (Barnes et al., 2015; Williams, 2002). In this form, the idea of ‘care’ could be useful to the disability rights activists, including the supporters of independent living. As already discussed, the independent living movement does not reject the idea of ‘interdependence’ but builds on it. The critique of self-sufficiency, presupposed by the independent living philosophy, is in concert with the analyses that emphasize the ethics of care (Mladenov, 2016).

From such a perspective, it is hardly surprising that the ethics of care has been subjected to interest and qualified support amongst the ‘second wave’ disability studies scholars such as Tom Shakespeare, Nick Watson and Bill Hughes (e.g., Hughes et al., 2005; Shakespeare, 2006; Watson et al., 2004). They complement the perspective of the 'care giver' with the perspective of the 'care receiver' and emphasize their common interests in the struggle against oppression:

> the parties involved in the caring relationship are perpetually invalidated because the value of care is measured against the autonomous adult male who neither requires nor delivers care. To be a carer or cared for – male or female, disabled or non-disabled in either role – is to be found wanting, to be other in relation to the masculine subject of modernity, to be reduced to 'the other of the same'. Those who give and receive care are marginalized, 'used and wasted' bodies, existing, by and large, on the margins of what counts as the truly human community. (Hughes et al., 2005, p. 265)

I will use the term 'egalitarian care' to distinguish this alternative understanding of 'care', based on the ethics of care, from the traditional approach of 'paternalist care'.[4] The perspective of egalitarian care helps highlight the emotional and relational aspects of personal assistance that remain in the periphery of the independent living advocacy because of its emphasis on rational bargaining and informed consent. Tom Shakespeare and his colleagues (Shakespeare et al., 2017) state that the relationships between disabled people and their personal assistants often resemble relationships between friends. Moreover, the concept of egalitarian care balances the focus on the rights of the assistance user – a distinctive feature of the independent living advocacy – with recognizing and taking into account the rights and the position of the assistant. Personal assistance requires flexibility in the relations between the service user and the assistant that is achieved through on-demand employment, hourly pay, part-time work and other elements of flexible employment. This feature could lead to suspicions that personal assistance amounts to yet another encroachment on the interests of workers under the conditions of neoliberal capitalism. A main concern of the ethics of care is to protect care givers (the greatest majority of whom are women) from the arbitrariness and violence of the free market (Barnes et al., 2015).

However, the reduction of personal assistance to a form of neoliberal exploitation is misleading and reactionary. It disregards decades of collective struggle of disabled people for equality, belittles the fragile achievements of this activism (the international independent living movement, centres for independent living, personal assistance schemes, deinstitutionalization, disability studies, CRPD) and normalizes everyday ableism, paternalism, medicalization and segregation that continue to oppress disabled people around the world and, in particular, in Bulgaria. The users of personal assistance themselves consider the good working conditions of their assistants as an important prerequisite for independent living (Mladenov, 2019a, p. 11). The models of personal assistance promoted by the independent living advocates emphasize that funding for personal assistance needs to allow payment of 'competitive wages', to cover 'all indirect labour costs' (including compensation for unsocial hours and over-time, social insurance and leave) and to maintain a 'safe and healthy working environment' (Ratzka, 2004, pp. 6-7). On their behalf, the assistants indicate higher levels of job satisfaction than the staff employed in traditional forms of 'care' such as home care, even when the working conditions of the assistants are nominally worse than the conditions of the home carers (Leece, 2006; Woolham et al., 2019). Last but not least, although they presuppose market mechanisms and formal bargaining, the relations between service users and the assistants include emotional, relational and informal aspects that articulate with the ethics of care and the concept of egalitarian care.

The Bulgarian Disability Policies

The analysis of contemporary disability policies in Bulgaria from the perspective of the social model and independent living reveals a number of barriers to disabled Bulgarians' independent living. We can use Article 19 of the CRPD as a guide. Point (a) of Article 19, which requires that disabled people are provided with 'the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement', concerns the barrier of institutionalization. Point (b), which requires 'access to a range of in-home, residential and other community support services, including personal assistance', concerns the barrier that arises when there is no (variety of) specialized support services, among which personal assistance gets explicitly mentioned. Finally, point (c) requires that disabled people have equal access to '[c]ommunity services and facilities for the general population' that are 'responsive to their need' and concerns the barrier that emerges when there is no universal access to mainstream services in areas such as education, healthcare and childcare.

When we compare the Bulgarian reality with the provisions of Article 19 of the CRPD, we can easily identify the main barriers to the independent living of disabled Bulgarians. Point (a) of Article 19 helps highlight the continuing placement of disabled Bulgarians in residential institutions for social care, without opportunities to choose where and with whom to live. Similar to a number of other former state socialist countries in Eastern Europe (Mladenov and Petri, 2020), the process of 'deinstitutionalization' in Bulgaria, financially supported by the European Structural and Investment Funds, has been effectively reduced to moving disabled people from large to small institutions such as 'small group homes' and 'centres for family-type accommodation' (CIL, 2012).

Although the living conditions in these newly created over the last decade residential settings for social care are usually materially better than the conditions in the large institutions, the practices and relationships between the residents and the staff members remain the same – disabled people are treated as patients and as a homogeneous group, their everyday lives get subjected to constant surveillance, their opportunities to choose are determined by the preferences and schedules of the staff, their personal spaces get systematically violated, and their participation in the lives of the local communities remains minimal or symbolic. In other words, the approach of 'paternalist care' continues to dominate in the small institutions. The researchers Nadezhda Deneva and Rumen Petrov (2016, pp. 7-8) describe succinctly the process of deinstitutionalization in Bulgaria thus:

> The large institution in the small village turns into a small institution in the big town; the space of the large institution (bedrooms, kitchen, dining room, living rooms) turns into the same rooms but within two separate buildings – the bedrooms, kitchen and dining room, into the CFTA [centre for family-type accommodation], the living room and another dining room – into the day-care centre [DC]. The users are 'socially included' by being moved in the morning from the CFTA into the DC, and back in the evening – that is, if there are transport and attendants available. The result – more funding and more jobs are provided, but the effect on the clients is limited to materially improved facilities.

Point (b) of Article 19 of the CRPD directs the analysis of the Bulgarian disability policies towards the lack of adequate specialized services in the community, and particularly towards the lack of adequate personal assistance. In 2018, as a result of a long and courageous advocacy campaign of parents of disabled children, Bulgaria adopted a new Personal Assistance Act (PAA), which entered into force on 1 January 2019. One of the aims of this legislation is to provide disabled people with opportunities for 'independent living' (Article 2), with the term being defined in the Additional Provisions of the act as 'the opportunity for a person with disability to make autonomous decisions about their life and to implement them, receiving the necessary support'. The mechanism for the provision of personal assistance, specified in the PAA, is meant to ensure that the users have the opportunity 'to choose who, when, where and how will implement the [support] activities' (Article 3).

Notwithstanding these declarations, the personal assistance provided under the PAA severely restricts the choice and control of the user. The needs assessment remains tied to the medical expert assessment of the ability to work [in Bulgarian: *медицинската експертиза на работоспособността*] that is strictly focused on the individual 'impairment' and does not identify the real needs of the disabled people. The grouping of candidates by degree of 'dependence' has a homogenizing effect, reproducing the main problem with the outcome of the medical expert assessment – the neglect of individual needs. At the writing of this article, the maximum number of assistance hours is limited to 168 hours per month or 8 hours per day, excluding the weekends. People who need more support are forced to use additional services which are often not available, especially in small towns and villages. The requirement to waive the monthly allowances for raising a disabled child and the allowance for attendant services deprives the people who use personal assistance under the PAA of funds to purchase additional support. The employment contract that is concluded with the assistant protects (at least nominally) the assistant's rights but limits the possibilities for flexible support arrangements. The pay, that in 2020 amounts to 1.2 of the minimum wage, is not sufficient to attract appropriate candidates for assistants. As a result of all this, as well as the continuing domination of the traditional attitudes towards disability in Bulgaria, in nearly all cases it is family members who are hired as assistants, which effectively reduces personal assistance under the PAA to a cash benefit for the care giver, contrary to the aims of the act. The approach of paternalist care continues to underpin this form of support as well.

Finally, point (c) of Article 19 of the CRPD helps highlight the lack of equal access to mainstream services in the community, conditioned by inaccessible environments and outdated practices and attitudes. A prominent example is Bulgarian education. The new Preschool and School Education Act (in force since 1 August 2016) provides a good basis for the development of inclusive kindergartens and schools, but in practice disabled children in Bulgaria still face widespread barriers to inclusion such as large classes, ableist expectations, focus on academic achievements, and inaccessibility of the built environment (Mladenov, 2019b). Many Bulgarian educators still hold the opinion that some disabled children are not suitable for mainstream schooling and even that there are children who are 'ineducable'. This attitude is reinforced by the inaccessible mainstream environments, the lack of public funds for modern assistive technologies and adequate personal assistance, and the adherence to outdated methods of education, teaching and assessment in kindergartens and schools (ibid.). As in the cases of deinstitutionalization and personal assistance, here too the Bulgarian disability policies are still dominated by the approach of paternalist care.

Speaking more generally, the change of the Bulgarian legislation and practices in line with the principles of the CRPD is still in its infancy. Although Bulgaria's new Persons with Disabilities Act (in force since 1 January 2019) includes many elements of the CRPD, it does this superficially and essentially retains the status quo of the medical expert assessment and, accordingly, the domination of the medical model of disability and the approach of paternalist care in Bulgarian social policy. This becomes clear when reading closely the definition of disability included in the new act. At first sight, the Persons with Disabilities Act (PDA) adopts unreservedly the definition contained in Article 1 of the CRPD by defining 'people with disabilities' as 'persons with physical, mental, intellectual and sensory impairments [*недостатъчност*] which in interaction with their environment could hinder their full and effective participation in public life' (PDA, Additional Provisions, §1). However, this progressive move gets immediately negated in the next provision that makes the meaning of the term 'people with *permanent* disabilities' totally dependent on the decision of the medical expert assessment:

> 2. 'People with permanent disabilities' [*Хора с трайни увреждания*] are persons with permanent physical, mental, intellectual and sensory impairments [*недостатъчност*] which in interaction with their environment could hinder their full and effective participation in public life, and for whom the medical expert assessment has established a type and degree of disability or degree of permanently reduced ability to work of 50 and over 50 percent. (PDA, Additional Provisions, §1)

It must be emphasized that it is the term 'people with *permanent* disabilities' rather than 'people with disabilities' that determines the access to basic rights and benefits for disabled people in Bulgaria. Considering this, the definition of the term 'people with disabilities' provided in Bulgaria's new Persons with Disabilities Act functions as a superficial ornament, a hollow decoration that does not make any difference to the actual practices of providing support.

Conclusion

The analysis of the contemporary Bulgarian legislation and practices indicates that the Bulgarian disability policies are still dominated by the approach of paternalist care. As an alternative, the present work formulated the idea of egalitarian care, grounding it in the studies of the ethics of care and the analyses of some of the most influential figures among the 'second wave' disability studies scholars. The idea of egalitarian care is conceptually attractive because of its potential to acknowledge both perspectives – of the supported person and of the person providing support, emphasizing the universality of the relations of interdependence. As discussed, the social model of disability and the independent living philosophy advocate egalitarianism and recognize the phenomenon of human interdependence as foundational for the human being.

However, the notion of egalitarian care presupposes the existence of practices in which the domination of the 'care giver' has *already been problematized* – conceptually, politically, socially. The 'second wave' in disability studies has emerged towards the middle of the 1990s precisely as a reaction to a decade-long debate happening within a discipline that had already gained institutional recognition. This debate, in turn, concerned reforms kick-started by disability activists in the late 1960s that had led to effective deinstitutionalization, introduction of direct payments, real personal assistance, and the gradual universalization of the access to public services in countries such as the United Kingdom and Sweden. The international consensus on the direction and meaning of these reforms has been reflected in the CRPD, which entered into force in 2008.

Bulgaria ratified the CRPD in 2012 but the translation of its principles into effective and sustainable practices still fails in making a real difference to the lives of disabled people in the country. In Bulgaria, disability continues to be heavily medicalized – the medical expert assessment that embodies the approach of paternalist care in its pure form still dominates the identification of the needs of disabled Bulgarians. Bulgarian deinstitutionalization has been reduced to moving disabled children and adults from large to small institutions – a process that leaves the practices and attitudes of paternalist care unscathed. The great majority of disabled Bulgarians who use personal assistance are forced to rely on their relatives for providing this type of support, which reinforces the attitudes, roles, habits and rituals of paternalism in both parties. Bulgarian educators still perceive disabled children overwhelmingly though the lens of their individual 'defects' that have to be 'corrected' by specially trained experts, following the individual-paternalist approach to disability. All these issues have also been highlighted in the alternative report submitted to the Committee on the Rights of Persons with Disabilities by a group of Bulgarian human rights organizations in 2018 (Alliance for Protection against Gender Based Violence et al., 2018).

The approach of paternalist care underpins the attitudes towards disability on the everyday level as well. My apartment in Sofia is served by an elevator in which a few years ago the elevator technician hung a new sign reading: 'The use of the elevator by unaccompanied children under 7 years of age and disabled people is prohibited'. In my view, the Bulgarian society, Bulgarian politicians and many Bulgarian disability organizations still understand disability issues in this over-protective and patronizing way that drastically diminishes the choices, rights and dignity of disabled people. In such a context, the substitution of the term 'care' with more neutral terms such as 'support', whose resonance with the principles of the social model and independent living is more direct and unequivocal, seems to me politically necessary and conceptually justified.

The present task of the disability rights activists in Bulgaria is to translate the ideas of the social model of disability and independent living, incorporated in the CRPD, into effective policies and practices. The attitudes, habits, roles and rituals of paternalist care are a main barrier to the realization of this vision. The Bulgarian analysts of disability who reproduce and assert the concept of 'care' and the ethics of care in their studies, while also supporting the efforts of the activists, could acknowledge these issues by developing a critical attitude towards the paternalist forms of care. On its behalf, the idea of 'egalitarian care' can be something more than a contradiction in terms only if it helps with the critical evaluation and problematization of the medical expert assessment of disability, kinship personal assistance, and segregated and stigmatizing 'inclusion' of disabled children in education.

NOTES

[1] The Bulgarian translation of the CRPD, available on the website of the Social Assistance Agency, disregards the distinction between ‘impairment’ and ‘disability’ by substituting both terms with the Bulgarian word ‘*увреждане*’ that is usually translated into English as ‘disability’: ‘*увреждането* [disability] *… се явява резултат от взаимодействието между лицата с увреждания* [persons with disabilities] *и различните пречки в заобикалящата ги среда, които затрудняват тяхното пълноценно и ефективно участие в обществото равноправно с останалите*’ (https://asp.government.bg/uploaded/files/4387-KONVENCIQzapravatanahoratasuvrejdaniq.pdf). Disregarding the distinction between ‘impairment’ and ‘disability’ is deeply problematic from the perspective of the social model of disability. In this article, I use a Bulgarian translation of the CRPD that I modify on the basis of comparing the Bulgarian version with the English version of the document. The CRPD has ‘authentic’ versions in six languages, one of which is English. The problems associated with the translation of the CRPD are discussed in Mladenov (2013).

[2] In the Bulgarian translation of the CRPD, available on the website of the Social Assistance Agency, we read: ‘*Хората с увреждания* [Persons with disabilities] *включват лица с трайна физическа, психическа, интелектуална и сетивна недостатъчност* [incapacity]*, която при взаимодействие с обкръжаващата ги среда би могла да възпрепятства тяхното пълноценно и ефективно участие в обществото равноправно с останалите*’ (https://asp.government.bg/uploaded/files/4387-KONVENCIQzapravatanahoratasuvrejdaniq.pdf).

[3] The English phrase ‘personal assistance’ is usually translated into Bulgarian as ‘*лична помощ*’ (‘personal help’). This translation is problematic from the perspective of independent living because the word ‘help’ shares some of the patronizing connotations of the word ‘care’. On the other hand, the kindred English phrase ‘personal assistant’ is translated into Bulgarian as ‘личен асистент’ and not as ‘личен помощник’ (‘personal helper’), which partly corrects the meaning of the term ‘*лична помощ*’ and increases its proximity to the ideas of independent living. This terminological discrepancy is reflected in the Bulgarian Personal Assistance Act.

[4] The distinction between ‘paternalist care’ and ‘egalitarian care’ resembles the distinction that the existential phenomenologist Martin Heidegger (1962) makes between two forms of ‘solicitude’ or, in German, *Fürsorge*. In the first form, which resembles ‘paternalist care’, *Fürsorge* amounts to standing in or serving as a deputy for the ‘cared for’: ‘This kind of solicitude takes over for the Other [i.e., for the ‘cared for’] that with which he is to concern himself. … In such solicitude the Other can become one who is dominated and dependent, even if this domination is a tacit one and remains hidden from him’ (Heidegger, 1962, p. 158). The second form of *Fürsorge* resembles ‘egalitarian care’ in that here the ‘carer’ intervenes not to take control over care but to give it back to the ‘cared for’: ‘This kind of solicitude pertains essentially to authentic care – that is, to the existence of the Other [i.e., the ‘cared for’], not to a “*what*” with which he is concerned; it helps the Other to become transparent to himself *in* his care and to become *free for* it’ (ibid.). On the relevance of Heidegger’s existential phenomenology for disability studies, see Mladenov (2015).

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Ina Dimitrova

‘NOTHING ABOUT YOU WITHOUT US!’ THE SOCIAL PSYCHIATRY PROJECT IN SOCIALIST BULGARIA

Introduction

An initiative to abolish guardianship (interdiction) for people with intellectual disabilities and mental health problems has been under way in Bulgaria for several years now.[1] It is centred around the Natural Persons and Support Measures Bill (NPSMB), which introduces procedures guaranteeing that the abolition of Article 5 of the Persons and Family Act will ensure that people with these disabilities are provided with effective supported decision-making that reflects their will and preferences. Considering the difficult practical and economic situation of these people and their carers in Bulgaria as well as the fact that guardianship is laden with the heavy historical and symbolic burden of a socialist legal instrument which resolved a number of challenges in a rather primitive way, this initiative is indeed praiseworthy. However, it is set into a broader context that enables us to clearly see an ineradicable characteristic of the local horizon of governing disability – namely, the paternalistic framework within which disability is invariably inscribed in Bulgaria. This ineradicable characteristic is of key importance insofar as it determines and will determine the politics, public attitudes towards, and self-identifications of people with disabilities. The aim of this article is, by looking back at the history of socialist psychiatry in Bulgaria, to show and analyse an important case of practical manifestation and consolidation of the medicalized paternalism that still exists in the country today. First, however, I would like to explain why I begin with the present-day battle over guardianship.

The reason is that the legitimating framework and context of the demand for abolishing guardianship is the UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Bulgaria in 2012. The CRPD is an extremely important document, unanimously defined as transformative both by its supporters and by its critics in the international discussion. It is a document that embraces the social model of disability[2] and, as such, is the very opposite of paternalism. In Bulgaria, however, the case of guardianship shows, in a paradoxical way, that a radically anti-paternalistic set of principles can be used to reinforce paternalism towards people with disabilities on the part of social actors speaking 'on their behalf' and 'for their good'. This is due to the fact that none of the organizations that have embraced the CRPD principles[3] is an organization *of* people with intellectual disabilities or service-users. All organizations fighting for the abolition of guardianship are of relatives and of care professionals providing psychiatric and social services.[4] At first glance, this might not look particularly dramatic – in a social and historical context of long-absent grassroots activism, why shouldn't its pioneers be precisely the carers of people with disabilities and solidary representatives of the caring professions? The answer is very simple: because this is exactly what the CRPD actually aims to do – to problematize and abolish existing forms of appropriation, substitution, silencing of the voices of people with disabilities themselves, and to prevent the domination of groups that traditionally speak on their behalf. Of course, the Convention is all 'for' solidarity with people with disabilities, but not without them – as the slogan of the independent living movement and of the social model of disability states, 'Nothing About Us Without Us!'.

The peculiarities of the Bulgarian situation, however, are obviously such that they do not allow any retreat from paternalism in attitudes, in policies, and in activism itself, which is always 'about' and very rarely 'of' people with disabilities.[5] This local pattern is so powerful that it has engulfed even the CRPD – a document that is the product of the most radical activist organizations in the West[6] – and distanced it from the 'Nothing About Us Without Us' principle. As a result, people with disabilities in Bulgaria reside in a social context that persistently affirms the principle, 'Nothing About You Without Us!'. 'Us' refers to all – undoubtedly well-intentioned, carrying the heavy burden of a completely ineffective system, of decades-long attitudes and notions that are more disabling than the disabilities themselves, and making enormous efforts – parents, relatives, social workers, experts. But the presence of good intentions does not reduce paternalism in any way – on the contrary, they are part and parcel of paternalism, even its most fertile ground. In this sense, this is appropriation of a progressive and emancipatory perspective that is readily integrated into the system and begins to serve the principles and traditional power relations it was meant to eliminate. The result is that patients (or service-users) continue to be viewed primarily as recepients and objects of action, medical treatment, care (Russo and Wooley, 2020).

This situation raises the question of what feeds this powerful local paternalistic machine that swallows and reworks everything for its own needs. In this article I do not seek to give an exhaustive answer to such a complex question. Instead, I will reconstruct and analyse the peculiarities of a similar appropriation, depoliticization and neutralization of a model with an emancipatory potential (such as is the social model enshrined in the CRPD and driven by similar principles), which took place in Bulgaria in the period of state socialism. This model is the so-called social psychiatry, which was operationalized in the system of outpatient care (what is nowadays referred to as 'community psychiatry') and took pride in introducing the open-door system and eliminating restraints.

The principal achievements of social psychiatry, and more generally, of the social perspectives on mental health in the West are largely focused on emancipating the patient, on the patient's achieving independence and self-management. The social perspectives in psychiatry, which have always served more or less as an alternative to the respective psychiatric 'establishment'[7] and as a critique of the social order and of the psychiatric institution itself, have often played the role of a conceptual zone in which service-users can find a more adequate vocabulary to express their suffering and frame their identity.

In Bulgaria under socialism, social psychiatry functioned through a dual stake: it was asserted and promoted by the psychiatric community – not as something marginal and auxiliary, but as a major historic achievement, as the authentic socialist psychiatric project that best demonstrated the power and humanism of socialist society. What is more, it was meant to be the 'showcase' of socialist psychiatry, a testimony to its 'great successes'. In practice, however, social psychiatry was reformulated for the practical needs of the psychiatric professional community. This resulted in a convenient inversion: it was not the social that penetrated into the psychiatric system so as to subvert it from within; it was the psychiatric system – as a medical undertaking at that – which was to penetrate into the whole social body so as to keep it healthy, treat and cure, closely monitor, and never abandon it.

In what follows, I will try to illustrate this thesis and use it to provide a more detailed historical perspective on the problem of the paternalistic framework within which disability has invariably been situated in Bulgaria. I will proceed as follows: First, I will describe the methods and data used. Next, I will outline the hopes pinned on social approaches towards disability in the West. In the third part, I will show what was at stake in a concrete international project on social psychiatry. Its choice is not accidental – actually, this is a project the Bulgarian psychiatric elite was officially involved in, a fact that is usually omitted in discussions on the history of psychiatry in Bulgaria.[8] In the last part, I will illustrate how the local psychiatric elite juggled with social psychiatry and inverted its horizon. Bulgarian psychiatrists had to embrace its principles because it was the most progressive and humane approach, and at the same time, to revise it so that it could serve them as a strategy for reinforcing their own professional positions.

As a result, the patient's path was tied to that of the psychiatrist and of the system – the latter invariably accompanied and 'integrated' the patient into the social environment, as they put it, but they never withdrew completely and kept the patient under surveillance in one way or another. This gives us an insight into the development of the fertile soil of the paternalistic principle, 'nothing about you without us!', which remains the dominating culture of disability in

Bulgaria to this day.

Method and Data

The data used in this study are from several sources. The first (and major) source are the complete issues of three journals: the platform of the International Association of Social Psychiatry, *International Journal of Social Psychiatry* (from its establishment in 1955 until 1990), and the two main scientific journals of the psychiatric community in Bulgaria under socialism, *Nevrologiya, psihiatriya i nevrohirurgiya* (Neurology, Psychiatry and Neurosurgery, 1963–1989) and *Byuletin na NINPN* (Bulletin of the Scientific Institute of Neurology, Psychiatry and Neurosurgery [SINPN], 1958–1984). I have also used other scientific publications of eminent members of the Bulgarian psychiatric elite as well as various programmatic documents, reports, and statistics. Additional context for interpreting the data and building a fuller picture of the period is provided by interviews and focus group discussions with psychiatrists and carers of persons with mental health problems (two focus-groups and four interviews). They were conducted under the project *Generational Patterns of Coping with Life Crisis: Biographical, Social and Institutional Discourses*.[9]

Qualitative methods of analysis were used, the main focus being on the ways the Bulgarian psychiatric elite (that is, the prominent speakers in the field of psychiatry, not all 'rank-and-file' psychiatrists) framed its social and professional position. This type of analysis investigates the Bulgarian psychiatric elite's meaning-making work as well as its work on creating a specific disciplinary culture. In this sense, the work of the elite in question can be investigated as a sort of self-advocacy. That is why here I conceptualize this professional group essentially as an interest group,[10] that is, an activist social group that has definite goals and aspirations, and which elaborates a strategy for achieving them through construction and mobilization of specific cultural repertoires. The latter outline the group's horizons, its interaction with other groups, with the available opportunity structures and with the possible allies. Such an approach is one of the main approaches in studying social movements and different types of collective mobilizations (Benford and Snow, 2000; Snow and Benford, 1992; Van Dyke and McCammon, 2010; Snow, Soule and Kriesi, 2004).

Among the qualitative methods, I have deliberately not included interviews with representatives of the Bulgarian psychiatric elite of the period of state socialism, part of whom remained key figures after 1989, too. My focus is exclusively on textual sources, on an archival corpus of textual traces. In it there are undoubtedly blank spots. It seems to me at this stage, however, that these blank spots cannot be filled – especially if the aim is to shed more light – by the voices of the representatives in question as they would sound today. At the least, the question of how we speak about socialism during post-socialism would be especially difficult and is far from resolved. The voices then and the same voices today would produce different stories and combining them would be rather detrimental to both.

A difficult problem that must be addressed before we proceed further is the question of how individuals with psychiatric diagnoses are referred to in Bulgaria. They are still mainly referred to as patients, mentally ill, persons with mental illness or disabilities. The more modern and enlightened terms in use in Bulgaria are 'users of mental health services' or 'of mental health'.[11] Naming is a problem associated with the need for destigmatization and for resisting the biomedical approach especially in the Bulgarian context. However, it is complicated further by the fact that the relevant social actors – that is, the activists who ought to spearhead the battle for eliminating the medicalizing labels that imply dependence and helplessness – are practically non-existent in Bulgaria. For this reason, here I will use mainly the term 'service-users', but when I am referring to socialism I will continue to use the term 'patients' because it seems more natural in the context of the quoted psychiatric voices of the socialist period.

Social Approaches in Conceptualizing Mental Health

Nowadays the main model for conceptualizing mental illness is the biomedical one. It provides the dominant explanatory schemes focused on biological factors, and largely determines the policies, practices, legislation as well as the public images, attitudes and self-identification of service-users (Beresford, 2005, p. 63). Among its important characteristics are its individualized focus – mental illness is viewed as an individual pathology and deficiency – and its paternalistic spirit. Traditionally, this model has modifications which contest, to one extent or another, its biological basis, the ways of treating mental illness, the scale of possible preventive measures, and so on. These modifications differ by extent of radicalism, by origin, and by goals, but all of them share the intuition that mental illness is connected, in a fundamental way, to the social environment and its pathologizing impacts.

These alternative models are usually identified as social models or social approaches and stem from different fields: sociology, psychology and psychotherapy, social work, social psychiatry and behavioural family therapy, transcultural psychiatry, women's movement and LGBT movements, disability movement, mental health user networks, recovery movement (Tew, 2005, pp. 13-14).

Among them we can distinguish some alternative models which were born in the field of psychiatry itself and therefore share some basic assumptions of the biomedical model (i.e., they remain 'mainstream' to some extent): they accept the concept of mental health but insist on the inclusion of a wider range of social, political, and economic factors beyond the individual when analysing mental illness and prescribing measures to improve mental health; they stress 'the importance of "nurture" as well as "nature"; of people's environment as well as their bio-chemical make up' (Beresford, 2005, p. 65). As Peter Beresford (ibid., p. 66) points out, '[t]he history of social approaches in the fields of psychiatry and "mental health" can be traced to the post-war social psychiatrists and perhaps most significantly, the "anti-psychiatrists" … [who] certainly sought to move from traditional medicalised undertstandings'.[12] Being one of the most eminent proponents of the social model of disability, Beresford (ibid., pp. 65-66) argues that they are not sufficiently radical in conceptualizing 'the concern with discrimination, social oppression and civil rights embodied in' (p. 66) this model.

Indeed, social psychiatry as a whole does not claim that 'mental illness' does not exist (Tew, 2005, p. 21) although, as we shall see in the next part, this is exactly what one of its main proponents ultimately claims. Despite this, however, its focus is firmly on oppression, exclusion, vulnerability:

> Whereas an illness model suggests 'bad luck' in terms of genes, viruses or biochemical disorders – something that could befall anyone indiscriminately, and where no one external to the person has any responsibility – a social model locates experience within an understanding of social relations in which power plays a determining role, both in terms of 'macro'-scale structural inequalities in relation to gender, 'race', class, age, sexual orientation and so on, and in terms of the 'micro'-scale dynamics of conflict, exclusion or abuse that may take place within families or other intimate social contexts. (Tew, 2005, p. 23)

This 'countercultural aspect' of social psychiatry vis-à-vis clinical psychiatry as well as its obvious political implications can be seen clearly in, for example, the German Democratic Republic and the Federal Republic of Germany after the 1960s (see, e.g., Schmiedebach and Priebe, 2004, p. 469). Especially curious is the situation in the Soviet Union because the social perspective on psychiatry and the ensuing organizational specificities (for example, dispensarization, and in particular, the different concepts of exactly what form it should take) were by no means a monolithic unity there – they were the subject of fierce battles (see Zajicek, 2009). Especially interesting is the fact that social psychiatry or the mental hygiene paradigm of the 1920s and early 1930s fell victim to Stalin's crackdown on a number of scientific fields; after the Second World War there was an attempt to revive them, but at the end of the 1940s the contradictions were de facto resolved in favour of an approach that firmly bound social and clinical psychiatry and neurology into a single field which, however, was dominated by a biomedical rationality (see Zajicek, 2009, pp. 225-227).

The conclusion that is important for this analysis is that the social perspectives in general – and social psychiatry in particular – usually have the status of critical and subversive assemblages of theory and practice. As the researchers in this sphere argue, the inclusion of the social into the discourse on mental illness provided a perspective committed to the social empowerment of the marginalized voices in the system. This also entails rejecting the image of service-users as passive objects of diagnosis and medical treatment (see Tew, 2005; Spandler, Anderson and Sapey, 2015).

In this sense, it is fundamentally important 'to keep social and medical perspectives separate, if we are to retain the conceptual "space" in which to view "medical model" practice as itself a potential source of abuse and oppression' (Tew, 1999, p. 437).

In the next parts I will show that socialist psychiatry in Bulgaria did the exact opposite – it merged the two perspectives and destroyed the conceptual space in question. Social psychiatry was completely appropriated by the psychiatric professional community which sought to win positions and capital through it. As a result, the medical paternalistic model expanded and came to dominate social psychiatry.

Joshua Bierer's Social Psychiatry Project and Bulgaria's Participation in It

The focus here is on a concrete Western, and later, international social psychiatry project in which Bulgarian socialist psychiatry was involved, yet the project's implications, influences, or their absence – as well as the reasons for that absence – are not mentioned at all in Bulgarian publications of the period. The central figure in this project was Joshua Bierer, who 'was among the first [psychiatrists] to experiment with open-door psychiatric facilities and to organize post-treatment social clubs for former patients [in the UK], later acting as a sort of figurehead in the international social psychiatry movement' (Savelli, 2018, p. 49). Bierer, along with Maxwell Jones, S. H. Foulkes, and Wilfred Bion, were the main representatives of British psychiatry who 'helped bring the concept of social psychiatry to the profession's attention, even if only temporarily' (ibid.) because of the subsequent rise of the biomedical approach.

The question of why Bulgarian psychiatrists' participation in Bierer's social psychiatry project is not mentioned at all in the Bulgarian publications of the period is very curious and merits special attention and study. The cooperation with Western representatives of social psychiatry was legitimate and official (albeit most probably also elitist, i.e., limited to the eminent figures in Bulgarian psychiatry). The Bulgarian psychiatric elite was part of Bierer's international social psychiatry movement. Nikola Shipkovenski was vice president of the movement for some time, as well as member of the editorial board of the journal *Socijalna psihijatrija* (Social Psychiatry), published in Zagreb, where the project in question had a very strong branch thanks to one of Bierer's most active followers, Vladimir Hudolin.[13] Bulgarian psychiatrists attended the international congresses of social psychiatry (several of them were held in Yugoslavia – again thanks to Hudolin and his peers), published articles in the *International Journal of Social Psychiatry* (although not too intensively) as well as in a collection edited by him (Hudolin, 1984), invited and interacted with fellow social psychiatrists from the Western countries at local congresses – as evidenced by, for example, the international symposium on social psychiatry held in Bulgaria in 1971 and followed by a collection of papers published by the Ministry of Public Health.

In this sense, it is a remarkable fact that Bulgarian socialist psychiatry was officially engaged in contact and exchange with an intensively developing emancipatory psychiatric project that sounded at times almost anti-psychiatric, as we shall see from several of Bierer's theses below, and which was strongly anti-somatic and anti-biological. An important part of its principles were shared and embraced by Bulgarian psychiatrists, albeit predominantly rhetorically – as, for example, those regarding the importance of introducing the above-mentioned 'open-door system', eliminating restraints, and developing a network of outpatient facilities.

Still, emancipating and empowering patients turned out to be impossible and unattainable for the local system even though Bulgarian psychiatrists[14] spoke of 'leading patients towards independence'. This 'independence', however, consisted in residing in a 'rehabilitation complex' that provided a competent assessment of the patient's ability to work, degree of social disablement, and potential opportunities for rehabilitation and resocialization as rehabilitation programmes for retraining and vocational guidance, day-care centres, centres for conducting planned rehabilitation activities, and sheltered workshops (Temkov, 1989, p. 174).

This paternalistic attitude towards patients, which doesn't 'leave them to themselves' (as the experts put it), was in stark contrast to the main stakes of Bierer's international social psychiatry project. I will sketch some of the emblematic priorities in its conceptual horizon, ambitions and practices, as documented in the *International Journal of Social Psychiatry* (IJSP). I want to stress here that the IJSP impresses with its diverse array of contributors – psychiatrists, social workers, psychologists, representatives of different and even of warring psychotherapeutic schools of thought, social scientists, and anthropologists, among others – from all over the world.

In the early 1970s, enumerating 'the Beliefs … of those, who have helped to create this world wide [social psychiatry] movement', Bierer (1973, p. 1; emphasis and capitalization in the original) directly declared:

> *'Madness' does not exist!* It is doubtful if 'Mental Illness' exists in the form that has been accepted for centuries. Social psychiatrists do not adhere to the belief that we live in a *sane* society. We believe that the so-called sane people are not as sane as they believe they are, and that the so-called insane people are not as *insane* as *we* believe they are!
>
> The *PSYCHIATRIC PATIENT* is a *HUMAN BEING*, the same as any of us. The *PSYCHIATRIC PATIENT* is no more the *'DANGEROUS ANIMAL'* one has to lock up. …

> We believe that the majority of mental hospitals can become superfluous. Full-time mental hospitals on a whole are likely to create Mental Illness or, at least make the mental state of the patient worse …
>
> We are modest enough to admit that psychiatrists alone cannot solve the difficult problem of mental illness and of maladjustment.

Several years later, he was already speaking of a social and of a medical model, and unambiguously criticizing the latter (Bierer, 1976). The social model accepted the above-mentioned principles as well as the radical transformation of the doctor-patient relationship, which aimed at eliminating the one-sided power relationship between them. This is also Bierer's main point in the editorial of the maiden issue of the IJSP of 1955. Arguing for a new, cooperation-based approach, Bierer (1955, p. 4) pointed out that

> the principle of equal partnership will tend to make the 'professional givers' – the psychiatrist, the social worker, the probation officer, *etc.* – less authoritative and less conceited; and the 'professional takers' – the patient, the criminal and the anti-social – more conscious of their role as equal partners in a communal task and, therefore, better able to carry responsibility. … This encourages the development of the spirit of co-operation. As a result, that which appeared impossible, unthinkable, has happened; inside public Mental Hospitals, the doors have opened … thus preventing their [the patients'] losing touch with the community and the world in general.

In an overview of the evolution of his ideas, five years later Bierer (1960, p. 171; emphasis in the original) described how he had realized that

> to treat the patient as an object – and often as a dangerous one – is fundamentally wrong; it only creates difficulties and exaggerates the illness. I conceived the idea that there is *a tremendous source of therapeutic potential in the patient himself*, and by making him a fully fledged partner in his treatment, and also in the treatment of his fellow sufferer, I realized that our whole approach could be revolutionized.

In accordance with these principles, many articles of the 1950s focused mainly on outpatient care and the introduction of the open-door system. Authors often shared success stories of opening doors and of this system's favourable influence on patients and staff, while also discussing the efforts that were being and should be made to secure 'the absolute prohibition of mechanical restraint, seclusion and tube feeding. These barbarities are degrading to the nurse and the doctors, as well as to the patient' (Bell, 1955, p. 42; see also Stern, 1959, p. 301). This spirit also informed the establishment of therapeutic social clubs (Stewart, 1956) as well as the various forms of group psychotherapy based on the principle that 'the patient is "openly" recognized as an important therapeutic aid and encouraged to function as such … [and the] therapist is the professional leader and a patient; he is the most vulnerable person of the group' (Moreno, 1958, p. 150).

In 1958 the IJSP published an article titled 'Teaching Citizenship to the Feeble-Minded Adult' (Fitzpatrick, 1958). This article shows that the therapeutic ambitions were directed at achieving maximum independence even for people with intellectual disabilities: the prime objective was 'instruction in how to lead an independent life' (ibid., p. 229).

Moreover, the focus was not merely on vocational rehabilitation as in socialist Bulgaria, but on teaching various practical skills – handling money, coping with everyday needs, travel, and last but not least, becoming aware of the forms of oppression and exploitation: 'those in poorly paid jobs became conscious of this and asked for something better; the number of patients asking for lodgings or finding them for themselves increased' (ibid., 231). Other articles also show that later, too, personal independence 'promoted to "the utmost"' was the prime objective of the psychiatric services and the 'Independent Living Units' existing in some hospitals in the UK (Campbell, 1971, p. 310). In addition, the point is made that often there was no need of '[s]pecial methods of inducing patients to govern themselves … for with open doors and a normal atmosphere the patient realizes that he is regarded as adult and so naturally behaves as a responsible citizen' (Stern, 1959, p. 301).

The same emphasis can be seen in the reflections on patients' vocational rehabilitation. Reflecting on the introduction of industrial therapy into mental hospitals in the Republic of Ireland, W. P. Berrington (1966, p. 90), for example, points out that

> we must ask ourselves if we have given back to the long-stay patient his courage or, indeed, his competence to take a bus-ticket, to work in the factory where he has to adapt to the management and not they to him; to use a telephone, buy his own clothes and toilet accessories, advertise in the local paper for a job, or manage his own budget?

This brief look at how a concrete social psychiatry project actually worked shows that it was obviously an alternative conceptual space for self-identification of patients as well as of experts. Opposing the medicalized notion of mental illness as individual pathology, it called into question the traditional views of 'sanity' and 'normalcy', and paved the way for the conceptualization of norms as a continuum of differences. This historically parallel project to the socialist one, a project to which Bulgarian psychiatrists had direct access, offered an emancipatory vocabulary and horizon to patients and sought to socialize psychiatry. By contrast, in Bulgaria under socialism the stake and objective of the 'social principle' in psychiatry was 'bringing psychiatric help as close to the social community as possible … both in territorial terms and in terms of its acceptance' (Zhablenski, 1989, p. 173). In other words, what we see is an inversion that was convenient for the psychiatric profession: it was not the social that penetrated into the psychiatric system so as to subvert it from within; it was the psychiatric system – as a medical undertaking at that – which was to penetrate into the whole social body so as to keep it healthy, treat and cure, closely monitor, and never abandon it.

This horizon desired by the psychiatric community in Bulgaria, however, remained far from reality and we therefore cannot speak of a situation analogous to the Western context of intensification and deepening of psychiatric power through its entry into everyday practices and through the very ways we conceive and govern ourselves. The Bulgarian psychiatric elite functioned as an interest group, as a community intensely looking for resources to move away from the marginal position it was in. As such, especially from the early 1970s onwards, its aim (or at least its dream) was paternalistic appropriation of multiple social zones, and social psychiatry seemed the most appropriate means to this end.

Social Psychiatry in Bulgaria: 'Bringing Psychiatry Close to Society'

Social psychiatry was precisely what the Bulgarian psychiatric community relied on in its attempt to get close to society.[15] That is because social psychiatry actually included everything that demonstrated and proved the effectiveness of psychiatry as well as the fact that it had renounced its inhuman past: prophylaxis, humane treatment, rehabilitation and reintegration, returning 'former mental cases' to work. As Ivan Temkov (1989, p. 175) pointed out, precisely social psychiatry had 'raised the authority of psychiatry and brought it up to par with a number of leading medical disciplines'. And he went on to add:

> Outpatient psychiatric service is one of the most promising developments in contemporary psychiatric therapy. It is a brilliant illustration of the idea of 'psychiatry amidst society'. This way of psychiatric service provision will gradually also change people's attitude towards mental illness and the mentally ill and make psychiatry equal with somatic medicine, so that care for the mentally ill will become financially equal with care for the somatically ill. (Ibid., p. 182)

These were the basic markers of the desired state of psychiatry – namely, 'making the social, economic and legal status of medical workers in the psychiatric sector equal in every respect with that of medical workers in other sectors of medical services' and 'overcoming the psychiatric stigma, correcting the negative attitudes and wrong notions in society about the nature of mental illness' (ibid.). Social psychiatry had to win capital for the psychiatric profession, securing the same standing and authority for the latter as the other medical specialties by demonstrating its successes. This would be possible, however, only when the stigmatizing attitudes in society – stigmatizing not only patients but also the psychiatric system itself[16] – were overcome.

These markers clearly show how the Bulgarian psychiatric community's goals and aspirations were framed, and how social psychiatry had to be operationalized so as to serve its interests. In this sense, social psychiatry was the grand strategy which this interest group mobilized to achieve its interests. The different practices and units it consisted of – outpatient care and its relevant components (dispensarization, mental prophylaxis, labour therapy and vocational rehabilitation, resocialization, legal defence, etc.), humane treatment in hospitals, and scientific research of the population's needs of psychiatric care and the ways it could be provided – can be viewed as different tactics within this complex strategy.

One of the key elements of this strategy, however, was the need to follow the model of unity of social and clinical psychiatry. Throughout the socialist period, the need for such unity was stressed by all members of the Bulgarian psychiatric elite. They used it also as a warning to those who 'wrongfully tended' to give priority solely to outpatient care. This unity was 'the guiding principle both in the elaboration and in the implementation of the model of psychiatric care and mental health protection' (Milenkov, Molhov and Beshkov, 1976, p. 132). There were also direct warnings:

> An important rule in the development and operation of the outpatient system is to avoid entering into an antagonistic contradiction with the inpatient psychiatric system. There are such wrongful tendencies in Bulgaria, too. Outpatient care cannot completely replace, let alone displace, the need for clinical services and inpatient care. Inpatient and outpatient care are mutually complementary stages and should work in unity and harmony. (Milenkov and Pancheva, 1980, p. 171)

This remained valid until the very end of the socialist regime in Bulgaria: 'There is no and should not be any significant difference in the treatment of mental illness in inpatient and outpatient settings. Encouraging outpatient psychiatric services is correct only within such a framework of psychiatric treatment' (Temkov, 1989, p. 179). Priority had to be given to the development of the outpatient system, but 'without opposing it to, or separating it from, inpatient psychiatry, as a series of unsuccessful attempts have tried to do' (ibid., p. 175).

These warnings had ideological grounds insofar as they sought to prevent the affirmation of 'the crude sociological "hypothesis of origination", i.e., of the social determination of illness' (Molhov, 1979, p. 335). But the more important reason for such intense insistence on the continuity of the two systems was, in the final analysis, the struggle for resources. This was explicitly declared in

1969, in a collective article by four of Bulgaria's leading psychiatrists at the time. In the article, titled 'Outpatient Psychiatric Care in Bulgaria – State, Tasks and Prospects of Development' (in Bulgarian), it is explicitly said that however humane the social principle in psychiatric care may be, however much we want 'not to separate the mentally ill person from the social environment', we cannot but

> point out that even the best outpatient care is incapable of endlessly reducing the inpatient bed stock … at the stage we are at now, the difficulties … come, for the time being, above all from the still insufficient number of [hospital] beds for the mentally ill and the feeble-minded. Most of the socialist countries are still faced with the big problem of building psychiatric hospitals and increasing the number of beds. (Uzunov et al., 1964, p. 66)

Even more important was the fact that the 'unity' in question ultimately had to be entirely under psychiatric jurisdiction. It was unity, but unity within the framework of 'psychiatric endeavour in our country' (ibid., p. 67), and this endeavour remained a medical undertaking.

Such an approach actually eliminated and neutralized the emancipatory impulses in social psychiatry. As a result, the medicalizing principle became the leading principle in all outpatient units. The imperative of unity de facto 'eradicated' the social and de-medicalizing horizon of social psychiatry and of the outpatient system, automatically returning them to the fold of the medical model. Bulgarian psychiatrists of the socialist period must have felt the subversive potential of social psychiatry, for the persistent affirmation of the unity of the two systems can be interpreted as an indicator precisely of fears that social psychiatry could emancipate and give rise to contradictions that would subvert the positions of psychiatry as a medical field. For them, the other medical specialties were a desired and natural ally as well as a zone that had to recognize them and which they wanted to infiltrate: plans were constantly being made as to how psychiatry would enter into all units of medicine, including, for example, into genetic counselling programmes (Milev, 1972). With such desired allies, there was no way Bulgarian psychiatrists would criticize or be particularly eager to move away from the medical model – something which social psychiatry does by definition. Hence, it is impossible to expect that the authority and power of the medical worker would be called into question (as Joshua Bierer so explicitly did) or that the efficiency of the purely medical means of resolving mental health issues would be contested – and thus, that there would be tangible de-biologizing and de-individualizing of mental illness. Social psychiatry had to be placed under medical rule and could not be left in the hands of other, non-medical, specialties such as psychology and defectology.

All of this goes to show just how strongly the focus was not on the patient but on the psychiatrist. Outpatient care was obviously meant to serve the

Bulgarian psychiatric community itself, helping it to multiply its functions, win authority, and last but not least, to make it equal with the ‘somaticists’, as the medical professionals were called at the time. This can be seen clearly also in Vasil Milev’s programmatic article of 1972 on the development of the psychiatric system in Bulgaria: on the international plane, outpatient care is the leading form, he wrote, and that is why it had to be developed, improved and brought closer to the population in Bulgaria as well. But what would that ensure? His answer wasn’t, for example, better treatment of, attitude towards, or independence of patients, but

> making psychiatrists and somaticists equal… Undoubtedly, in future, in the later stages of communist society, we will probably come close to a ratio of 1 to 1… According to our preliminary, very approximate, estimates, in the phase of the developed socialist society there ought to be one psychiatrist per at least ten somaticists… Unfortunately, however, in Bulgaria at present out of every one hundred doctors fewer than three are psychiatrists… This is a significant disproportion. (Milev, 1972, pp. 10-11)

Also indicative in this programmatic article is the insistence that outpatient care must ‘focus most of all on the healthy population through mental prophylaxis and mental hygiene’ (ibid., p. 11). This desired expansion towards the ‘healthy’ sectors of the social body is very clearly seen in the Ministry of Public Health’s 1976 Programme for Protecting and Improving the Mental Health of the Bulgarian People. It obviously sought to ensure that psychiatry would encompass multiple zones and perform counselling, supervisory, controlling, enlightening functions. The Programme proposed that the principals of auxiliary schools and directors of complexes of various medical counselling rooms should be psychiatrists; that psychiatrists should perform ‘periodic mental hygiene [examinations] of the syllabi, curricula and timetables for students in educational establishments of all kinds and levels’ and ‘hygiene analysis of the polygraphic and technical layout’ of textbooks and school aids, etc. Things are similar in the SINPN’s 1973 Directive Programme for the Development of Psychiatric Care in the People’s Republic of Bulgaria until the Year 2000 and the Ministry of Public Health’s Guidelines for the Development of Specialized Psychiatric and Neurological Care until 1990, whose third part, ‘Scientific Research Activity’, begins with an item devoted to social psychiatry.

In all subsequent assessments of the general state of psychiatry in Bulgaria until the end of the socialist regime, it is continually stressed that ‘despite the unquestionable successes achieved in the socialist development of our psychiatry, there is still an underestimation of its role and importance as a main medical discipline with decisive specific and integrative functions in medical care for the population in general and in the training of healthcare personnel’ (Molhov, 1982, p. 29). In the relevant publications we also see a number of complaints on the part of psychiatrists. For example, the obvious public disrespect for the expert opinions of doctors at dispensaries is stressed: 'we must fight for respect for the competent opinion of our dispensary on the part of the relevant bodies! The judicial and labour bodies must be convinced that the psychiatrists at our dispensaries are already accomplished specialists, highly moral people educated in the ideas of socialist humanism' (Nastev et al., 1969, p. 80).

All efforts of the psychiatric elite to assert themselves by appropriating the complex of social psychiatry were hindered, however, by a very curious factor that made them realize, at least to some extent, that their interests were essentially *shared* interests – not only of psychiatrists but also of their patients. This became possible in a negative way – namely, through the already mentioned shared stigma, which prevented psychiatric expertise from expanding successfully.

In their efforts to win authority, affirmation and more resources, Bulgarian psychiatrists encountered a problem which other medical specialists did not have – the stigmatizing attitudes of society towards their patients and hence towards the psychiatric system itself. Studies from the period show that the stigma towards the mentally ill was stronger than the stigma towards other people with disabilities (Todorov, 1989, p. 220). The strong stigma can be inferred, for example, from the following quote: 'With great love for the [mentally] ill and dispensaries, difficulties of all sorts are being overcome – including the reluctance of [mentally] ill people to be dispensarized, some of them being stubbornly supported and hidden by their loved ones' (Stankushev, 1969, p. 8). In the 1980s, when the existence of a strong stigma towards the mentally ill in Bulgarian society was already being discussed quite actively, this stigma was unambiguously framed as a factor which actually worsened the position of psychiatrists themselves, and vice versa – their marginal position vis-à-vis the other medical spheres strengthened the stigma towards patients:

> the objective difficulties facing contemporary psychiatric theory and practice ... are related primarily to the great complexity of the subject of their research and the insufficient, in our opinion, funds allocated for this research. One is left with the impression that psychiatry has to catch up with the other medical disciplines. This has an unfavourable effect on society's attitude towards the mentally ill. (Todorov, 1989, p. 220)

In *Essays of a Psychiatrist* (in Bulgarian), Todor Stankushev (1985, p. 6) wrote that the aim of the whole book was actually to overcome the stigma, the negative attitude of Bulgarian 'society as a whole towards the mentally ill. Even now, in the area of the scientific and technological revolution, mental illness continues to be regarded as something strange, and regrettably, as something well-nigh shameful.' But the figure highlighted as the victim of this attitude was again that of the psychiatrist: 'This creates additional problems in the work of the psychiatrist' (ibid.). When the attitude of society changes, the mentally ill

> and their loved ones will feel much more at ease to turn to the psychiatrist for help – moreover, at the beginning of the illness when the possibilities for treatment are the best. Thus we doctors, too, will get greater satisfaction from our work, and the meetings with our patients will be free of embarrassment and much more relaxed, more pleasant. (Ibid., p. 179)

In other words, Bulgarian psychiatrists were locked into a vicious circle because of the specificity of mental illness as such. Psychiatry could acquire more prestige and funding if it proved it was effective – if it 'cured' and did not allow its patients to become 'disabled', that is, if it provided an effective outpatient system. But beyond the control of psychiatrists, the social environment and public attitudes turned out to be a powerful factor. Through the mental illness stigma, society radically rejected former patients, 'harming them even more than the illness itself', as Marina Boyadzhieva (1981, p. 430) pointed out. This external but powerful factor reflected on psychiatrists themselves and became a problem for them, too. And because of the clinical focus of Bulgarian psychiatry, the main destigmatization strategy they proposed was through even more biologization. Biologizing a given 'pathology' was a relatively easy and quick way of destigmatizing,[17] of developing the attitude that 'the mentally ill person is an ill person like any other … and [that] mental disease is in essence a biological phenomenon and the attitude towards it should be the same as that towards every ill person' (Todorov, 1989, pp. 218-220). The same biologizing approach is found in Stankushev (1981). Biologizing mental illness was unambiguously represented as a mechanism of destigmatizing the psychiatric system.

All this testifies to the process of medicalization of social psychiatry in Bulgaria in this period, which also led to the impossibility of viewing the latter's embodiment – outpatient care – as a counter-medicalizing project. Bulgarian psychiatrists – precisely as medical workers – had no intention of withdrawing from any zone of the patient's path, implicitly embracing the principle 'nothing about you without us!'. This is especially evident in the above-quoted warning against any 'deviation' from the clinical perspective as well as in the experts' reluctance to free anything from their supervision and control, including 'the voluntary forms of self-help'. The latter were viewed not as a way of getting patients out of the system and making them independent, but as the exact opposite – as a way of keeping psychiatrists in charge of every single stage of the patient's path, the aim being 'ever wider inclusion into the sphere of psychiatric services of voluntary forms of self-help and mutual help, such as are the organizations of patients with alcohol problems, the mutual help groups of families with chronically ill members, etc.' (Zhablenski, 1989, p. 173). At the same time,

> the spontaneous organization of patients' self-help groups in some countries … probably in Bulgaria as well … is expedient … [A]ssessments … have shown full consensus as to favourable results, therefore it is recommended that self-help groups be encouraged to cooperate and collaborate with a number of psychiatric services … that will guide their activity. (Temkov, 1989, p. 182)

As early as in 1966 it was being stressed that patients' clubs ought to always be co-organized under the direction of the neuropsychiatric dispensaries.

In other words, the patient's path was invariably under the direction, control and supervision of the psychiatric system.[18] Always by the patient's side was the psychiatrist, who 'doesn't leave the ill person to himself, but is closely involved with his fate' (Nastev et al., 1969, p. 137).

Conclusion

The bottom line of the social psychiatry project in socialist Bulgaria, which can be found in various forms in many articles of the period, was summed up in 1989 in the collection *Social Psychiatry* (in Bulgarian) as follows:

> Viewed logically, it should be accepted that treatment of mental disorders in outpatient settings will have a distinct social character serving as a basis for the application of other therapeutic methods [different from those applied in inpatient settings]. Regrettably, in our psychiatric system this is not the case. The reasons lie not only in the organizational and material deficiencies of the psychiatric outpatient institutions but also in the insufficient development of social psychiatry in our country and in the inability of Bulgarian psychiatrists and their assistants to apply different psycho-social interventions. (Temkov, 1989, p. 180)

The desired successes of the system were obviously not achieved. The Bulgarian psychiatric system was chronically understaffed, students in medicine did not want to specialize in psychiatry, there were no properly trained social workers, rehabilitation therapists, psychologists, and psychotherapists, mental health diagnostics was not up to standard, psychiatric services were limited, poor-quality and not accessible everywhere and to everyone, vocational rehabilitation was insufficient and limited to uniform activities that did not help patients to develop (Temkov, 1980). This had a twofold effect: some of the people who sought support and treatment turned to alternative options outside of official psychiatric care (for example, 'yogism', as we see in the 1973 Programme for Development of Psychotherapy elaborated by the Centre for Neurology, Psychiatry and Psychotherapy at the Medical Academy in Sofia); others simply hid or were hidden, as noted by Stankushev (1969, p. 8); still others remained assigned to the available psychiatrists without any opportunity of replacing, criticizing them, or complaining. In other words, it turns out that the underdevelopment of the field and the chronic deficit can be thought of to some extent as conditions of the impossibility of resistance – especially of collective resistance – on the part of patients.

However, the system did have some ‘successes’. They were in the areas associated mostly with forms of isolation, institutionalization, deprivation of rights. The statistics are telling: in the form of praise for the system’s achievements, it was noted that ‘guardianship as a form of protection of the rights and interests of the mentally incapacitated [was being applied ever more widely]’. With the active participation of doctors from the outpatient psychiatric network, 1,576 patients were placed under guardianship at the end of 1967, as compared with 94 in 1954. In 1961, twelve patients were sent for forced treatment, and in 1967 – 357’ (Nastev et al., pp. 143-144). The other dismaying numbers referred to social care facilities (homes for disabled people and older persons): the total number of such homes in the period from 1955 to 1961 increased from 61 to 91; and of the beds in them, from 2,917 to 6,002 (Central Statistical Directorate, 1962, p. 214). By 1967, the number of social care homes had grown to 135, and of beds to 11,000 (Nastev et al., 1969, p. 145).

We had better bear in mind this historical case as a warning when we mobilize the CRPD’s radically emancipatory project. Bulgarian history shows how another potentially emancipatory social project (based on principles to a certain extent similar to those of the contemporary social model of disability), which was formally promoted by the then ideology, was practically appropriated by the system, reworked for its internal purposes, and turned into nothing but an adjunct to the medicalized paternalistic model. Just as social psychiatry was medicalized and ‘paternalized’ to the benefit of the psychiatric field itself, so too it may turn out nowadays that the CRPD serves mostly the expert professions, while service-users remain mostly in the passive dependent position of objects of care.

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NOTES

[1] For detailed information and discussion on the Natural Persons and Support Measures Bill and the concepts of capacity to act, best interest, will and preferences, etc., see Stavru (2016).

[2] On the specific characteristics of the social model, see Teodor Mladenov’s article in this issue as well as part three of this article.

[3] Actually, not all principles are embraced – or at least not all consequences of the CRPD which would require relevant legislative amendments. The otherwise very good analyses made, for example, by the Bulgarian Center for Not-for-Profit Law (BCNL, 2011; BCNL, 2014), do not even mention the consequences of the CRPD that are most intensely debated in the West – for instance, Article 14, which guarantees the

right to liberty and security of person; Article 15, which guarantees freedom from torture or cruel, inhuman or degrading treatment or punishment; Article 17, which guarantees the right to integrity of the person (this article was strongly contested during the discussions of the draft of the CRPD and was included solely at the insistence of the activist groups involved in the discussions). These are among the most difficult provisions of the CRPD because they practically require fundamental changes in the traditional legal provisions related to people with mental health problems – both with regard to medical treatment and to key aspects of criminal law (psychiatric treatment without consent, detention, use of restraints, issues of criminal responsibility, etc. – see Bartlett, 2012; Bartlett, 2009). In Bulgaria, however, the discussion is focused on Article 12 and several others (articles 23, 29, 13, 19, and 24), which are not directly relevant to the above-mentioned most sensitive and most difficult provisions requiring fundamental legislative reforms in key spheres.

[4] Since they are undoubtedly professionals in this area and know what is required by the principles of the new paradigm on life with disability – namely, the social model of disability and the CRPD based on it – they are probably also aware of the conspicuous absence of the people with disabilities themselves. An attempt to correct this is the Born Ready campaign (https://www.bornready.me/) – a successive step in the initiative to abolish guardianship, in which these selfsame organizations turn the spotlight on self-advocates. The 'spotlight' consists in a short video featuring persons with disabilities who declare their resolve for attaining self-fulfillment (solely through the professions they dream of pursuing, not through other social roles as well – which somehow painfully reminds us of the hypertrophied focus on work and vocational rehabilitation under socialism and of an already criticized type of disability activism in the West).

[5] An exception in this regard is the Center for Independent Living – Sofia, for example. The fundamental importance of forming organizations *of*, not *for*, people with disabilities with regard to their emancipatory project can be seen in the document that underpins the social model, *Fundamental Principles of Disability* (UPIAS and the Disability Alliance, 1976).

[6] This in itself is not unproblematic, as one can see in the Western discussion on the issue (see, e.g., Spandler, Anderson and Sapey, 2015). But this is a subject that is beyond the scope of this article.

[7] For instance, this was the case even in the Soviet Union, where in the 1920s a network of neuropsychiatric dispensaries was started by a group of psychiatrists who defined themselves as social hygienists and entered into conflict and competition with clinical psychiatry. This group endorsed de facto a form of social psychiatric project and in the battle for its implementation they played a psychiatric 'countercultural' role. They lost the battle in the 1930s, when they were accused of subverting the very essence of psychiatry, turning it into 'psychobiology' focused on the concept of disadaptation (Latypov, 2011; Sirotkina, 2002; Solomon, 1989; Zajicek, 2009). Also curious is who was the inspiration of the Soviet social hygienists and, in particular, the father of 'dispensarization' in the Soviet Union, Lev Rozenshtein. Actually, he was directly inspired by Adolf Meyer. Meyer was a key figure in American psychiatry in the first half of the twentieth century. He rejected Emil Kraepelin's biomedical approach as 'rigid somaticism' and defended the idea that the psychiatrist must work with 'the personality' of the patient. This led to the recognition of the importance of the social environment and to the introduction of a 'dynamic' psychotherapeutic approach (see Double, 2005; Morrison, 2016, pp. 69-70).

[8] It seems that the history of psychiatry in Bulgaria is most often discussed in terms of the domination of the 'Pavlovian model' (see, e.g., Popova, 2016; Hristov, 2016; Chehirian, 2016), which also places emphasis on the interaction between the individual and the environment, but this interaction is usually thought of in a mechanistically-somatizing-reductionist mode. This is especially visible in Chehirian (2016; 2017) and is undoubtedly valid, but it should be borne in mind that 'Pavlovianism' itself had the potential to be part of, and was mobilized within the framework of, different psychiatric rationalities. For example, in 1936 Pavlov was defined as an opponent of 'the mechanistic views of his more zealous followers' insofar as 'he had always believed in the importance of "the role of the personality, and its activity and other qualities"' (Zajicek, 2009, p. 51, fn. 144, citing Giliarovskii, 1936, p. 907).

[9] Bulgarian National Science Fund, No. 2763, Contract DN 05/9 of 14 December 2016.

[10] On the characteristics of interest groups as social actors pursuing collective goals and interests, see Snow, Soule and Kriesi (2004, pp. 7-8).

[11] A clear example of the lack not only of unified terms but also of awareness that the different terms are the product of fundamentally different paradigms in attitudes towards and policies on persons with mental health problems is the text of the National Strategy for Mental Health of the Citizens of the Republic of Bulgaria 2020–2030, which uses the terms 'users', 'mentally ill', and most frequently, 'patients'. It is obvi-

ous that the authors of the Strategy were oblivious to the fact that the way they refer to the users of their services is of key importance.

[12] Here – thanking the anonymous reviewer for their completely appropriate comments demonstrating the much more complicated history of social psychiatry and anti-psychiatry which includes numerous, specific to the different historical periods and contexts, interactions, agreements and contestations between the actors involved – I think a qualification is in order. The schematization offered here is oversimplified because it applies solely to the activist and emancipatory projects which address mental illness and the ways of managing mental health problems. In other words, I am interested in social models in psychiatry insofar as they are framed and mobilized as an *activist toolkit*. Precisely as such, they ought not to deal with the complexity in this field but to simplify so as to have a chance of turning into effective interventions.

[13] His work was also influential in Bulgaria inspiring, for example, the creation of 'clubs for alcoholically-ill' which were 'similar in structure to Hudolin's "groups of alcoholics" but also had their own, Bulgarian, social-psychological specificity' (Boyadzhieva, 1988, p. 223).

[14] Most often Dimitar Panteleev, a key figure in the field of vocational rehabilitation and inventor of the literary psychogram method (see Hristozov, 1988, p. 166), and in 1989 also Ivan Temkov (1989).

[15] The idea of being 'close to society' in the form of 'mental hygiene and mental prophylaxis' was present in socialist biopolitical rationality from its very beginning (see Hristov, 2013; Golemanova, 1987). Here I will not focus on the concrete uses of 'mental hygiene'; I will view it as a component of a larger-scale undertaking – namely, 'social psychiatry'.

[16] This phenomenon is sometimes referred to as 'stigma by association' (Spandler, Anderson and Sapey, 2015, pp. 71-72).

[17] Biologization as a way of destigmatization can be inscribed within different rationalities – it is used effectively in various activist projects of patients in the West, for example. This is also confirmed by one of the comments of the anonymous reviewer of this article – namely, that biologization does not necessarily have to serve psychiatric confinement. This is undoubtedly true, but the point I am making here is that biologization served not so much psychiatric confinement as *psychiatric paternalism* because it affirmed, maintained and insisted on the invariable coupling of the patient (precisely as someone who is simply 'ill' like any other ill person) and the psychiatrist (precisely as a doctor like any other doctor) and on the patient's dependence on the psychiatrist. That is to say, power was exercised precisely by opening up, by dispersing psychiatric care outside the clinic in the outpatient system, but invariably under the jurisdiction of psychiatry, not of other professions or alternative and service-users' grassroots practices.

[18] Those whom the psychiatric system readily abandoned were in fact the cases regarded as 'hopeless' – people with intellectual disabilities, or the then so-called 'feeble-minded' (*oligofreni*). They were sent to social care homes where they were supposed to be 'looked after' (Temkov, Marinova and Svatovski, 1979).

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Margarita Gabrovska

(UN)DESIRED IMAGES: EVERYDAY ATTITUDES TOWARDS PEOPLE WITH COGNITIVE IMPAIRMENT AND MENTAL ILLNESS

Children and adults with congenital or acquired cognitive impairment are perceived in a very contradictory way by society. Because of the impossibility to understand the motivation and explain the behaviour of people with cognitive and intellectual disabilities, the natural reaction of others is often to spontaneously retreat and avoid contact, or to attempt to create a generalized, simplified image of this group of people so as to explain and predict a behaviour that is incomprehensible to others.

Such a collective (often unconscious) effort may result both in bringing the ‘incomprehensible’ group closer to the community by representing it as harmless and well-intentioned, and in its ever stronger rejection by constructing a collective image that demonizes it.

This article aims to study those two possibilities by tracing everyday practices in the public representation of two groups of people in Bulgaria: children living with cognitive impairment and adults living with mental illness. It traces the way the images of these two groups are present in the Bulgarian public sphere and the extent to which the social attitudes projected on these images ensure their integration into or exclusion from the community. In other words, we are looking for an answer to the question: What does a ‘normal’ society need in order to accept a group of ‘different’ people? Does its acceptance have to do with information acquired thanks to the person’s morphological physical features (e.g., the specific eye shape of people with Down syndrome), socially acceptable behaviour (e.g., the person’s ability to smile, to say ‘hello’, to speak in a moderately loud voice, to look ‘neat’), speech, age, predictability of actions, life experience?

> I think people aren’t explicitly afraid of madness, they don’t say to themselves, ‘I’d rather have a physical disability than schizophrenia.’ For them madness is something they don’t think about… As a society, we cannot

> become empathetic because we cannot imagine what it's like to hear voices – it's much easier to imagine what it's like to be blind or deaf. It's hard to associate yourself with mental illness because it is a breakdown of the mental apparatus; it's hard to empathize with it.[1]

Boundaries of 'Normality'

The concept of 'norm' has different dimensions. Provisionally, a person is considered 'normal' if they are healthy, that is, if they do not have a severe physical or mental disability, have passed successfully through their developmental phases, and are not in an unbearable cultural or value conflict (Onchev, 2001).

Since mental health is a term associated with the state of emotional, mental health and perception, one can speak of mental health norms. On the other hand, however, there are social norms which sociologists associate with the observance of *informal conventions regulating behaviour in society*. There is also a third perspective based on the understanding of morality as a system of rules of moral behaviour in society which determine and regulate the behaviour of its members and the capacity of the individual to understand and follow these rules. In this sense, any behaviour deviating from what is accepted as normal is usually subjected to social 'constraint' through relevant attempts to define and frame it. This approach towards 'differentness' naturally refers us to the well-known theoretical concept of stigma elaborated by Erving Goffman (1963), who views stigmatization as a specific social process that attacks the levels of 'differentness'.

In essence, stigmatization is an interactive social process in which specific human traits are assumed to be not only different but *deviant*. It is also a form of social comparison that can be found in every society regardless of the cultural or historical context. The process of social stigmatization is collective, as is the process of collective acceptance of difference.

Stigmatization forms a shared, socially maintained and often enduring concept of norm. That is also why the process of stigmatization is directly connected to the processes of alienation and, ultimately, exclusion. Although every human feature can be stigmatized, the dominant community always has the powers and the means to decide exactly which differences are unacceptable in perpetuity. One may hypothesize that stigmatization is driven by, inter alia, the urge to categorize differences, to outline the admissible deviations from the norm, and to acquire a feeling of control over life.

The attitude towards disability, however, has always depended exclusively on the presence of an external sign of disability. That is because the visible peculiarities – morphological features of the face and body, the presence of mobility aids, etc. – indicate to the average citizen that this is not an instance of spontaneous, inexplicable, or (presumed-to-be) threatening behaviour, but a behaviour that is predetermined by a specific condition/disorder of the person in question. The external sign brings explanation, knowledge; it seemingly even has the power to 'exonerate' its carrier in the eyes of the community, to serve as a bridge between the 'normal' and the unacceptable, incomprehensible behaviour (Suziedelis, 2006). This is confirmed by parents of children with autism:[2]

> Sometimes I wonder whether it wouldn't have been better if he were in a wheelchair… like other children from the Community Support Centre; then at least I wouldn't have had to explain and blush.
>
> [W]e have problems with society now, too, especially those of us who have children with mental illness. A visible disability can be seen. But suddenly, when they look at her – she doesn't correspond to her age, she's 30 but has the mental age of a 12- or 13-year-old. Be it on the bus or at the bus stop, if she breaks into tears she starts shouting because she has a specific way of crying – she wails and screams. Whenever she doesn't have her way or you slightly disagree with her, even if you just say 'no' when she asks something, she can start screaming and people will immediately start saying, 'How ill-mannered she is!' We're trying to deal with this attitude… I still haven't come to terms with it.

Although it gives rise to labelling, an external sign of disability often serves as a signal to the public that the disabled person might need support, care and assistance in their everyday life and, as a whole, it arouses empathy. In cases of cognitive impairments that do not always have specific external signs, we may suppose that the public reaction will be significantly stronger and negative because the deviant behaviour will be attributed either to 'bad manners' or to hostility, which is felt to be an immediate threat to the individual, the community, and public order.

> Generally, people are very sympathetic towards people with physical disabilities and illnesses, towards those with some specific needs… they tend to be teary, compassionate, sentimental, which is also a type of stigma – you have to pity him because he will never have the life he should have.

Images: Children with Cognitive Impairment

Probably very few people don't know that children with Down syndrome are called 'sunny children'. Unlike people suffering from cognitive impairment but without any morphological signs of it, attempts at demonizing children with Down syndrome have been firmly rejected for at least a decade now. Historically, women who gave birth to children with this genetic disorder were actively encouraged to leave them in an institution as it was presumed that such children had little, if any, chance of having a full life. In other words, it took a long time, as well as many international advocacy and information campaigns, for public attitudes to change and make the mental transition from 'monstrous children' to 'sunny children'.

As for children in general, we may also look for arguments in the traditional perception of the child as a symbol of purity, innocence and goodness, which is at odds with the negative idea of deviance. The idea of unacceptable behaviour is associated rather with 'bad parenting' and very rarely attributed to difficulty in development or to a disability that impedes the child's self-regulation, self-reflection and possibility to participate in social life in the way expected by others. This last is especially valid for children with 'hidden' impairments such as those on the autism spectrum. Unlike them, children with Down syndrome have distinctive features that make them identifiable – this, in turn, can have a positive effect on the attitude of others as it signals the need for aligning and adapting communication with them.

The image of people with Down syndrome as 'sunny children' has several problematic aspects that lead to alienation of this group from the life of society and merit attention because, despite the good intentions with which it was created, it is ultimately once again a generalized, stigmatizing image.

Thanks to the many international advocacy campaigns supporting the integration of marginalized communities and raising public awareness of the challenges facing people with disabilities, an ever larger part of the public is learning about aspects of life with disability. But does the image of people with Down syndrome as 'sunny children' ensure unconditional acceptance, or does it reduce matters to cultivating public tolerance conceived of in its original (religious) sense – as endurance?[3] Endurance and forbearance as a specific attitude towards the subject's behaviour usually discreetly imply making an effort to endure an unpleasant, irritating event or phenomenon, something that is beyond one's comfort zone. This attitude is qualitatively different from acceptance in that it implies that there is an 'irritant' which, for some reason, has to be endured, not accepted and evaluated in their unique entirety.

Recent years have seen a positive trend in policies designed to foster a positive attitude towards people with disabilities – namely, a declining emphasis on the friendliness and harmlessness of the group that is meant to be included, as its main trait (and principal worth). Conversely, there has been a growing emphasis on the skills and potential of people living with different disabilities.[4] This specific, significant change of approach can be seen also as indicative of the changes taking place in the way of thinking about and behaving towards a given phenomenon in a society.

The exclusive emphasis on the 'affectionate kindness' of children with Down syndrome as their definitive trait could be accepted as indicating society's failure to recognize the worth of the members of this group. Their depiction as gentle or harmless is often followed by their problematic association with passivity, consumption without any contribution to society, lack of potential for autonomy and development. This approach contributes to 'endurance', not to acceptance or inclusion which require preserving the other's dignity and thinking of and evaluating the other in terms of their own abilities and uniqueness. Last but not least, an unrealistic image of and expectations about those who are 'different' are created in society – an image and expectations that do not facilitate but impede their social integration.

The public image of children on the autism spectrum is the very opposite of that of children with Down syndrome – whereas the stereotype of the latter is associated with friendliness and sociability, the prevalent traits in the image of autistic children seem to be aloofness, self-absorption, often also aggression. Among the reasons for this is that autistic children are usually noticed in public because of their 'socially unacceptable' behaviour, which may include self-harming, screaming, self-stimulating noises, various motor stereotypes or destructive behaviour. Few realize that in the majority of cases, such behaviour is due to sensory overload as many autistic people suffer from sensory hypersensitivity, and is by no means intended to cause harm or to disturb public order.

There is also another stereotype of autism – namely, the ascription of extraordinary qualities, talents and abilities to people on the spectrum. Although this holds true for some (the so-called high-functioning autistics), this generalized notion of all people on the spectrum does them and their loved ones more harm than good. In both cases, what we see is reductionist thinking of the autism spectrum which leads to misconceptions about autistics. The autism spectrum is diverse and complicated, and any attempt to reduce it to a specific, explicable phenomenon is bound to be futile. Some authors have defined it as a 'narrative condition' (Yergeau, 2018, pp. 1-2, citing Duffy and Dorner, 2011) because its content and personal meaning can be understood only through the stories about it and the shared individual experiences of people on the spectrum and their carers.

One of the reasons why people are much more confused about autism than about Down syndrome is that autism is a *spectrum* disorder, meaning that it refers to a very wide range of conditions. Another is the common misinterpretation of autistic behaviour as a refusal to follow the mores and to take part in the life of society in a socially acceptable way, that is, as a rejection of society which, in turn, seems to react spontaneously by rejecting such behaviour.

It is also important to note that autism spectrum disorder (ASD) is still regarded as a novel disorder – unlike Down syndrome, which is much more identifiable. Autism has often been compared to a 'pandemic' because of the many cases diagnosed in recent years. This is a controversial thesis because, according to the international psychiatric community, the incidence of autism in the past was not very different from what it is today – the only difference is that the condition of autism was not known as such.

The stereotypical thinking about children with cognitive impairment as 'eternal children' who will never leave the innocent world of childhood is a problem that reveals also society's incapacity to deal with their natural growth and transition to the world of adults. The insistence on the idea that these people practically 'will remain children forever' because they are commonly seen as helpless, incapable and dependent is frustrated by the inevitable fact of their physical growth and maturity. All of this has a series of effects related to perceptions of one's own body, sexuality, autonomy and responsibility thought of in the context of the individual abilities of every individual but invariably present in the mature years of his or her life. This is a significant problem that merits special attention and study.

Images: Mental Illness

According to the Bulgarian *Dictionary of Psychology*, 'cognition' means a cognitive act in which a person acquires, organizes, or structures and uses knowledge; a system of rational-meaningful components of the psyche as opposed to its emotional-affective components (Desev, 1999, pp. 219-220). Another definition is 'the capacity to understand, think and learn, and to resolve complex tasks in an adequate and economic way' (Mechkov, 1995, pp. 89-90). Impairments in this capacity are found both among children, as discussed above, and among adults suffering from various forms of mental illness. The stigma of mental illness in Bulgaria is very strong, and this is unsurprising – it is a natural continuation of the commonplace negative attitude towards children with 'invisible' impairments such as ASD.

> They used to refer to her invariably as 'the child', but she was a woman of 40 who had never seen a psychiatrist, never undergone treatment, never worked – she just sits and colours all day long… they speak with a psychiatrist by phone… and I tell them, 'What do you expect to happen, you're 25 years late in coming [to see a psychiatrist], what do you want to happen?! No, most probably we won't be able to help you' – that's the sort of withdrawal from the real world we're talking about. Imagine being so unable to accept that your child has a mental illness and needs help that you withdraw from the world and create a whole new reality – I don't know if you can grasp the scale of this…

Eva Kittay, one of the groundbreaking philosophers in the field of care ethics drawing public attention to the problems of people with disabilities and their carers, highlights a particularly important aspect of care for people with cognitive disabilities – the way individual members of the affected community or the whole community are represented in different public discussions. She calls for paying the necessary attention to the problem of the exclusion of certain groups (or of their representatives) from the political debate on measures concerning the life of the relevant group (Kittay, 2009, pp, 130-131).

> We see this exclusion especially clearly when those people who are usually invisible do make an appearance in the theoretical work. Their presence is primarily used to underscore a point, to seal an argument, or to provide a con-

> trast between those within and those outside the scope of the theory. In their role as placeholders rather than participants, as instruments of an argument rather than the subject of discussion, they are invariably misrepresented, and reduced to stereotypes. (Ibid., p. 130)

This problem can be seen clearly in the context of Bulgarian reality as well, in particular when it comes to the dominant public image of adults with mental illness, an image built with the 'significant contribution' of media:

> Mentally Ill Man Brutally Kills Dog in Blagoevgrad
>
> Aggressive Mentally Ill Man Arouses Police in Sofia
>
> Mentally Ill Man Barricades Himself in His Home
>
> Mentally Ill Man Assaults Nurse[5]

The stigma of adults suffering from mental illness in Bulgaria comes from their generalized public image as people who have a set of anti-social characteristics that drive society to distance itself preventively, seeing them as an immediate threat to its life. Some of the most common prejudices against people with mental illness in Bulgaria are that they are: 1) 'unpredictable'; 2) 'aggressive'; 3) 'acting spontaneously and irrationally'; 'incapable' of participating in the life of the community. This generalized image is due to the inability to understand, and hence, to empathize with the mental suffering and disintegration felt by the mentally ill, and it is confirmed also by the observations of the professional community on the stereotypes of mental illness in Bulgaria:

> First, that [mentally ill] people are dangerous; they are dangerous in an absolutely unpredictable way – right now, all of a sudden, they'll pull out a knife and kill you; they are dangerous, aggressive, unpredictable, they can't work, they can't create lasting relationships, they can't be accountable for their own actions, they shouldn't have children because they can't look after them; this is untreatable, it can never be cured: 'Once mad, forever mad.'

Those stereotypes are the product of psychological defence mechanisms as well as of the lack of information and public dialogue on issues concerning life with mental illness. In addition, there is very little specialized care for these groups of people and for their rehabilitation in Bulgaria, which impedes – and often makes impossible – their inclusion into the life of society. An article on the state of psychiatric care in Bulgaria (France 24, 2018) quotes the President of the European Psychiatric Association as saying that '[i]t is extremely dangerous for physical and mental health to spend hours and hours doing nothing.' The same article also notes that under the communist regime, there was a farm near the psychiatric hospital in Kurilo where the patients could work, which was a form of rehabilitation.

Whereas the process of learning and practising new strategies of coping may include professional or educational activities, it must be clear that work or education are not the goal of rehabilitation activities – just as learning to swim is not the goal of aquatic therapy. The main function of rehabilitation activities is to support people with mental illness in developing capacities to manage its symptoms in everyday life, in a supportive and caring environment.

The stigmatization and exclusion of people with mental illness in Bulgaria can be traced back to the late nineteenth and early twentieth centuries, when the term 'moral insanity' began to be used in Bulgarian clinical (and forensic) practice (Mircheva, 2016). Gergana Mircheva (ibid., p. 7) points out that a normative reference to the concept of moral insanity is contained in Article 3 of the 1905 Regulations for Caring for the Mentally Ill, which stipulates that mentally ill shall be considered 'all persons who, due to abnormal mental organization, even without demonstrating some severe mental impairment, display impulsive and morbid inclinations or significant moral shortcomings.' Regrettably, such a tendency towards negative public representation and condemnation has survived in Bulgaria to this day, the main collective tendency being towards placing people with mental illness at a 'safe' distance from the life of the 'normal' society. This tendency is excused with arguments regarding the need to protect the lives of the individual members of society as well as the established order and norms of social/shared life.

> If anything can truly help to overcome stereotypes, it isn't information campaigns – it's personal experience and, moreover, positive personal experience. If you've never met someone with mental illness and you come along and encounter someone who has mental illness, but you encounter a positive story, you see they have a chance. What do the media do? They publish headlines such as 'Schizophrenic Kills His Mum'; the portrayal [of people with mental illness] is totally negative. There are statistics that people with mental illness don't commit more crimes than the others, but despite this those myths are maintained because we need to have someone who is the bad, the strange, the odd guy.

In Lieu of a Conclusion

The public images of children and adults with cognitive impairment in Bulgaria, examined in this article, have quite a few similarities. Despite the well-intentioned and often condescending attitude towards children with cognitive impairment which includes positive symptoms (as in genetic disorders such as Down syndrome), there is mostly a lack of policies and practices aimed at their social inclusion in the life of the community without reducing them to a collective image in which their harmlessness is their principal worth.

The case of adults with mental illness is the very opposite – what we see is demonization of a collective image of 'the mad' and panicky rejection of this group of people because their stereotype is laden with negative characteristics used as an excuse for their social exclusion. It is noteworthy that a different mechanism of exclusion is at work in the two cases – in the first case through seemingly positive efforts at naming and defining, and in the second through overt, aggressive stigmatization of a collective image (as in the first case) of 'abnormality'.

> Why are those people out in the streets, why don't they treat them, why don't they take their pills, why aren't they in a special place where someone will care for them because they can't, and will never be able to, care for themselves.

The case of children with ASD and of others whose disabilities are not visible at first glance seems to be delicately in-between the two noted above – the innocence of childhood still has a (temporary) advantage but, over time, they are bound to be stigmatized as the undesired, different Other. Changing this unhappy prospect is not up to children and adults with cognitive impairment, it depends above all on the collective efforts and sensitivity of us 'normal' people.

NOTES

[1] Quote from a focus group discussion with mental health specialists conducted under the project *Generational Patterns of Coping with Life Crisis: Biographical, Social and Institutional Discourses* implemented in 2017–2020 with the financial support of the Bulgarian National Science Fund.

[2] Unless otherwise indicated, all subsequent quotes are from biographical interviews conducted under the project *Generational Patterns of Coping with Life Crisis: Biographical, Social and Institutional Discourses*.

[3] The Oxford Dictionary defines 'tolerate' as '1. Allow the existence, occurrence, or practice of (something that one dislikes or disagrees with) without interference. 1.1 Accept or endure (someone or something unpleasant or disliked) with forbearance', cf. http://www.oxforddictionaries.com/definiton/english/tolerate (accessed 15 December 2018).

[4] Telling in this respect are the following international campaigns: the Canadian Down Syndrome Society's 'See the Ability' campaign, the 'Don't DIS my ABILITY' campaign in New South Wales, Australia, and UNICEF's 'It's About Ability' campaign.

[5] The online media which published these four headlines are deliberately not named to avoid generating traffic to websites that use unethical language.

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ADDING LIFE TO DAYS

Scientific innovations constantly open new horizons for treatment and control of diseases that were considered to be incurable. The development of technology and artificial intelligence, research and discoveries in genetics, neurology, oncology, radiology, pediatrics, and other spheres, have revolutionized medicine, increasingly expanding the range of people who are given a (new) chance to live a full and meaningful life. In all likelihood, in the foreseeable future, artificial organs, tissues and blood, medical robots and sensors will radically change our ideas of health and disease, of diagnostics and treatment, of suffering and pleasure.

Today, however, there still are diseases whose cure remains elusive. There still are conditions we euphemistically call ‘serious illnesses’ – ‘life-limiting’, ‘life-threatening’ or ‘incompatible with life’ (Petkova, 2015). That is why the decades since the 1960s and 1970s have seen the intensive development of *palliative care* for children and adults – specialized medical, psychological, social, and spiritual support for patients with serious illness and their families.

Contemporary palliative care aims to relieve the physical suffering of patients with serious illness (Toleva, 2004). But that is not all. Palliative care specialists say their aim is not merely to add more days to the life of patients but to add more life to their days. The goal of palliative care is to help preserve the personal dignity, to provide the highest possible quality of life for patients and their families, to ensure full social realization and civic activity. That is why the sphere of palliative care is becoming increasingly professionalized and formalized – the issues of disease, disability, suffering and death have left the private sphere of the families concerned and have become the *object of deliberate and sustainable health and social public policies* (Cassel, 1986).

Bulgaria and Cyprus, however, are still the only EU countries without a legal framework for the provision, scope, and control of palliative care.[1] In Bulgaria there are no data on the number of people in need of palliative care, on the types and incidence of their diseases, on the geographical distribution of patients, and on their personal needs and their families’ problems. Without such basic information, the subject of palliative care will inevitably remain confined to the realm of ‘individual cases’ of unhappy families ‘unhappy in their own ways’, and cannot be converted into thought-through public policies.

That is why a team of the IDA Foundation developed a project titled *Mapping Pediatric Palliative Care Needs in Bulgaria*. The project won financial support from the TELUS International Community Board and was implemented in the period between October 2018 and June 2019 by the following team: Dr Boyana Petkova (physician), Aneta Morfova (psychologist), Margarita Gabrovska, PhD (bioethicist), Svetla Encheva (sociologist), and Venelin Stoychev, PhD (sociologist).

The project included a *pilot study* on pediatric palliative care needs in Bulgaria consisting of: 1) an online questionnaire survey of public opinion and 2) in-depth interviews with doctors, patients, and parents. The online questionnaire was open between November and mid-December 2018, and was filled by 801 respondents via SurveyMonkey. A total of 28 people – doctors from Sofia, Plovdiv, and Stara Zagora, psychologists, parents, and patients – responded to the invitation for interviews.

The project results have proved that there is a huge need for an in-depth study on pediatric palliative care needs in Bulgaria. Approximately five to eight thousand children in Bulgaria need palliative care. At the same time, there are vast differences of opinion, including among specialists, as to what pediatric palliative care consists of and how it ought to be organized.

In Bulgaria, the issues of child suffering and child mortality are still regarded as personal issues of the families concerned, not as a social problem that must be addressed by deliberate public policies. There is an urgent need for an in-depth debate on the value of children's lives and on the priorities of Bulgarian society.

Introduction

Contemporary notions of 'an ideal world' do not include ill children and suffering. But nature presents us with floods, earthquakes, wildfires, disease and death. Some cultures accept these natural phenomena with humility and submission. The promise of the modern Enlightenment for possible happiness on earth still prompts us to challenge nature, to strive to alleviate pain and suffering, to fight disease and pursue our dreams (Ariès, 2008).

Modernity is ambivalent, however. On the one hand, classical modernity standardizes, establishes 'norms' and 'standards', unifies, rationalizes, fragmentizes. Classical modernity measures disease in terms of deviation from the norm, bureaucratizes treatment, develops standards and protocols that are designed to exclude emotions, to minimize the impact of chance, to measure disability and the likelihood of recovery through statistical conceptual tools – in a nutshell, to turn the issues of life and death into the subject of an economic rationality. That is why resources are 'invested' in health, in healthcare, in children, etc., in the same way as in any other economic enterprise, and health insurance systems are expected to lead to 'added value', to a profit understood most generally as able-bodied taxpayers contributing to GDP growth.

On the other hand, also at the macrostructural level, modernity builds and reproduces a consciousness of belonging to the imagined community of a *Humanity consisting of (potentially) rational citizens* who are part of Us, with whom we weave the 'invisible threads' that hold together our common, shared world. In this sense, care for and attention to every member of Humanity who is in distress is care for the conditions of possibility for the existence of Humanity itself.

Of course, those two trends develop simultaneously and their manifest forms constantly interfere at the everyday level. We mention them here only to elucidate the macrostructural premises of the public discussions that pose a series of moral dilemmas: To what extent should doctors talk with patients, or save their precious professional time? Should non-specialists try to understand a super-professionalized scientific subject-matter that may be unfamiliar even to specialists in related spheres? Is it right to give birth to a baby prenatally diagnosed as disabled? To what extent should treatment be provided to patients who haven't contributed and/or are unlikely to contribute to a society's economic development? What are the moral boundaries of resuscitation, abortion, assisted suicide, and so on?

Those questions are examples of a value debate in which there are no universal, acontextual answers – there is an entire thesaurus of possible solutions. The modern world produces, by definition, a vast variety of value systems, but when it comes to human values there neither is nor can be a universally recognized grading scale. That is why it is so important to conduct a public debate on the definition of the *common interest*, of *the common good* – of the conditions of possibility of the field that allows fair and just pursuit of citizens' private interests.

Here we understand the *common interest as a striving to give birth to and raise healthy children who will have a chance for full social and civic realization*. Pregnancy planning, monitoring, prophylaxis and prevention are the instruments that protect the public interest most efficiently and effectively. But even the best prophylaxis cannot prevent certain illnesses. Such cases require specialized medical competence, professional equipment, (expensive) medications. The common interest is to enable the health system to identify, through screening and regular checkups, such illnesses as early as possible and to intervene adequately before there are more serious complications, recurrences, chronification and/or disablement.

But although nowadays more and more (pediatric) diseases are curable, there still are some that are not. There are 'serious illnesses' that threaten the life (and/or limit the life expectancy) of some (child) patients. What is the common interest in these cases? When should a pregnancy with a diagnosed fetal abnormality be terminated on 'medical grounds' and when should the parents be entitled to make an informed decision whether to keep the 'fetus'? When is it right to invest precious resources (time, equipment, expertise, medications) in risky attempts to prolong the life of a suffering child, and when is it right to alleviate or end their suffering? When can a child with a serious illness stay in their family, and when should they be provided with professional medical and social care in various specialized institutions? Could raising such a child in the family threaten the psychological development and social life of the other children in the family? How should a child who is, for example, a cancer survivor, be re-socialized so as to protect both the child's interests and the interests of the other children in the family and community? And so on.

We in Bulgaria haven't yet conducted a reasoned public debate on the common interest in this sphere. We haven't even begun such a debate. In this sense, the present report has precisely a pilot character of mapping – its goal is to construct a *reference framework* for more detailed future studies, to outline the possible boundaries of the field of pediatric palliative care in Bulgaria, to develop research sensitivities and a terminological toolkit that will enable a deeper understanding of the subject. That is why the presented findings and conclusions have the character more of hypotheses subject to further empirical verification than of established 'facts'. They have the status of questions that merit public discussion.

(Mis)Conceptions of Palliative Care

If we assume that the children and adolescents (aged 0 to 18 years) who need palliative care are a certain part of the population and if we take as a point of reference the Scandinavian countries, Germany and France, about which public data are available, then we could estimate that the annual number of children and adolescents in Bulgaria who are in need of professional palliative care is approximately five thousand. The indicators of maternal and child health in Bulgaria, however, are several times worse than those in the above-mentioned countries,[2] therefore it is reasonable to estimate that the number of children and adolescents in Bulgaria who need palliative care could be in the range of six to eight thousand.

The results of the present qualitative pilot study show that in Bulgaria there is still a lack of clarity about what (pediatric) palliative care means. As one of the interviewed doctors put it, 'if the parents learn that there is a palliative care specialist in our hospital, they will probably say to themselves that we haven't yet diagnosed their child but we are already about to bury him or her.'

Still, the in-depth interviews allowed us to identify several different conceptions on the subject. The most typical notion of palliative care includes a *palliative care specialist* who is on the staff of a healthcare facility that treats serious illnesses and who advises the other doctors, the patient and their family how to alleviate the patient's physical suffering. According to some interviewees, this palliative care specialist may also take part in informing the family of a serious diagnosis or of the death of their loved one, but again within the premises of the hospital concerned. Here palliative care is associated with death and the last moments of life.

The second type of notions of palliative care is that there should be *palliative care units* in every hospital that treats serious illnesses. According to the respondents, these units may include different specialists in palliative medicine, psychologists, psychiatrists, rehabilitation therapists, speech-language pathologists, etc. The palliative care units should be in, or in immediate proximity to, the hospital so as to enable 'fast access to other specialists, equipment and facilities should the need arise'. In this view, the purpose of palliative care is not so much to support the ill child but, rather, 'to protect the other children at hospital units who have a better chance of recovering', sparing them the sight of a dying child by moving the latter to another room.

The third typical notion of (pediatric) palliative care identified by the survey includes building a *separate hospice*. As a rule, the hospice is expected to be located somewhere in a park or in a forest, 'in a quiet and peaceful place, not as in our case between two busy boulevards'. At present, the facilities that come closest to this notion of palliative care are the so-called homes for medical and social care for children (HMSCC).[3] But here, too, there is a lack of understanding that the ill child can be part of the community and that the members of the community can be part of palliative care, providing support to the child and their family, expressing compassion and sharing a common world.

Symptomatic of the lack of information and debate on the subject of (pediatric) palliative care in Bulgaria is the fact that during the in-depth interviews almost all doctors asked the interviewers what we meant by palliative care, where we expected palliative care to be provided and how we expected it to be organized. Such a response is explicable considering that *in Bulgaria palliative medicine is not taught in medical school, the experience of Bulgarian doctors who have worked abroad is very specific, and there is no legal framework for pediatric palliative care*.

Palliative care is not mentioned at all in the Medical-Treatment Facilities Act. According to Article 96 of the Health Act, palliative medical care includes 'medical observation; healthcare aimed at providing care to the patient, removing pain and the psychological and emotional effects of the disease; moral support to the patient and his/her relatives.' The Health Act claims that '[t]he objective of palliative medical care shall be to maintain the quality of life through reduction or elimination of some immediate signs of the disease, as well as the related adverse psychological and social effects.' Although the Act stipulates that the requirements regarding the provision of palliative medical care in Bulgaria are to be set out in an ordinance issued by the Minister of Health, such an ordinance has not been issued to date. Insofar as the subject-matter is legally regulated at all, this is done through Ordinance No. 49/2010 on HMSCC, Ordinance No. 6/2018 on Medical Standard 'Medical Oncology', and Clinical Pathway No. 253 'Palliative Care for Patients with Oncological Diseases', which provides for up to twenty days in hospital in six months during the terminal stage for adults.[4]

To put this into perspective, let us remind the reader that the idea of (pediatric) palliative care includes support for the whole family of a child with a serious illness. In this sense, palliative support for the parents and siblings continues also after the child's death.

However, the issues of the quality of life, full social realization of the ill child, contacts with peers and friends, care for the other children in the family and in the community, professional and civic realization of the parents, and so on, are not considered to be part of pediatric palliative care, according to the typical notions of palliative care in Bulgaria – that is, 'a palliative care specialist in the hospital', 'service' provided by the HMSCC, or even 'hospice in the park'.

Very few of the respondents in the in-depth interviews conducted under the project had a clear and detailed idea of what (pediatric) palliative care means (should mean) and how a modern hospice for children with serious illnesses should operate. Hence, the results of the online questionnaire survey are also unsurprising. Fewer than 10% of the respondents to the questionnaire had ever heard of a hospice for children, and fewer than 1% had heard of it often. The overwhelming majority of respondents (85%) did not remember ever hearing of a hospice for children with serious illnesses before our survey. Let us remind the reader that the participants in the survey are very active and well-informed people, with significantly higher incomes and education than the average in Bulgaria, who are interested in health and social issues.

The Insider's Point of View

In this report on the pilot study we will not go into details on some critically important issues, such as the motivation of doctors, their relationship with patients, opportunities for professional and career development, cooperation with colleagues at the international level, teaching, and so on. We will focus only on the context of the problem of pediatric palliative care in Bulgaria: *to what extent does the Bulgarian healthcare system protect the common interest* of having and raising healthy children? To what extent does the established and functioning institutional environment guarantee prophylaxis and prevention, early diagnosis and adequate intervention in child healthcare before there are complications that require (expensive) additional resources, take time, and sap emotional energy and public trust?

We must say straight away that the interviewed doctors well know and weren't surprised by the official statistics, according to which Bulgaria is ranked last in the EU when it comes to maternal and child health. The problem is that, according to many of the doctors, between six and eight out of every ten children who are diagnosed with a serious illness and die could have been saved if there was an efficient screening and early detection system in Bulgaria. For example, here is the frank opinion of a doctor from Sofia with years-long experience in pediatrics:

> We have many cases in which we lose patients because the system hasn't ensured diagnostics, because the system hasn't ensured [adequate supply of] medications. Sometimes we're talking about medications that cost 20, 30, 40 euros – which is a shame.

Whereas it may seem that this opinion was voiced in an objective, detached manner, without personal emotions, many of the other interviewed doctors refused to accept that the facts about child mortality in Bulgaria should be analysed in an entirely impartial manner and that the doctor must be a person with 'a heart of ice' who switches off their emotions when they are at work. That is why:

> Every single loss is very distressing for me. I've chosen a specialty in which patients don't have to die.

During the in-depth interviews, the doctors gave many examples of babies and young children arriving at the specialized hospitals too late because of bad roads and shortage of transport incubators and ambulances; development of severe abnormalities because of saving money on tests and screening; mothers arriving at the hospitals with conditions threatening the lives of their babies, telling the staff, 'I had leucorrhoea but no one tested my discharge', or 'they didn't order a vaginal swab because they said it was a common fungal infection found in all women'. Here is the conclusion of a neonatologist:

> We don't have a unified protocol on how to monitor a pregnant woman. As a result, everyone does what they've made up their minds to do. The final result is many lost patients and sometimes severe abnormalities that lead to children with conditions that are incompatible with life.

Although they put it in different words, all interviewed doctors insisted that:

> Bulgaria as a state, as institutions, is very much in debt to its children.

This debt begins to be incurred long before children are born, even long before they are conceived:

> Including something that is extremely important: [the other countries of Central and Eastern Europe] provide prenatal diagnostic testing for families. This is very important to the other societies because that's how they invest in future healthy generations.

In Bulgaria, the usual (political) response to accusations of malfunctioning of the state (in this sphere) is that healthcare is expensive. This is not the place to cite the numerous economic studies conducted in recent decades which unambiguously prove that it is far more advantageous for a society to invest in healthcare than to pay for the consequences of a poorly organized healthcare system. But there certainly is a financial problem and this problem is not unimportant. Almost all interviewed doctors could reel off a detailed list of missing equipment and medications. Also important are the resources allocated for rewarding doctors for their professionalism. Doctors insisted that it is impossible to support oneself solely on one's salary at a state hospital and this has an adverse effect on patients:

> The heavy workload of doctors, who are forced to take on a second or third job, limits your capacity to pay attention to your patients.

However, the present pilot study has found unambiguous evidence in support of the thesis that the main problem of (maternal and child) healthcare in Bulgaria is not the lack of resources – it is the way the available resources are managed. The contrast between the officially declared assets of some directors of state and private hospitals, which amount to several million leva, and the salaries of doctors, nurses and lab technicians even in the medical-treatment facilities managed by those directors, shocked the Bulgarian public.[5] Whereas in countries with a very well-developed healthcare system in the Western world the differences between the salaries of the highest-paid and the lowest-paid doctors in the same specialty are by a factor of 1- to 2-fold, many doctors in Bulgaria say that here the differences reach a factor of '15- and even 20-fold'. At the same time, Bulgaria remains the only EU country where more than half of the healthcare costs are covered by individuals, not by the health insurance system. In addition, there is a huge problem with the legitimacy and efficiency of the healthcare financing system. Here is a very typical example given by a geneticist from Sofia:

> I can spend BGN 600 on something I don't need but which is included in the clinical pathway. But I can't do a test that costs BGN 400, which I need but which isn't included in the clinical pathway…

Here is another very typical example that sums up perceptions of the efficiency of clinical pathways in Bulgaria:

> The problem is above all an administrative one. The [National Health Insurance] Fund harasses us a lot. The [clinical] pathways are the most inconvenient possible [method of] work. We are forced to transfer children from one pathway to another because the longest one available to me is 15 days. But there's no place in the world where a baby weighing 700 grams can be discharged in 15 days.

As a result of this, the specialized hospitals generate losses if the doctors conscientiously fulfill their duties (to the youngest patients):

> We report doing some sort of tests, but in reality we do much more than what we report.

This ‘much more’, especially when we are talking about pediatrics, includes the time devoted to reassuring and convincing parents. Only one of the participants in the study was categorical that his job was to diagnose and prescribe treatment for the child, not to deal with the issue of whether the parents believed him and would follow his prescriptions. All other doctors and psychologists were categorical that care for the parents is part of the care for the child, that ‘50% of the child’s treatment is in reassuring the parents’, that ‘if I don’t win the parents over as an ally, I can’t be sure I’m doing the best for the child’. Some doctors pay a price for this attention: ‘my boss scolds me a lot for what she claims is paying too much attention to the mothers and for spoiling them’; ‘many colleagues are angry with me for explaining to parents, claiming that in this way I’m creating the expectation that they, too, must explain, but they don’t want to.’ But talking with parents isn’t what devours the doctors’ time:

> A quarter of my time is spent on administrative work – three out of twelve hours.

Administrative work in itself isn’t what the doctors are most indignant about. In every sphere of work in modern societies there is a need for formalization, accountability, and (mutual) control. The bigger problem is that the way administrative work is organized doesn’t help doctors perform their professional duties, it hinders them:

> This happens constantly, definitely. They constantly … come to me with strange diagnoses. And we question the parents and they tell us something completely different. Very often, they have been warned. They know that this isn’t the [true] diagnosis, the doctors have simply written it down so that the child can be admitted to the hospital for further assessment.

On the other hand, falsifying diagnoses because of the requirements of the clinical pathways is entirely morally justified. Here is a typical opinion that none of the interviewed specialists called into question, especially if it refers to critical situations involving children with serious illnesses:

> We must reckon with what’s provided for by the pathway, not with what the child needs. But no child will survive if we do only what’s written in the pathway. That’s why we do everything [necessary] for the child and when at the end we finally do the paperwork, nobody else will be able to understand [from the paperwork] what really happened.

Thus, the healthcare system in Bulgaria has succeeded in doing something that defies modern physics, that is, splitting reality and building parallel worlds:

> We write a diagnosis – yes, the child has this diagnosis, but it isn't the only one the child has. We have parallel worlds: one documentary and one that treats the child. We orally brief one another on what's happening with the child.

There is no doubt whatsoever that the poorly organized clinical pathways, which force doctors to reside in two parallel worlds, are a profound problem of the Bulgarian healthcare system. But here there is an even deeper, systemic problem: some interviewed doctors directly declared that the healthcare system in Bulgaria is less a 'health-loving' than a 'health-loathing' system that views patients 'as an ATM'; that the system doesn't encourage protection of the common good through prevention, prophylaxis, early diagnostics, and sparing intervention – it encourages dubious and unnecessary hospitalizations, tests with unproven effectiveness, and artificial deficits (of access to specialists and equipment). Here is how things look in the eyes of a doctor from Sofia:

> Prevention is the best treatment. It's a matter of lack of organization. If this thing [prevention] is organized, it will cost less. We don't do neonatal screening, for example. We let patients become disabled and then pay them disability allowances, albeit low ones.

Thus, the parallel worlds, or, to call a spade a spade – the normalization of fraud – has turned into a state policy.

> I'm categorical that Bulgaria is a country with a policy that is genocidal towards children… Bulgaria is the only country in which doctors dare to issue fake vaccination certificates, for example.

But could things be different? What did the doctors who have experience working abroad, in other healthcare systems, say?

> Everyone's motivated there. One [of the incentives] is financial. Doctors have one of the highest living standards. But that's not all. The system is designed in such a way that they have to constantly prove themselves. The system obliges them. You may have worked for twenty years but you can't rest on your laurels, the system obliges you to prove yourself and to develop… But what's it like here? Here we beg for money from the Bulgarian Christmas[6] and from donors. It shouldn't be like this…

In addition, systemic reasons are also to blame for the state of the Bulgarian healthcare system:

> There we learn from our experience. Here it's like, 'Hush, hush, a child's died. Thank goodness the mother refused an autopsy so there won't be any lawsuits.' That's because there are no rules, you can always be found guilty. Back in the past, when a patient died they got together, discussed, looked at the mistakes. That's no longer the case. We don't learn from our experience. This model must be restored and expanded to include psychological support.

Hence, according to both doctors and parents, the problem in Bulgaria doesn't consist in the shortage of resources but in our attitudes towards health (and illness), in management capacity and administrative culture:

> Is it really a matter of money? What can't you afford financially – to invite the parents in the room, to talk with them frankly? Is that what we can't afford financially?!

Parents

According to interviewed neonatologists, 85% of the disabilities of children in Bulgaria born weighing less than 1,500 grams are due to a preventable infection during pregnancy.[7] But practically all parents who took part in this study were very responsible during the pregnancy and were regularly monitored by their supervising doctors:

> I got pregnant straight away. Everything was perfect. I was monitored during my pregnancy.

In some cases among the interviewed parents of children with serious illnesses suspicions of fetal problems appeared during pregnancy, while in others the children were born completely healthy, without any visible symptoms of illness:

> Ida[8] was the perfect child [when she born]. All her indicators were perfect. She was completely healthy. I had eight ultrasound scans, everything was perfect. I attended courses for pregnant women, exercise classes for pregnant women. I knew how to breathe, I knew how to push. She had an Apgar score of 8.9.

According to National Statistical Institute data, the majority of deaths of children and adolescents up to the age of 19 in Bulgaria occur in the first year of life – approximately and more than half of the annual total. Among the interviewed parents there were parents of a child who had developed the illness after the age of one:

> She was born weighing 2.4 kg, measuring 45 cm. At first everything was fine – she cooed, she smiled. She started walking at one year and one month. She walked well and stepped well. They said there was nothing wrong with the baby.

Mothers are usually the first to realize that there's something wrong with the baby:

> But then she started having seizures. I hadn't seen a baby, I didn't know what it was, I was a first-time mom, she'd be fine, I was told. The nurses didn't believe me, they just wanted me to go away.

Not only first-time mothers but also mothers with more experience are subjected to such mistrust:

> She started having seizures. But they told me, 'ha ha, she's a baby, she's just colicky'. Over time, she had different types of seizures. She was my second child and I knew this wasn't colic.

It is difficult to imagine what parents go through from the appearance of the first symptoms of illness until a moment such as this one:

> And they brought Ida back after the evening bath. At last, she'd had a seizure in front of a doctor and they realized I wasn't a crazy mom and finally believed me. A young woman doctor, she was still a postgraduate student, she discovered that Ida had stereotypical movements.

The attitude of nurses towards patients is the subject of another, much more detailed analysis. But we must mention even at this point that many of the interviewed doctors pointed out that not only nurses but also doctors themselves in Bulgaria need to be trained how to communicate with patients (including with children), how to tell that a patient is hiding information (voluntarily or involuntarily), how to break the news of a serious diagnosis, how to talk with family members, and so on. Most of the interviewed doctors admitted that medical workers in Bulgaria follow the behavioural models of 'older colleagues', of 'the boss of the clinic'. The doctors who have worked abroad showed much greater sensitivity to this aspect of care for the patient:

> In the UK you never ever blurt it out in front of the child and mother on the next bed. Here a doctor doing the morning round will just casually say, 'But haven't you understood that you have such and such serious illness'…

Many of the doctors who took part in the study said they aren't encouraged to pay too much attention to patients and/or their parents. The specialists who explain to parents in more detail usually feel obliged to justify their decision to devote time to the parents as part of the care for the patient, not because the parents' feelings are so important. Thus, parents are often left outside 'the field of interest'. This is how this looks from their point of view:

> We passed from 'I don't know what's wrong with this child, but she'll be fine' to an elderly professor who said, 'She's very beautiful, she can't be seriously ill.' This went on for eleven years. We never got a definite diagnosis.

As several other studies, this study also found that parents in Bulgaria are sometimes pressured (probably with the best intentions) to give up their seriously ill children:

> There was no psychologist. People would drop in and tell me that these children are not to be cared for [at home]. They told me, 'you'll have another one', 'give birth to another one'. It was doctors who told me this. They told me, 'these children are not to be cared for [at home], your husband will leave you', 'it's not known if she will live'.

On the one hand, this is a matter of personal moral choice. On the other, however, this issue is the subject of deliberate health and social public policies. During this study our team also met doctors from specialized institutions caring for seriously ill children (with multiple disabilities) who cannot be cared for at home anywhere in the world. But it is a matter of public debate as to whether parents in Bulgaria can exercise their right to keep their baby if a disability is detected during pregnancy or after birth. The healthcare and social welfare systems should be reorganized so as to enable parents of seriously ill children to receive adequate medical, psychological and social support, allowing them to care for their ill child at home without 'being left by their husband'. The deficit of palliative care in Bulgaria is the reason why many parents feel completely abandoned and why many doctors take on extra duties:

> In Bulgaria, not only do they have such a serious diagnosis but they are also left to themselves, on their own, without any support. Now the family has become known thanks to television, but they have been in this situation for five years now. A doctor can't also be a psychotherapist, psychologist and friend and, at the same time, carry medical responsibility.

Many of the participants in the study were of the opinion that there is a systemic problem here, it's not just a matter of the character flaws of one doctor or another:

> This is a major deficiency here, we are very much behind in this regard. Patriarchal medicine still dominates the profession. There they don't have a problem with communication. There the top luminaries insisted on being called by their first names, even when talking with patients. There they are open-minded, they want to ask, to talk. In Bulgaria everything is depressing.

The parents we met had decided not to part with their children despite their serious conditions. But this doesn't eliminate the existing problem:

> We've never thought of leaving her. During the 27 days in the neurological unit, this is what half of the doctors told me over and over again – leave her. All specialists told me, 'Leave her, it's for your own good. One can't live with such a child.' But you can't think this is right, this is a child, a soul…

None of the interviewed parents expressed any regret at having decided not to part with their ill child. They were rather of the opposite opinion:

> A woman I know [whose child has Down syndrome] took her child back from a medical and social care facility on the sixth year. The father left. She found a soul mate. They are in Finland now. Ida is developing well in Finland, she's a sunny child…

But whereas in Finland and other West European societies parents receive institutional support, in Bulgaria many people with seriously ill children feel they are all alone:

> My husband panicked. 'I can see how you're slowly going mad,' he told me again and again. But then, he goes to work, he's with other people during the day. At night we cry together.

Not all fathers, however, share the mothers' tears. The behaviour of some dads justifies the warnings of those who say, with good intentions, that 'you can't care for such a child, your husband will leave you':

> Things between me and my husband were getting worse because of Ida. We're supposed to be together but we aren't. He goes out regularly… He says, 'I can't, I don't want to, I feel awful', and stuff like that…

There are no official statistics on the subject in Bulgaria, but the personal impressions of the participants in the study were that eight out of every ten families with seriously ill children fall apart:

> My husband has never said, 'I'm leaving.' Many husbands have left their wives. Many of my friends have been left single mothers. The truth is that it was a nightmare for them. You're abandoned, you're jilted, you're the woman who can't bear him a healthy child. You're no longer a woman. You're defective. You're a carer. 'I'm off to look for another woman.' He says to himself, 'it's time to move on.'

When we asked respondents with seriously ill children who live in Western

Europe the same questions about the relationship in the family, they were sincerely dismayed. In Bulgaria, however, many parents feel a sense of deep guilt because of the missing public health policies and start punishing themselves:

> We have become one with Ida. We had no friends, didn't go out, didn't go on holiday. We lost each other as partners. We didn't have sex for two years. I told myself, 'I have no right to be happy, I have an ill child, I have no right to a life of my own.'

Within the framework of this pilot study, we met only mothers, not fathers, of seriously ill children. But they told us they know of cases in which not fathers, but mothers decided to leave their children and their partners:

> There are also opposite cases – at the swimming class there were two dads whose partners had left them. One dad had a child with autism. The child's mother had said she couldn't bear it any longer and left.

Similar impressions were expressed by other respondents from Sofia and elsewhere:

> Other mothers say they can't take it anymore, they can't cope anymore. I can't blame anyone…

The philosophy of pediatric palliative care requires providing psychological support to the child's parents as well. In Bulgaria, this issue is still beyond the scope of the healthcare system:

> There was no psychologist [at the hospital]. I looked for a psychologist myself, on a private basis. I really was in a terrible crisis…

Absolutely all mothers we met feel they need professional psychological support. But they don't always get sympathy from those around them:

> I asked at the hospital if they had a psychologist. They laughed at me and said Ida was too young for therapy. I said I was looking for a psychologist for myself. They told me to look for one outside [of the hospital]. They didn't care about the mothers. Their job was to treat the children.

On the other hand, it seems there is still a social stigma about therapy in Bulgaria and many people, especially men, refuse psychological help because they 'aren't crazy':

> My husband refused a psychologist. He came to one meeting only. He said: 'My wife's crazy. I'm well. I don't need [help]. If my wife's well, then I'll

> be well too.’ He developed metabolic syndrome. The endocrinologist asked him, ‘What’s wrong, have you gone bankrupt, has somebody died.’ He had pre-diabetes. I’m an extrovert. I talk a lot, I share things with people. He is alone, he keeps all his feelings to himself.

According to testimonies of Bulgarians whose child was diagnosed, cared for and died in Germany, the practice in Germany is to give the child to the mother immediately after delivery, making sure they are together at the hospital during the initial tests and treatment. In Bulgaria, due to the lack of physical space and public understanding, ill babies are very often separated from their parents:[9]

> They didn’t let me see her. I saw Ida for the first time on the fourteenth day. I was already in depression. This is a great tragedy. A nurse brings her to you for five minutes. You cry nonstop, all you do is pray, you stop eating, bathing.

In the absence of an institutionalized practice of providing professional psychological support to parents, the burden is (sometimes) taken over by (compassionate) relatives and friends:

> I stopped answering the phone, I didn’t talk with anybody. I distanced myself from everybody – my mother, my father, my sister…
>
> A friend of mine came and started knocking on the door. She said, ‘Come out, you can’t stay inside all the time. You must go on living.’ After an hour or two I opened the door. Because I felt sorry for her. I was crying inside and she was crying outside. Eventually, I opened the door. She took me out for a little while.

Respondents from Germany said that immediately after a child is diagnosed, the director of the hospital himself or herself (together with the doctors, psychologists, and palliative care specialists in charge) meets the whole family of the child and explains, in a very humane and clear way, the nature of the illness, the forecasts, and the possible strategies. In Bulgaria parents are left to cope on their own, and usually turn for help and advice to online forums of parents of seriously ill children:

> The forum helps a lot. Purely socially, for information, for sharing. Most mothers of such children simply withdraw into themselves.

All parents interviewed in this pilot study expressed gratitude to the forum:

> The people who helped me the most were other mothers. That’s when I met R., B. They helped me. It was there that I found this psychological support.

> It was there that I felt understood. I left my family but I found them. On the sixth month we met in person. It was unique! Being able to hug someone who's your soul mate…
>
> It was there [on the internet forum] that I poured out my life, my heart and soul. X [my husband] would tell me, 'you're living in the computer' – and I really was. These people were my family.

Besides being a place where one can pour out one's heart and meet soul mates, the forum also helps with completely practical – everyday but also life-saving – advice:

> She has photosensitive epilepsy. The first year we, happy parents, decorated her room with lights, with what have you… Ida fell into a seizure. We could have lost her. No one had told us anything. We learned everything from the mothers on bg-mamma.com. No doctor had told us anything, but the mothers did…

The tales of (self)-isolation, withdrawal into oneself, estrangement and depression, which are commonplace in Bulgaria, are in stark contrast to those from abroad, where the parents of a seriously ill child not only keep their old social contacts but also expand them with new ones, meeting, exchanging visits and celebrating holidays together with their ill children. In Bulgaria the hardest thing for parents turns out to be going outside of home:

> The psychologist told me, 'Even if you have to drag yourself along, you simply must return to work.'

But 'dragging oneself along' cannot help either if there is no adequate social support for parents, who have to cope not only with the financial burden but also with social prejudice:

> At some point I hired a student [to babysit her] for four hours so that I could do some work. But everyone I've offered a job as a babysitter has rejected it because they are afraid. I haven't been able to find another babysitter.

To deal with this difficult situation, some parents try taking their children to work. But even if their employers and colleagues are welcoming, which isn't necessarily the case in Bulgaria, still:

> Taking this child to work is a bit agonizing. You think of her nonstop. You can't concentrate. You have to feed her, to give her medicines. You can't work properly.

At the same time, parents start feeling guilty, torn between the psychologist's requirement that they return to work (which seems very selfish to them) and the feeling of responsibility for their seriously ill child:

> Mothers write that they take them to swimming classes, to rehabilitation therapy, to riding classes, to rehabilitation therapy again. And I say to myself, 'What kind of a parent am I.' I'm racked with guilt. I say to myself, 'I'm quitting, my child's more important to me.'

Here we must once again underline how shocked the parents from Western Europe were by the question about feeling guilty. The common assumption in Western Europe is that illness is part of life and that although we may not have the power to cure it, we do have the power to organize our common world in a meaningful way. In Bulgaria we didn't come across any mother who hadn't been racked with guilt and self-blame for years:

> Of course I felt guilty. This is a nightmare you live through. You feel guilty – 'what have I done.' Everyone goes through this… It's inevitable…

Here is another very telling account:

> I felt guilty: about not being conscientious during my pregnancy, about not giving birth properly. You tell yourself everything… God's punishing me. You're angry at yourself. I blame myself. … I can write you a mile-long list – everything is my fault. And I punish myself, I deprive myself because of what I've done, because my child is ill.

This feeling of guilt is exacerbated by Bulgarian society itself through those who can hurt us the most – our loved ones:

> My mother took it extremely hard. She decided that it's her fault. She's convinced that mitochondrial diseases are passed down from the mother's side.

Despite what the doctors tell them, parents of seriously ill children very often suffer from self-blame:

> The doctors tell you that it doesn't depend on you, but you don't believe them. There were many misdiagnoses of Ida's condition. But I don't blame them, I blame myself for having believed them.

The absence of rational, informed discussion on the issues of child disease, suffering, and death in Bulgarian society leaves room for premodern practices of social control and social regulation:

> My mother-in-law contributed a lot with all her epithets, insinuations, direct insults…

We must expressly note that the next quote is about the life of a very highly educated family with high incomes and prestigious professions:

> My husband used to tell me, 'I made you pregnant with a healthy child, but you damaged her, you destroyed her.' Going on to call me names: because you're this, that, and the other. We've been through very rough patches… 'I made you pregnant with a healthy child, but you damaged her, you destroyed her.'

It is noteworthy for our pilot study that the above quote does not describe an isolated case; rather, it represents the dominant cultural situation in Bulgaria. All interviewed mothers were categorical that Bulgarian society does not know how to react when it encounters a seriously ill child:

> It's a classical reaction – everyone crosses their fingers, looks away… You don't have to click your tongue, to moan, to tell the parents how sorry you are for them. In Bulgaria you're told, 'Don't look at them'. When you see someone without an arm, without a leg, you mustn't look at them. Presumably because you may be infected or something by looking at them…

Here is another very telling account which shows the urgent need for a public awareness-raising campaign in Bulgaria:

> Ida is small for her age. We take her out in a special wheelchair that looks very much like a normal pushchair. And in the park there are those grandmothers who'll tell me things like, 'Girl, why are you stopping this child's development?! Let her walk.' I say nothing the first time, the second, the fifth time. Finally, I say, 'If you think I don't want my child to walk, you're wrong. But she can't and probably never will be able to…' This thing with people knocking on wood, spitting, crossing their fingers, happens all the time…

Even the most well-intentioned relatives and friends often cannot find a way to express their compassion and support:

> People don't know how to react. They try to say something kind and considerate to you. But the things they say are horrible, actually.

There is nothing horrible in the accounts about Germany. Not only is everyone kind, considerate and supportive – the families have happy memories of wonderful moments together. Of course, in Germany there are children's hospices for palliative care where parents can leave their ill child for a few days while they are on holiday, and there are also professionally trained nurses who care for the ill child at home. In Bulgaria we didn't find anything of the kind:

> We've never been to the movies together. Never ever. We've never gone out for dinner. It would be wonderful to have day care. Mobile care as well. A nurse who can come home. That's invaluable!

Even if the family can afford to go on holiday, the anxiety remains that the ill child should not be shown so as to avoid upsetting and disturbing people, she should be kept at home:

> We haven't been on holiday because she cries a lot, but people go on holiday to rest and have fun, not to see and hear a child crying…

There are places where a child crying won't upset holidaymakers. But this doesn't mean that parents don't feel anxious:

> What's upset me is that we, for example, have never been to the mountains together. I have to stay home to care for her. There's no way.

If a solution is found, it is not the result of institutionalized public policies, but usually of ordinary human kindness:

> In our case it was a neighbour, the mother of a friend. We were very close with her son. One evening this woman simply came over. She said, 'Look, you need a break, I'll look after Ida, you'll tell me what I have to do. You'll take your other child and go to the seaside.' At first I thought I misheard… We went to the seaside. This was something unbelievable! It was a breath of fresh air. This is something that should exist [as an option]… Another world…

Without specialized support from palliative care specialists in a cultural environment that is hostile to people with disabilities, parents of seriously ill children must get accustomed to reality:

> It took me a long time to accept that she won't change, she won't get well.

The problem is that many serious illnesses are progressive and involve a lot of pain and suffering for the child if she is not cared for by trained professionals (Dowden, 2009). To give the reader an idea of the existential situation of parents of seriously ill children in Bulgaria, who are not beneficiaries of public policies on pediatric palliative care, we must note that in every single interview the parents spontaneously raised the issue of euthanasia:

> In Bulgaria it is illegal and that's why we started thinking about the option of going to Belgium…

None of the interviewed doctors said that the issue is subject to discussion at all. Although some gave examples involving other doctors:

> To me, there's no question about it. There's no such dilemma. When I started work, an older female colleague told me, 'Stop fretting, it's better if she dies now as a baby than to be looked after for 16 years and die then.' But we now have medicines for cystic fibrosis. Yes, they aren't a panacea but [children] live. We shouldn't divide them into curable/incurable, disabled/able.

The problem is that in Bulgaria the subject of children's suffering is confined to the private sphere of the family and therefore becomes an impossible moral dilemma for deeply distressed parents who have to make very difficult decisions:

> Dr X was the only honest doctor who told me directly, 'Do you want me to tell you the truth or do you want me to reassure you.' She said, 'There are two options – there are some medicines we can play with. The other option is, you stop the medicines and things happen very quickly and very painfully…' I couldn't bring myself to stop the medicines.

Conclusions and Recommendations

The findings of this study show that in Bulgaria there is a huge lack of information on the subject of pediatric palliative care. Even among specialists in the healthcare sector there are enormous differences of opinion as to the scope and essence of pediatric palliative care.

At the same time, there is growing awareness of the need to develop pediatric palliative care and to build a children's hospice. The overwhelming majority of participants in the study think that there is an urgent need to build a children's hospice financed by the state budget, not by the National Health Insurance Fund or private investments.

In Bulgaria there are enormous deficits in institutional medical, social and psychological support for families of children with serious illnesses. At present these deficits are only partially made up for by support from voluntary self-help groups.

It is of utmost necessity that the issues of children's suffering and death leave the realm of the private lives of the families concerned and become a subject of public healthcare and social policies.

In this sense, the project team has formulated the following recommendations:

1) Organizing and conducting a large-scale public awareness-raising campaign on the issues of pediatric palliative care and children's hospices.

2) Initiating specialized courses in pediatric palliative care for medical specialists.

3) Encouraging a meaningful ethical and moral public debate on the issues of children's suffering and death.

4) Conducting a national survey on the needs of pediatric palliative care in Bulgaria and on the possibilities for building a children's hospice.

5) Examining the existing legislation and proposing a legal framework for pediatric palliative care.

NOTES

[1] See Gabrovska (2018).

[2] According to Eurostat data, the child mortality rate in Bulgaria dropped from 9.7 per 10,000 in 2006 (the year before the country's EU accession) to 6.4 in 2017. Despite this, Bulgaria's child mortality rate is almost double the average in the EU, France and Germany (3.1 to 3.6 per 10,000 in 2017) and three times higher than in the Scandinavian countries (2 to 2.2 per 10,000).
Of course, the opposite hypothesis is also possible: since the quality of child healthcare in those countries is higher, the survival rate is also higher and the number of children in need of palliative care there is larger than in Bulgaria.

[3] Interviewed doctors gave as an example above all the homes in Stara Zagora, Varna, Blagoevgrad, Ruse, and Burgas.

[4] In 2017 this clinical pathway was amended, increasing the per diem per patient from BGN 51 to 65, but reducing the number of days from twenty to ten in six months.

[5] Bulgarian media were especially curious about the financial status of the Director of the Sveta Ekaterina Hospital in Sofia, Prof. Gencho Nachev, who declared assets worth more than BGN 6 million in 2018.

[6] 'Bulgarian Christmas' is an annual campaign raising funds for seriously ill children.

[7] Which shouldn't have been the case if the National Programme for Improving Maternal and Child Health was functioning properly.

[8] All names of children mentioned in the interviews have been changed to 'Ida'.

[9] This holds true for overcrowded hospitals in Sofia, but not for other specialized university hospitals in Bulgaria.

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Galina Goncharova

THE GENERATION OF THE TRANSITION IN BULGARIA AND THE SENTIMENTAL NARRATIVE OF DISABILITY

The year 2020 marked the 30th anniversary of the passage of the Americans with Disabilities Act (ADA). Defined as a landmark piece of civil rights legislation, in the decades since it was passed into law the ADA has inspired other legislative and public initiatives to eliminate discrimination against individuals with disabilities in all areas of public life, including jobs, schools, and transportation, its anniversaries invariably prompting historical recapitulations (of the successes and failures) of the independent living movement[1] – not only in the US but also in other countries around the world. Even a cursory review of the many popular and widely accessible online materials shows that the ADA triggers over and over again an extremely reflexive and sensitive memory of the struggles for social and political recognition of stigmatized, marginalized and segregated individuals and communities. Thus, journalistic and academic articles, websites of various organizations and media outlets highlight the ADA's historic role in bringing about 'the change in the way we look at disability, the way we define disability'; trace 'glorious' genealogies of revolts and protests such as the Capitol Crawl (a protest where scores of activists abandoned their crutches, wheelchairs, and other mobility-assistance devices and crawled up the steps to the Capitol Building[2]); point out central figures such as Ed (Edward) Roberts, the first alumnus of the University of California, Berkeley, who used a wheelchair and breathed through a respirator, the father of the independent living movement; draw parallels and find causal relationships with the history of the well-known UK disability rights organization Union of the Physically Impaired Against Segregation (UPIAS) and the development of Disability Studies.[3]

In one of the many discussions on the legacy of the ADA, sparked by its 30th anniversary, Judy Heumann, an internationally recognized leader in the disability rights community and a lifelong civil rights activist, and Katherine Perez, Executive Director of the Coelho Center for Disability Law, Policy, and Innovation at Loyola Law School, pointed out that the passage of this law was a landmark achievement of the civil rights movement and has had such a strong impact on the young generation of Americans with disabilities that they have come to be called ‘the ADA generation’. It was the result of the efforts of the old or first generation of disability rights activists who had grown up together in ‘segregated schools’, rehabilitation centres and camps. They were not afraid to speak out, to protest and defend their interests personally as well as collectively – by way of public initiatives and acts of resistance. Thus, they managed ‘to shift the narrative of disability from a medical disorder to a mandate for justice’, to bring life with physical or mental disabilities out of the closed orbit of the images and storylines of hopelessness, helplessness, need for protection and charity (Climaco, 2020).

More generally, the above-noted discussion reproduces the main points of a very intense international public debate on ‘disability culture’ understood as construction of a common identity through arts and life-stories, and of a history of ‘the oppressed’ and ‘the resisting’ as a source of pride, not (self) pity. The attempts of various scholars to classify the disability narratives which are conceived and rationalized in scientific discourses and acquire popularity and legitimacy through social policy and activism gravitate precisely around disability culture. Thus, according to Donileen R. Loseke and Sara E. Greene (2020, p. 2),

> Three genres of narratives of disability are the most common. The *medical narrative* of disability [which is ‘condemned’ by Heumann and Perez] is a story of disability as an individual tragedy best ameliorated through the application of professional interventions …; the *social narrative of disability* equates disability with oppressive structural barriers and attitudinal constraints that are part and parcel of a capitalist world organized around ableism; emerging narratives of disability … problematize and destabilize the very idea of “normality” or portray disability as a complex and nuanced intersection of bodily, social, and cultural disadvantages.

These genres are informed by the ‘narrative turn’ in the social sciences of the 1970s and 1980s, which affirmed the cultural meanings and moral worth of narratives of lived experience,[4] moving away ‘from conceptualizing people as made by society to conceptualizing society as made by people’ (Loseke, 2019, p. 10).

Can we transplant such activist genealogies and scientific reflections on the discursive reality of disability into a local, Bulgarian context? One of the few insightful commentaries in the Bulgarian (online) public sphere specifically on the ideological legacy of the ADA is by Petar Kichashki, former European Network on Independent Living (ENIL) South Regional Coordinator (2012–2013), member of the Bulgarian Commission for Protection against Discrimination in 2017, Executive Director of the Institute of Modern Politics since 2013, and ‘active advocate of people with disabilities’. In an article on the 28th anniversary of the passage of the ADA, posted on his blog, Kichashki (2018) concludes that there are substantial, difficult-to-overcome differences in the attitudes and policies on disabilities in the US and the countries of Eastern Europe, including Bulgaria. Whereas in the US people with disabilities demand 'independence and freedom' and regard the state as just 'one of the players in the field', albeit 'the most important' one, that should respond to their demands by giving them 'an equal start', in the countries of Eastern Europe and in Bulgaria in particular – by virtue of the notion of unlimited state power that was dominant in 'the former socialist camp' – the state is expected to grant privileges and resolve all (personal) problems. Pessimistic as this situation appears to be, Kichashki argues that it can change if 'a critical mass' of people speak up – which, unfortunately, hasn't happened yet (as of July 2021). To paraphrase his words, there isn't a consolidating, emancipatory narrative of disability in Bulgaria that can serve as a basis for effective (political and legislative) protection of the civil rights of 'the oppressed'.

Kichashki's reflections are especially relevant if put in the context of the 2018 and 2019 mass protests of Bulgarian mothers of children with disabilities. Although they cited international instruments that are fundamental to the independent living movement, such as the UN Convention on the Rights of Persons with Disabilities, and explicitly stressed that their demands were not for 'money' but for 'reforms', their slogan was 'The System Kills Us'. This slogan implies a passive position dependent on the state/state institutions, and assigns the mothers and their children a martyrial status that provokes a strong emotional reaction and over-recognition. Furthermore, the pronoun 'us' suggests the idea of the inseparable biological-and-social bond between the mothers and their children, who are forced to suffer and bear the burden of disability together. As a whole, the protests were conducted in a symbiotic and sacrificial mode: wearing black T-shirts with the slogan 'The System Kills Us', the mothers held the hands or pushed their 'invalidized' by 'the system' children in wheelchairs – some pushed wheelchairs carrying plastic skeletons with black balloons – on their way to the Bulgarian Capitol (the Bulgarian Parliament building), where they were turned away because of inappropriate attire (Panayotova, 2018). The message conveyed by these protests was in stark contrast to the traditional 'scenography' and messages of such protests in the countries where the social model of disability has been embraced. For example, one of the most influential activist organizations in the US against the legalization of assisted suicide and euthanasia is called 'Not Dead Yet'.[5]

An analysis of the (a)symmetries vis-à-vis Western mobilizations may also draw more positive conclusions about disability rights activism in Bulgaria. Although in a way they appropriated or silenced the voice of people with disabilities themselves, the protests in question nevertheless put issues of vital importance to marginalized groups and identities on the agenda and more or less contributed to the passage, at the end of the last decade, of long-postponed and long-expected laws such as the Personal Assistance Act and the Persons with Disabilities Act. Insofar as the majority of the participants in them are coevals of the so-called democratic transition, they bear the 'battle wounds' and scars of the multiple economic changes, social crises, and shifts in cultural layers and paradigms that have taken place in Bulgaria since the fall of communism in 1989. They were faced simultaneously with the late effects of the socialist ideological framework of disability (including the notion of the nanny state) and the (ab)uses of EU directives and programmes promoting dignified and independent living. Last but not least, just as the Capitol Crawl in the US, so too the black-T-shirt-clad marches on Parliament may claim a representative place in a history of the contemporary Bulgarian civil rights movement, insofar as the protests of mothers of children with disabilities date back to 2012 and, along with their 'confessions' on various traditional and social media platforms, had already accumulated symbolic capital. There is something very symbolic about the fact that the slogan 'The System Kills Us' was raised thirty years after the protest demonstrations of mothers against chlorine pollution in the city of Ruse, which are regarded as some of the very few acts of open resistance against the totalitarian regime in Bulgaria. Raising slogans such as 'Life for the Children of Ruse!', these protest demonstrations also conveyed a message about fighting for physical and social survival and, furthermore, one of their organizers was a mother of a disabled child.

How does the generation of the transition understand and organize the battles for social justice for people with disabilities in Bulgaria? To what extent do the public representations of living with disability and the relevant life-stories manage to empower – or, conversely, to disempower – people with disabilities in Bulgaria? Which are the main tropes, central figures and events in these representations? To what extent do they reproduce the medical or the social narrative of disability, or do they form an authentic, original local discourse of resistance against repressions by the system/systematic repression?

To answer these questions, this article draws on 35 biographical interviews and 10 focus groups with informal and formal carers (parents and childminders, psychologists, social workers, NGO members, etc.) of people with disabilities, conducted in Varna, Plovdiv, Pleven, Lovech, and Sofia in the 2017–2021 period under the project *Generational Patterns of Coping with Life Crisis: Biographical, Social and Institutional Discourses* financed by the Bulgarian National Science Fund at the Ministry of Education.[6] The main thesis is that the findings of these biographical interviews and focus groups can be viewed as cultural production of a sentimental narrative that defines care and support of people with physical and intellectual disabilities in Bulgarian society through paternalistic images, heroic storylines and de-autonomizing metaphors. Whereas its symbolic tools are relatively stable – promoting the notion of 'supermoms' and 'superkids' who suffer or overcome fateful limitations and injustices – its uses are heterogeneous, unstable, and contradictory. Insofar as this narrative largely represents the lived experience of the generation of the transition, which is characterized by multiple personal and social crises and changes involving breaking with the socialist legacy and adapting to neoliberal European models of active citizenship, it has failed to become a unifying platform or basis for a serious public debate on the needs and rights of people with disabilities in Bulgaria. It has, however, made visible existing discursive contexts, stigmatizing attitudes, and social representations that deprive people with disabilities in Bulgaria of political agency.

Over-Responsible Mothering

Mothers are on the frontlines of the protests of people with disabilities in Bulgaria. The interviews in question also asserted their status of principal, or even sole, representatives of a group in dire need of social support. These interviews very often began with 'Hi, my name is … I'm a mother of a disabled child…' and quite often ended with an acknowledgement of the role of parental associations in coping with existential crises, securing certain social benefits/services, and organizing 'the resistance' against 'the system', in which it was the mothers again, not the fathers, who were leaders or active members. Thus, the responsibility of caring for the offspring – biologically determined during pregnancy and after childbirth – was expanded and extended over the entire life cycle, and the caring role became constitutive of individual identity, coming into play even in the field of social solidarity and social action. The marking of the beginning and end of the life-story through the parental status and achievements confirm the conclusions of a series of contemporary studies on caring roles in families with disabled children. According to these studies, mothers of disabled children tend to have overwhelming responsibility for the caring role, expanding it over a longer period of time and extending it to broader community or societal concerns (Ryan and Runswick-Cole, 2008, p. 205; Traustadottir, 1991). Indeed, a large part of the respondents in our study were members of parental associations and organizations (such as the majority of mothers in Varna), took part in the campaigns for abolishing guardianship (interdiction) for people with intellectual disabilities and mental health problems in Bulgaria, created social enterprises (such as the parents of a boy on the autistic spectrum in Plovdiv) and, as noted above, took part in protests.

In the Bulgarian case, however, the mirror pairs of caring for the well-being of the family and of the community do not only point to certain models of self-realization and activism through motherhood; they also provide an insight into the meaningful framework of the sentimental narrative of disability – not merely the intertwined fates or life-trajectories of the over-responsible mother[7] and her son/daughter with physical and/or mental disabilities, but also their tragic and unprecedented bond affecting human existential grounds, social statuses, and social actions.

The framework in question 'merges' – to the point of indistinguishability – traditional and paternalistic stereotypes of raising children in society with modern medical and medicalized images of biological/bodily and social dysfunctionality. Even a cursory analysis of the many instances in which this framework was reproduced uncritically in media coverage of the 2018 and 2019 protests of mothers of disabled children shows that – although at first glance it served a just cause – its uses actually implied that the protesters' battles for rights were bound to be futile. For example, the headline below the photo of mothers standing behind disabled adults in wheelchairs on the *Dnes.bg* website reads 'Being born with a disability is a verdict. The children who go nowhere' (Tsvetanova, 2018). It directly refers to, or maybe even quotes, the introduction of a TV documentary by well-known Bulgarian journalist Mirolyuba Benatova, titled *Zalozhnitsi na detsata si* (Hostages to their children). The documentary, aired in 2015 and much praised by our respondents, was introduced by Benatova, who also outlined a horizon of utter hopelessness and doom, the only difference being that she focused on the carers: 'Instead of abandoning their children to the state, thousands of parents, who are normal people, decide to take on the responsibility of raising their children and this turns out to be a verdict.'[8]

The Social Confinement and 'Silencing' of Disability

The notion of disability as a 'verdict' was also evident in the interviews under study, where the respondents identified it with the diagnosis given by a particular doctor: 'his words sounded like a verdict' (Teodorina, 47, cares for her son who has autism, BA in Bulgarian Philology, MA in Psychology, Pleven, 23 April 2018). But it was, figuratively speaking, more like a 'sanitizing regimen' for care and support of disabled people established by a whole consilium with a constantly expanding or changing lineup and unusual 'statute of limitations'. In most cases, the first thing mothers were told after hearing the 'shocking' and almost incomprehensible conclusions of the doctors – 'turricephaly', 'hypotonic cerebral palsy', or 'spastic quadriparesis' – was the following: 'Leave her, you'll have another baby' (Elitsa, 44, cares for her daughter who has hyperammonemia, electrician, Plovdiv, 21 November 2017). Returning home from hospital, they were greeted with the words: 'It's you who gave birth to him so it's you who'll care for him' (Gabriela Detelinova, 46, cares for her son who has moderate mental retardation, focus group, Varna, 18 August 2017). Later, their children were denied admission to kindergarten on the grounds that they would 'obstruct the process' and that 'these are specific needs' (Nesrin, 57, cares for her daughter, one of triplets, who has cerebral palsy, social worker, President of the Joy for Our Children Foundation, Varna, 18 August 2017). But this was only the beginning – from then on, motherhood was presumed to be the only moral corrective of any effort to deal or cope with the registered deviations from the medical or social norm. Thus, when Tsvetomira (71, member of the Parallel World Association, preschool teacher by education, housewife, Plovdiv, 20 November 2017) said she wanted her son, who has been diagnosed with 'moderate mental retardation', to study in a 'normal school', 'the psychiatrist in charge of her son's case' scolded her: 'You're a bad mother, you're harming your child! You must enroll him in an auxiliary school, he'll be fine there, he'll be among his own kind there!' Whereas professionals/experts invoked their authority and medical expertise to release or confine mothers and children to a socially sanitized or sterilized womb/capsule of disability (Goncharova, 2018, p. 9), to this end husbands, relatives or neighbours invoked the shadows of the ancestors and accused the mothers of crimes against the family and the community:

> The people I met in hospitals – in fact, most of the mothers were on their own. Because their partner had left them, telling them: 'It's your fault!' Because, I don't know, this was what happened to me, at least. If there's no one to blame for the illness, it's somehow difficult to accept the illness. If you know who's fault it is, then everything is fine, we feel reassured now that we know it's her fault. It's she who gives birth to freaks. We don't have any others like that in our family, where did this misfortune come from? This is the sort of things you hear… When mothers get together they don't just gossip about what's going on – we also talk about everything that's happened to us and how everyone around us has responded. And all of us used to say the same things. Somehow these are strange things, why did it happen to us, why is God punishing us, what have we done. But it's easiest to blame the mother for giving birth to such a child. (Asya, 39, cares for her daughter who has intellectual impairment, social worker at the Sunny House day-care centre for adults with disabilities, focus group, Varna, 18 August 2017)

The above quote reproduces paradigmatic asymmetries/scenarios of the 'male domination' in families and institutions responsible for care for children with disabilities. As various Western scholars point out, mothers, much more than fathers, are held to account for failing to cope with the role of 'the good parent' (Read, 2000; Runswick-Cole, 2007; Blum, 2007). And whereas 'it has been frequently suggested that a child with impairments produces a dysfunctional family, mothers have, in turn, been blamed for producing a dysfunctional child' (Ryan and Runswick-Cole, 2008, p. 206).

The above quote also shows that at least part of the respondents have accepted and internalized their role/prescribed identity of destroyers of sound family relationships and violators of biological/human laws who must bear the exceptional burden of/punishment for the child's disability. The stinging comments of midwives and doctors did not undermine the confidence of Bogdana (68, cares for her daughter who has Down syndrome, insurance agent, pensioner, Varna, 17 August 2017) that 'the truth is that it's mothers who are the primary carers of these children' and, like many other members of what she called a 'parental cooperative', it's she who took her daughter to therapy appointments, negotiated with school staff, dealt with red tape, argued with social workers and labour office employees in order to secure a dignified life for her. In addition to this, mothers' tasks include (especially in cases of severe and multiple disabilities) daily personal hygiene and toileting care, lifting wheelchairs, coping with severe bouts of illness and crises, etc., against the background of a shortage of money, depressions, divorces, failure to find a job or underperforming in education, etc. In parallel with that, ‘the children’ are subjected to insults in the street, make enormous, often futile, efforts to learn to read or write, at times bang their heads on the wall, suffocate, and remain confined to their rooms. Divorce is the least ‘punishment’ for raising them and multiplying dysfunctionality. Denitsa (43, cares for her son who has hydrocephalus, member of the Maria Family Centre Association, souvenir maker, BA in Social Management, Varna, 19 August 2017) had to put up for months with her partner’s demonstrative departures from home for assignations with his mistress against the background of a total lack of financial support from him, while Tsvetomira was continuing to share an apartment with her ex-husband and to cook for him every night. Communication with medical experts followed a similar pattern. In some cases, they were seen as ‘deities’, in the words of Galya Koycheva (focus group, Varna, 17 August 2017), whom one prayed to constantly and didn’t stop thanking when they gave the right diagnosis and prescribed the right medicines; in others, as in the case of the psychiatrist of Tsvetomira’s son, they were seen as an insurmountable opponent the encounters with whom left scars for life. The attitude towards ‘medical treatment’ was similar. All respondents had tried out various therapies – kinesitherapy, hippotherapy, amino acid therapy, etc. – and mastered various skills under EU programmes and projects. Therapists/ therapies were regarded as the ‘mainstays’ of care. ‘We’re lost without them,’ one of the participants in the focus group in Lovech (26 April 2018) admitted.

As a whole, the biographical narratives/life-stories represented the mothers in a very heroic and self-sacrificial light (‘Have you ever wondered how I/ we cope?’ was a key line in the interviews) and exaggerated, in sentimental codes, the fatalistically shared and/or overcome biological and family suffering. Denitsa took stock of the hardest time of her life as follows: ‘We’ve been fighting for all of twenty-five years. It’s true that it was a very difficult journey and it’s true that we’ve been insulted and told things that made our hearts hurt, but we kept on going and got to where we are today.’

The frequent reference to or enumeration of the achievements of the ‘freakish’ sons and daughters (Asya, Varna) – learning the alphabet, learning to talk, display of musical or other gifts – often ended with the admission: ‘My life is my child’ (Kalina, 40, cares for her son who has cerebral palsy, member of the Maria Family Centre Association, souvenir and gift maker, vocational therapist, Varna, 19 August 2017).

As Gergana Mircheva (2021) notes in her analysis of the interviews with mothers of children with autism, in an ethical perspective the attitude towards children is thought of in paternalistic terms and gives rise to a specific type of ‘pathogenic vulnerability’ which ‘turns out to be reciprocal and leads to a “sharing” of children’s and parental identities’. Thus according to the respondents, the first five or ten years after birth were taken up by ‘joint’ exhausting work at home or at rehabilitation centres and consulting rooms where commands were issued and carried out in order to achieve the coveted ability to stand upright and walk. Then the work in question continued with the entry of schoolchildren, parents and resource teachers into classes and classrooms of special schools. Finally, in day-care centres teachers, parents and ‘youths’ strove to find the way to successful socialization together – carefully explaining the value of money, discussing the subject of gender and sexuality, and/or singing Alla Pugacheva songs.[9] Although they strongly stressed the importance of free interaction with peers in all those places, it was the mothers (as well as the teachers) who practically organized, controlled and filled it with an own symbiotic meaning, even openly admitting this. The participants in the focus group in Varna (17 August 2017) unanimously concluded that ‘we are smothering them, but neither we nor they have a choice’.

‘The truth about caring for these children’ applies to all forms of social solidarity and support. The ‘struggle’ referred to by Denitsa expands indefinitely from the most modest to the most ambitious private or state initiatives related to the needs or rights of people with disabilities – mothers equally passionately engaged in battles for opening or maintaining day-care centres and for guaranteeing their right to choose whether to be appointed as personal assistants of their children or not (as in the case of the 2018 protests). This ‘struggle’ has turned mothering not only into ‘the best cause’ but also into ‘a profession for life’ that often serves as a corrective for performance of roles with regard to every formal/expert position in the social sector. If they manage to ‘break away from care’ for their child, including from care as a personal assistant, they choose an education or a job that again has to do with care – they start studying social management and/or psychology at university, take jobs as carers at family-type placement centres and sheltered homes, make souvenirs in social enterprises, etc. A main issue pointed out by the mothers in the interviews was the shortage not merely of qualified but of sufficiently emotionally committed social workers, therapists, resource teachers, etc. For their part, the respondents who are professionally involved in care strove to follow the example/exemplarity of the ‘supermoms’. A manager of a day-care centre said that she only needed to glance at ‘the youths’ to realize that ‘something happened in the corridor two minutes ago’ (focus group, Varna, 17 August 2017).

In this way the ‘struggle’ of the mothers and their ‘advocates’ practically deprives people with disabilities to a large extent of a voice of their own and of any possibility to run their own lives and manage their social chances. As Teodor Mladenov (2021) points out, ‘the approach of “paternalist care” continues to dominate in the small institutions’:

> disabled people are treated as patients and as a homogeneous group, their everyday lives get subjected to constant surveillance, their opportunities to

> choose are determined by the preferences and schedules of the staff, their personal spaces get systematically violated, and their participation in the lives of the local communities remains minimal or symbolic.

Supermoms and Superkids

Along with everything else, the reflection on 'the truth about caring' – or the socially ascribed 'peripherality' (Shearn and Todd, 2000) and blame for the dysfunctionality of (the families of) the disabled – creates images of what Galya Koycheva called 'supermoms', that is, mothers who go through all possible physical and mental breakdowns, stand up against all possible injustices, and organize protests on behalf of their sons and daughters. However, it also imagines people with disabilities as 'superkids', ascribing them (simultaneously) two radically different but equally intensive modes of existence and rewarding them with social recognition invariably articulated in highly emotional terms. Regardless of their age – be they babies or youths – these superkids are infantile sufferers and martyrs, they are extremely helpless, vulnerable, and infinitely dependent on their carers. But they are also unique heroes and 'stars' showing tremendous courage, overcoming pain and suffering, and learning to do the same things as their able-bodied peers despite their congenital physical and mental impairments and limitations. Thus, Tsvetomira, for instance, said she was so proud that her son Martin had successfully completed high school in spite of his psychiatrist's humiliating recommendation that he be left 'among his own kind', but added that she couldn't forget his sleepless nights full of anxiety and panic attacks about the fact that he 'couldn't memorize things'. In a similar vein, Dimana (45, housewife, village near Lovech, 26 April 2018) said that she had felt 'incredible emotions' while caring for her bedridden daughter Viki who had severe cerebral palsy, epilepsy, microcephalus and 'profound mental retardation'. She described in detail the sad and happy moments – from looking for medicines for life-threatening conditions and suicidal thoughts to celebrating birthdays in front of the apartment building because 'you must show your child and the other children that you accept your child'.

The accounts of care professionals were also very emotional. A participant in the focus group in Plovdiv (20 November 2017), a 50-year-old childminder at the Trakiya-2 Family-Type Placement Centre in the Sveti Konstantin i Elena Social Services Complex, kept repeating that she loved the children in her charge so much that she regularly brought them some of the meatballs she made at home for her son and her husband, because 'they, poor dears, don't have a mum and dad'. Malina (57, social worker, former teacher at an auxiliary school) admitted that she was 'furious at the system' which remained indifferent to the problem of the future of people with disabilities after their parents grow old and die. In her view, people with disabilities could have only an infantile status, to which she ascribed exceptional moral agency and high existential meaning:

> They can teach you many things, the things of life as they see them. This keeps you alive, this stimulates you, it gives you strength to interact [with them] more and more because, I'll admit it, in all those years they've taught me, in particular, so many things; I call them 'children' – to me they are children, as they are also to their parents. Although ours are quite old – we have 54- , 56-year-olds, but they are children to us.

The Cultural Production of the Sentimental Narrative

From the spaces around apartment buildings to auxiliary schools and family-type placement centres, the sentimental narrative of the hardships and achievements of the supermoms and superkids has been transferred to the cultural industries, constructing a memorable image of the discursive boundary between the parables about the harsh reality and the modern fairy tale with an open ending. Thus in 2018, Maria Alexandrova, an 18-year-old student from Vratsa living with severe cerebral palsy, captured the attention of the national media when she successfully challenged the University of Cambridge to adapt its Advanced English examination to her specific needs, becoming the first person with cerebral palsy in Bulgaria to ever try and successfully take the exam.[10] Maria and her mother were invited on *Slavi's Show*, the most popular late night TV talk show in Bulgaria at the time. Obviously building on previous coverage of the story, the talk show's host, Slavi Trifonov, expressed his admiration for 'a girl who cannot move but who can fight and dream' and said how amazed he was that 'one of the most prestigious universities' had changed its rules because of 'Maria's disabilities'.[11] One of the participants who auditioned for the 2021 season of *Bulgaria's Got Talent* was Atanas Klecharov, an 18-year-old dancesport dancer with Down syndrome. His act brought tears to the eyes of the judges, one of whom (Lyuben Dilov Jr) admitted: 'I always tear up when I see a child with Down syndrome, I think that they are the better people, special divine creatures.' Tragically, Atanas died of Covid-19 three weeks after the audition, and his coach's story about 'the incredible perseverance' of 'the sunny boy', which turned him into 'the only child with Down syndrome in Europe who was a dancesport dancer', headlined the reports about his death (24 Chassa, 2021; Standart News, 2021). Even the design of the website of the Union of Disabled People in Bulgaria, the nationally representative organization of people with physical disabilities, relies on the symbolic coordinates of 'fights' and 'dreams': at the top of the home page, three athletes, their muscular torsos straining forward, are racing in racing wheelchairs; the Union's logo, a stick figure in a wheelchair, forms the front wheel of the first wheelchair.[12]

Perhaps the most remarkable example of the heroizing of both the vulnerability and moral strength/endurance of people with disabilities and their loved ones is the above-mentioned TV documentary by journalist Mirolyuba Benatova. The interviewed members of the parental association in Varna did not only recommend it heartily; they are the leading characters in it. Against a background of sombre music, three of our respondents tell about their backbreaking 'hardships' and 'traumas'. Next to them youths/adolescents lie in bed and make unintelligible sounds, sit in wheelchairs and glance desperately at the camera, or do special exercises on equipment or on the floor of their rooms under their mothers' encouraging commands.[13] The off-screen narrator (Benatova) informs viewers about the invariable and basic (according to the concept of the documentary) characteristics of people with multiple disabilities: 'They are children who never grow up, emotionally and mentally they remain children forever – they don't start talking, they don't become intelligent – they are persons by law, but in reality they remain children confined in adult bodies.' The main, explicitly articulated, message is that they as well as their parents are subjected to a 'genocide' that must but cannot be stopped because of the monstrous indifference and repressive bureaucratic system of the state/state institutions which refuse to take on the fatal burden of disability. This is confirmed by the mothers' confessions, in which the different stages and turning points in life with disability are marked in the same discursive mode as that in the interviews – from stigmatizations to visits to rehabilitation centres to acknowledgement of the symbiotic, organic bond between mother and child. Denitsa, Kalina, and Diyana (54, cares for her daughter who has cerebral palsy, philosophy teacher, member of the Maria Social Centre Association) from the Varna focus group tell about the accusations against them such as 'What sort of woman are you, you can't give birth to a normal child', about their 'descent into hell' and eventual realization of 'the truth' that 'my life is my child'.

Regardless of whether they personally took part in the documentary or not, whether they repeated their own words or recognized themselves and their sons/daughters in the ideal characters in Mirolyuba Benatova's script, the majority of respondents from the Varna focus group were unanimous that the documentary had played an enormous role in their battles against 'the system'. At the very least, after the documentary was aired in 2015, that same year they were granted the until then denied permit by the municipal authorities to open a day-care centre for adults with disabilities, the Sunny House, which is operating to this day. In the organization and dramaturgy of the protests, they used the grim images and central message of the documentary intensively. Next to 'the children' they placed skeletons and told reporters about 'the genocide in Bulgaria' and 'the absence of light in the tunnel'.[14] In synchrony with the symbolic repertoire of the documentary, the 'supermoms' and 'superkids' are metonymic images of the welfare state that is impossible in Bulgaria and of the most wronged citizens who are in vain expecting the latter to restore their trampled dignity. Hence, the negative/expressive metaphors of kinship as an expression of the respondents' absolute discontent with the status quo were entirely logical. For Galya Koycheva (focus group, Varna) and the mothers pushing wheelchairs in the squares, 'the state is a stepmother for the people caring for a seriously ill or disabled person'.

In other modes of self-reflection and assessment of (the demonstration of) commitment to the cause of people with disabilities in Bulgaria, however, the respondents critically distanced themselves from the sentimental narrative. They shared it up to the point where it corresponded to their 'personal suffering' – to the intimate experience and painful rationalization of the stigmas and the lack of effective support for the disabled. Galya Koycheva repeatedly noted (in her biographical interview, in the focus groups, and in informal conversations with this author) that the mothers were fully aware that they were overdoing care and that they wanted to have a life of their own as well as independence and a future for their children but, on the one hand, they had to reckon with the (un)predictable onset of symptoms and conditions – fits, long illnesses, additional or new 'regressions' in their children's development, and on the other, with the lack of financial stability, sustainable social services, qualified specialists, etc. In general, beyond the existential and/or pragmatic experience, they have become very sensitive to ambivalent public uses and the 'potential for creating pathological dependencies'. They mocked the visits by local politicians bringing presents and cakes on holidays, laughed about deliberately wearing old baggy clothes so as to evoke pity from the members of the commissions granting disability status (focus group, Varna), voiced indignation about being widely regarded, together with their children, as 'unfortunate crushed creatures' (focus group, Lovech). Here is how Stanimira (34, cares for her daughter who has spina bifida, housewife, Varna, 19 August 2017) formulated her doubts about the relevance of the popular representations that rely on an emotional effect:

> Whenever there's talk about a family of a child with disabilities, they are always shown as suffering; the child is shown as being in need. There's a family in our association which helps people with disabilities conquer Mount Musala. When they make reports about Zahari and Viktoria, they always show the daughter suffering and being carried piggyback by her father. No one shows her walking on her own, without assistance – managing to walk for, say, two or three hundred metres with her little crutches. They show her father carrying her, doing everything for his daughter. Society helps those who are in need, not those who manage to cope. So it's more expedient for the families of children with disabilities not to fight but to hold out a begging hand because they know they'll get something.

As this quote shows, however, despite – or rather, within the framework of – the described and demonstrated critical attitude, people with disabilities in Bulgaria are still framed by the various social schedules, institutional regimes, and cultural ideological constructs of the sentimental narrative of disability – at least at the level of their socialization, social realization, and public recognition. In her insightful study on ableism, Ina Dimitrova (2019) shows how the Bulgarian mothers' mobilizations of 2018 were not driven by the idea of social justice and protection of their rights or of the rights of people with disabilities in their capacity as repressed or marginalized groups, but by a shared 'utopia of productivism' that demands contributing 'at any cost' to social well-being with work and productivity. Without discussing in detail her examples – statements such as 'the integration of children with disabilities will make them more useful to the state' and 'I love my child, but I want to work, in order not to turn into a parasite for the state' (Dimitrova, 2020, pp. 76-77) – I will only note that in the course of the protests, the demands for access to work and education, which originally united the mothers, eventually divided them not only on the basis of the political groups supporting them but also on the basis of the degree of their children's physical and intellectual disabilities.[15] It was no accident that after taking part in all sorts of public initiatives and demonstrations for six years, Galya Koycheva refused to participate in the 2020 protests because 'there's simply no way that young people with multiple and severe disabilities could find a job, unlike those with slight disabilities, just as there's no way I could take anything other than an hourly job because I have to care for my son around the clock'. There is a particular significance in the fact, discussed in detail also by Ina Dimitrova (ibid., pp. 79-82), that the nationally representative organizations of people with disabilities in Bulgaria vehemently opposed the mothers' demands (for introducing personal assistance), reinforcing their status and right to receive direct state subsidies.

'Active Generations' or 'Children of Their Time'

In their article titled 'Liminal Still? Unmothering Disabled Children', eminent British researchers Katherine Runswick-Cole and Sara Ryan (2019), 'mothers, academics and activists' (as they define themselves), reflect on the possibility of developing new forms of maternal activism based on 'collective action' and 'the disability commons'. They argue that this can be done by 'unmothering' or by dismantling the dominant narrative of 'good mothering' that is 'underpinned by psychologisation and patriarchy', as a result of which mothers of disabled children 'have been positioned within a particularly toxic space by health, social care and education professionals' (ibid., pp. 1135, 1137). They expressly note that the approach they propose is informed by various mother-blame techniques they have witnessed and experienced over the 20 years or so of their motherhood, as well as by a revision of their earlier views (set forth in their much cited paper: Ryan and Runswick-Cole, 2008) on 'repositioning' mothers in the context of their experiences of disability by taking into account factors such as gender, ethnicity, age and social class. Although they do not explicate and discuss it, Runswick-Cole and Ryan in fact shed light on the specific dynamic of the value attitudes of the young generation of disability rights activists in the UK, the US and around the world, to which Katherine Perez also belongs.

It is quite likely that the disillusionment of mothers like Galya Koycheva with the protests in Bulgaria also came as a result of a recapitulation of the years spent in over-responsible mothering, with the substantial difference that she did not refute but reaffirmed it. Responding to the question of how she would like to be introduced in this issue, she decided after some hesitation that her diplomas in health management and psychology were not to be mentioned, and that she preferred being introduced solely as a mother/parent of a person with multiple disabilities and as an activist. She explicitly pointed out that the word 'person', not 'child', should be used because her son had long since grown up into a 'youth' and was now 27 years old.

Although this apparently insignificant point seems to be academically irrelevant, it offers an insight into the moral dilemmas, the moments of 'rise and fall' of a generation of Bulgarian mothers who matured to the chants and echoes of the first demonstrations against the communist regime and the first free rallies, and raised their sons and daughters while staging protests dressed in black T-shirts and pushing wheelchairs with skeletons in them. The majority of the publicly most active respondents were born in the 1960s or 1970s and their children, as the interviews have also shown, are mostly 'youths' – young men and women who have passed through the same stages of growing up and the same medical, educational, and social care places/institutions. All of them have experienced the tangible influence of the socialist culture of disability – 'the paternalism and populism of the policy of "special care"' (Pachamanova, 2018, p. 35) – as well as the medical model of disability, which gave doctors an excuse for suggesting that newborns with 'handicaps' should be left in social care homes, and that mothers who have kept their disabled children should spend months and years isolated in distant rehabilitation centres.

As Galya Koycheva attested, the cores of the future parental associations that would emerge at the start of the twenty-first century and of the protest networks established a decade later were formed precisely in these rehabilitation centres. Meanwhile, the children became 'persons' or 'users' as a result of the decentralization and deinstitutionalization of social services, which started in the 1990s and gathered momentum after Bulgaria's EU accession in 2007 thanks to EU programmes encouraging the development of various forms of integration based on the social model of disability. It is no accident that the respondents cited the slogan of the independent living movement (whose structures in Bulgaria were established as early as 1995), 'Nothing About Us Without Us!', as well as the warnings of its leaders about the harmful consequences of pursuing 'copy/paste policies' in 'the sphere of Bulgarian governance culture and practice in the field of disabilities' (Mladenov, 2008). They criticized the 'piecemeal reforms', the lack of continuity in financing certain social services, the destruction of the valuable infrastructure of auxiliary schools because of incorrect implementation of the deinstitutionalization agenda. Over-responsible mothering was the only thing that guided their adaptations to the constant social crises and the subsequent radical changes in the social care sphere which often generated mutually contradictory images of 'living with disability' – of those barely learning to walk in rehabilitation centres and of the racing wheelchairs of 'invalids' that have replaced the prostheses but not 'the steel will' of the socialist heroes of labour with disabilities. Thus, their emotional representations of personal and collective resistances against social inequalities in present-day Bulgaria continued to follow the socialist cultural repertoire. In the same way, their total economic dependence on (the men in) the family and the promises about creative and sheltered jobs at social enterprises were at times compatible and at others incompatible social realization scenarios. In both cases, their nights were sleepless – because of their partners' affairs or because of the deadlines for making souvenirs come holidays (as in Denitsa's account). Hence, it is unsurprising that the cultural production of the sentimental narrative of disability turned out to be at once a curse and a saving anchor. In her conversation with Slavi Trifonov, Maria Alexandrova explicitly stressed that she had accepted the invitation to appear on his show because of the thousands of people like her who are hardly visible and who should be talked about in public. Guided by a similar but not identical logic, the respondents strictly followed Mirolyuba Benatova's recommendation that they shed tears and express strong emotions in the media in order 'to be noticed' and 'to help' their children.

* * *

In their book on the sociological theory of generations, June Edmunds and Bryan S. Turner (2002) define a generation as 'an age cohort that comes to have social significance by virtue of constituting itself as cultural identity' (ibid., p. 7). Hence, they distinguish between active and passive generations, arguing that active generations, formed in response to traumatic events, use available resources to innovate in the cultural, intellectual or political spheres, while passive generations accept the status quo with little to no resistance (ibid., pp. 16-23). This concept directly corresponds to the concept of generations of scholars like Michael Corsten (1999), according to whom every historical generation establishes a dominant semantic order in its discursive practices.

Although they reproduced the same storylines in the interviews, the respondents did not identify themselves with or speak on behalf of the generation of the transition in Bulgaria; nor did they share a common understanding of the rights of people with disabilities and their carers. In this line of reasoning, they are neither an active nor a passive generation, insofar as they tend to be dominated by new and old semantic orders united in a general narrative about the difficult motherhood and childhood in Bulgaria. To put it otherwise, in the field of disability in the Bulgarian case there are no glorious stories, there is no conquest of the Capitol; all there is are a sentimental narrative and personal testimonies that re- or deconstruct it. It is certain, however, that there is an unutilized potential for a narrative turn that will beneficially separate and emancipate 'mothers' and 'children', 'persons' and 'users' from the actors and action or agents and agency of caring because, as Galya Koycheva put it: 'At least we have learned storytelling.'

NOTES

[1] See https://cil.bg/about-us/ (accessed 13 July 2021).

[2] Jennifer Keelan, an eight-year-old suffering from cerebral palsy who crawled up the steps along with the adults, became a symbol of the landmark event.

[3] See, e.g., Little, 2020; Lantry, 2020.

[4] The narrative turn has been of crucial importance for the activism of people with mental illness, whose narratives of lived experience of institutionalization have managed to change the moralizing attitudes towards psychiatric care.

[5] For more, see https://notdeadyet.org (accessed 13 July 2021).

[6] With the exception of Galya Koycheva, whose biographical interview is published in this issue, all parents and participants in the focus groups have been anonymized and given pseudonyms.

[7] For more on the models of over-responsible mothering, see Iakimova, 2021.

[8] The documentary is available at: https://www.youtube.com/watch?v=s2FLH9URSlw (accessed 13 July 2021).

[9] At least this is what we project team members saw when we visited the Riviera Day-Care Centre for Adults with Disabilities in Varna.

[10] For more about Maria's story, see Alexandrova, 2019.

[11] The 5 May 2018 episode of the talk show featuring Maria is available at: https://www.slavishow.com/%d1%88%d0%be%d1%83%d1%82%d0%be-%d0%bd%d0%b0-%d1%81%d0%bb%d0%b0%d0%b2%d0%b8-5-%d0%be%d0%ba%d1%82%d0%be%d0%bc%d0%b2%d1%80%d0%b8-2018-%d0%b3/ (accessed 13 July 2021).

[12] See http://www.disability-bg.org/ (accessed 13 July 2021).

[13] The documentary features four families – four mothers (three of whom participated in our study) and two fathers with their children, who describe their experience of disability in close-up.

[14] See Ivan Kulekov's video report of 11 October 2018 for Deutsche Welle at: https://www.dw.com/bg/%D0%B2-%D0%B1%D1%8A%D0%BB%D0%B3%D0%B0%D1%80%D0%B8%D1%8F-%D0%B4%D0%B5%D1%86%D0%B0%D1%82%D0%B0-%D0%BD%D0%B8-%D1%81%D0%B0-%D0%BE%D0%B1%D1%80%D0%B5%D1%87%D0%B5%D0%BD%D0%B8-%D0%BD%D0%B0-%D0%B3%D0%B5%D0%BD%D0%BE%D1%86%D0%B8%D0%B4/a-45843820 (accessed 13 July 2021).

[15] I would like to acknowledge at this point that this article was largely inspired by informal conversations with Ina Dimitrova about the representations of disabilities in Bulgaria and Bulgarian parents' activist ideologies, for which I thank her.

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Gergana Mircheva

CARE WITHOUT LIMITS? THE EXPERIENCE OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

Theoretical Perspectives and Hypothesis

By way of an introduction, I will begin with an excerpt from an interview with Radost,[1] 45, university lecturer with a degree in economics, mother of a child with autism:

> People very often forget that children aren't custom-made. They aren't robots, they aren't cars, and although there may be no reason why the model is wrong, every child is particular. And different. … You pray and hope for some very small progress and, most of all, you learn to be patient. … You simply say to yourself: 'I must fight'. … In other words, let's try, let's integrate, let's pay the high price of this therapy, it isn't cheap at all, let's train specialists, let's do research. There's nothing wrong with that, it doesn't mean that we don't accept that [children with autism] are diverse, that they are very precious and make our world special.

In this excerpt, the image of the child that is not custom-made introduces, in a concise form, some of the main problems addressed in this article: the tension and balance between typicality and difference, between normality and pathology, between stable and unstable identities in caring relationships with children with autism spectrum disorders (ASD). Particular children – such as all children more or less are, according to the respondent – put to the test social stereotypes of the good life and stretch the existential boundaries of care for others. Where do/should those boundaries end, is care all-encompassing, how hard is it for those involved in it, and can it be liberating for them? This analysis explores the possibilities for amending the parental perspectives – adjusting the focus to the vulnerable other, respecting their perspective, combining the notions of their disability with those of the preciousness of their identity. In a nutshell, what I am interested in here are some of the ethical issues that are evident in parental images of children with autism, drawn from biographical interviews and focus groups conducted with parents: mostly mothers, two fathers, and one adoptee grandfather of a child with ASD.

Kristien Hens, Ingrid Robeyns and Katrien Schaubroeck (2018) have pointed out six clusters of research topics which they think should be on the agenda of the emerging field of 'autism ethics'. They are the following: the very concept of an autism spectrum, which is too heterogeneous and hence problematic; the question of whether autism is primarily a disorder or an identity; the ethical questions and challenges that parents of autistic children face; metaethical questions related to the widely-debated role of empathy as a criterion for moral agency and as a capacity to assume moral responsibility; the ethical consequences of epistemological questions linking autistic knowledge and knowledge of autism; and last but not least, a cluster of questions that have to do with social justice, stigma, and paternalism. Issues from those clusters of topics will be discussed in this article, too. Its overall structure follows this order of topics, occasionally departing from it when required by the logic of the exposition. The subsections present and problematize certain conceptual and ethical oppositions.

The main subject of study is to what extent, why, and how parents' images adopt, modify, combine and/or contest different normative models of dealing with their children's condition. Parental care is examined in the context of ethically relevant concepts, such as 'normality' and disability, normative moral agent, good life and good parenting. These concepts filter parents' personal experience, which is typologized in order to identify possible recurrent patterns. The emphasis is, on the one hand, on how parental reflections and experiences are related to the 'ethical divide' (Barnbaum, 2013) between discourses of 'the neurotypical' and of 'the neurodiverse'. On the other hand, the focus is on the ethical concepts of care, vulnerability, dependency and autonomy as well as on the attendant moral issues of stigma and social exclusion.

The methodology of the study is based on an interdisciplinary approach, combining biographical research methods and concepts from the field of bioethics and feminist ethics, including ethics of care (Gilligan, 1982; Kittay, 1999; Held, 2006; Slote, 2007; etc.), critical disability studies and social studies of autism (e.g., Waltz, 2013; Silverman, 2012; Hollin, 2014).[2]

The hypothesis of the article is that parental accounts represent ambivalent images. They are both negative and positive; they evolve and intertwine over time. Parents' strategies towards their children have a potential for fruitful combinations between the biomedical model of autism as a deficit and the social constructivist concepts of autism as neurodiversity. Parents strive towards medical and social normalization of their children, but also respect their difference, thus attaching ethical value to it. Although they treat their children as very dependent and vulnerable at the biosocial level, they are also inclined to perceive them as worthy personalities and strive to turn them into future autonomous subjects. Despite all controversies over whether people with ASD have moral capacity, their autonomy can be interpreted in a relational mode. It is not the freedom of self-sufficient rational moral agents – ergo, of equipollent liberal subjects – it is the interdependency of human beings in a communitarian ethics of care which underlies the dynamics of the 'interconnected' identities of children and parents. The interdependency between caregivers and care recipients also underlies stigma by association, and generally, the establishment of a deep bond that changes and expands the existential and ethical horizons of those involved in care. But caring relations are neither idyllic nor unambiguous or static – they themselves are under threat of the degeneration of care into paternalism and of 'love's labour' (Kittay, 1999) into a crushing burden beyond the space of personal autonomy. Thus, this article puts the problematic of the 'autism epidemic' into the context of key contemporary debates in ethics and philosophy.

Facing the Diagnosis

Whereas in the 1960s autism was regarded as a very rare condition, recent statistics show that its prevalence is increasing at an alarming rate around the world.[3] Yet even today, approximately 80 years after the psychiatrists Leo Kanner (1943) and Hans Asperger (1938) introduced the term 'autism', coined by Eugen Bleuler (1911), to designate a new nosological entity,[4] the causes for this 'explosion' as well as the definitions, etiology and therapies of ASD still remain controversial.

In the 1940s and 1950s, the dominant theories were the several varieties of psychoanalysis, which reduced the cause of autism to the lack of maternal warmth. In more recent times, 'biological psychiatry reduced it to an individual biochemical imbalance, and other models of the condition defined it as a set of learned behaviours, a metabolic disorder, or a genetic "error"' (Waltz, 2013, p. 71) or a vaccine side effect. Even more radical battles are fought over therapies, which range from behavioural practices (Applied Behavioural Analysis) to early intervention techniques, pharmacological treatments, and diets. According to the fifth (2013) edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), the autism diagnostic criteria include two types of behavioural symptoms: A. Persistent deficits in social communication and social interaction across multiple contexts; B. Restricted, repetitive patterns of behaviour, interests, or activities.[5]

The word most often used by parents of children with other cognitive disabilities to describe their initial reaction upon learning of their child's diagnosis is 'shock'. When, however, the medical diagnosis is postponed and the certainty of the scientific label is absent, as in the cases of ASD, parents pass through a different type of psycho-emotional challenges. In our study, the narratives of parents attested to a gradual departure from the zone of normality, to creeping fears of unfolding abnormality. 'No parent wants to believe it, to accept it; people struggle with this problem for years,' said Neda (32, nurse, currently a housewife, cares for a son with autism). The majority of respondents went through a long, distressing period before their child was diagnosed, which involved the following: underestimation of the problem on the part of pediatricians, shortage of specialists, especially in the provinces, a long wait for specialized checkups and tests, unspecified diagnoses, lack of a 'roadmap' for forthcoming therapies (Radost), their high price, and the great anxiety over the uncertainty of the diagnosis and the child's future.

Coping with this 'terrible psychotrauma' (Teodorina, 47, philologist, cares for a son with autism), such as the appearance and labelling of the disorder is, involves going through the stages of denial and grief, according to many of the respondents. They described their experiences in psychologizing terms, which shows that such terms have been internalized and are used widely – at least when one is initially faced with an identity crisis. To quote Lilia (46, psychologist by education, cares for a 16-year-old son with autism):

> I cried for two nights because I lost the child I had dreamed of. I accepted the loss and forced myself to love this other child whom I didn't know, didn't want, he wasn't the child of my dreams. This is very difficult to admit, believe me, but it's true. No mother dreams of having, and is ready to get, a disabled child. This isn't her child. The child she had dreamed of has died. And you must come to terms with the loss, you must get over it and manage to start loving this child. And if you love him, everyone around you will love him too.

Although rarely, descriptions of negative emotions associated with denial, with a dramatic adjustment to the new realities were missing in some parental accounts. Radost's was a case in point. Already during her pregnancy, she and her husband accepted the high probability (established through prenatal screening) that their child would be born with Down syndrome and decided to keep him. The appearance of another issue in their child's development did not cause an existential crisis either:

> I don't want anyone to perceive me as suffering and unfortunate, definitely not. How? This can happen to anyone, anyone can find themselves in a situation where they have a loved one with a disability… That's life. … Hard as it may be, you must swallow your ego, stigma, and all sorts of prejudices in order to cope. We didn't have a problem with acceptance, our relatives and friends did because there is a lack of information about this problem in [Bulgarian] society.

Acceptance of the child's diagnosis involves a series of challenges, which many respondents summed up with military metaphors: 'merciless battle' and 'war, every day'. Care turns out to be a struggle – not just for coping with the promises and limitations of the medical model of autism spectrum disorder but also with the stigmas and 'disorders' of the social system.

Assuming the parental role entails also assuming the stigmas which spread from the disabled child to the individuals with whom he or she is in a close social relationship. As Erving Goffman (1963, p. 30) notes, the problems faced by stigmatized persons and their loved ones 'spread out in waves, but of diminishing intensity'. Winnie Mak and Rebecca Cheung (2008, p. 532) use the term 'affiliate stigma' to refer 'to the extent of self-stigmatization among associates of the targeted minorities'. Internalized prejudicial attitudes, stereotypes, discriminatory behaviours and discrediting effects of biased social and institutional structures affect, to one extent or another, the relationship between caregivers and care recipients (ibid., pp. 532-534). For their part, Janice McLaughlin et al. (2008, p. 18) point out that 'those psychological and affective realities … undermine the emotional well-being of disabled people [and] can be just as disabling as structural barriers'. The same is true for their caregivers.

As the child grows up and begins to be socialized, the stigma increases: 'when someone makes fun of my son … I feel as if they've made fun of me' (Radost). Stanislav (33, with secondary vocational education, cares for his four-year-old autistic son) said one of the reasons why he moved to the UK with his family is precisely the stigma of people with disabilities in Bulgaria. The father of a child with autism, he himself suffered from dyslexia in his childhood and now self-identifies as being on the autism spectrum although he has not been formally diagnosed: 'Imagine a world in which everyone is against you. Literally … This is what growing up with autism in Bulgaria is like.' This world is in stark contrast to that of Yanislava (28, with a university degree, mother of a three-year-old child with suspected autism), who moved to the Netherlands ten years ago – she was adamant that people with autism are not stigmatized there, and went on to add: 'I'm very happy that I'm not in Bulgaria…'. These accounts reveal some of the local specificities of the 'autistic cultures' (Silverman, 2012) in Bulgaria, the UK, and the Netherlands, each one of which includes different normative horizons of perception and treatment of ASD and people with ASD.

Coping with the crisis and accepting life with autism is a process that occurred in different ways for the respondents and, in some cases, was still ongoing. Quite a few respondents admitted that they had even had suicidal thoughts but had overcome them because of the need to care for their child: 'You don't have the right even to commit suicide' (Irina, 28, with a university degree, mother of a four-year-old autistic son), because 'you must save yourself first so as to help [your child]' (Aneliya, cares for a son with multiple disabilities: 'my job has always been that of a mother'). In this way, the modeling notions of the role of the good parent are also actualized. As Teodorina put it: 'I try to be good to people … Not to do anything bad and to observe my own moral laws. Besides this, I love him [my son] very much and he is the meaning of my life.' According to Aneliya, acceptance comes 'the moment you realize that there's no cure. The moment you realize that the most important thing in this world is … to do everything possible to make your child happy, that's all you need to do. Whatever it costs you.'

This experience of the respondents can be described most eloquently with the metaphor of 'the transparent self' – 'a self accommodating to the wants of another; that is, a self that defers or brackets its own needs in order to provide for another's' (Kittay, 1999, p. 51).

Disability or Identity, Typicality or Specificity

A large part of the debates around autism can provisionally be grouped under the heading of the opposition between the medical and the social model of disability. This opposition is key to contemporary disability studies. It can be thought of as the conceptual basis of the opposition between autism as a disorder and autism as a form of difference (and identity) (Hart, 2014). In the 1990s, Judy Singer coined the term 'neurodiversity' to represent ASD as a form of natural and even positive variations in neurocognitive functioning that should be celebrated, not treated as a disorder (see Bumiller, 2008; Orsini, 2009; Antze, 2010). The main critique against the neurodiversity paradigm is that it expresses the interests and needs only of the so-called high-functioning autistics and not of the low-functioning ones, as well as that it ignores the suffering described by some autistics themselves. A number of scholars, however, have taken more flexible, combined approaches that subvert the hard-and-fast oppositions between the biodeterministic and the social constructivist concepts, between the need for therapy and respect for difference, while bearing in mind the mixing of normative models at the everyday level, including in parental care (Savarese and Savarese, 2010; Cascio, 2012; Kapp et al., 2013; Hart, 2014).

What position did the interviewed parents in Bulgaria take within the framework of this debate? All think that children with ASD need therapy depending on their condition, and at the same time, the majority view the different children and their specificities as precious. In the words of Mariyana (39, philologist, mother of a seven-year-old son with ASD): 'Yes, these children are different, yes, we're proud of them, but all of us are trying to change this because one day these children will be left without us and they must be absolutely capable of dealing with everything [on their own].'

The use of different medical terms ('condition', 'illness', 'disability') laden with different connotations by the four mothers who took part in a focus group in Sofia (on 12 May 2018) reflected, in turn, the heterogeneity of the medical concept of ASD. This heterogeneity, by virtue of which it includes disorders with very different characteristics, has certain ethical consequences. Hence the question: Should we approve of the fact that individuals with very different characteristics are diagnosed under one and the same medical term if that gives them access to services and institutional support? Or, conversely, does being diagnosed with ASD have undesired social consequences? The latter were noted by Stanislav: ‘Being diagnosed [with ASD] in Bulgaria is [tantamount to] suicide.’ Bogdan (59, economist), had also decided against having his son certified as an autistic in order to be eligible for social allowances. In his words: ‘If there is a document, there is a problem’ – that is, an obstacle to the labelled person’s normal social functioning.

Some respondents directly criticized the standards for granting disability status in Bulgaria. The statistical standard imposed by the imperatives of biopolitics was criticized as incapable of encompassing the specificities and complexities of the person. According to Krasimira (44, statistician and social activist, mother of a son with autism), the so-called territorial expert medical commissions (TELK), the bodies granting disability status in Bulgaria, should even be abolished because they ‘don’t give any assessment of where [the person] is on the spectrum or what his needs are. They simply give a purely formal assessment, a made-up one… And that’s all for the sake of some money that’s given in cash and you’re left to fend on your own…’ Hence, the standard for disability status is ethically invalid because it is formal, hollow and doesn’t even guarantee proper institutional support.

A key pair of concepts around which parental perceptions are framed is that of ‘normality and difference’. For many parents, normality is absent not only in terms of a medical deficiency but also in terms of shattered notions and expectations of a normal and ordinary but nonetheless good human life. According to Teodorina: ‘The other thing that distresses me is that he will never have close friends, he won’t have an intimate relationship, he won’t have a family.’ The loss of this horizon is the first ordeal in accepting otherness beyond normality. The notion of ‘the different children’, shared by most parents, could be discriminatory, but it does not have negative connotations. The majority of parents gravitated towards the socially acceptable scenarios of ‘normality’, but at the same time many of them were inclined to view difference in a positive light. Here is what Bogdan said about his son:

> When he gets on a public transport vehicle, he starts talking so loudly that everyone turns around … If you are very self-conscious, at some point … you immediately take tough measures, such as telling him to shut up, stop talking, etc. The result is that he stops talking … Because he realizes right away that there’s a problem. And this makes his problem worse. In other words, at some point you tell him that he’s mad. The right reaction is simply not to react.

The father’s refusal to keep trying to normalize his son’s behaviour reflects the dynamics of his individual development and acceptance of his child’s disorder. This presupposes ethical resistance against all forms of social behaviour that display intolerance towards difference.

Most life-stories were not confined to the disabled children’s limitations; they stressed their abilities. For example, Katerina (51, hospital storekeeper), whose son has Asperger's syndrome, described him as the 'epitome of a gifted person', while Irina (28, university degree, cares for a five-year old boy with autism) called her child 'a little professor'. The word 'incredible' was used frequently by the respondents. It is obvious that for them, 'being normal' is relative insofar as everyone, whether 'normal' or not, has both abilities and inabilities. In this way, the 'norm/abnormality' opposition is called into question and its repressive function is suppressed. In the words of Mirela (54, grandmother of a four-year-old boy with autistic markers and an unspecified diagnosis): 'If you think about it, you'll realize that everyone is autistic. Because everyone is different.' The same effect, of inversion, was achieved through the opposite proposition in which everyone's difference and, at the same time, shared humanity were thought of as the norm: 'For me, children with autism are entirely ordinary children who can love, laugh, cry' (Gabriela, 38, with secondary education, mother of 15-year-old twins with autism).

A commonplace in the interviews was the notion that children with autism live in a parallel world of their own. According to many respondents, this world is more authentic than the world of everyone else ('they are better than the other children'). In children with ASD there is no deceit or hypocrisy (they are 'pure souls', forthright) and, at the same time, they feel the disparaging or disapproving attitude of 'normal' people towards them. Children with ASD were defined by the respondents as different, not least in the sense of 'unique'.

Rejection of the concept of 'normality' in favour of that of difference-as-uniqueness is found mostly among parents of children with ASD, and much less so among parents of children with other intellectual disabilities. This may be due to the absence of intellectual deficiency in part of the autism spectrum disorders, which makes it easier to break away from the gravity of 'norm' and the effort to catch up with it at any cost. As Katerina put it: 'I've accepted him, he's unique. To me, he's not disabled … maybe that's how I manage to preserve myself.'

Studying the meaning of disability to families, Elizabeth Larson (1998) also focuses on mothers' contradictory emotions, which she summarizes in a life metaphor, 'the embrace of paradox'. The embrace of paradox is 'the management of the internal tension of opposing forces between loving the child as he or she [is] and wanting to erase the disability, between dealing with the incurability while pursuing solutions, and between maintaining hopefulness for the child's future while being given negative information and battling their own fears' (ibid., p. 873). The paradoxical maintenance of a 'tenuous emotional compromise' (ibid., p. 871) in which there is room for optimism becomes, according to Larson, 'a driving force which energize[s] the mothers to seek solutions' (ibid.), a strategy for attaining inner balance and for coping with the destructive effects of these 'opposing forces'. Although she notes that they are different, she also points out similarities between 'the embrace of paradox' and the maintenance of 'positive illusions' (Taylor and Brown, 1988, 1994, cited in ibid., pp. 872-873) as ways of increasing personal motivation and improving subjective well-being. I largely accept Larson's account of the ambivalent structures of parental representations of disability, but not her entirely psychologizing explanatory model. In this regard, I agree with McLaughlin et al. (2008) who insist on contextualizing emotional distress in broader societal expectations of children and parents and in the normative pressure for their 'governmentality'. One of the goals of this study is to establish to what extent, and in what forms, the ambivalent parental experience and the hybrid identities it produces contest the normative conventions about living with disability, about parenting, childhood, agency. Those are conventions of 'normality' which have a prescriptive (and hence normative) character and whose content is determined by psycho-medical and more general sociocultural scenarios, including moral norms.

Ethical Challenges Facing Care: Striving for Cure or for Alternative Modes of Living with Disability?

Although they were inclined to attach value to their child's difference, many of the interviewed parents in Bulgaria largely supported the medical model of disability. In the words of Gergana, who is both a caregiving parent and manager of a centre for social services, 'parents usually end up following the medical approach – going to the doctor's, being given a prescription for a syrup for learning to talk or to walk…' Although there were mothers like Krasimira, who declared, 'I go mad when I hear of treatment,' some parents obviously hoped for a miraculous cure and complete 'normalization' of their child. Many of the interviewed parents said they had tried out different – medically validated and alternative – therapies for their child. As Katerina put it, 'parents of autistic children are the biggest experimenters'. Along with the therapeutic methods of psychology, psychiatry, speech therapy and ergotherapy, the alternative methods some of the parents relied on make up a long list: from hyperbaric chambers and gluten-free and dairy-free diets to 'the thick books, the old teachings' or 'gong therapy' (Aneliya) to 'all sorts of faith healers, hags' or 'miracle-working rocks' (Irina). Some parents, such as Dilyana (resource teacher and grandmother of a boy with autism), were of the opinion that 'the family is the best therapy'.

However, as Hens, Robeyns and Schaubroeck (2018) point out in examining such questions:

> Some techniques … raise the question of what the purpose of intervention should be: is it permissible to aim at "normality" for one's autistic child, or is it better to accept one's child's autism as a neutral neurological difference? In addressing these difficult questions, ethicists could draw on theories of the social construction of mental disorders; of parental rights and duties in moral, social, and political philosophy; and of children's autonomy and needs, as developed in philosophy of (special needs) education ….

Insofar as one can judge from the interviewed parents' care practices, a possible criterion in determining the boundaries of (non)intervention in the child's identity is the presence or absence of suffering in the child. Aneliya, for instance, welcomed the concept of autism not simply as a deficit, but as a valuable difference, yet said she thinks parental intervention is necessary when the child self-harms. Aggression towards self or others is a criterion for the need for therapy according to Irina, too. In Lidiya's view, therapies should target 'these children's inabilities, not their differences', because although a cure is impossible, 'we aim at normality'. 'Normality', according to her, includes above all the ability to look after oneself physically, to find 'a purpose and motive in life' and to survive without parental care – in other words, the social repertoire of maternal care for 'normal' children, too. Radost's view was the most reflexive, as it were – she said she sees a logical contradiction in the understanding that respecting neurodiversity rules out certain autism therapies as a form of violence against the different identity of people with ASD. According to Radost, the idea of character education and correcting the behaviour of children is a fundamental idea around which human culture is built, therefore children with ASD cannot be an exception. What is more, doing nothing about their emotional and communication deficits would doom them to social exclusion and unhappiness. In her words, there's no doubt that 'neurodiversity is positive, these are very precious people, very interesting, and their way of seeing the world as well as knowing their problems in perceptions makes us better people. There are definitely things we can learn from them instead of just expecting them to paint a genius painting or to write genius music.' Therapies, however, could not change the neurological nature of autistics, their different sensitivity; they could only enable them to adapt to and integrate into the social world.

The views of Dilyana and Mirela were more extreme. Dilyana said that, unfortunately, it is much more important for a child with ASD to learn to tie their shoes than to have some exceptional talent, because they wouldn't be able to realize it if they don't have basic skills. According to Mirela, if there is no other way to get the condition under control, the child has to be 'trained' in order to become manageable – but she, too, wasn't entirely sure about 'what's the right thing to do'. However, Miroslava (38, with a university degree), whose seven-year-old son has Asperger's syndrome, said she definitely doesn't want him 'to lose everything that he is' in order to become like a 'normal' child. Radost was also of the opinion that 'synergy' is possible between the conventions and standards allowing integration into society, and the precious individual difference. At the same time, she stressed that 'not everyone is Rainman. The majority aren't.'

According to Eva Kittay (1999, p. 166): 'Maybe there is a fundamental sense in which a mother cannot fully accept the disability of her child, even as she accepts the child.' Speaking of socialization for acceptance of the child as a main parental function in general, we must distinguish between acceptance and normalization: 'There is the "acceptance" which grants the difference, which demands acceptance *of the difference* and *in the face* of the difference' (ibid., p. 167), while normalization is 'the desire for acceptance *despite* the difference' (ibid., p. 168). Kittay (ibid., p. 33) cites feminist philosopher Sara Ruddick (1999), in order to outline the fundamental elements of maternal care. According to Ruddick (ibid., pp. 167-168), they are three: 'preservative love, fostering growth, and training for social acceptance'. When caring for a severely disabled child, Kittay (1999, p. 33) argues, they 'may have to be accompanied by a lifelong commitment to day-to-day physical care for the charge. … Socialization for acceptance may involve less effort directed toward the training of the charge and more to changing the expectations and grounds of acceptance of society itself.' This process of socialization occurs in two stages: First, I refuse to accept that my child isn't normal. That's because what they do is normal for them. Thus, normality is redefined according to the child's individuality. Besides this, however, I must see my child the way others see them – so that I can mediate between the others and my child, that is, so that I can negotiate my child's acceptability. In this sense, socialization is a two-way process – socialization of the child to the world but also of the world to the child, which requires socialization of self so as to accept the child and establish some own normality. Acceptance 'was a very long process,' Aneliya admitted. 'But the moment I managed [to accept my child], my life became a million times easier.'

As noted above, suffering is an invariable part of the process of acceptance of one's child's disability. But it continues after that, too, in the struggle with the public administration, with financial problems, societal barriers and stereotypes as well as with the difficulties of providing all-encompassing care. In this 'descent into hell' (Milena, 41, cares for a daughter with Cornelia de Lange syndrome), suffering sometimes take over: 'My life is doomed… For every disabled child, there is a victim – be it the mother, grandmother, or sibling' (Neda, a nurse by education, not working at present, cares for a 12-year-old son with autism).

Many parents view their child's disability as a tragedy, judging from the interviews with Bulgarian parents – as well as from a number of foreign studies. The situation of Bulgarian parents, however, is made worse by the local specificities – the flaws of the social security system and the economic situation in Bulgaria, which were criticized by the majority of the respondents. In the words of Svetlina, who cares for a nine-year-old son with autism:

> A person who doesn't have own financial resources and has a problem child is simply totally excluded from society, totally – it's no accident that the logo [on my T-shirt] is 'The system kills us'. That's true, literally, and it's genocide, not a metaphor.

At the same time, countering suffering is a main part of the battle waged by the respondents on a daily basis. But they did not share stories containing provocative answers to the provocative question, ‘how dare you be happy *because* of your disability and not *in spite* of it’ (Campbell, 2012, p. 216). Such attitudes, which are theorized by Western scholars, were not found among the interviewed Bulgarian parents. For example, here is what a mother of a child with autism said: ‘As if there’s anyone who wants to have a disabled child… You must be brainless to want this.’ Arguably the only exception (to some extent only) was Stanislav, who referred to biological theories in defining autism as a specific form of evolutionary progress. He described the condition as an evolutionary move by nature in its attempt to achieve ‘a new human brain that processes abstract information in a quicker and easier way’ – without the mediation of speech and writing. This view explains why Stanislav’s acceptance of the diagnosis was not accompanied by disappointment – just as he wouldn’t be disappointed ‘if the child doesn’t like, let’s say, seafood’. The emotional background of his account did not contain the tragic tone characteristic of other parents’ accounts, and his trivialization of his son’s disability suggests another type of normalization – that of a person who accepts, calmly and with understanding, the ‘norm’ of difference.

To sum up, the interviewed Bulgarian parents’ images of children with ASD are open to normative as well as to alternative discourses of living with disability and, in this sense, they are hybrids of the different layers they are made up of. Here I accept the concept of hybrid identities elaborated by Dan Goodley (2011, pp. 168-170) referring to Homi K. Bhabha (1985), and by McLaughlin et al. (2008, p. 79) referring to Gilles Deleuze and Felix Guattari (1987) in studying parents’ contradictory and uncertain notions of their disabled children. Uncertainty is viewed as a characteristic of the parental role in general, which, moreover, has a specific creative potential; it subverts stigma and unlocks emancipatory energies.

Between Duty and Empathy: Autism and Moral Psychology

One of the current debates in the field of autism ethics is about the grounds of moral agency, and more specifically, about empathy as a condition for acquiring the status of moral agent. The issue of impairment or lack of empathy in people with ASD, however, is part of the wider debates on the so-called full moral status/capacity of people with cognitive disabilities and especially those with radical cognitive disabilities (such as anencephaly). Hence here I will summarize some of the major lines of these ethico-philosophical debates.[6]

Moral status is often viewed as a threshold concept and a range concept. The issue of moral status has become important because of its bearing on the rights that depend on its ascription – beings that fall below the threshold of full moral status do not enjoy the same rights that other beings, which possess that status, do. Most generally, the approaches in determining the criteria for conferral of full moral status are of two types: individually-based and group-based. In the first type, full moral status is based exclusively on certain biological or psychological attributes of the individual. Conversely, group-based approaches are based on facts about the individual's membership in a biological or social group, or the individual's relationship with other members of that group.

The individual attributes that are most often defined as criteria for full moral status are the following: (minimal) capacity to communicate (Berube, 1996; Francis and Norman, 1978); capacity to value or to care (Jaworska, 1999; 2007); capacity to love and to be loved (Kittay, 1999); or capacity to form relationships based on reciprocity of care (Mullin, 2011). All approaches based on individual attributes, whatever they may be, exclude some human beings from full moral status.

One of the fundamental individually-based approaches is in essence Kantian. It sees moral status in terms of the respect demanded by the possession of attributes such as autonomy or moral responsibility (e.g., Korsgaard, 1996). Possession of an autonomous will entails being respected, being treated as an end and not as a mere means. According to many, however, the threshold for moral status set by this Kantian paradigm is too high for people with severe cognitive disabilities.

The group-based approaches can be divided into two types. Those of the first type regard membership in the species *Homo sapiens* as sufficient for full moral status and ground that status in a species-based attribute (e.g., rationality, connection by birth to all other human beings, etc.). The second type of group-based approaches regard 'human being' as a 'thick', multilayered normative concept that is grounded in language and social practice, and which cannot be reduced to the biological category of *Homo sapiens* or to any descriptive category associated with it.

The debates on the construction of moral agency leave little room for consensus and are rife with internal contradictions and conflicting views. According to Peter Byrne (2000), for example, appeal to the rational nature of human beings as the basis for the ascription of moral status is too narrow because it ignores other aspects of humanity that make the concept of 'human being' so rich.

There are ethical approaches which are based on Humean moral sentimentalism, not on Kantian rationalism, and place empathy at the centre of morality. This applies to a large extent to the ethics of care as a feminist paradigm influenced also by the achievements of modern psychology. This analysis accepts some of the key concepts of the ethics of care as a necessary supplement to rational ethics, but disagrees with another part of (for example) its psychological determinations.[7] One of the key representatives of this school of thought, Virginia Held (2006, pp. 9-13), identifies the major features of the ethics of care. First, the central focus of the ethics of care is on the compelling moral salience of attending to and meeting the needs of the particular others for whom we take responsibility (for example, caring for one's child). Second, the ethics of care values emotion (such as sympathy, empathy, sensitivity, and responsiveness) as a moral criterion that has priority over rational criteria. Third, the ethics of care calls into question the abstract and universalistic rules of the dominant moral theories. It is guided by the compelling moral claim of the particular other. Hence the intermediate position of the ethics of care in the conflicts between individual (egoistic) interests and universal moral principles. The ethics of care proceeds from the assumption that persons in caring relations are acting for self-and-other together, neither egoistically nor altruistically. The fourth characteristic of the ethics of care is that, as a feminist ethics, it reconceptualizes traditional notions about the public and the private, and its fifth characteristic is that it conceives of persons as being relational and interdependent, morally and epistemologically.

If, however, empathy is not just the primary mechanism of caring and a higher ethical value but also a general criterion for morality, as Michael Slote (2007, pp. 4 and 8) claims, to what extent, if at all, can we view people with autism as moral agents? And treat them with respect and recognition of their dignity entailed by their possession of moral capacity? According to a number of psychopathologists and social scientists, ASD can be viewed as a disability of empathy (Baron-Cohen, 2005, p. 172). Yet although empathy is assigned a key social and psychological role, it does not have unquestionable definitions in theory.

Most authors assume that empathy is a multifaceted construct, but some focus on its affective components (Hoffman, 1976; Aaltola, 2014), and others on its cognitive components (Baron-Cohen and Wheelwright, 2004; Kagan, 1984). Affective empathy is the capacity to emotionally respond to the expressive behaviour of others, while cognitive empathy is the ability to adopt another person’s perspective and understand their thoughts and feelings. Researchers, however, disagree both on the issue of whether individuals with ASD are deficient in affective or cognitive empathy, and on the issue of whether one or other form of empathy is primary. Most studies are devoted to high-functioning autistics, the prevalent opinion being that they lack cognitive empathy. Cognitive empathy implicates theory of mind, that is, the ability to ascribe various mental states to oneself or others. In affective empathy, the response to another’s expressive behaviour is automatic (nearly reflexive), not necessarily compassionate or consoling.

Without underestimating the ethical implications of empathy, authors like Timothy Krahn and Andrew Fenton (2009) argue that neither should they be overestimated, that is, that a certain degree of moral agency should not be denied at least to high-functioning autistics. They appeal for more nuanced approaches to the issue and for moral pluralism – that is, for ‘an approach to moral agency that views it as graduated and layered rather than as an “all or nothing” set of capacities’ (ibid., p. 158). Krahn and Fenton point out that some individuals with ASD engage in morally adequate behaviour, demonstrating an ability to observe ethical norms, and moral concerns and conscience, albeit not spontaneously but through rational mechanisms. According to Jeanette Kennett (2002), moral thinking in people with ASD can be explained with a Kantian rather than a Humean account of moral agency. Individuals with ASD can achieve moral autonomy not through empathy but by virtue of a concept of duty understood as a natural predisposition of the mind, not as a psychological emotion. They 'can develop or discover moral rules and principles of conduct for themselves by reasoning, as they would in other matters, on the basis of patient explicit enquiry, reliance on testimony and inference from past experience' (ibid., p. 351).

In the accounts of the interviewed Bulgarian parents, the issue of the moral status of their children was not of primary concern. That is because most of the respondents are parents of children under 18 who are still in the process of moral development. Some of the parents spoke with sorrow about their children's inability to make friends, others stressed their honesty and lack of guile. Paradoxically or not, Dimitra (45, cares for a daughter with autism) defined them as 'very affectionate in principle, very warm-hearted children'. Gabriela also disagreed that autistics do not feel emotions: 'If I start crying, they come up to me and if I don't stop, they start crying too, trying to calm me down – that's some kind of emotion as well, isn't it?' Many of the mothers underlined the specific sensitivity of children with ASD to the attitude of others towards them. According to Neda, 'These children feel the person opposite them.' Such observations support the thesis that children with autism have an emotional world of their own which, however, is not deficient in affective reaction to the world of the neurotypical.

'Dependency Work': Between Paternalism and Mutual Vulnerability

The interviews with Bulgarian parents of children with ASD conducted to date demonstrated the specific tension between the ethical requirements for autonomy and so-called independent living on the one hand, and, on the other, the concepts of the interconnection and interdependency of human beings as manifested between individuals 'intertwined' in relations of care. The concepts of autonomy and vulnerability discussed below have ethical implications both for caregivers and for care recipients, in this particular case, adults and children with ASD. In other words, if we apply Eva Kittay's (1999, p. 37) position on the relation between dependency worker and dependent to the relations between parents and children with ASD, the latter are exposed to opposite risks: 'servitude on the one hand, and paternalism on the other'. At the same time, in them we can find a potential for moral development of both caregivers and the cared for, chances for expanding their existential horizons, chances for emancipation and for rediscovering the world as one that is more diverse, fair and inclusive.

In the 1960s, the independent living movement emerged in the US as a continuation of the civil rights movement of disabled people (Morris, 1993). In this conceptual framework, the meaning of the word 'independence' was redefined in opposition to the so-called ideology of independence. As Jenny Morris (ibid., pp. 22-23) points out:

> In Western industrial societies, this term has commonly been associated with the ability to do things for oneself, to be self-supporting, self-reliant. When physical impairment means that there are things that someone cannot do for themselves, daily living tasks with which they need help, the assumption is that this person is 'dependent'. And in Western culture to be dependent is to be subordinate, to be subject to the control of others.

According to the activists of the independent living movement, however, independence does not consist in having the physical or intellectual capacity to care for oneself without assistance, but in having assistance when and how one requires it as well as in having the right to have personal relationships and the right to participate fully in society.

Liberal ethics and the ideal of equality understood as relations between free and independent equals have been subjected to a thorough critique by authors such as Eva Kittay and other exponents of the feminist ethics of care. Kittay (1999, p. xiii) argues that the 'fiction' of independence must be debunked. Her critique of social contract approaches in moral and political philosophy is based on the argument that they ignore the normative significance of dependency and vulnerability. Mutual benefit and cooperation between rational, equal individuals presuppose reciprocity. Reciprocity, however, is impossible for people with cognitive disabilities and this excludes them from the social contract.

Other care ethicists seek different approaches that revise but do not reject the concept of autonomy; rather, they complement it. For instance, according to Michael Slote (2007, p. 57), 'a morality of empathic caring requires one to respect other people's autonomy and not just or simply to be concerned with their welfare.' He argues that autonomy is a relational concept insofar as it depends on the way we have been raised, on how we have interacted with others and the world in general – all this has determined our capacity to think and act autonomously.

The interviewed Bulgarian mothers of children with autism said they sought to encourage their child's development – according to the generally accepted standards of development but also according to their child's specific characteristics. In their search for a balance, however, many of them realized that it is impossible to secure independent living for their children, and although they keep striving towards it, they do not view their children as future autonomous individuals. They recognize their merits and respect their difference but not their autonomy. In the words of Teodorina: 'You are looking after a baby your whole life and that's your prime concern. There's no way he can be autonomous, it's impossible, it's very difficult to separate such a child from the mother for a longer time, it's absurd.' The majority of the respondents, however, hoped anxiously that although it would be difficult, it was possible that one day their children would be able to cope with life on their own. The primary concern of all parents was to do their best to prepare the child for that ordeal once they are no longer around.

It is no accident that Kittay (1999) calls care for children with disabilities 'dependency work'. As our field study has also found, this is unpaid work done mostly by women by virtue of tradition, sexism, and sexual taboo. Moreover, care for a child with ASD is associated with a model of blame that 'is morally value-laden with cultural expectations about the cause and responsibility of illness and disability' (Larson, 1998, p. 866). But regardless of whether the father perceives the mother as 'poor-quality goods' (Antoniya, 42, social worker), or cannot accept his own role in the production of offspring, it is usually he who ultimately cannot bear the burden of living with disability and leaves. Even when the father remains in the family, he often plays only a supporting or even a walk-on role. The patriarchal model of family relationships in Bulgaria evokes the notion of the child-as-punishment, a notion that puts to the test the cultural norms of exemplary masculinity and the traditional gender roles in caring for the child. Often fathers of children with ASD long refuse to accept that their child has a problem, and when they eventually do, distance themselves emotionally from the process of taking decisions about the child's medical treatment and future.

Mothers bear the brunt of the burden of care in their attempt to help their children's development, to protect them from stigma and to socialize them. But the children's dependency on their mothers has a mirror effect – the mothers' dependency on their children. 'Your life revolves solely around this child … You are completely bound to this child,' said Teofila (30, cares for a son with autism). In Neda's words: 'We are very attached to them, we can't live without the children.' Thus, the children's vulnerability gives rise to a dependency relationship that turns out to be reciprocal and leads to a 'sharing' of children's and parental identities which merits special attention. In order to understand the different possible consequences of this interdependency and shared vulnerability, it is necessary to conceptualize the very concept of 'vulnerability'.

According to Catriona Mackenzie, Wendy Rogers and Susan Dodds (2014, p. 2), the concept of vulnerability has been the focus of debate and discussion in three main areas. The first is feminist ethics of care, the normative significance of vulnerability and its importance for moral and political philosophy, examined by Alasdair MacIntyre (1999) and Martha Nussbaum (2006). The feminist focus on vulnerability also draws on Robert Goodin's (1985) consequentialist theory of vulnerability which places duties to protect the vulnerable at the centre of moral obligation. The second area in the focus of debate is that of bioethics, where 'vulnerability is viewed as an ontological condition of all human existence and as a marker to identify those who require extra care, where the especially vulnerable are those "whose autonomy or dignity or integrity are capable of being threatened"' (Mackenzie, Rogers and Dodds, 2014, p. 2, citing Kemp, 1999, p. 9). Third, Judith Butler (2004; 2009) explores the ethics of 'corporeal vulnerability' – that is, vulnerability as an ontological condition of humanity that is inherent in the human body, which is precarious and vulnerable – to violence, abuse and contempt as well as to care, generosity and love

(Mackenzie, Rogers and Dodds, 2014, p. 2-3). The precariousness of human life 'generates ethical obligations to ameliorate suffering and redress the inequities that exacerbate vulnerability' (ibid., p. 3). From this perspective, Bryan S. Turner (2006) examines the concept of corporeal vulnerability in the context of human rights discourse, which seeks to mitigate this ontological vulnerability.

Identifying 'a subset of situational vulnerabilities that are particularly troubling', which they refer to as 'pathogenic vulnerabilities', Mackenzie, Rogers and Dodds (2014, p. 9) point out that

> These may be generated by a variety of sources, including morally dysfunctional or abusive interpersonal and social relationships and sociopolitical oppression or injustice. Pathogenic vulnerabilities may also arise when a response intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones.[8] … A key feature of pathogenic vulnerability is the way that it undermines autonomy or exacerbates the sense of powerlessness engendered by vulnerability in general.

This issue, which is related to the risks of paternalism that are inherent in parent-child care relations, requires further research. It is very important to interview autistic children themselves, and more so, adults with ASD so as to hear their voices, inasmuch as this is possible – while observing all ethical and psychological requirements for interviewing children and adults with ASD. Giving voice to the testimonies of people with ASD themselves is the task of future research, which is necessary in order to check the hypotheses of the project for an 'ethics of autism' outlined here. This will enable more definite conclusions as to what extent parents' images and strategies for therapy and support are shared by their children, if at all. Still, the interviews conducted to date allow us to propose a tentative definition of the ethical boundaries of parental care: the latter is legitimate as long as it does not jeopardize the feeling of happiness and the relative autonomy of the child as a person, as long as it enhances the child's capacity to feel happy and encourages activities that make them happy. This care, however, does not passively accept either the child's condition, insofar as it causes them suffering and social isolation, or the disqualifying mechanisms and consequences of socio-medical normality. It strives towards socialization and development of the emotional life of the child with autism, without succumbing to the power of the 'Norm'. At the same time, the carers themselves need care – they need social alleviation of their burden, overcoming the drastic deficits of social justice and solidarity, especially in the Bulgarian public and institutional sphere.

The negative images of the limitations, suffering and burden of dependency, identified in this study, intertwine with positive images that lend meaning to life with disability. Many of the parents have learned to perceive their child not as a punishment but as a gift that belongs to other modes of human being, beyond 'the power of reason' and its instrumentality. According to Antoaneta, the gift of these children is in their 'special mission': 'they teach us many things – they teach us to be patient, but also to stand up for own opinions.' The loss of the 'normal' life horizon, which in the parents' accounts discussed above marked the beginning of the life crisis, is rethought as a valuable acquisition. The mothers' inclusion into new social and political communities has transformed the nature of care. The latter has overcome the individual suffering confined to the private space of one's home and 'come out in the streets' as care for the public participation of people with disabilities and amelioration of social suffering. The creation of 'parental alliances' in Bulgaria, their inclusion into activist communities and their connection to the comprehensive processes of (re)construction of parental identities require a separate analysis.

All parents interviewed in this study think that interaction with their child leads to mutual personal growth which transcends the physical aspects of care. What is more, it also transcends the medical model of disability and has ethical implications. Parent-child interaction can have unexpected transformative effects which subvert the medico-social constructs of (ab)normality:

> My son used to boast: 'Ooh, I have a friend who's in a wheelchair!' What an amazing point of view! This was nothing unusual to him because he grew up with such people. … It's my psyche that's ill, not his. (Katerina)

The normal and abnormal can switch places when parental identities fail to 'harden' because they are under constant pressure for change. Then 'spoiled identity', to use Erving Goffman's (1963) term, contains a positive potential for reinventing one's own meaningful and emotional world.

Children's smiles bring smiles to parents, turning into a source of joy and inspiration. These smiles can be self-ironic, consciously distanced from the notion of the tragedy of life with disability. As Radost said, laughing, 'as for care itself, I think autism endows us with the joy of overcoming freaking out in all its many forms.' To Katerina's mind, attaining personal happiness is not an idyllic but a comprehensive state that requires insubordination at times.

What gives parents the most strength, what gives meaning to all their sacrifices, is love – without any plans and expectations for the future, without promises of happiness. This love transcends both the biologically determined maternal instinct and the exceptional prestige of intellectual achievements and rationality in modern culture. Instead, it feeds solely on – but does not demand – reciprocated love which, in turn, overcomes the nature of the disability and gives us an insight into ultimate meanings of the human condition.

Conclusion

Care creates a moral bond based on trust, but also on a 'delicate emotional balance' (Kittay, 1999, p. 36) and 'inequality of power [which] is endemic to dependency relations' (ibid., p. 34). Although children are more vulnerable in these relations, each party is dependent on the other in a specific way. The heavy weight of care-as-burden presses the life horizon of parents, but care-as-love expands it. Parents (mostly mothers) share the stigmas, suffering and joys of their disabled children. In this relationship there is always an unshared part, an autistic absence, which is made visible by 'the transparent self' of the carer. Although care is not reciprocal, children with ASD ought to be granted full moral status. In their attempts to sustain it, parents follow dynamic patterns of coping which hybridize normative and alternative scenarios of the good life, medical norms of the neurotypical, and socio-moral values of neurodiversity and difference. The life-stories of Bulgarian parents of children with ASD contain evidence if not of the abolition then at least of the weakening of the monopoly of normality, with its entire set of values, over the 'legitimate' experiences of the respondents. The normative scenarios of normality are being called into question, renegotiated, and/or (partially) rejected. Care is not boundless, but its possible limits are constantly pushed; its uncrossable, ethically legitimate boundary, however, remains the dignity of the child with autism and the possibility for finding meaning in the child's difference. In the battles for their children's rights, parents are involved in a process of parallel construction of 'shared identities' – of their children, but also of their own. The two aspects of care, which can enslave and liberate, acquire meaningful unity if they are thought of as aspects of an experience that changes over time. It can be summarized with the advice of Anton (47, businessman, cares for a son with a pervasive developmental disorder) to parents in a similar situation: 'Don't give up. Look for opportunities, look for nuances of life, don't get yourself into a cul-de-sac that has no exit – there's no such thing, there's always a solution.' Hence the 'politicization' of life with disabilities, whose nuances transcend the limits of the family tragedy in quest of different ethical senses and meanings of self, community, and humanity.

NOTES

[1] All names of respondents have been changed to maintain anonymity. This article is based on biographical interviews and focus groups with a total of 15 respondents conducted under the project *Generational Patterns of Coping with Life Crisis: Biographical, Social and Institutional Discourses* implemented in 2017–2020 with the financial support of the Bulgarian National Science Fund, as well as on 11 semi-structured interviews I conducted between April and September 2020 (face-to-face, by phone, online, via questionnaire) under my *Social Images of Autism* postdoctoral project at the Faculty of Philosophy, Sofia University 'St. Kliment Ohridski', within the framework of the 'Young Scholars and Postdoctoral Students' National Programme financed by the Bulgarian National Science Fund.

[2] Here I would like to thank the anonymous reviewer of this article, who rightfully pointed out the absence of references to studies by Bulgarian authors, mostly psychological, on the issues of autism. Indeed, this conceptual layer is missing in the article as local expert attitudes merit a separate analysis. This article focuses primarily on parental images as articulated by the respondents themselves and interpreted in an interdisciplinary perspective. The emphasis in it is not on psychological but on certain ethical and cultural anthropological issues.

[3] One in 88 children are diagnosed with autism in the United States (Baio, 2012).

[4] A nosological entity is a medical condition classified as a separate disease. Nosology – from Greek νόσος (*nosos*) 'disease' and λόγία (*-logia*) 'study of' – is the branch of medical science that deals with the classification of diseases.

[5] For details, see https://www.autismspeaks.org/autism-diagnosis-criteria-dsm-5 (accessed 14 February 2021).

[6] For a review of these debates, which is used also in this study, see *Stanford Encyclopedia of Philosophy*, 'Cognitive Disability and Moral Status', at: https://plato.stanford.edu/entries/cognitive-disability/ (accessed 14 February 2021).

[7] Here I have in mind, for instance, the idea of 'natural' and 'normal' human capacity for empathy understood as a statistical notion (Slote, 2007, p. 34). Deducing qualitative characteristics from quantitative data is conducive to conflating normality with normativity (see Canguilhem, 1978) and to what Ian Hacking (1990, p. 169) calls 'probabilization of the Western world', referring to the global cultural consequences of the deduction of (value-)normative prescriptions from statistical probabilities. I also disagree with the concept that women are morally superior to men because they have greater empathic tendencies. This, in turn, is explained with the higher levels of testosterone that makes men more aggressive and less socially perceptive and empathic than women (see Slote, 2007, p. 72).

[8] This can happen, inter alia, in the case of parents caring for a disabled child (endnote mine).

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Niya Neykova

THE ‘MALE’ VOICE IN CARE

This article builds on a previous analysis (Neykova, 2019) of the challenges facing families with disabled children in Bulgaria, and more specifically, of the understanding of gender roles and care ethics thought of within the framework of family relationships. It aims to expand the conclusions made in that analysis, focusing solely on the male voice in the corpus of interviews collected under the project *Generational Patterns of Coping with Life Crisis: Biographical, Social and Institutional Discourses* (a total of 51 biographical interviews, 24 expert interviews and 16 focus groups, with field studies conducted in Varna, Plovdiv, Lovech, Pleven and Sofia). The article will analyse only the interviews with men – that is, nine individual interviews and three interviews with male participants in the focus groups. It interprets the family as the central institution in a period of crisis. The main question it seeks to answer is what are the gender-specific roles of men and women in it. More specifically, the male voice is found to be not only different and complementary to the female voice; it voices a specific way of thinking ‘outside the system’ and even a sort of resistance against the traditional notions and state policies of care.

The gender-specific ways of dealing with a crisis, examined in this analysis, turned out to be characteristic of a wider context, that is, they may be defined more as psychologically determined than as constructed by local culture. By revealing them at the level of life-stories, this article aims to go beyond the stereotypical gender discourse in which men are represented mostly as ineffective in providing care because they cannot emulate (or take over completely) the role of women. Bearing in mind that such an interpretation may prove problematic, but proceeding from specific differences found in the empirical material, this analysis will try to give voice to men, distinguishing their voice as different from the female voice.

The life-stories analysed here are comparatively few in number because the prevalent ‘voice’ in care for ill people is female (the vast majority of interviews with people from various formal and informal associations involved in care in different cities in Bulgaria are with women – this was not planned methodologically but found ‘onsite’). This shortage of interviews with men, however, makes them even more important for analysis. It also gives us grounds not to limit our study to a specific life problem (for instance, illness of a child or of an older person), but to look more generally for the ‘male’ voice on the issue of care less as a contextual than as a gender specificity. Hence, the analysed sample includes men caring for children with disabilities (four in all) as well as men caring for elderly loved ones, such as parents, relatives, or spouses (five in all), and men professionally employed in the field – in the analysed sample, psychologists (three in all).

In Bulgaria, there is a lack not only of specific studies on parents of children with disabilities, their gender roles, the construction of their personal, family, and social identity, quantitative studies establishing whether there is a connection between the father's active participation in caring for a disabled child or leaving the family and various socioeconomic, educational, ethnic, cultural factors; there is also a lack of broader studies on the presence of men in the field of care, be it in a personal or professional capacity. The analysed corpus of interviews is small, but it can serve as a basis for answering such questions precisely because the respondents were not deliberately sampled by gender. The men included in the sample were those who are actually involved in care alongside women. As such (even though male carers are a minority), they can represent a very little-known position on care.

The main reason why I chose to analyse this topic is to be found in the already researched, and explicitly present in almost all interviews, dividing line drawn by the respondents themselves between the 'male' and 'female' form of care – in terms of degree of involvement, specific acts, and efficiency. Whereas in my previous analysis (Neykova, 2019) this was examined in terms of family dynamics, the focus solely on the male experience seeks to shed light on an even less-known aspect of care, whose importance has been pointed out only in recent years in a global context. A number of psychological studies have shown, for example, that the father's voice in families with disabled children is eclipsed by the mother's voice and experiences, or that it is even absent altogether. This is attributed to various factors, one of which is that the male figure remains stereotypically 'absent' – in general, men are described as 'missing', 'unwilling to accept', 'ashamed', 'distancing themselves', 'indifferent', 'incapable' of coping with the crisis situation, and so on.

Besides real-life bad behaviour, such negative assessments may be due also to specific differences in attitudes within the family, where men usually expect women to be not only mothers but also wives, while women expect men to invest more in their role as fathers than as husbands. A number of studies conducted in a wider, European, context, have shown that the marital relationship has a direct impact on the father-child relationship as well as that fathers think that the quality of their relationship with their spouse has a direct impact on the child's development (for an overview and bibliography of such studies, see, e.g., Salle, 2009). In any case, many psychologists warn that fathers' experience of suffering has been largely ignored as well as that fathers often fall into the trap of social expectations about their role as the 'strong sex', they do not show their feelings and therefore seem to reaffirm those stereotypes. This was also partially confirmed by the analysis of the gender and family specificities in the entire corpus of interviews under the above-mentioned project: it found a series of existing, and expressed by the respondents, notions of the different psychological and emotional capacities of men and women, which were described stereotypically – as general observations rather than through arguments and examples (Neykova, 2019). That is why this article aims to analyse the interviews with men so as to identify the specificities of their discourse and perception of the crisis and of care for the ill precisely through real-life cases, not through the generalizing perspective of women.

At the same time, the male voice in care is marginalized not just at the family but also at the institutional level and at the level of society at large in Bulgaria. Symptomatic in this respect are both the strong feminization in the field of professional care for the ill in Bulgaria and the mostly 'female image' of the participants in various political and civic causes related to overall improvement of the life of vulnerable groups (a concrete example is the public visibility of a group such as that of mothers of children with disabilities).

Once again, such a reduced presence of male figures is most probably often due to their actual unwillingness to participate in care, their passivity or indifference, shame, etc., as a personal moral choice. At the same time, the stereotype of 'the morality of women' is rejected a priori in this analysis; care is not viewed as a predetermined role specific to women but precisely, and much more, as a matter of personal morality (Neykova, 2019). This article aims to give voice to men as participants in care, in the real-life cases in which they are intensively involved in care provision. In other words, it aims to look for the good examples of participation as well as for men's specific motives, experiences, and strategies for the future. This author refuses to accept gender distinctions in participation in care provision (that is, rejects the idea that men or women ought to participate to a different extent in care provision), but sees gender distinctions in the way this participation is experienced. The very distinction between a 'male' and 'female' account of care, of course, is theoretically premised and deduced both from the observations on the whole corpus of analysed interviews and from more general observations on the life-stories and the specific ways people see themselves as actors in the latter as well as vis-à-vis the standard that gives them a guarantee of 'normality' (see Koleva, 2002). My purpose, most generally, is to highlight the significance of the male voice not as mutually replaceable with the female voice, but as a specific voice that complements the latter.

On the other hand, the analysis highlights the need to understand care in several dimensions: as physical, psycho-emotional, and conceptual-worldview.

Women's Shadow

Purely theoretically, the position of men should be viewed in relation to the other participants in care provision. Thus, for instance, the father-child relationship is strongly influenced by three factors: the mother's characteristics, the mother-father relationship, and the wider social context (Doherty, Kouneski and Erickson, 1998). Or the relationship between men and their parents whom they are caring for is directly dependent on the idea of kinship ties and relevant duties (or lack of duties) in the culture they are situated in. For its part, the relationship between men professionals in the field of care and the field itself is influenced by the institutionalized feminism, and they see their role constantly in comparison with their women co-workers. In fact, there is a correlation of strong individual qualities, motives and strategies, and at the same time, expectations and social norms regarding men.

In this line of analysis of the interviews, we may conclude that men always think of their role in care provision as complementing that of women. This was usually not explicit in their accounts, which remained centred around their personal experiences; rather, the figure of the woman carer was mentioned literally as a constant shadow of presence – of a mother, wife, sister, daughter. This is probably due not only to the narrative specificity of the male account, which as a whole was limited to a minimal number of episodes of provision of purely physical care, but also to awareness and appreciation of the mutually complementary gender roles. Or in other words, whereas in the women's accounts in the analysed corpus of interviews the male presence was strongly minimized in the description of their lived experience in which relationships with the child, with institutions, doctors, and society at large were much more present and men were represented as absent (in the best cases, only as physical absence of the working breadwinner; in the worst cases, as totally absent), in the men's accounts women were represented as an invariable, self-evident, and unquestionable presence. Prima facie, this could immediately be interpreted as the existence of much greater social expectations about women in the field of care provision, as gender inequality in this field, but I would interpret it in a somewhat different way – precisely as an understanding regarding the complementarity of gender roles, as taking this complementarity for granted. This seems interesting to me also with regard to a previous conclusion about the almost complete absence in the interviews of a family story and of any existentialist conceptualization of the family as one of the things that legitimate the individual's role and purpose in life (Neykova, 2019). In the predominant account of the crisis, which was limited mainly to the practicalities of coping with it, the family and its strength and cohesion – not in terms of distribution of tasks, but as a fundamental social unit – seemed to be much more a 'male' responsibility. For example, one of the main motivations of a man who is caring for his wife who has manic depression, is precisely the family:

> [Interviewer: What motivates you to stay with your wife, to care for her and to devote all your energy to her?] The family, nothing else. It is something I believe in very much. The family is of significant importance to me and once we have founded a family and have children, I can't imagine myself breaking

> up the family and leaving the children without parents, because everything changes when you have a family. No, my goal has always been to keep my family together, to keep our relationship normal, not merely to put up with each other, not to have a purely formal relationship. (Kaloyan, 62, cares for his wife who has manic depression, agronomist, 15 May 2018)

Or according to a man who cares for his elderly parents (with the full support and help of his wife):

> The most important thing to a person should be his family, bringing up these wonderful, loving people only in a loving family, because you can't teach love to your children if there's no love in your family. (Angel, 56, cares for his father who has dementia and for his mother who has Alzheimer's, priest, 18 May 2018)

We

Actually, the interviews suggest that if there is any tension between genders, it was mentioned only in women's accounts: in them the generalizations about men's behaviour were often in the form of accusations and disappointments. In this context, Diane Pelchat (1994) has found that accusations against the other parent in a family in crisis, suppressing one's suffering and anxiety out of fear of increasing the other's suffering and anxiety, impede interaction and mutual help. According to her, mothers feel hostage to everyday tasks and say they have no time for their husband, while fathers mention rather the lack of time for the couple and the mother's overprotection of the child.

It is no accident that the accounts of fathers who are actively involved in caring for a disabled child were usually in 'we' form, but 'we' does not stand for 'I and the child', as in the accounts of mothers, it stands for 'I and my wife': 'we have told ourselves that he isn't different …we have accepted … that we have no choice … that we will fight to the end, that we will do everything we can' (Anton, 47, cares for his son who has a pervasive developmental disorder, owner of a car dealership, 23 November 2017); or: 'That is where we actually did the first diagnostics and were told that he has such deviations on the autism spectrum' (Bogdan, 59, cares for his son who has autism, economist, currently an accountant, 1 June 2017); or a man who supports his ill wife and accompanies her so that they can '"open the doors" of different institutions': 'Perhaps the speed with which we acted helped' (Stoil, 75, cares for his wife who has cancer, hydraulic engineer, 4 May 2018).

The female figure in men's interviews, just as the male figure in women's interviews, was not fleshed out, it remained in the background (which is explicable, considering the specificity of biographical interviews), but in the women's interviews the role of men was usually delegitimated, the emphasis being on its absence and insufficiency, while in the men's interviews the role of women was legitimated precisely by taking it for granted. Women were mentioned in men's accounts mostly in the context of domestic care, of contacts with institutions: 'I have nothing to do with the institutions. My daughter takes care of contacts with institutions. She knows all of them. We have no problem' (Asen, 72, cares for his adopted grandson who has autism and for a boy in foster care who has cerebral palsy, pensioner, 24 November 2018).

This recognized, and demonstrated by men, complementarity of gender roles was accompanied also by concrete examples of the superiority of some 'male' ways of coping with the crisis. This may be interpreted as an expression of the need to legitimate men's role, a need felt much more strongly by men than by women, whose role seems self-evident. In the interviews, this was expressed as generalities:

> Men are much better at working with children and have more experience than women. This isn't my opinion only. In general, if you think more carefully about it, you will see that I'm right. Women are involved because of the traditional model of the [educational] system, it is feminized, but now a growing percentage of men are becoming teachers. (Bogdan, 59, cares for his son who has autism, economist, currently an accountant, 1 June 2017)

> It's good, up to a point, to find information on the internet, but from that point on finding information on the internet is bad for you. [Interviewer: Why?] Because when we happen upon some crazy moms… and things acquire apocalyptic dimensions… Mothers – maybe it's normal now, psychologists will probably say – have a reason to dramatize and present the situation always in extreme ways, which are unreal, which aren't true, but perhaps they do so because they are more emotional – this is their child and this prevents them from taking an impartial view of the situation. And they present things more dramatically. (Biser, 51, cares for his son who has hemophilia, telephone technician, 23 April 2018)

Or it was expressed in the form of advice about a specific behaviour, alternative to that of women:

> Psychologists recommend avoiding hugging so as to prevent and not allow disappointment… As regards close, mother-like hugs, I always tell my women colleagues: 'When you sit by the child's side don't hug him, he can't accept you as a mother because she has an idealized image, but let him accept you as the significant adult at the moment. This is what being close means…' (Dimitar, 52, psychologist, 10 May 2018)

Care in Different Contexts

This discrepancy in the assessments of men's and women's involvement in care provision is due also to a fixation on care at the physical level and/or on care at the psycho-emotional and conceptual-worldview level. In the generalizations of part of the respondents, the weak presence of men in the field of physical care was equated to absence of men in the field of care. At the same time, this presence or absence should be viewed in a much more nuanced way. Thus, for example, Michael E. Lamb et al. (1985, p. 884) distinguish three components of paternal involvement, the first two of which are quantitatively measurable, while the third is, rather, qualitative:

> (1) the extent of the father's actual *interaction* with his children, (2) the extent of the father's *availability* to his children, and (3) the degree of *responsibility* assumed for the children. "Interaction" refers to the father's direct contact with his child, through caretaking and shared activities. "Availability" is a related concept concerning the father's potential availability for interaction, by virtue of being present or accessible to the child whether or not direct interaction is occurring. "Responsibility" refers, not to the amount of time spent with or accessible to children, but to the role father takes in making sure that the child is taken care of and arranging for resources to be available for the child.

In this sense, assessments of paternal involvement should not be based solely on the presence (or absence) of the father or the duration of his interaction with his children; they should recognize the role of the father as a multifaceted actor in children's development.

Thus, most generally, some scholars emphasize the similar functions (duties and responsibilities) of the two parents, while others argue that they should have different roles that complement each other and facilitate the good functioning of the whole family. One of those roles is that of care provider for the child, but Daniel Paquette (2004a) proposes another type of carer as well, that of 'activator'. He argues that the father develops – primarily through physical play – an 'activation relationship' with his child that fosters the child's social development, sense of self-efficacy, and openness to the outside world. This complements the more typical role of the mother, who has an attachment relationship with her child 'aimed at calming and comforting [the child] in times of stress' (ibid., p. 193). What is important in this theory is that it recognizes the meaning and uniqueness of the father-child relationship and the complementary parental roles that contribute to different aspects of the child's development. Despite the reasonable critiques by some scholars such as Lori A. Roggman (2004) and Catherine S. Tamis-LeMonda (2004), who point out that extreme role differentiation between mothers and fathers would limit the spheres of the father's involvement, the recognition of the father's unique role in bringing up the child, the different and specific ways in which '[b]oth parents are involved in the two key dimensions of parenting, emotional warmth and control' (Paquette, 2004b, p. 237) reveal precisely the complementarity of the two parents, who prioritize different aspects of care. Assuming that there are two poles of attachment, Paquette (ibid.) claims that

> both mother and father ensure the child's protection, but with a different balance of security and openness: the mother primarily tends to calm the distressed child, whereas the father tends to place the child in situations in which the child is obliged to confront the surrounding environment directly while at the same time providing protection by imposing limits.

It must be noted, however, that both parents, although by different means, act or should act in all contexts of the child's life (play, care, education, etc.). In the interviews conducted in Bulgaria, the different type of involvement and the prevalent voice of women led to the feeling of a lack of emotion and empathy on the part of men as well as to the need of express legitimation of their role – that is, the need to prove that men are sensitive, but they express their sensitivity in a different way, not necessarily in the way women do.

All of the above is also connected to the development of the scientific approach towards care for people with disabilities, which is increasingly stressing the need to hear also the male voice in crisis situations. A number of empirical studies show that on average, there is no difference between the sensitivity of fathers and mothers (e.g., Broom, 1998; Parke and Sawin, 1976; Pelchat, Lefebvre and Bisson, 2003). Some studies examine the infant-father attachment relationship in terms of attachment security (Cox et al., 1992; Goossens and van IJzendoorn, 1990; De Wolff and van IJzendoorn, 1997), others focus on the effect of fathers' sensitivity, proving that good fathering has a direct positive impact on children's cognitive development (Fagan and Iglesias, 1999; Tamis Le-Monda et al., 2004), emotional communication skills (Carson and Parke, 1996), and social accomplishment (Franz, McClelland and Weinberger, 1991).

Here I want to emphasize once again that variations between paternal and maternal sensitivity should be viewed in an interpersonal context, within the framework of the family (Bouffard, 2010). In other words, since the female figure is invariably present (as noted above), if we want to understand the sensitivity of the father, son, husband, male medical specialist, we must take into consideration the mother, daughter, wife, woman colleague, and the relationship between them. In addition, we must also identify the psychological, social, and functional differences in men's and women's roles in care, viewed not as mutually replaceable but as mutually complementary and therefore capable of creating and maintaining a comprehensive, systemic unit of care such as the (recomposed) family, or a more successful institutional setting of care.

Most studies have found that children with disabilities contribute to reinforcing the traditional division of gender roles in the family: fathers are less involved in physical care, but play a main role in helping to ease the emotional burden of mothers. Apparently fathers are better at recharging through rest or some leisure-time activity. To quote one of our respondents, Ivan, who cares, together with his wife, for his mother-in-law who has dementia:

> The recipe is, how shall I put it – you go out, have a change of scene, get together with positive-thinking people so that you can recharge. You get out of the house, you must go out … you must force yourself to go out. There are many recipes, I can tell you many recipes, but they cost a lost of money [laughs]. (Ivan, 40, cares for his mother-in-law who has dementia following a stroke, musician, 17 August 2017)

Psychologically speaking, it seems that men find it easier to admit their weakness with regard to the needs of the disabled person they are caring for and are much more inclined to try to fit into the present, to look for concrete solutions, but also to be bolder in their relationship with the disabled person, provoking his or her abilities and doing things most women wouldn't even try to do.

Rejecting the Tragic Dimension

These observations were confirmed also in the analysed corpus of interviews even at the narrative level. As a whole, men's life-stories were shorter in length but specific in representing the crisis situation: in their accounts, distressing descriptions alternated with mundane details about everyday life, and generally, the emphasis was on concrete actions and successes. We may say that an overall tragic narrative was absent in men's accounts. This is probably due to several facts. The first is that they tended to be reluctant to talk about the crisis and illness:

> You don't have to talk about it without being asked. Because otherwise you're likely to fall into the other category: 'I'm vegan.' Just because you're vegan you feel obliged to tell it to everyone you meet. In other words, if someone asks you, tell them, if someone wants to know, tell them, if it's important – for example, the teacher at school or kindergarten, or someone who's directly involved – tell them, but otherwise there's no need to bother everyone because at some point you'll start talking and they'll run away from you. (Biser, 51, cares for his son who has hemophilia, telephone technician, 23 April 2018)

Generally, the interviewed men tried to avoid turning the illness or care for the ill person into their primary narrative identity. Another reason for the absence of an overall tragic narrative may be the fact that men are rarely asked specifically about how they feel and therefore do not have a ready narrative. This absence may also be due to the fact that it is usually women, not men, who communicate with the relevant institutions, which requires giving a more orderly account of their situation.

Confidence in the Future

In men's accounts, there was also more faith that they would succeed, that a solution would be found:

> [Interviewer: What advice would you give to everyone in your situation?] Don't give up. Look for opportunities, look for nuances of life, don't get yourself into a cul-de-sac that has no exit – there's no such thing, there's always a solution. (Anton, 47, cares for his son who has a pervasive developmental disorder, owner of a car dealership, 23 November 2017)

Their faith is not religious – most of the interviewed men sounded like agnostics or atheists, although they did not want to declare it explicitly. Their faith is, rather, pragmatic: confidence that they will find a way to cope with the crisis situation. The interviews showed that such confidence is more characteristic of men than of women. This is consistent with the findings of other researchers in an international context, according to which carers undergo a specific process of change that leads to transformation of their beliefs, values, and way of life (Pelchat, 1994; Pelchat and Lefebvre, 2005). For example, most parents of a disabled child change their mindset regarding prejudice about physical, mental, and intellectual deficiencies, learning to see the strengths, competencies and potential of people with disabilities. One of the main mechanisms of perception of the child's disability is appreciation of the joy the child brings, which facilitates the process of their adaptation/transformation in the crisis situation. In this sense, as we also found in the analysis of the family as the object of ordeal (see Neykova, 2019), there is no transcendent perspective on what is happening in the family, including on the period of crisis, and moral issues are discussed in terms of the individual (usually as a narrative about an overcome or existing feeling of guilt, or as a narrative about the carer's self-sacrifice), or in terms of society (mostly as a narrative about the unfulfilled moral responsibility of the state and institutions for the suffering of the child and the child's carer), and very rarely in terms of the family – as a form of joint struggle to overcome the crisis and of moral growth of everyone involved in it, albeit each in a different way.

The family – regardless of whether it is caring for a disabled child or an elderly person – remains a marginal subject and, as we have seen, was mentioned in men's rather than in women's accounts. It was present there as a value and as a supportive environment, but not as shared experiences of growth, search for existential answers, or creation of a shared philosophical paradigm interpreting the crisis situation. Even when the respondents' accounts were not about their personal emotions, they remained very pragmatic. For example, in his account Ivan, after explicitly rejecting belief in miracles ('I'm not saying that one should be an atheist or something of the sort, or that one shouldn't believe in anything, but one should be as practical-minded as possible… If you stop thinking logically and hope for some sort of miracles, you're lost – at least, that's what I think'), went on to reason along very pragmatic lines in his explanation of the problematic relationship between the individual and the state:

> Many people are becoming more and more like us, but if we think about it, we'll see that the state is actually losing from this. Why? Because one ill person engages one or two people who are of working age. But in fact you can't work and give money to the state through taxes so that it can govern through this money. To my mind, this is to the detriment of the state, too. (Ivan, 40, cares for his mother-in-law who has dementia following a stroke, musician, 17 August 2017).

Thinking 'Outside the System'

The interviewed men's accounts showed that they refuse to resign themselves to the system and are more inclined to think outside it. They usually look for solutions beyond the system. This way of thinking is applied at several levels – at the individual as well as at the institutional and more general cultural level.

On the one hand, men spoke more from the perspective of the emancipation needs of the ill person himself or herself. For example, after Biser met at a camp other people suffering from hemophilia like his son, he decided to act counter to public expectations: 'Under the influence of a boy who said, "Don't overdo care for us," I let him attend PE classes for the first time, he's in the third grade, and he's very happy' (Biser, 51, cares for his son who has hemophilia, telephone technician, 23 April 2018). Bogdan, a single father of a son with autism, spoke in his interview about his son's desire to distinguish himself from him by choosing a religious identity that is different from his father's:

> You know he's Buddhist, don't you? [Interviewer: How come he chose to be Buddhist?] Oh, as a counter-reaction against me. A counter-reaction against me. [Interviewer: Why?] Well, this is the classical model. By and large, this isn't the natural protest of the son against the father, which is normal; it's rather a place which an autistic needs to have as his own personal place. (Bogdan, 59, cares for his son who has autism, economist, currently an accountant, 1 June 2017)

One of the most characteristic features of this way of thinking is the normalized thinking about the future (unlike the usual maternal narrative of the horror and inconceivability of the future). This was also evident in the interviewed men's notions of three of the most complex issues that usually cause strong anxiety in women: the notions of the disabled person's future professional development, marital status, and quality of life.

In the life-stories of the interviewed men who are caring for a disabled child, the issue of the child's future professional development was rethought positively:

> He is like a musician who plays very well but can't read musical notes… We're thinking about a job in construction machinery because he is good with

> equipment… he takes things apart and puts them back together… This is the situation for the time being – what will happen, we'll see… (Asen, 72, cares for his adopted grandson who has autism and for a boy in foster care who has cerebral palsy, pensioner, 24 November 2018)
>
> [A]fter the eighth grade, we managed to enroll him in an art school where, you know, the deviation range is much larger and there's much more tolerance, on the one hand, and on the other – the teachers are mostly men, which is a plus. (Bogdan, 59, cares for his son who has autism, economist, currently an accountant, 1 June 2017)
>
> He loves animals very much… I keep telling him, 'I'll make you a vet…' (Anton, 47, cares for his son who has a pervasive developmental disorder, owner of a car dealership, 23 November 2017)

Similar conclusions can be drawn when it comes to the issue of the possibility of marriage in the future, which the fathers did not rule out:

> Girls have always wanted the same thing ever since cave times. The best hunter in the cave who will bring you the biggest catch. That's how things are. We're talking about the prevalent case now. That's why I take him along wherever I go, secretly hoping that he can meet someone more decent who doesn't fit the standard description of a woman. (Bogdan, 59, cares for his son who has autism, economist, currently an accountant, 1 June 2017)
>
> [Interviewer: Do you think about the future, whether he'll get married?] There's no point in thinking about it, we're at the beginning now… so far I haven't thought about it because so far he more or less hasn't caused problems with this disorder… and the therapy for which so far the state has provided us with material… the most important thing to me is to have the necessary medication… What reassures me is that medicine is advancing very rapidly… (Biser, 51, cares for his son who has hemophilia, telephone technician, 23 April 2018)

The life of a disabled person during leisure time is not subject to stigmatization either:

> It will be very good to break with the stigma that since he's a child with hemophilia he must be watched and protected like the apple of our eye – to prevent him from falling, etc., because in this way he stops watching out for himself since he knows that there's always someone who'll catch him, you know, there's always someone who'll tell him, 'Don't touch this.' That's why maybe, within reasonable limits, it's good for him to fall sometimes, to graze his knees a bit, to hurt himself so that he'll know how things stand… His friends know, that's to say, if they beat him, they beat him more carefully… (Biser, 51, cares for his son who has hemophilia, telephone technician, 23 April 2018)

> We long wondered how to protect him from cars… Now that he's grown up, we said to ourselves about the bicycle, 'Who dares wins!' – we let him ride a bicycle, may God protect him… [Interviewer: Does he ride a bicycle?] He does like crazy. He who couldn't learn to walk, and I used to say to myself that he'll never be able to ride a bicycle – because it takes concentration … but just look at him now – he rides a bicycle, he skateboards… no one in our family can skateboard, but he can… And he does everything by himself. He's a big fighter… He's very stubborn, especially when it comes to something he wants to happen – he doesn't let go until it happens… (Anton, 47, cares for his son who has a pervasive developmental disorder, owner of a car dealership, 23 November 2017)

This specific 'male' thinking 'outside the system' is manifested not only at the individual level but also in a specific rebellion against the system: fathers' refusal to let their child be diagnosed. This has negative consequences, including the complete lack of any form of institutional help (material, physical, mental), but is perceived as a specific way of fighting a system that simultaneously categorizes, stigmatizes, and unifies:

> This was our idea with Kremena, his mother – to arrange things specially for him so that he will be completely equal with the other children so that he can have a diploma… And the other thing is that if they keep living this way their whole lives, they get so used to it that it's hard for them to judge what their own abilities are… (Anton, 47, cares for his son who has a pervasive developmental disorder, owner of a car dealership, 23 November 2017)

Bogdan, who cares for a son with autism, also described his encounter with the system's proposals for socialization – in this particular case, in an auxiliary school for children with disabilities:

> On the second or third day, when I saw what it's like there, I directly disenrolled him. [Interviewer: What was it like there?] Terrible. Those were children in a very serious condition, children who had no communication whatsoever. He had been worked with and there was some improvement, but this would have instantly sent him into regression because any system that isn't targeted at the individual but based on some average case is simply fatal. … If there's a document [formal diagnosis], there's a problem, I'm telling you this professionally. Especially now, it's only now that the personal data protection regulations have come into force that the requirement to submit a medical certificate when starting work has been scrapped. (Bogdan, 59, cares for his son who has autism, economist, currently an accountant, 1 June 2017)

Once again as a strategy for his son's successful realization in the future, the father has not registered him as autistic anywhere, which practically means that he isn't eligible for any form of financial assistance. We may interpret the father's concern about his son's future and emancipation project as psychologically much more important factors than the specific needs and difficulties in the present.

Finally, it is also noteworthy that in the accounts of some of the interviewed men there was a sort of shift of perspective on the problem – from the personal and family perspective to a social perspective. This was part of a narrative device in all interviews, regardless of gender, but it was usually associated with expression of attitudes towards institutions and the absence of adequate state policies – while in the men's interviews there were also reflections on more general characteristics of the contemporary cultural situation: 'The problem is associated with things in Bulgaria, and not only in Bulgaria, with the spirit of the times; it's not associated with his specific condition' (Bogdan, 59, cares for his son who has autism, economist, currently an accountant, 1 June 2017). Such a broader perspective is consistent with the findings that mothers are focused mostly on the microcosmos (everyday life, attachment relationship), while fathers are focused mostly on the macrocosmos (the functioning of the family, the child's 'normality', socialization, etc.). Fathers also tend to generalize their experience in the crisis situation, going beyond the family and taking a social position involving a new interpretation of respect for disability (Pelchat, 2009).

Adaptation Strategies

As the study by Diane Pelchat and Valérie Bourgeois-Guérin (2009) has shown, the factors causing uncertainty are the same for both parents of a disabled child; what is different is the way they react to those factors and their choice of adaptation strategy. For example, it has been established that fathers tend to focus their energies on a day-to-day basis (Peck and Lillibridge, 2005) and on loosening the unhealthy attachment bond between mother and child, encouraging their partner to be physically and emotionally more present for them and for the other children in the family (Pelchat, Lefebvre and Bisson, 2003).

Based on the analysed interviews, we can draw general conclusions about Bulgarian men and women as carers, regardless of whether they are caring for children, elderly people, or patients. More specifically, we found that there are gender-specific differences in the way Bulgarian men and women perceive and react to the crisis situation. Most of the conclusions from the empirical material are identical to those of different studies conducted in Europe and elsewhere, which shows that these differences are not specific to Bulgaria. Whereas the Bulgarian context (the communist legacy of perception of illness, institutionalized confinement or confinement of care to the family, the traditionally patriarchal division of tasks, internalized stigmatization, avoidance of public debate on the subject, etc.) has a deep impact on the concrete challenges facing carers of ill people in Bulgaria, the gender-specific differences in the way Bulgarian men and women perceive and react to the crisis situation prove to be characteristic of a wider context.

Conclusion

In this article, we presented the voice of Bulgarian men who are actively involved in caring for a seriously ill person. The analysis of their life-stories in a crisis situation helped us to identify certain specific characteristics of their perceptions, strategies, and reactions.

As we saw in a previous analysis, the family (including the extended family) is the most effective environment for the socialization of people in need of care. Examining the dynamics of the family as a unit, we also saw that on the domestic level, there is a return to the traditional gender roles and their complementarity (Neykova, 2019). In a sense, the ill people themselves, who are often confined to a narrow milieu, do not need mirror images of care. Even in the successful examples of inclusion of different participants in care, the existing complementarity of roles risks being interpreted through codes associated more generally with the contemporary crisis of the family and the contestation of the traditional gender roles in it. It turns out that in a crisis situation, two general specific characteristics of contemporary postindustrial societies are delegitimated – on the one hand, the symmetrical rather than complementary functions of the family members, and on the other, the narrowing of family to the nuclear family, with growing exclusion of the extended family members from everyday decision-making. In other words, the situation of crisis around the ill person who is cared for in a family setting may prove to be a situation of double crisis.

In the successful cases of joint involvement in care, such a crisis is avoided by abandoning the stereotypes about gender roles and their power struggle and the quest for complete equality of roles in care provision, and, instead, conceiving of 'male' and 'female' roles in care precisely as mutually complementary, that is, as providing different forms of care. The need for such an approach was also evident from the interviews, in which respondents of both genders, but mostly women, spoke of each other in terms of stereotypical generalizations inscribing the debate into a wider cultural context of a feeling of inequality. That is why this article examined care in several dimensions – physical, psycho-emotional, and conceptual-worldview – showing that the successful cases of coping require involvement of both men and women at all those levels. At the same time, however, it demonstrated that men and women are involved in care in different ways.

In the accounts of women in the analysed corpus of interviews, the support or lack of support from men was described mostly in terms of physical presence/absence and involvement in day-to-day care (it is usually women who undertake day-to-day care for the ill person, while men undertake to support the family), and not in terms of gender-specific psycho-emotional or conceptual-worldview characteristics of the perception of the crisis situation which could be complementary to those of women. As the men's accounts showed, an example of a psycho-emotional characteristic found mostly in their interviews is the focus on the family, even in the form of emotional support for the woman carer as well as in the form of elimination of the stigma of the tragic dimension as a whole. Men much more often care for ill people through the emancipatory project about their future, even if this entails greater strictness or show of fearlessness in the present. Judging from the interviews, men are much more inclined to think 'outside the system'. The male point of view also helps to avoid reducing life to physical care; it helps to turn it into a cause as a conceptual-worldview model, that is, to open up the intimate to the public sphere. It is a transcending point of view that is less dependent on the immediate experience of suffering.

Assuming that the personal characteristics and value choices of every individual are stronger than the dividing lines between gender roles, this article did not seek to compare or contrast them – on the contrary, it sought to demonstrate that the interviews with men showed that their main ways of coping with a crisis situation are different from those of women, and that the strongly marginalized male voice in care ought to be heard.

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Stoyan Stavru

‘LAWS FOR TRASH’: CARE IN THE AUTUMN OF LIFE

(The Bulgarian Context)

> There was a peasant who had a son. When the son grew up, his father began to think about how to marry him to a good girl. He loaded his horse cart with plums and went from village to village selling them. ‘Come on over, I’m giving away plums for trash, plums for trash!’ he shouted. Women, maidens, grandmas, young brides all rushed about, sweeping their houses. They did their best to collect the most trash so that they could get as many plums as possible. Eventually, a pretty girl came up to him. She was clutching a kerchief with a small amount of trash in it. ‘Well, well, pretty girl,’ said the man, ‘you’ve collected so little! How many plums should I give you for so little trash?’ ‘I would’ve brought more, uncle, but we have none at home. What I’ve brought is what my neighbours gave me for helping them sweep their houses,’ she said. The man was delighted to hear this. Such a clean and hard-working girl who didn’t have even a speck of trash in her house would make the best housekeeper.
>
> *Plums for Trash*
> **Elin Pelin**

Introduction

Given the specific demographic problems facing all of Europe as well as Bulgaria in particular, issues concerning intergenerational relations and the need to adopt special legislation on the legal status of older persons are being increasingly raised on the agenda of politicians. Although there are numerous specialized legal provisions protecting various age-based interests, those provisions are scattered in various legal instruments. Interaction among them presupposes good knowledge of all relevant legal instruments – a task that may be impossible not only for older people but also for many central and local government officials. It is precisely the idea of uniting and systematically regulating all issues related to the elderly which is at the basis of several legislative initiatives in Bulgaria that are presented below.

1. Background

In the 2017–2020 period, ***three bills*** focused on care for the interests and protection of the rights of older persons can be traced in the legislative activity of the 44th National Assembly of the Republic of Bulgaria. Depending on whether their *emphasis* is on the need for support (care) or on the protection of the rights (autonomy) of the elderly, these three bills can be classified into two groups:

- *Older Persons Bill* (OPB), Incoming Ref. No. 754-01-47 of 26 July 2017, and Older Persons Bill (OPB), Incoming Ref. No. 954-01-73 of 18 September 2019, whose content, for the purposes of this analysis, can be assumed to be identical (both bills were introduced by the BSP[1] for Bulgaria parliamentary group);
- *Protection of the Rights and Interests of Older Persons Bill* (PRIOPB), Incoming Ref. No. 954-01-62 of 5 September 2019 (introduced by the United Patriots parliamentary group).

All three bills were ***not passed*** by the National Assembly.

The debate on the earliest bill, ***OPB, Incoming Ref. No. 754-01-47 of 26 July 2017***, is particularly revealing of the *arguments* why a special law on the elderly was unnecessary. That bill did not pass at first reading in plenary on 2 May 2018 as it failed to gain the required majority (the vote was 78 in favour, four against, and 95 abstentions). The main objections at the plenary debate came from Rumen Genov, MP of GERB. He raised two main questions:

- What was the point of passing such a law which *addressed needs existing in all age groups* in Bulgaria, not just among people aged over 60: ‘They [the measures on care for the elderly proposed in the bill] don’t differ very much from those on care for the other age groups. I keep saying that I see no point in selecting a particular group of people and placing them in a privileged position vis-à-vis the others.’[2]
- Was it necessary to adopt such a law, considering that *the regulations proposed in it already existed* in various Bulgarian legal instruments: ‘let’s not forget that every law or draft law that has to be put to the vote, passed and enforced should resolve some sort of issues that have remained exclusively unregulated until now, or regulate some sort of newly emerged necessity.’

This is also the gist of many of the opinions submitted to the relevant parliamentary committees,[3] which, in discussing the different issues regulated in the bill, referred to the Social Insurance Code, Health Insurance Act, Social Assistance Act, Employment Promotion Act, Integration of Persons with Disabilities Act, Protection from Discrimination Act, Health Act, etc. It was noted that ‘[t]he Republic of Bulgaria follows a *horizontal principle* [emphasis added] of legislative regulation of social relations regarding older persons.’[4] The bill did not cover comprehensively the multisectoral policy for the elderly as implemented, therefore its passage would result in ‘duplication of rights and responsibilities under various statutory instruments’ and in ‘misspending of public funds'.

The arguments for rejecting the two bills of 2019 were analogous, now referring also to the already adopted Social Services Act. This is the tenor of the statement of Nikolai Sirakov, MP of GERB, for example: 'this law doesn't propose anything novel that currently cannot be found in other statutory documents. The relationship and connection with the elderly on the part of institutions is a horizontal policy that is reflected in many other statutory documents.'[5] ***PRIOPB, Incoming Ref. No. 954-01-62 of 5 September 2019***, did not make it to the full house, either, as it was defeated in the Committee on Labour, Social and Demographic Policy by a vote of eight in favour, one against, and eleven abstentions.[6] Nor did ***OPB, Incoming Ref. No. 954-01-73 of 18 September 2019***, which likewise failed to garner enough support from the Committee on Labour, Social and Demographic Policy (the vote was six in favour, three against, and eleven abstentions).[7] The proposed bills were also criticized for the *declarative character* of the provisions in them, especially of those declaring the rights of older persons.[8] Regarding the achievement of the objectives given as reasons for the adoption of a special law on the elderly, references were made to the Updated National Strategy for Demographic Development of the Population in the Republic of Bulgaria (2012–2030) and the National Strategy for Active Ageing in Bulgaria (2019–2030).

As a whole, the thesis of the abstainees – the number of those who voted against was negligible, the bills were defeated because the majority of MPs abstained from voting – was that '*the effective legislation contains sufficient guarantees* [emphasis added] for the exercise of the rights of older persons'.[9] The response can be summarized by the statement of the sponsor of PRIOPB, Incoming Ref. No. 954-01-62 of 5 September 2019, the Chairperson of the Committee on Regional Policy, Urban Development and Local Self-Government, Iskren Veselinov, MP of the United Patriots: 'there are numerous positions, rights and opportunities which are spelled out, which are dealt with, of course, in other bills, too, but the prime objective, I repeat, of this bill is to lay down a framework law and to enshrine these relations and obligations of the state in our legal system.' The thesis regarding the framework character of the PRIOPB failed to persuade the required number of MPs.

The *next part* of this article will present the main proposals contained in the aforementioned bills, while attempting to clearly outline the differences between the two approaches taken by the sponsors of the bills. To ensure an easier and structured perception of the comparison between those two approaches, the information is presented also in the form of tables.

2. Comparative Presentation of the Two Approaches Taken in the Bills

One of the most important issues in discussing the raison d'être for adopting a special law on older persons is the issue of who falls within the scope of the term ***'older persons'***. In the effective Bulgarian legislation[10] there is a legal definition only of the phrase '*older persons above working age*' – namely, persons who have attained the age entitling them to a contributory-service and retirement-age pension, as determined by Article 68 (1-3) of the Social Insurance Code (SIC). The provisions of Article 68 of the SIC stipulate that the age of entitlement to a contributory-service and retirement-age pension is to be increased gradually over time until it reaches 65 years for both men and women. This age was accepted in the PRIOPB, while the age indicated in the two versions of the OPB[11] is 60 years. This particular age, 60 years, was reasoned with its 'tacit acceptance' within the UN.[12]

In any case, the bills referred to a category of persons defined solely on the basis of age, *regardless of* the following:

- whether the person has been granted a contributory-service and retirement-age pension, which is conditional not only on attaining a particular age but also on having a minimum contributory service;[13]
- whether the person meets the legal definition of persons with disabilities: individuals who have a physical, mental, intellectual and sensory impairment that impedes their full and effective participation in public life;[14]
- whether the person meets the legal definition of persons who are unable to look after themselves: persons who cannot independently meet their everyday household needs (shopping, food preparation, eating, maintaining personal hygiene and home hygiene), needs for social networking and inclusion in community life.[15]

The only criterion under which a person becomes eligible as a beneficiary of the bills was the attainment of a particular age – a criterion also applied by Bulgarian legislation in providing for a special legal status for children aged up to 14 years (with the status of infants), and 14 to 18 years (with the status of minors).

One of the most important *differences* in the ***approach*** taken in the OPB and in the PRIOPB is related to the objectives and essence of the proposed instruments and mechanisms regulating the special status of the elderly (see Table 1).

The OPB proceeded from the assumption that age in itself – by virtue of its advance in time – 'hinders' full manifestation of personality and that older persons are gradually alienated not only from the others but also from themselves. To correctly address this natural process and turn it into an integrated part[16] of the life of Bulgarian citizens, the state should conduct special ageing-related policies, including the elaboration of a system of measures for support. The OPB was guided by the idea of *care* designed to ensure a full and active life based on intergenerational solidarity.

The PRIOPB was based on the assumption that age – by virtue of existing negative social stereotypes – leads to gradual restriction of older persons' participation in social and political life, whereby the elderly are isolated and marginalized, including by placing them in the humiliating situation of poverty.

The correct management of these negative processes requires that the state declare 'specialized' rights for the elderly, taking into account their specific form of social vulnerability. The PRIOPB was guided by the idea of *autonomy* which should be ensured by encouraging older persons' independence and respecting their dignity.[17]

Table 1

approaches	**POLICIES** on older persons	**RIGHTS** for older persons
bills	OPB Incoming Ref. No. 754-01-47 of 26 July 2017; OPB Incoming Ref. No. 954-01-73 of 18 September	PRIOPB Incoming Ref. No. 954-01-62 of 5 September 2019
	BSP for Bulgaria PG	United Patriots PG
age	60 years	65 years
regulate	*measures for support*	*subjective rights*
	age *'hinders' one's personality*: the elderly are alienated from themselves and from the others, and society must help them	age *limits participation* in public life: the elderly are isolated and must be helped to reintegrate into society
emphasis on:	care	autonomy
objectives	**a)** full and active life;	**a)** protection of the rights/interests of the elderly;
	b) full participation in public life	**b)** maintaining quality of life and dignity
key concept	attaining **solidarity**	respecting **dignity**

The above-mentioned difference in the approaches taken in the two bills is evident in the ***concrete regulations*** contained in them (Table 2).

The OPB provided for different forms of assistance for the elderly, attempting to systematize the possible concrete *measures for supporting* them. It is on this point that the OPB was criticized for failing to exhaust all measures for support provided for older persons in the current Bulgarian legislation and, instead, contributing to the fragmentation and redundancy of the legal framework. The measure for support with the lowest intensity was the declared duty of the state to create conditions for older persons' access to healthcare services and to information. The OPB provided for the possibility of care in a foster family (foster care) when their children, grandchildren, and collateral relatives up to and including the second degree are deceased or unknown, or if they cannot or do not wish to care for the everyday needs of older persons.[18] The families providing foster care were to receive financial aid (money) and aid in the form of social investments (foster care goods/services). The third group of measures for support were designated as incentive measures – creating temporary privileges for the elderly in specific spheres of public life, aimed to accelerate the attainment of due adequate possibilities for older persons. The incentive measures had be justified and proportionate to the objectives which they pursued. In the fourth place, the OPB provided also for different forms of special assistance for older persons, including financial support for access to and use of services according to their individual needs, as well as provision of a monthly allowance to bring their income up to the poverty line and for social integration. The OPB envisaged the establishment of a specialized body, a National Council for Older Persons, as well as the designation, within the executive branch of government, of a coordinator of the implementation of the policy in support of the elderly. It also provided for the adoption by the National Assembly of a National Strategy for Active Ageing, and for a National Programme for Support of Older Persons adopted by the Council of Ministers. Those were to be the two documents by which the state policies on the elderly would be specified and realized in practice.

The PRIOPB placed emphasis on protection of the interests of older persons – as indicated in its title – declaring a series of *subjective rights* that ought to be guaranteed to older persons. It is on this point that the PRIOPB was criticized for its declarative character as well as for duplicating the already recognized, at various statutory levels, rights of all Bulgarian citizens. Among the specified rights of older persons were the right to dignity and respectful treatment, including through empowerment and protection; the right to participate in public life (through the so-called Council of Elders); the right to work; the right to appropriate, fair and accessible services ensuring quality of life (living standard), which were to be specified in a Council of Ministers ordinance and popularized through a national information platform; the right to material aid, providing a minimum monthly allowance bringing elderly people's income up to the poverty line. The PRIOPB prohibited the exploitation and discrimination of older persons as well as all forms of neglect of older persons, consisting in 'failure to pay appropriate attention or to provide services to an older person to the extent where the neglect causes or is likely to cause harm to the older person'. The PRIOPB provided for the establishment of an Inspectorate under the Minister of Labour and Social Policy as a specialized body with inspectors having a number of oversight functions and powers. It also provided for the adoption by the Council of Ministers of a National Strategy for Active Ageing, whose implementation was to be ensured by the adoption in each municipality of annual programmes and plans for realizing the rights and interests of older persons.

Table 2

CONCRETE REGULATIONS		
bill	**OPB**	**PRIOPB**
approach	**measures for support**	**declarations of rights**
concrete regulatory **instruments**	**1.** Conditions for access	**1.** Right to appropriate, fair and accessible services
	2. Foster care	**2.1.** Right to dignity
		2.2. Right to participate in public life
		2.3. Right to work
	3. Incentive measures	**3.** Prohibition of exploitation, discrimination and neglect
	4. Special assistance	**4.** Right to material aid
specialized **bodies**	National Council	Inspectorate
strategic and programme **documents**	National *Strategy* for Active Ageing (National Assembly)	National Strategy for Active Ageing (Council of Ministers)
	National *Programme* for Support of Older Persons (Council of Ministers)	Annual programmes and plans for realizing the rights and interests of older persons (municipality)
approach	**CARE**	**EMANCIPATION**

Also interesting are the provided possibilities for creating ***communities*** of older persons, whose objectives are different in the different bills (Table 3).

The OPB obliged local self-government bodies to create *clubs for older persons*, which were designed 'to contribute to the expansion, enrichment and maintenance of the social contacts and active life' of the elderly. It stipulated that at least one club should be created in every settlement inhabited by more than 100 older persons, and another club per every 15,000 population. The access of older persons to the clubs was to be unlimited and they were to participate in the latter's activities free of charge. The clubs were to organize and conduct activities and events of a social, health, cultural and other such character, as well as auxiliary economic and appropriate work activities. Their maintenance and operational costs were to be covered by the municipality.

The PRIOPB provided for the establishment, on a voluntary basis and at the initiative of older persons, of *clubs of elders* in municipalities, each one of which would have a representative in the so-called Council of Elders. The Council of Elders was to be consulted about municipal annual programmes and plans for realizing the rights and interests of older persons living or permanently residing on the territory of the relevant municipality. Both the clubs and the Council of Elders would be founded, managed, financed, and terminated according to the procedures set out in the People's Chitalishte Act (PCA).[19] Membership in a club of elders was to be personal and open to everyone aged 65 and over with a registered address in the relevant settlement. The PRIOPB also obliged all municipalities to support and encourage the establishment of non-profit organizations as well as informal ad hoc communities including, on a voluntary basis, older persons from the relevant settlement who were united to realize the municipal programmes on older persons' rights and interests.

Table 3

	COMMUNITIES of older persons	
bill	**OPB**	**PRIOPB**
	clubs for *older persons*	**clubs** of *elders*
established by	local self-government bodies	older persons themselves
objective	**1.** social contacts	**1.** participation through consultation
	2. ensuring an active life	**2.** ensuring an independent life
access	unlimited/free of charge	voluntary/membership dues
	(MUTUAL) CARE	EMANCIPATION

3. The Issue of Older Persons in the Context of Intergenerational Relations

The most important issue, to my mind, remains that of the way the bills outlined the framework of ***intergenerational relations*** within which they proposed their concrete legal regulations concerning the legal status of older persons (Table 4). It is precisely within the structure of this framework that one should find the answer to the question of why older persons ought to receive special care (measures for support) or special forms of respect (subjective rights) from the next generations. The answer to this question cannot be found in the text of the bills themselves, but it can be inferred from the sponsors' reasons appended to the draft legislation.

The OPB is a bill that is *utilitarian in tone* as it took a more pragmatic approach encouraging reciprocity: 'care is gratitude' on the part of children and grandchildren to their parents and grandparents. Parents' care for their children at the beginning of their lives is the reason justifying the reciprocal duty of children to care for their parents at the end of their lives. But that is not all. The main reason for the state's commitment to the welfare of older persons is their economic and historical contribution to the development of Bulgarian society.

In this sense, the reasoning of the OPB begins with the 'admission' that '[n]ot always … do the younger generations succeed in providing the well-deserved gratitude to and understanding for the previous generations, which have contributed to the country's economic growth.' This quote seems to be premised on the assumption that Bulgaria is, by rule, in a constant state of 'economic growth' – a premise whose possible invalidation in the future would cast doubt on the legitimacy of the demanded care for the elderly. The reasoning of the OPB seems to rely on a sort of 'historical exchange': the elderly are entitled to a secure old age because they have contributed to the nation's present economic growth.

The PRIOPB is a bill based on *deontological reasoning* which, however, is partially self-refuting because of the implicit contradiction in the declared intentions of its sponsors. The contradiction is between the essentially absolute requirement of 'respecting the dignity' of older persons which, however, is rife with emphasis on the possibility of 'utilizing the potential' of older persons. Thus, the reasoning of the PRIOPB postulates the following 'categorical' imperative: 'It is our duty to ensure a dignified old age to our parents', followed directly by the stipulation: 'It is time we admitted that older persons are not a burden but a potential we must utilize.'[20] It is declared that the bill was intended to overcome 'the intergenerational tensions' by ensuring 'continuing participation' of older persons in social, economic, cultural, intellectual, and civic activities as well as in the decision-making process, and not just by 'utilizing the[ir] capacity for physical activity or participation in the labour force'. The reasoning goes on to note, however, that the correct resolution of the existing intergenerational tension can be achieved by ensuring 'a possibility for growth of the "silver economy"' as older persons are 'consumers in many sectors and contribute via employment'.

The *concrete instruments* for achieving intergenerational solidarity (Table 4) fit within those two different frameworks. The OPB staked on commitments on the part of the state aimed at raising mutual awareness and acceptance between generations, bridging the social gap between generations, and encouraging volunteering. The state was to replace the family in caring for the elderly when their relatives cannot or refuse to participate in meeting their daily needs. The PRIOPB expressly obliged the families of older persons as well as the households they live in with other people to care for their health and mental wellbeing and to provide the necessary support in meeting their essential needs. The PRIOPB aimed to ensure appropriate, fair and accessible services enabling older persons to live a meaningful and beneficial life in society, which recognizes them as an important source of knowledge, wisdom and experience. The services provided to the elderly must recognize their social, cultural and economic contribution and guarantee that they receive priority in the provision of essential services.

Table 4

INSTRUMENTS for achieving **intergenerational solidarity**		
bill	**OPB**	**PRIOPB**
tone	‘**utilitarian**’	‘**deontological**’
type of reciprocity	**secure old age** = *historical* exchange	**dignified old age** + ‘*here-and-now*’ exchange
kind	state-provided **measures** and **mechanisms**	older persons’ **rights** and family’s **duties**
objectives	**1.** *mutual acceptance* of generations	**1.** recognition of older persons’ contribution and provision of *priority*
	2. *bridging the social gap* between generations	**2.** recognizing older persons as an important *source* of knowledge, wisdom and experience
	3. encouraging *volunteering*	**3.** ensuring a *meaningful* and beneficial life

Final Conclusions

The adoption of a ***special law*** on the legal status of older persons entails the introduction of a series of concrete legal instruments necessary to ensure a full life for the elderly: these include not only the measures for support specified in the OPB but also legal instruments that do not exist in the current Bulgarian legislation, such as the so-called lasting power of attorney (*Vorsorgevollmacht*) (Stavru, 2011b), advance directives, and living wills (Stavru, 2016, p. 75). In this regard, we may say that although poverty is the main, critical problem determining the quality, and hence, independence of life of the elderly in Bulgaria, the Bulgarian legislature can nevertheless provide additional legal instruments addressing the *specific needs* of people at the end of their lives.[21] The omissions in this commitment on the part of the state would become considerably more visible and easier to manage if there was a unified legal framework on the rights of older persons. Even that alone is sufficient reason to support the passage of a law on the elderly.

Apart from these ‘pragmatic considerations’ in addressing the specific issues of old age, however, there is a fundamental issue I believe will become increasingly relevant in the discussion of any regulation of the legal status of older persons – the issue of ***intergenerational relations***. Intergenerational relations have been subject to different narratives, including those about the elderly’s economic contribution (the growth narrative) and transfer of experience (the wisdom narrative), which can be found in the OPB and PRIOPB respectively. As the number of people above working age grows and as young people become increasingly sensitive to the negative effects of environmental and climate change, social tension between those of active working age and the elderly will grow. This can undermine the traditional narratives about the contribution and preciousness of the elderly, which are still being used to counter the negative stereotypes of old age. It is by no means impossible to imagine a future[22] in which old-age policies are made by a grown-up Greta Thunberg (and like-minded others) who in 2019 declared[23] that they 'will be watching' the generations ruling the world today and their actions aimed at preserving nature and planet Earth. In the perspective of *climate anxiety*, the elderly's economic contribution could easily turn into blame for leaving an unforgivable carbon footprint.[24]

Table 5

<table>
<tr><th colspan="4">INTERGENERATIONAL RELATIONS</th></tr>
<tr><td colspan="4"><i>Aspects</i></td></tr>
<tr><td colspan="2">environmental</td><td colspan="2">social</td></tr>
<tr><td colspan="4">Solidarity</td></tr>
<tr><td colspan="2">shortage
of <i>natural</i> resources</td><td colspan="2">shortage
of <i>economic</i> resources</td></tr>
<tr><td colspan="4">Regulations</td></tr>
<tr><td colspan="2">forms of <i>rejection</i></td><td colspan="2">forms of <i>care</i></td></tr>
<tr><td colspan="2">new laws ensuring the natural resources necessary for the normal existence and quality life of the future generations (the generation entering politics)</td><td colspan="2">new laws ensuring the social resources necessary for a dignified active life of older persons (the generation retiring from politics)</td></tr>
<tr><td colspan="4">present (working-age) generations:
exchange</td></tr>
<tr><td><i>wisdom</i></td><td colspan="2">for</td><td><i>gratitude</i></td></tr>
<tr><td colspan="2">ancestors must show wisdom and ensure a future for their descendants</td><td colspan="2">descendants must express gratitude and ensure a present for their ancestors</td></tr>
<tr><td colspan="4">scenarios</td></tr>
<tr><td colspan="2">European Green Deal</td><td colspan="2">Greta Thunberg's speech</td></tr>
</table>

The increasing complexity of intergenerational relations – in the context of a very fast-growing intergenerational web of competing narratives of the past and the future – requires a more differentiated approach in the legal regulation of social relations in which age turns out to be a defining factor. This is neither about discrimination nor about privileges – it is about recognizing the specific situation of the members of the different generations in a grander, larger-scale narrative that is often beyond the capacities of the political – the narrative of humanity and the Earth. The definitive issue in this narrative is that of ***intergenerational justice***, a central part of which is the *responsibility* between generations:

a) the responsibility of parents to ensure a full, active life for their children. This responsibility requires not only contributing to the country's economic growth but also showing wisdom consisting in rejection of certain forms of destruction of nature;

b) the responsibility of children to ensure a decent old age for their parents. This responsibility requires not only caring for the elderly but also recognizing their independence and dignity, which out to be preserved even in the most severe cases of elderly dementia.

Bulgaria is not an exception from the processes requiring systematic and careful consideration of the issues of intergenerational justice. These processes include discussions of proposals for the passage of a special law on the elderly. Without necessarily looking for which Bulgarian laws contain the least 'trash', juggling with 'horizontal policies' and 'statutory duplications', I believe we should accept the challenge of speaking about one of the most urgent problems facing humanity today. Not only we ourselves as individual human beings and as members of sovereign political communities but also the human generations that are part of our lives are engaged in increasingly competitive relations.[25] Such competition has always existed, creating tensions between generations. Nowadays, however – given the unprecedented acceleration of social life and on the eve of apocalyptic forecasts about endless economic and social crises – the different generations must intensify their dialogue and try to achieve a sustainable intergenerational contract on the essence and content of their mutual responsibilities.

NOTES

[1] Bulgarian Socialist Party.

[2] See Shorthand Record of the 133rd Plenary Sitting of the 44th National Assembly of the Republic of Bulgaria, available at: https://parliament.bg/bg/plenaryst/ns/51/ID/6159 (in Bulgarian). The bill was defeated also in the Parliamentary Committee on Labour, Social and Demographic Policy (Record No. 13 of 4 October 2017) and in the Parliamentary Committee on Economic Policy and Tourism (Record No. 11 of 11 October 2017). It was supported only in the opinions submitted by the Bulgarian Chamber of Commerce and Industry and the Bulgarian Medical Association. The Bulgarian Chamber of Commerce and Industry supported in principle also the subsequent PRIOPB, Incoming Ref. No. 954-01-62 of 5 September 2019.

[3] See Record of the 4 September 2017 meeting of the Committee on Incomes and Living Standards at the National Council for Tripartite Cooperation, available at: https://parliament.bg/pub/cW/20170929042444Ptotokol%20zased.%20KDJR%20na%20NSTS%20otn.%20ZVH,%20754-01-47.pdf (in Bulgarian). See, e.g., the opinion submitted by the Centre for Psychological Research as a nationally representative organization of people with disabilities, which stated that '[t]here is no way that parallel legislation on every area of life can be created for every social group. This is not only a bad but also an impossible legislative technique.'

[4] See Opinion, Outgoing Ref. No. 02-142 of 21 August 2017, of Biser Petkov, Minister of Labour and Social Policy, available at: https://parliament.bg/pub/cW/20170901095439Stanovishte%20na%20MTSP%20po%20ZVH%20754-01-47.pdf (in Bulgarian).

[5] This opinion was voiced during the debate on OPB, Incoming Ref. No. 954-01-73 of 18 September 2019, at the 21 November 2019 meeting of the Parliamentary Committee on Regional Policy, Urban Development and Local Self-Government. See Record No. 22 of 21 November 2019 of the Committee.

[6] The vote was held at a meeting of the Committee on 13 November 2019. The bill was defeated also in the Committee on Regional Policy, Urban Development and Local Self-Government (by a vote of eight in favour, none against, and eight abstentions, held on 21 November 2019) as well as in the Committee on Interaction with Non-Governmental Organizations and the Complaints of Citizens (by a vote of three in favour, none against, and seven abstentions, held on 21 November 2019).

[7] The vote was held at a meeting of the Committee on 13 November 2019. The bill was defeated also in the Committee on Regional Policy, Urban Development and Local Self-Government (by a vote of seven in favour, none against, and nine abstentions, held on 21 November 2019) as well as in the Committee on Interaction with Non-Governmental Organizations and the Complaints of Citizens (by a vote of two in favour, none against, and eight abstentions, held on 21 November 2019). It was also defeated in the Committee on Economic Policy and Tourism (20 November 2019) and in the Healthcare Committee (21 November 2019).

[8] See Opinion, Outgoing Ref. No. 01-00-219 of 30 September 2019, of Vladislav Goranov, Minister of Finance, which states, inter alia: 'Such a legislative approach does not flow from the constitutionally established principle of rule of law and is not in the interest of legal certainty; nor does it follow from the rules of the Statutory Instruments Act, according to which social relations in the same sphere are regulated by a single rather than by several statutory instruments of the same rank, while social relations appertaining to a sphere in respect of which a statutory instrument has been issued are regulated by an instrument that supplements or amends the said instrument rather than by a separate instrument of the same rank.' Vladislav Goranov's opinion is available at: https://parliament.bg/pub/cW/20191009033127stan_MF_ZID%20954-01-62.pdf (in Bulgarian).

[9] See Opinion, Outgoing Ref. No. 02-229 of 4 November 2019, of Biser Petkov, Minister of Labour and Social Policy, submitted in connection with the debate on PRIOPB, Incoming Ref. No. 954-01-62 of 5 September 2019, available at: https://parliament.bg/pub/cW/20191112093737stan_MTSP_ZID%20954-01-62.pdf (in Bulgarian).

[10] See Para. 1.26 of the Supplementary Provisions of the Social Services Act.

[11] For the sake of brevity, the two versions of the Older Persons Bill introduced by the BSP for Bulgaria parliamentary group (PG) are henceforth jointly referred to as 'OPB'.

[12] See Shorthand Record of the 133rd Plenary Sitting of the 44th National Assembly of the Republic of Bulgaria. During the debate on OPB, Incoming Ref. No. 754-01-47 of 26 July 2017, MPs repeatedly referred to the existing framework in Austria. The Federal Senior Citizens Act (*Bundes-Seniorengesetz*) of Austria takes a differentiated approach: all persons of Austrian nationality or nationals of a Contracting State of the Agreement on the European Economic Area with residence in Austria, who: a) based on a law or contract, receive a pension of any kind, or b) have reached a certain age – 55 years for women and 60 years for men.

[13] See Article 6 of the SIC.

[14] See Para. 1.1 of the Supplementary Provisions of the Persons with Disabilities Act.

[15] See Para. 1.27 of the Supplementary Provisions of the Social Services Act.

[16] For the thesis (increasingly affirmed with the development of biomedicine) that old age is a disease that must be treated, not a part of life that must be accepted, as well as for the 'neurotic effect' of this new attitude towards the natural processes of ageing, see Slavova (2018, p. 69).

[17] Actually, old age – 'the autumn of life' – is not a right but a privilege (Montaigne) to be grateful for. This of course does not rule out the obligation to respect and honour this privilege.

[18] Other forms of such care are the so-called 'assisted living' (older persons who do not yet need permanent care rent housing, concluding, together with the rental contract, a contract on provision of essential services, including cleaning, essential care, medical services, etc.) known in Austria and Germany, as well as the so-called 'multigenerational homes' (*Mehrgenerationenhäuse*) (ordinary families live together with lonely elderly people, allowing them to reside in their homes, in combination with mobile services provided by the municipality), also found in Germany.

[19] According to Article 8 of the PCA, a chitalishte (community cultural centre) may be instituted by at least

50 natural persons of full capacity to act in rural settlements and 150 in urban settlements, who adopt a decision to this effect at a constituent meeting. The Statute adopted at the constituent meeting regulates, inter alia, the sources of the chitalishte's financing.

[20] The idea of a 'dignified old age' in the PRIOPB can easily be continued in the concept of a 'dignified death' – a possibility the bill's sponsors did not comment upon, or may not even have been aware of.

[21] Not to mention the still missing regulation of the possibility for granting a medical power of attorney, including for expressing informed consent on behalf of an unconscious person – an issue that arises not only in the case of elderly patients but of all patients regardless of their age. See Stavru (2008, pp. 44-45); Stavru (2011a, p. 91).

[22] On the so-called 'ethics for a broken world' discussed in a series of lectures on the history of philosophy conducted in an imaginary future class in a world where all resources have been exhausted because of overexploitation and destruction by the previous generations, see Mulgan (2011).

[23] 'Greta Thunberg's full speech to world leaders at UN Climate Action Summit', a video of her several-minute-long speech which moved millions of people, is available at: https://www.youtube.com/watch?v=KAJsdgTPJpU.

[24] It is not impossible to imagine a future in which the young generations not only don't accept their predecessors' economic, political and environmental legacy with gratitude but, moreover, declare it to be toxic and categorically reject it.

[25] This growing competition between generations is one of the reasons for the European Commission's communication 'Towards a Europe for All Ages'. The Guiding Principles for Active Ageing and Solidarity between Generations, jointly agreed by the Social Protection Committee and the Employment Committee and adopted by the Council of the European Union in 2012, point out that 'it is necessary to maintain a balanced distribution of resources between age groups'. The Council Declaration on the European Year of Active Ageing and Solidarity between Generations (2012) also stipulates that active ageing and solidarity between generations require 'recognition of the values of all age groups and their contribution to society, thus promoting positive perceptions and attitudes towards all age groups; engaging them in decision-making (policy formulation and implementation), paying special attention to their opinions and concerns'.

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Desislava Vankova

HEALTH-RELATED AGEING – DETERMINANTS AND DEBATES

Introduction

Ageing and health are often debated in their interdependence. Trivially, old age is seen as the determinant of bad health. Traditionally, demographic ageing is accepted as a public health problem. Combating these negative stereotypes related to population and individual ageing is a moral and professional responsibility. This article discusses health-related ageing from the position of a medical doctor and public health researcher in Bulgaria.

The historic **political** changes in 1989[1] and the subsequent **economic** transformations led to ongoing healthcare reforms. In parallel with these processes, a **demographic transition** has been taking place, called the '**third transition**' in the (post)socialist world, which also affects healthcare systems (Chawla et al., 2007). The third transition is characterized by a significant 'greying' and 'shrinking' of the Eastern European nations. The share and number of elderly people will continue to grow, and by 2025 one in five people in most postsocialist countries in the region will be over 65 years old. Population ageing is common for the whole European continent, but there are clear differences between the developed European economies and the countries of the former Comecon. The cumulative effects of all the transitions reflect on public health, for example increasing mortality among workers, especially men. While in the 1960s the differences between developed and planned economies in terms of life expectancy were only two or three years, in the 1990s the differences deepened and life expectancy became about ten years shorter in Central and Eastern Europe. The 'good news' is that the life expectancy indicator is slowly but steadily rising for most countries in the region, including Bulgaria (OECD, 2014).

As part of the former Comecon, Bulgaria is 'ageing' demographically, but ageing in its own unique way. According to the United Nations (UN, 2019), Bulgaria's population will decline from 7.2 to 5.2 million by 2050, making Bulgarians the fastest shrinking nation in the world (the next nine are also in Eastern Europe). In its current territorial boundaries, the population in Bulgaria after the Second World War was 7,029,349 (1946) and increased to 8,948,649 in 1985. Since then, there has been a steady trend of negative reproduction – the last census showed that the population had decreased by 1,583,899 and was

7,364,750 in 2011 (NSI, 2011). In 2025, more than one in five Bulgarians will be over 65 years old, while in 1990 people in this age group were only 13% of the total population. In terms of overall births and deaths, Bulgaria follows the European trends of a steady increase in mortality and a decrease in birth rates. However, the sustainability of the negative natural growth in our country is also due to the lasting trend of young people's emigration since 1990 to this day.

In the Bulgarian context, we are participants in '**the fourth value transition**', which is a result of the previous three political, economic and demographic transitions. In the field of social medicine, health promotion and bioethics, the term was introduced and developed by this author (Vankova, 2016).

The definition is dynamic and encompasses the evolutionary transition of virtues and policies, which describes and outlines the necessary unifying and sustainable changes in Bulgarian society, and in particular in public health, in order to achieve a better quality of life and health. The boundaries between the various social, scientific and educational fields are constantly 'melting' in favour of improving health. Basic and applied science, philosophy and ethics, education and practice are integrated to critically analyse the orthodox medical models with their popular analogues at the level of everyday life.

This is a difficult social and public health transition, taking into account the prevailing myths (debated below), but also the facts of the last 30 years. According to analyses by *The Economist* (2003), in 2003 Bulgaria needed 63 years to reach the average European standard of living (45 years are left), and 'national self-confidence and dignity are unconditionally determined by the standard of living in which a nation lives today. The poor man cannot have self-confidence, in the mass case he cannot be worthy' (Semov, 2004). Many Bulgarians live in stress, anxiety and insecurity. The link between anxiety and feelings of ill health has been statistically proven (Hofstede, 2001, p. 191). Many of the feelings and attitudes associated with stress increase with age (Minkov, 2002). Overcoming this 'anxious culture' is part of the 'fourth value transition' and can even be defined as one of the most important tasks of the younger generations of society.

Globally, as in this article, the idea is defended that people over the age of 65 are human and social capital, a thesis initiated and supported expertly and politically by international organizations such as the World Health Organization (WHO) and the World Economic Forum. In addition, public attention is increasingly focused on the humanistic concepts of health promotion, health-related quality of life, and the determinants of well-being of the elderly individual and society at large.

Which are the main pillars of these concepts that set the agenda of healthcare for the elderly in Bulgaria and around the world? What are the popular views and myths with which these pillars come into conflict and to what extent is this conflict predetermined by post-socialist conditions and lifestyles? How can the persistent prejudices regarding old age be 'dismantled' and the quality of life of the Bulgarians improved?

This article will try, if not to answer, then at least to discuss the questions formulated above by analysing in detail the myths and realities of/about the 'significant others' (Goncharova, 2017; 2019), people over 65 years.

The Health of the Elderly. Health Determinants and Inequalities

The field of social medicine connects, and often unites clinical practice, prevention and non-medical care for vulnerable social groups such as the elderly. Social medicine approaches health holistically, taking into account the influence of all determinants – behavioural, biological, social, environmental, ethical, legal, systemic factors. Social medicine enriches the dominant biomedical model through the development of research and through practical health promotion interventions. This is also the disciplinary field in which biological predispositions, behavioural, natural, and social determinants of health are debated.

Every single person ages in their own unique way. However, there are common characteristics of normal physiological (not pathophysiological) ageing. The vital processes of ageing are inevitable, although the human body, through homeostasis, maintains stability, adapting to the changing conditions.

Physiological ageing proceeds at different individual speeds and is manifested in the inability to maintain homeostasis under emergencies, as the changes occur due to ageing and are not the result of a disease. The elderly's capacities to react during stress and illness are reduced, although the physiological decline associated with ageing varies from individual to individual.

Old age is not synonymous with disease, but the diseased conditions of people at the age of 65 often become chronic, which has a lasting effect on the health and social needs of the elderly individual. In addition, polymorbidity often causes a level of disability. From a public health perspective, this means an increasing burden of coronary heart disease (CHD), heart failure, stroke, Type II diabetes, osteoporosis, depression, dementia, visual and hearing impairments, etc.

With the development of society, we lead an increasingly sedentary life, and our physical capacity progressively decreases with age. Immobilization due to physical limitations leads to a low self-esteem and a feeling of dependency, low levels of self-care. Life and social crises related to ageing often remain out of the focus of monoparadigmatic biomedical approaches. Moreover, care for the elderly often takes place 'behind the scenes' of the public (Karamelska, 2019). Older people go through turmoil in their professional life, such as loss of professional status, respect, prestige, as well as loss of relatives, family ties, widowhood, isolation, etc. All these facts can lead to financial insecurity and cause stress and psychological changes, isolation, loneliness. The 'loneliness' epidemic leads to twice as many deaths as obesity (Action for Happiness, 2021).

Even in the absence of serious disease, there is health heterogeneity among the elderly (Lafortune et al., 2009; Liu, 2014), which is due to significant differences in biological and social functioning, the variety of integrative effects of many factors (**determinants of health**) that are in constant interactions.

The determinants of health are all personal, social, and environmental factors that determine the health of individuals and populations. They are also positive factors that stimulate the strengthening and improvement of health and negative factors that are harmful. Globally, their first systematization into four groups of health determinants was made in 1974 through a political report of the Canadian Minister of Health Marc Lalonde (1974). Thus the idea of 'health promotion' has evolved. The report has had a transformative effect on the way the world has been approaching health, outlining a conceptual framework for a holistic understanding of health as a result of human biology, the environment, lifestyle, and healthcare organization. The four classical groups of determinants called 'Lalonde's Model' are the lifestyle (behaviour) that largely determines human health (according to various sources, from 30% to over 50% – EP, 2011; Lalonde, 1974); the healthcare system; the external environment, including the economy and ecology; and genetic factors. The development of epigenetics and human genome research are transforming science and supporting the holistic approach to health, providing further evidence of the power of human behaviour as a health determinant.

Lalonde's Model does not differentiate the social determinants that focus research interest through the development of other modern models of health policy analysis, such as the Dahlgren-Whitehead Rainbow Model, which integrates the determinants of natural and social environment, economic conditions, access to health services along with individual characteristics and lifestyle (Rohova, 2014). Health is most sustainably influenced by the way of life, which in turn is greatly influenced by socio-economic conditions and cultural traditions. The interdependence of these determinants is axiomatic and the success of health promotion interventions is guaranteed only when the planned activities are complex and affect not only behavioural but also social determinants.

It has been scientifically proven that the population's health, as well as individual health, depend on social factors no less (even more) than on genetic factors, factors related to human behaviour and healthcare services. In Europe, as early as 1840–1850, Chadwick's and Shattuck's reports proved the link between poor working and living conditions, poverty, and high mortality (Tulchinski and Varavikova, 2004). At the end of the last century, Professor Thomas McKeown's (1976) classical study provided indisputable evidence of the need to plan public priorities for improving health. He examined various interventions and measures since the second half of the nineteenth century that have contributed to the improvement of public health and reduction of mortality, and concluded that innovations in clinical medicine have a lesser effect on overall health improvement than changes in the environment and social factors.

In the twenty-first century, the development of the idea of the social determinants of health, as well as the WHO's and other international organizations' efforts to reduce health inequalities, have led to a more detailed classification of the external factors, including absolute and relative poverty, as essential health determinants (Marmot, 2005; WHO, 2021). These global public health trends have been reflected in Bulgaria, too (Feschieva and Kerekovska, 2005).

On the other hand, health systems, as a separate determinant, are assessed as the least influential on health. For example, the USA spends the most money on healthcare ($9,400 per capita in 2017) and yet still has one of the lowest life expectancy rates among all developed countries (79 years, ranking 31st) (Tello, 2018). It has been proven that in order to improve health, it is not just the healthcare system that needs to change. Research shows that social determinants predetermine between 30% to 55% of health outcomes, and the contribution to health of non-medical sectors exceeds that of the health sector (WHO, 2021). Therefore, the health determinant ‘behaviour’ is a powerful factor. However, a healthy lifestyle change demands transformation in the social determinants, in all the conditions in which people are born, grow, work, live, and grow old.

Our genes can determine the predisposition, but our health, including at an older age, depends to a large extent on the choices we have made. What exactly is a healthy lifestyle? The analysis of scientific research in the field leads to the identification of five main areas that have the greatest impact on the risk of premature death and can be defined and measured as follows: (1) Healthy diet, which is assessed on the basis of reported intake of healthy food such as vegetables, fruits, nuts, whole grains, healthy fats and omega-3 fatty acids, and unhealthy food such as red and processed meat, sugar-sweetened beverages, trans fats and sodium; (2) Healthy level of physical activity, which means practising moderate to intense physical activity for at least 30 minutes a day; (3) Healthy body weight, by measuring the body mass index (BMI); (4) Smoking – there is no healthy smoking; ‘healthy’ here means zero cigarettes per day; (5) Moderate alcohol intake, which should be defined by quantity and quality.

There is reliable scientific evidence regarding the key influence of healthy habits on the quality of life and longevity. For example, a large-scale study conducted by Harvard University on the impact of healthy habits on life expectancy analysed data from 120,000 participants – more than 78,000 women between 1980 and 2014 (34 years in total), and over 40,000 men in the period from 1986 to 2014 (28 years in total). It has been proven that if the participants follow the healthy behaviours summarized above, their life is significantly longer – by 14 years for women and 12 years for men (if they had these habits at the age of 50). People who live unhealthy lifestyles (compared to the five areas formulated above) are much more likely to die prematurely from cancer or cardiovascular diseases (HPFS, 2021; NHS, 2021).

The collection of lifestyle data began in the mid-1960s as part of the social indicators studies in the developed countries. Initially, in the Scandinavian countries and in the USA, broad national programmes for the development and introduction of ‘social indicators’ were launched, including those for lifestyle, because it became clear that economic indicators alone were not enough to assess the well-being of citizens (Rapley, 2003). In 1970 Varna hosted the World Congress of Sociology, where reports by American and Western European authors on the relationship of lifestyle with quality of life and health were presented. In 1978, again in Varna, an international symposium of Comecon researchers was held, dedicated to the unified system of social indicators in the Comecon member-states. Today, comprehensive longitudinal sociological surveys, including an assessment of health behaviour, are very important in view of their comparative European perspectives, such as the European Social Survey (ESS) and the European Health Interview Survey (Eurostat, 2019), among others. One of the most reliable sources of data on the population's health status, and in particular of the elderly, are the population registers, which are freely available and allow for comparative analysis: for Europe – the Survey of Health, Ageing and Retirement in Europe (SHARE) and the English Longitudinal Study of Ageing (ELSA); for the USA – the US Health and Retirement Study (HRS).

Bulgaria is already part of the European family and the national data is part of the European sociological surveys and comparisons. Analyses have proven that the social and health 'price' of the political and economic transitions and the ongoing demographic one in Bulgaria is one of the highest among the other post-communist countries. The huge changes in the social and health insurance systems, education and healthcare were accompanied by unknown social phenomena, such as poverty, unemployment, demographic crisis and a general decline in the quality of life. The fourth transition is the possible path we must take to 'cure' social erosions by restoring or creating values that keep a society healthy, despite the social contradictions associated with ageing in our (post)socialist society. During the transition, it will be necessary to overcome the contradictions between the growing life expectancy and the quality of life deterioration due to the increase in the years spent in poor health; between the growing number of elderly, poor and dependent people in Bulgarian society and the declining number of the economically active, who bear the burden of the large number of retirees. The politically declared care for the elderly is in contrast to the spreading overt or covert discrimination against them (ageism). In this regard, age discrimination in healthcare also contributes to the unequal treatment (directly or indirectly) based on older age (Ray et al., 2006).

These contradictions paint the gloomy picture of an ageing society and are the result of, or they themselves create, myths about the elderly, about the ageing society. What are they and what is their place in Bulgarian society?

Myths and Realities about the 'Significant Others', People over 65

As early as the end of the twentieth century, with the emerging trend of an ageing population, the UN and the WHO initiated public discussions seeking to introduce the concept of active ageing and to debunk the myths about the elderly and their role in modern society (WHO, 1999; UN, 2002; WHO, 2002;

MACA, 2007). This article debates some prejudices about older people that have been in the author's research focus for a decade (Vankova, 2013; 2019). The debate is developed by the author and systematized in five controversial areas or myths.

The first myth that has been spreading for years is the generalized statement that **the demographic ageing is a natural disaster, and that this is an inevitable health and social crisis which is an insurmountable threat to society**. Yes, demographic ageing is a fact, but it is clear evidence of the achievements in public health and clinical medicine. Forecasts about a change in the age structure of the population have been made for a long time, because demographic ageing is not a sudden event and societal adaptation is a necessary and possible process. Yes, people live longer and will live longer, and often their physical and mental condition does not change significantly. Many countries and smaller communities are successfully tackling demographic ageing by supporting people to stay healthy and independent as long as possible. The Silver Economy initiative (OECD, 2000), which relies on independent, wise, socially active and energetic older people, was proposed as early as the beginning of the twenty-first century. We support the thesis that instead of being presented as a problem, the increase in life expectancy is a reason to celebrate. Moreover, the ageing of the population provides an opportunity to rethink health policies for the good of both younger and older citizens (Lloyd-Sherlock et al., 2012). Nationally, harmonization with international standards has required that terms which are often associated with ageing – such as 'disability', 'disabled', 'incapacity', 'permanent and temporary disability', 'handicap' – go through evolutionary bioethical developments (Ivkov, 2020; Mancheva, 2018).

The myth that constantly accompanies the theme of demographic ageing is the claim that **older people are only a financial burden to society because caring for them is expensive and they do not contribute significantly to community life**. It is true that healthcare costs are rising often out of control. Moreover, the medical and social care for the elderly associated with increased needs is expensive. Thereafter, the perceptions about ageing and the elderly remain stereotyped and generalized. The routine use of DALYs (disability-adjusted life years) as a measure of health will always prove that the elderly are a social and financial burden. Importantly, many older people continue to contribute to the cultural and economic development of society (Lloyd-Sherlock et al., 2012). Yes, demographic ageing is a major challenge due to its impact on: the economy by influencing the workforce balance; the social funds through increased needs, etc. However, economic analyses show that rising incomes of medical staff, new technologies, and an ageing population are key drivers for health expenditure growth (OECD, 2019). Fortunately, life expectancy will increase, so a way must be sought to reduce commercialization in healthcare and to invest in efficient and effective technologies.

Healthcare costs do not necessarily increase with age. Generally, the highest costs are in the last year of a person's life, regardless of age. A key indicator for studying the population's health is the monitoring of the quality of life and the functional status, including of the elderly. It has been proven that effective outpatient management of hypertension, diabetes and other chronic diseases, as well as the application of relatively cheap health promotion interventions (regular physical activity, increased health literacy, etc.) improve the health status of the elderly (WHO, 2020). Population studies show that social capital (trust, mutual support) is a protective health factor for the elderly, even for those suffering from depression or other chronic diseases (Holmén and Furukawa, 2002; Nilsson et al., 2006; Gallegos-Carrillo et al., 2009; Litwin and Stoeckels, 2014).

Societies in which respect and care for the elderly is a social value have a brighter future. Research in medicine and clinical psychology has proven that in communities where older people feel loved and supported they assess their health-related quality of life higher (House et al., 1988; Cacioppo and Patrick, 2009). Furthermore, older people also create social capital, they are not a burden to society but a glue that could strengthen the community and the society.

The next myth covers **the perception of old age as a disease, which in turn 'discounts' the idea of prevention and healthy behaviour at an earlier stage of life**. Old age does not mean illness, disability and dementia, and the elderly are not always infirm and helpless. However, the fact that there are many folk sayings with a similar meaning shows the existence of national values, which implies difficulties in overcoming these myths. For example, the Bulgarian sayings '*Starost – neradost*' /'Old age – unhappiness' or '*Glava pobelyava, akal izvetryava*'/'Head turns white, mind evaporates' (Kyoseva, 2008).

Correcting the negative stereotypes that old age means illness and permanent disability is a moral responsibility. Studies show that the negative attitude towards the biological processes of ageing in young people is directly related to the deterioration of health in later life (Greenstein and Holland, 2015). Preventive healthy behaviours, accepting ageing as a natural stage of life, and a positive attitude towards older people are ways to deal with the fear of ageing. Growing up is a physiological process and after a certain number of years people need more care and attention, and this is normal. The demographic ageing of society requires new models of healthcare that provide not only treatment but also rehabilitation, as well as various types of psychological, educational, social, and health services.

However, every person ages in a different way – ageing depends a lot on healthy behaviour. Research proves that we are 'designed to move' (Vernikos, 2016). However, many people refuse to understand this and are thus preparing themselves for difficult ageing, depending on their physical activity (Lewis and Hennekens, 2016). Therefore, people over 65 are a heterogeneous group (Liu, 2014). The challenge of ageing is to adapt and learn new ways to deal with the difficulties arising from physiological body ageing. Here, too, older people are different, some refuse to learn and develop, while others are open to innovation and desire change.

There is also a myth that **people over the age of 60 do not accept, cannot use, or misunderstand technology**. Globally, people over 60 are one of the fastest growing internet communities. In Bulgaria, the process of older generations' acquaintance with new technology is slower but sustainable. The main obstacles are the language barrier and the relative/absolute poverty of retired people. Fortunately, these obstacles are being overcome because nowadays computers or mobile devices are more and more available, providing internet access and ways to overcome the geographical isolation of the elderly.

In 2007 the European Commission approved the so-called Silver initiative, 'Aging well in the information society' (Obi et al., 2013). Today we are witnessing the implementation of this initiative with the full penetration of information technology everywhere.

The myth that **older people have an incomparably worse quality of life than younger people** is also supported by population-based research, which has found low self-assessment of health-related quality of life in people over 65 years of age. On the other hand, young people assess their overall quality of life through the prism of their future prospects, so unemployment and insecurity are the problems they have to overcome. While for older people, well-being is determined mainly by their health and how long they will be able to maintain their autonomy and independence. Viewed in this way, the 'news' that we live longer and in better health is good for people over 65. Metaphorically, wise adults learn to 'travel light' (Greenstein and Holland, 2015).

Scientific data from many studies – such as America's GS Survey, Eurobarometer, etc. – which examine the change in well-being (quality of life subjective assessment) show that young people assess highly their well-being, but with age this assessment decreases and reaches the lowest value in the age group of 40 to 50 years. Then these subjective assessments begin to rise and are highest at the end of life, forming the so-called U-bend. Age-related well-being in the Western countries has the typical U-trajectory. However, this is not valid for Eastern European countries, including Bulgaria, where the well-being curve descends steeply with age, which means that older Bulgarians have a lower quality of life in comparison to the Western European elderly. An interesting fact is that in Japan as well as in Bulgaria, older people assess their quality of life lower and the well-being curve also goes down, the so-called J-curve of life (Commission on Measuring Well-Being, 2011). Consequently, the cultural and historical context is essential and the mechanical transfer of public health policy models is not a sustainable investment. Predominantly, when asked 'How are you?' the Bulgarian 'knocks on wood', often avoids answering positively so as 'not to be heard by the devil!' and 'not to provoke envy!'. The 'dismantling' of these persistent prejudices, as well as the mythologies regarding old age, in order to improve the quality of life of the Bulgarians, is part of the already defined fourth value transition.

Conclusions

In a world where many changes are unpredictable and sudden, global ageing is a predictable long-term demographic trend. In Bulgaria, these processes are part of the 'fourth value transition' through which we should rediscover the role of the elderly as a resource of knowledge and wisdom, but also rethink longevity as a 'dividend' for society (Chan, 2012, p. 3). The central social idea is that if we can ensure that older people live healthier lives, if we can be sure that by our actions we extend the life continuum in the middle, not just at the end, these extra years can be as productive as any others.

Investing in the health of the elderly is a sustainable public strategy, and health promotion as a holistic humane idea and real care provides the methods and approaches to achieve a healthy society with growing life expectancy and quality of life. The WHO introduced the term 'health promotion' in 1986, as a response to the societal needs for proactive healthcare. The WHO's classic definition is: 'Health promotion is the process of enabling people to increase control over, and to improve their health' (WHO, 1986).

As early as the end of the last century, the focus shifted from conventional medical technologies to the individual and societal responsibility for health, due to rising pharmaceutical costs and the potential opportunities to manage these trends by investing in 'the health of the healthy'. The main resources for this are the individuals and the communities with their adequate health motivation (De Leeuw, 1989; WHO, 2021). The WHO strongly supports the transition from medical determinism to an integrative approach that unites all parties to promote health and to prevent disease.

In the Bulgarian public health field these processes can be accepted as part of '**the fourth value transition**', uniting themes of sustainable societal changes to achieve a better health-related quality of life in opposition to the banalized myths regarding ageing, which have lost their social mobilizing potential.

There is an imperative need for integrative approaches to the health of the fastest growing social group, the elderly, in support of active ageing. The WHO offers five main approaches: prevention, behaviour change, health education, empowerment of people and communities, and social change. These health promotion approaches are applicable if there are ethical prerequisites determined by the degree of social acceptance and by the levels of public control over the efficiency and effectiveness of these approaches. Hopefully, Bulgaria is taking its first steps towards 'the fourth value transition'. This article has the ambition to be such a step, summarizing the content of the five approaches in the context of health-related ageing:

Prophylactics of the chronic diseases at a later age should begin in the period of early childhood (Valtcheva, 2019), in high school (Georgieva, 2016) and at university (Boncheva and Dokova, 2019), and should continue throughout life. It has been proven that people with more positive emotions in childhood live longer and in better health (Action for Happiness, 2021). Getting older is inevitable and this is the only way to live longer. Health promotion enables people to influence and improve their health.

Healthy behaviour change is the key to better health at a later age. Priority should be given to **anticipatory measures**, including the promotion of healthy behaviours.

Behaviour change is driven by solid scientific evidence and education. Here are some convincing scientific facts: poor health due to lack of physical activity 'accounts for 22% of coronary heart disease, 22% of colon cancer, 18% of osteoporotic fractures, 12% of diabetes and hypertension, and 5% of breast cancer' (Lewis and Hennekens, 2016, p. 137).

Health education – as a sustainable process of building subjective health literacy, namely: health knowledge, beliefs and behaviour to improve and maintain health.

Adult health education is key for a full and independent life. The US Center for Disease Control recommends 'aging in place' as a safe, independent and comfortable life (Harvard Medical School, 2020).

Caring for the elderly, especially for those with 'frail health', requires integrative transdisciplinary approaches and training for both medical staff and family members. There are many successful community models around the world which are based on the benefits of health education and the need for integrated care for the elderly (Keough et al., 2002; Arai et al., 2015).

Empowering people to reach their full potential – with the global and national increase of life expectancy, maintaining the physical independence of the elderly is becoming a major clinical and public health issue. The key activities here are part of the anticipatory measures to encourage healthy behaviours.

Concepts such as 'active ageing' or 'healthy ageing' (WHO, 2002; Pushkarev et al., 2019) and their adoption in a national context (MLSP, 2019) play an important role in utilizing the full potential of the elderly in society. The monitoring of social indicators such as health-related well-being and quality of life of older people is also an expression of progressive developments in science and society as a whole (ESS, 2008; Eurostat, 2019).

Social change – to make healthy choices easier is an approach closely related to harmonization with European legislation, to the investment in universal health coverage, in social protection by strengthening the national legal framework for the protection of the human rights of the elderly (Stavru, 2019). Further, the social policies, the public health policies, need to ensure rational participation in the labour market for people over the age of 65, with well-preserved working capacity and health. Social entrepreneurship as well as corporate social responsibility are key steps in this direction.

Healthcare has to adapt in order to meet the needs of the growing elderly population: in addition to emergency and hospital care, access to primary health care settings, provision of long-term care, rehabilitation and palliative care, maintenance of home care (the so-called 'patronage care') are of great importance (European Social Fund, 2021). Population ageing increases demand for healthcare services, especially for long-term care. This fact puts more pressure on family members, especially on women, with about 13% of the female population over the age of 50 reporting that they provide informal care at least once a week for an dependent relative or friend. The share of the population aged 80 and over is expected to double by the year 2050 (OECD, 2019). Therefore, the introduction of effective models for long-term care (Praznovszky, 2019) is a key investment to meet the future needs of Bulgarian society.

In conclusion, and in the name of the future, we look back at the cultural experience layers of old age and its various images represented in art. Growing up is a journey through time and the opportunities for realization, resocialization and expansion of horizons in the last section of the life continuum are equal in meaning and significance with those in earlier life periods.

At the age of 71, the writer Isabel Allende[2] in her TED Talk (TED2014) serves as an example of how to age actively, beautifully and with passion, despite the difficulties.

The researchers Mindy Greenstein (clinical psychologist, born in 1965) and Jimmy Holland (psychiatrist and oncologist, 1928–2017), have summarized the experience of two generations in geriatrics and positive psychology in their monograph *Lighter as We Go: Virtues, Character Strengths, and Aging.*[3] The cultivation of certain virtues, which the authors (Greenstein and Holland, 2015) summarize in seven groups, is perhaps the recipe for a balanced welcome of old age, which is inevitable! The seven virtues are: (1) The Virtue of Transcendence – related to the personal understanding of the meaning of life and human existence; (2) The Virtue of Humour – the ability to joke about what we fear is a successful way to overcome it; laughter heals, there is evidence of it (Bennett and Lengacher, 2009); (3) The Virtue of Humanity and Social Justice – it is our sense of connectedness, of sharing with others, even with our pets; (4) The Virtue of Courage – not fearlessness, but the courage to be ourselves; (5) The Virtue of Wisdom – depth in understanding life and in following an ideal we want to achieve; wisdom is often associated with old people; (6) The Virtue of Temperance – 'Be moderate in everything' is prescribed by every physician to her or his patients, regardless of age. In order to enjoy good health, to have happiness in the family, to have peace, the first condition is to be at peace with yourself and to be able to forgive; (7) The Virtue of Passing on to the Next Generation – the elderly have a unique opportunity and sacred responsibility: to build bridges from the past to the future. The joy of communication between generations consists not only in telling facts and stories, but also in education, in the transmission of philosophical virtues for a meaningful life.

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NOTES

[1] At that time the author was a third-year medical student.
Contextual clarification for those born 'after the changes': Before 1989 there was the so-called 'zoning' and if a secondary school graduate from Burgas wanted to apply to study medicine they could do so only in Varna. They were not allowed to apply in Sofia, Plovdiv or Pleven.

[2] Isabel Allende (born in 1942) is a Chilean writer, a representative of magical realism. Her books reflect her life, which has been a series of turbulent events. In her youth, the writer was a socialist and supported the progressive government in Chile (she is a niece of Salvador Allende, President of Chile from 1970 to 1973). A defender of those politically persecuted by Pinochet's military dictatorship, she was forced to emigrate to Venezuela where she wrote her first book, *The House of the Spirits*. In the United States, the country in which Allende has chosen to live today, she has established a foundation for the protection of women's rights and once again has a strong and active civic position.

[3] The monograph was presented at the 13th International Symposium on Myelodysplastic Syndromes held in Washington, DC, from 29 April to 2 May 2015 (http://mds.kenes.com/).

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Galya Koycheva

CARING 24/7

An interview by Galina Goncharova

Could you please introduce yourself?

I've recently been taking on multiple social roles, so I find it harder and harder to introduce myself. I love this social term, 'social roles', because people don't always realize that they have and play different roles depending on the context. So how would I describe myself? My name is Galya Koycheva and I've been a parent of a person with disabilities for 23 years now. I got married in a small town in Bulgaria and gave birth to a premature baby without having any indications of this during my pregnancy. I didn't have any problems, I worked till the last minute, I'd been transferred to a more appropriate job – there were such options in the 1990s. One morning, I suddenly got labour pains and my cervix dilated; till the very last minute I just couldn't believe I was going into labour. I gave birth in the small town my husband and I were living in at the time. In a sense, this turned out to be disastrous for us because the baby didn't get proper medical care. He was placed in an incubator but wasn't put on a ventilator, so he stopped breathing at some point. They called a medical team from [the nearby city of] Shumen who resuscitated him, restored his breathing, moved him to the hospital in Shumen and spent the next two months fighting for his life. We didn't know if he would live or die, if he would be able to breathe or not, if they would take him off the ventilator so that he would start breathing on his own or not. In fact, his premature lungs were the major problem. I was 23 years old, this was my first child, my husband was my high school sweetheart, we had a long and beautiful relationship… This came as a great shock to us. We simply didn't know what was happening to us and there was no one to tell us because there had been no such cases in either mine or my husband's family. To my mind, we didn't get adequate support from our families, either. I was in one hospital, in one maternity ward, while the baby was in another maternity ward. Thanks to many contacts and strings pulled, we were moved to the same ward. I must say that many people helped me. Fortunately, there was a neonatologist in Shumen who took our case to heart and cared exceptionally for this baby. She managed to make him breathe, live, start his second life. For almost two months, this baby was known as baby X, he didn't have a name because he was hovering between life and death. We hadn't given him a name. We hadn't decided how to call him because he was born unexpectedly, two months premature. Back then ultrasound scans still didn't show if the baby was a boy or a girl, so I didn't know the baby's sex. There are very few families where the diagnosis is known from the very beginning of the child's birth, especially in the cases of disability from childbirth. In our case, the neonatologist I told you about, Dr Gramatikova – may she live long and prosper! – succeeded in dealing with the child's condition. She immediately appointed the appropriate tests, lumbar punctures and scans, which were duly performed. And by the end of the second month we knew the diagnosis: spastic quadriparesis, spastic cerebral palsy.

What did you know about cerebral palsy?

Cerebral palsy is often caused during birth, it's common in premature babies or twins, where one twin is asphyxiated by umbilical cord occlusion, because oxygen deprivation damages the neurons in the brain in various ways. Later, I spoke with doctors, in particular with Dr Gramatikova. She told us that it was simply a matter of time – had he been born in the hospital in Shumen, he would have been moved from one floor to another and put on a ventilator, but he was placed in an incubator and left for hours without a ventilator and he gradually asphyxiated and turned blue... And something else they told me at the time – that the struggle in maternity hospitals is for babies to be born live, not for babies to be born healthy. Yes, he will be born in the small town, in Novi Pazar, but will die in, let's say, Shumen, because that's where the ambulance will take him. He was born live in one hospital but might pass away in another… We managed to save this baby's life, and thanks to many contacts and strings pulled I was admitted to the maternity hospital so that I could care for him and he would get used to me. My other shock was that I stayed for 21 days in a maternity hospital where women checked in, gave birth, and left, while I was isolated. Yet it's important for the mother to connect with her baby in the first hours, the first days after birth, isn't it? I was alone in a room and went to feed him every three hours. The way I cared for him was very unusual, but my memories of that time are very vivid. I welcomed the new year 1995 in hospital with him. Later, we were discharged and that's how our fight for his life began anew. A premature baby with all sorts of concomitant disorders, lung disorders in particular – in the first months, we lived in complete self-isolation to avoid any contact with other people, with viruses. Warmed rooms, total hygiene. The people at the hospital helped us a lot – we had a physical therapist while he was still in the incubator, who taught us what to do at home. Of all parents of disabled children I know in Varna and elsewhere in Bulgaria, I believe I'm probably the only one who started giving physical therapy – massages and stretches – to a baby weighing two kilograms. He had spastic quadriparesis, which I think is the more common form of cerebral palsy – the other form, dyskinetic cerebral palsy, is less common, I think. Anyway. Back then there was no internet, no textbooks, nothing to learn from on your own – all I could do was ask doctors and specialists, and that's how I learned how to care for him. We brought the baby home from the hospital, we hadn't bought him a pram until he was almost six months old because it was winter. No going out, no guests, no drinking for the newborn's health – I remember that my mother-in-law, who was in a senior position in a factory, said her colleagues had expected her to treat them to a drink to celebrate the baby's birth. Once we brought him home, I took over and although I was just 23 years old, my cares began. Back then there were almost no nappies in the shops. I swaddled, I fed him – he had a problem with the sucking reflex, later with the breathing reflex, all those things – on hindsight, I often wonder how I managed to cope, how I intuitively felt what I should do. Constant physical therapy – in the morning, massaging and stretching this tiny baby, same thing in the afternoon, feeding him on schedule. I'm very strict and I followed a very strict routine – even now we're constantly on various strict routines. But he used to fall ill very quickly and got pneumonia when he was just six months old. While he was in an incubator he got his first pneumonia, which kept him in hospital, and now he had to be hospitalized again in his sixth month – in Varna, where he was given a series of injections. I will never forget it – this tiny, skinny baby was given 45 injections. On the tenth month we went to Shumen again, I was lucky again because the neurologist at the neonatal ward paid us attention and told us, 'You won't be able to deal with this on your own, you must go to the children's rehabilitation centre in Momin Prohod.' So after going from hospital to hospital, I ended up in the rehabilitation centre with a ten-month-old baby who absolutely didn't move and only lay on his back, he couldn't sit up, he couldn't crawl, he ate only formula because we had to catch up on his weight. With a bag of luggage, my husband took me to Momin Prohod. This is a children's rehabilitation centre near Sofia, and I thought it would be like going to the hospital for a few days. The manager welcomed me and said, 'Mums, the course here is three months long – three months physical therapy, three months at home.' Thus began our long saga which I always mention, the first ten years or so of my son's life – treatment at rehabilitation centres. This was my school, this was my encounter with such children and their parents. The first time I stayed at the rehabilitation centre, there were no vacant rooms, it was bursting at the seams – parents, all sorts of mothers, of all ages, very young children and slightly older ones – so they gave me a room on the fourth floor. In this rehabilitation centre the fourth floor was for children from care homes. This was in 1995. I can't forget what I saw there. Children in pajamas who can't move, crawling on the floor and crying, 'mum, mum', placed on potties in a row, fed on schedule, and I with a baby locked up in one of the tiny rooms which was the isolation room. There wasn't any other vacant room. The view from this isolation room was of northern forests and I wrote letters to my friends – back then we still wrote letters by hand. We did almost seven three-month courses there. That's how he grew up. We spent many birthdays there, we stayed in hospitals many more times because he used to fall ill despite doing physical therapy – he constantly had breathing problems. He had pneumonia several times while growing up. Until his seventh year, I cared for him on my own at home and in these rehabilitation centres and hospitals.

How did his father feel?

His father constantly took us to those rehabilitation centres, loaded with bags, bathtubs, wash basins, food. I'd go in boots and come home in sandals – the seasons had changed in the meantime. Being away from one another – there were no mobile phones, no internet, he called us on landlines in the corridor of the rehabilitation centre. The nurse would come and call me and I would run along the corridors to get to the phone. He came to see me when he could because he was working full-time. We've continued living like that to this day. We didn't realize very well what was happening to us, but we had the ambition, especially I, to do everything the specialists told us.

Did you have hope?

For many years, almost until his seventh year, I fought for him to start walking. We did everything possible to get him to start walking eventually, but we somehow didn't take many other things into account – that he first had to learn to sit up, to crawl, to stand upright, then to take a step… This is a process. When he was around seven years old I realized that he would never be able to walk, but I didn't despair. We have continued doing all sorts of physical therapies to this very day. Movement is our way of life – in the ways he can move. But his diagnosis is quite serious – moderate mental retardation, quadriplegia. He had difficulty learning to talk and started talking in his third year. We read a lot of children's books in these rehabilitation centres. But we were on a very strict, military-like routine – therapeutic procedures, feeding, sleeping, therapeutic procedures, feeding, sleeping. That's where I met the mothers. After putting the children to bed early in the evening, the mothers used to gather in circles in the lobbies – knitting, reading, watching the black-and-white TV set, telling each other incredible stories. Those were the parental communities in which we learned from one another because you could see more or less what happened as the child was growing up. A lot of hopes were pinned on physical therapy, but things ultimately depended on the parent. There were parents who would exercise their child for an hour, then place him in a wheelchair and forget about him until the next day and the next exercise. We who continued on our own, consistently, in every which way, were very few in number. I didn't put my son in a wheelchair until he was almost ten years old – we rode a bicycle, he walked with a walker. I did everything possible to get him to stand upright. What was happening with me during that time? Perhaps the hardest thing was the exceptional isolation, because when you start caring for such a baby or child, everyone you know is at work, everyone's busy. First, all the responsibility and care is yours. Being a very jealous mum and a control freak, I almost never left him with someone else. I was afraid of other people. The thought of leaving him so I could go somewhere never even crossed my mind. He must have been five or six years old when my husband and I ventured to go out for a cup of coffee together, to be seen together. It was either one or the other of us. We were constantly on a very strict routine – breakfasts, meals, physical therapy, sleep, physical therapy again, feeding again, washing, all sorts of care. If he fell ill, he took five or six cough syrups, antibiotics for a sore throat, against diarrhea, vitamins – constantly following this medical model.

Couldn't you leave him with someone for a couple of hours?

There was no one I could leave him with. Very rarely – my mother-in-law was working at the time, we didn't have any other relatives around. My parents lived in Varna, but we were living in another town at the time. On the whole, they were afraid of looking after him, while I was afraid of leaving him, I suppose. I had worked throughout my pregnancy and it was time for me to return to work. This was a big problem and I had to decide whether to quit work or not. I decided to stay on, to return to work. But who was to look after him? I hired a babysitter – back in those days this was something revolutionary. My husband and mother-in-law were so upset that they well-nigh accused me of not being a proper mother because I couldn't possibly leave my child. But I decided that since I worked in shifts at a factory, I could work half-time. So I hired this babysitter, she was a student at the time, but after a year and a half I could no longer keep up with this rhythm – coming home from work and starting all over again, doing physical therapy, feeding, cleaning, cooking, catching up on housework at weekends… At some point I started getting terrible migraines. Everything coincided with his growing up – with his fifth or sixth year. We continued going to the rehabilitation centre and living as usual, but we started looking around for places this person, this child could go to. For example, I used to take him for a short while to a nearby kindergarten. There were no integration policies for children with disabilities at the time. Then my mother heard about Karin Dom, a day care centre in Varna providing services for children with special needs and their families. We were among the first users of Karin Dom's services. I regularly went to Varna where they taught me exercises. When he turned six we decided this child was ready for a group – that's what they told us at Karin Dom. He learned to talk when he was about three years old. Back then there were almost no animated movies, so I used to show him pictures of animals and tell him what each animal did, trying to teach him to speak. I read him stories in verse a lot, and actually that's how he started talking. He started repeating the end of phrases in verse. It turned out that he had a very good memory. He memorized whole books and poems and can recite them to this day, but he couldn't think logically. Thus, in the year 2000 we decided to move to Varna because of Karin Dom and medical services. We were sick and tired of travelling back and forth to Varna, Sofia and Shumen… I was so preoccupied with caring for this child that I never thought I'd do anything else. Caring for him took up all my time and energy, twenty-four hours a day, seven days a week. In parallel with that there was his physical therapy, his concomitant disorders, and the need to start investing in his mental development – teaching him to talk, to understand; generally, showing him the world. Showing him that there's something else beyond the window of the room to which he is confined. What saved me was books, music, meeting people along the way – specialists who gave us a chance. I was eager to learn everything I could about cerebral palsy and asked a lot of questions – I wrote down in notebooks countless exercises, information about the diagnosis, which I got from people at the rehabilitation centre because after staying for months there I knew the whole staff. I used to ask the nurses about the stories of the rehabilitation centre, about how everything had happened, why these rehabilitation centres were created, who were their first users. I met some very courageous mothers there, we've kept in touch to this day – at least five or six parents from different parts of Bulgaria. I will always say that this support – the parental communities and informal self-help groups – have helped us a lot to survive.

So can you tell us a bit more about the history of these rehabilitation centres?

These rehabilitation centres were created in Bulgaria in the 1950s and 1960s. They are several in number – one is in Momin Prohod, it's very well known, and there are others in Tuzlata near Balchik, in Kotel and Bankya – those are the ones I know of. It all started with the polio epidemic. Before a vaccine was invented, polio was a terrifying disease, crippling thousands of children – mostly from the waist down. These rehabilitation centres were created for them, providing treatment and physical therapy with mineral water and exercises. They lived in large rooms, as in barracks. The rooms were heated by wood stoves. The rehabilitation centres had schools for the children who were there for extended treatment. Many families moved house – for example, to Momin Prohod – in order to be closer to their children. The children stayed at the rehabilitation centres during the whole school year and went home only for school holidays. The rehabilitation centres were for children with polio. Back then the overwhelming majority of premature babies or babies with problems at birth did not survive. The development of birth technology, of incubators and things like that, led to a higher survival rate, but also to a higher rate of disabilities – impaired vision caused by oxygen overdose, cerebral palsy, occasionally Down syndrome or various genetic disorders. Thus, these rehabilitation centres began to accept more and more children with disabilities. At some point the schools at the rehabilitation centres were closed down, but the rehabilitation centres remained as medical facilities. And children with disabilities went there en masse.

What were the rehabilitation-centre doctors and staff like?

What can I say? Typical barracks-like medical care. The doctors did rounds every morning at 7 am, we cleaned our rooms ourselves, breakfast was at a fixed time, then lunch.

Did you have any more personal contact?

They got to know us over time, we even became friends, but we didn't really have a close personal relationship. But the saga we lived through no longer exists, this long stay away from home – it's now said that children with disabilities should be in their families, in a family setting, that there should be services in the towns and cities themselves instead of us having to travel 500 km in order to use mud, aquatic therapy, physical therapy. Being away from home for months and living apart from our husbands. Fortunately, my family didn't break up, but many others did. In some of the best years of our lives, from the age of 23 to 30, my husband and I actually lived apart – in two opposite parts of the country. Returning home with this baby and growing-up child, everyone would look at us, wanting to know what had changed, why we stayed there, did we enjoy the holiday, how we felt after the holiday. They still say that we went on holiday.

They were not very understanding and I've even had conflicts with my mother-in-law. As a mother I was more like a coach – actually, I've been into sports myself. My personal story: I've graduated from a college of veterinary medicine. I love biology and animals – especially horses. The fact that I'd studied medical disciplines – anatomy, physiology, neurology – helped me a lot to understand my son's disability, to have a correct attitude towards his diagnosis. On the other hand, the fact that I'd been into sports helped me a lot in giving him physical therapy. I was a runner, I went to aerobics classes for four years, I knew all sorts of stretching methods and I didn't let that child be. I had fights with my husband and mother-in-law, who accused me of harassing the little one. They wept and cried – they were firmly against this. I had learned all about body pressure points, I knew which ones to press so as to teach him to move and he cried while I did so, while my mother-in-law cried in front of the door. But I didn't give up and now I'm very happy that I managed to work with this child in this way and have achieved results. He couldn't learn to walk but he learned to sit up, to crawl, he walked with a walker until he was almost ten or twelve, but then he grew too tall and was in danger of toppling – things became more and more difficult. We've tried everything that was available at the time – this tough physical therapy, newly introduced laser therapy, amino acids… We've tried out hyperbaric oxygen therapy, we've tried out horse-riding. My son was able to stay on horseback for 40 minutes, which was an exceptional record for us. Horse-riding had an excellent effect on him, but eventually we had to give it up too. Simply because he grew up. That's why they often say that you have to do everything you possibly can while they are young, because as they grow up many things can't be done for purely physical reasons. You can't get him on a horse because you need a winch, you can't get him into a swimming pool because you need a winch, he can no longer walk the way he did because his body begins to contract. He's 23 now and I'm continuing to keep his vitality – to make sure that he keeps moving, that he wants to move in his own way.

What about communication – how do you interact with him?

In addition to everything else, he has autistic traits – repetitive movements. He must always be told beforehand what will happen next. He used to have many meltdowns – if, say, the music stopped, the cable TV or the electricity went out, he would start screaming… It took him a long time to understand that these are processes – that the technicians will come and fix the electricity. He was constantly crying about something. That's why no one wanted to look after him. So I never thought that I would work, let alone study – I knew that I would care for this person till the end of my life, this was the exclusive focus of my life.

When did this change?

It's a very long story. Moving to Varna, I moved back to my parents' apartment at first… In our life since our son's birth, we've been moving house and adjusting the physical environment to his needs almost every five years. In Varna we've had to change apartments three times because of accessibility issues – which has cost us quite a lot of money. In the big city of Varna, however, I received much better support. Here I met other parents of children with disabilities, new communities, Karin Dom. It so happened that, at the age of seven, my son was admitted to a school for visually impaired children under a programme for children with multiple disabilities, which played a key role in his development. This marked the beginning of Ivailo's socialization based on the social not medical model of disability. The people at the school worked, and still work, according to an American model – four children per class, two teachers plus five specialists. They worked with the children much more individually. Nowadays this is literally a luxury, but back then it was possible because there were fewer children. The school had and has very good facilities and equipment, and very enthusiastic specialists. The positive effect becomes evident years later. You see how this little person, this child, begins to become an individual. A friend of ours who hadn't seen him for several years was amazed at the change and said that he had 'become human'. You could see it in his eyes – you could see that he had begun to understand the world. Fifteen or sixteen years ago these were isolated, confined children who couldn't develop socially because the medical model of care imposed at the time consisted, essentially, of confinement to an institution – in our case, to a rehabilitation centre. The breakthrough came from Karin Dom in Varna and its school for children with multiple disabilities, which created the first parental communities in Bulgaria. They told us: 'Yes, you are parents of such children – now we'll take you to McDonald's, we'll take you to the puppet theatre together. We'll go for a walk in the city centre together with these wheelchairs.' This was a process. It was a process that started in the late 1990s or 2000. People continued to stare at us in the street, they continued to feel sorry for us and to wonder why the two of us were smiling together, talking to each other and laughing. As he grew up, he gradually began to get sick less often – because of his concomitant disorders, he kept getting sick with the flu and had chronic rhinitis, because of which he was constantly missing school or was sick during the school holidays. In his last years at school he was a bit healthier and I happened to become a consultant in an organization of parents – a parents' foundation which created a centre for children with special needs. We thought it was good to have a parent acting as mediator between specialists and parents – we felt like true pioneers. We furnished the centre with donations, we found the right way to do things by trial and error, we created a position for a psychologist for parents, we regularly invited parents to our so-called 'parents' coffees' and Super-Parents' Club. That is where I matured, where I had a break from caring for my child who was at school at that time, and where I could do many things for other children. And I simply felt very well. I used to see him off to school and go to work with great enthusiasm, eager to show the other parents how important it is not to rely solely on specialists, because a specialist works with the child more or less for half an hour twice a week. I was eager to show them that the 24/7 specialist at the child's side is the parent who, however, must be taught and supported, who must be very open to everything specialists are doing and learn to do it with her or his child at home. In other words, I was eager to show them that there must be continuity, that we mustn't expect results achieved with the help of others or think that this is a temporary condition. Of course, it's very hard to tell a parent that her or his child will always be in that condition or will never get well. All parents of children with disabilities go to such centres hoping for a miracle. There was a mother who used to tell me, 'Don't take a picture of him here now.' I used to organize birthday parties, I was involved in aquatic therapy projects, we would go to swimming pools, I used to organize parties for parents, camps in the mountains, and she used to tell me, 'Don't take pictures of him, I don't want him to have memories of being in that place.' 'That place' was a sunny children's centre where we celebrated all sorts of things – it still exists. In that same centre, they came to train us for the profession of 'specialist in social work' under a project targeted at parents of children with disabilities – and that's how I met the lecturers from the Technical University of Varna. I saw what they were doing and that's when I got the idea that I was doing this job anyway and was constantly involved in the social sphere, so I should start studying social work. Before that I had started working for a cosmetics company, organizing private parties and selling cosmetics, my idea being that I needed to have some kind of income – but that's a very long story. In my life, I've tried to start work, any kind of work, several times, but care for my son has pulled me back – it's like having a rubber band around your ankle or trying to fly with a stone tied to your leg. You fly and fly for a while, but then you are jerked back to the ground. There were times when I hit rock bottom. Long, bitter winters spent at home because it's cold outside. You can't go anywhere with this wheelchair, he's sick and can't go to school, so you don't go out for months and months. The only times I went out was to buy bread and milk and to exchange a few words with the shop assistant before hurrying back home – this was my only contact with other people for days. I very rarely spoke with some of my friends, who were at work during the day, and we talked only by landline. I learned not to complain about caring for my child, because at some point no one wanted to listen: 'How are you?' 'We're sick again.' 'How are you?' 'I'm giving him medicines again, I'm washing him again, we're watching cartoons again.' No one wants to listen to such things, however compassionate they may be – not even my best friends with whom I've kept in touch for years. I learned to speak positively, to say what we *can* do, to say different interesting things. I thought a lot then, I analysed many things – we spent years in isolation. We got a cat. Cats are part of our life, they are easier to take care of. We got the cat because we wanted to have something that moves in our home, something around this person that can move – I can talk about animal therapy, felinotherapy and hippotherapy for hours. The relationship with animals is unique, we've had several cats in succession over the years. Animals are unique, our children feel them and become very attached to them – just as the animals become very attached to our children as well. Animals don't discriminate between people based on disability. Cats and horses are a lot of fun. We have a cat right now, too. A new cat, two years old. He often asks, 'Where's my cat?' He cares for it a lot – like a baby brother, baby sister, friend. Besides this, I treat him in exactly the same way as I would treat a healthy child. I regularly ask him, 'Have you fed the cat? Go see what the cat's doing! Where's your cat?' I get him to do things. He can't feed the cat on his own, he asks me what the cat eats and I bring him the food box. Everything I do with him is what I would do with a healthy child. I treat him as if he's healthy, this is also something recommended by the people I've met over the years – that we must treat them like healthy people, we must set them tasks, interact with them and get them to do more or less the same things as their able-bodied peers. It's a very long story, but let me give you an example. We started listening to Bulgarian music so that he could learn to understand the words. At some point he not only started talking – he started singing, because his memory allows him to reproduce words and music. It's unique because he has spastic lungs and is chronically short of breath, yet he sings. And he was the absolute star at all school celebrations. He recited poems and sang songs. Bulgarian songs. Over the years, he started listening to all sorts of other music, too. We are music fans, both of us, and we often tell his father to leave us alone because we're having a youth disco party, we turn up the volume and go wild to the sound of all kinds of music. Staying home made us rediscover other ways of developing and having fun. Of key importance to us were the rehabilitation centres, and especially the school for visually impaired children which was an absolute light in the tunnel – for the first time ever, other people took him from me and started caring for him. The first five years I was there as well – walking, listening, watching, learning, attending different classes; I saw unique things. And then he grew up. He simply grew up. To come back to the subject of studying at university – I realized that since I was in this sphere anyway and wouldn't be able to do anything else, it would be good to educate myself in this area. It was a very big challenge because I didn't know if I would be physically able to attend lectures at all. I was advised to enroll at the Technical University of Varna, it was the closest to our home and the cheapest possible option. I applied for admission according to the rules, I passed all entrance exams and, at the age of 40, found myself in a university. Perhaps this was the turning point in my life at which I started caring for myself. When he turned 16, I went abroad with a friend of mine for three days – he was 16 when I ventured to physically separate myself from him for the first time. I managed to persuade my mother and my husband to let me go away for three days. This trip gave me a lot – I saw myself from a different perspective, I returned to my old self and decided I would go to university, I applied for admission and was admitted to a full-time Bachelor's degree programme. I tried to learn everything I possibly could from university life and courses – from the teachers, from contacts with fellow-students, whom I told a lot about our children, about what we were doing. They saw me regularly on TV, on Facebook and other media. My teachers were very supportive and in May 2019 I completed my Master's degree. This is my next social role because I've had the unique opportunity to see the problem from all viewpoints – as a parent, as a person working in the sector, as a student and, since I'm president of an NGO at present, as a civil society activist. At present we are running a day-care centre for young people with disabilities.

Have you managed to maintain your intimate relationship with your husband?

Yes, but in our case he was the one who suffered much more – and continues to suffer – about having such a child. He feels he's to blame, he feels like a failure. He has been accepting things a bit better in the last few years. That's not least due to the process that can be seen throughout Bulgaria – people with disabilities have become much more visible and the shame and stigma that existed some ten years ago have declined. But he suffered a lot, there were times when he didn't want to go out with our son, he was very distressed and constantly blamed himself, saying over and over again, 'I'm to blame, it was I who took you to that hospital, look at the other families now – they have healthy children. We are failures…' He can't come to terms with it. But then I've never thought about it in this way – first of all, because I've done everything I possibly can for this child, just as I would have done for any other child of mine. In a different way, naturally. But that's perhaps because I was in constant contact with other parents and other children with disabilities and I know I've done the impossible for our child, and not only for him but for other children, too… But my husband, as well as most other fathers of children with disabilities, can't get rid of the thought that they have fathered a disabled child. The male ego makes him say, 'Just look, the others have healthy children.'

But there's always a risk that your loved one may end up in a critical situation that's out of your control, isn't there? For example, your child may die from a drug overdose.

Yes, but in that case the child is lost, while we continue living with this problem every day. In your example the problem is over; whether you accept it or not, there's an end – no more care, no more daily washing, feeding, carrying, looks, dealing with certain things. It's over. I've thought all sorts of things. I have a friend – several friends, actually – whose disabled children have passed away. Of course they suffer, of course we are compassionate, but in such cases the problem somehow comes to an end. In the alternative case, you live constantly with it and no one knows until when. You have to distribute your time, your energy, health, thoughts, because life is a long marathon and if you want to be adequate for this child… At some point I realized that if I kept investing my entire self as much as I did in the first years, at some point I'd burn out. I even felt how the child had begun to develop more than me, demanding more from me – yet another story, yet another cartoon, yet another this, that or the other… And because you are living in isolation, you – a healthy person – become like a disabled person because you are isolated. I had forgotten how to speak, how to communicate with others as I had no one to speak or communicate with. That's when I realized that if I didn't start caring for myself in some way, I would be of no use to him. So I started reading, going out more. The father-child relationship is very interesting. The child himself started asking for this other person, eager to communicate with him on a 'man-to-man' basis, calling 'Daddy, daddy' nonstop until his father finally went to him and then asking him that they read together 'about helicopters, about Jackie Chan, about this that or the other'. When this child began to develop certain abilities and to demonstrate them, his father was attracted, he was now able to communicate with him. This child was no longer the soulless puppet we kept exercising, feeding, taking to hospitals, changing its diapers – he started to communicate with him and the child himself found a way to engage him; it was a very interesting process. I'm simply a bit more broad-minded. I've always thought, 'Okay, so what, I've survived' and gone through all sorts of horrific, nightmarish thoughts, but maybe everyone I know has some kind of problems. I've never thought of myself as being someone very special. I simply felt it was my duty to do my best for this child. And not to abandon him – this is what I was actually told to do at the maternity hospital: 'Yes, mum, you have the right to abandon him, think about it for a couple of days and make up your mind.' And then I pictured where I would be leaving this baby, in some social care home – while I would be at home – what he would eat, what he would do. And this actually gave me the answer that I shouldn't leave him. Subsequently, I was given to understand many times that having decided not to abandon him at birth, it was now up to me to deal with anything and everything. And since this is what the pattern is like – in most cases, the mother is always at the child's side while the father is always at work – at some point the mother gets burnt out by the endless caregiving, while the father gets burnt out by the endless going to work. Another issue we haven't discussed at all here is the economic dependence of the person who stays at home, the caregiver – in most cases the woman, the mother.

Yes, the majority of mothers in our study noted this dependence.

Being dependent and begging for money. However tolerant your partner may be, over the years he's bound to get fed up now and then – you're the eternal… like an appendage, that's what you and the child are. That's why we fought so keenly for the legal recognition of the status of parents caring for children with disabilities, even if just for the sake of the caregiving parent's self-esteem, for the financial, moral and ethical reward of their work, for recognizing that the two parents are equal. That's because one is said to be at work, but what about the other? The other parent provides care 24/7 – which you will be paid for if you are a personal assistant, a psychologist, a physical therapist, a bus driver, a cook. You are all those things at once, around the clock, but this type of care isn't recognized. And we have to keep explaining what we do 24/7… But, as some participants in the focus group also said, life triumphs in spite of everything. Most of our children pull through and go on living in spite of everything – all sorts of serious diagnoses, severely handicapped, nonverbal. They go on living in spite of the prognosis that they would survive two, three or five years at the most, and they are over 20 years old now. Good care by contemporary families prolongs their lives, which raises a series of other questions: What happens after they turn 18, how do we care for these young people and their families after they turn 25, 35 or even 50, what happens after we are no longer around? Very often parents say something that is terrible but absolutely true: 'We want our children to pass away before us so that we can be sure that they will be well cared for by us...'

Do you know any children who were cared for by their parents for years, but are now left on their own?

Personally I don't, not yet, but there were several cases that were reported by the media – for example, that a mother caring for her only daughter, who is disabled, in some village had passed away. I'm expecting this to start happening on a larger scale very soon – many parents of day-care centre users are quite elderly, in their 70s or 80s, the users themselves are in their 40s or 50s, and the alarm bells are ringing very loudly about the need to resolve this problem. There's also the problem of the economic dependence of one parent and the utter exhaustion of the other. The problem of the other child in the family and how they feel, whether they are involved in caring for their sibling. How will they be supported when their parents are no longer around? Those are very frightening questions. The needs are increasing in number and in kind, but there's no one to resolve them. Nor are there any clear policies – what do we do when a child is born, what do we tell the parents, what do we offer them, what deinstitutionalization process are we promoting, considering that we aren't really supporting families and they keep abandoning their children, be they healthy or disabled.

But recently there's been a lot of talk about job opportunities for people with disabilities in Bulgaria, hasn't there?

There are different cases, but here we must say once again that people with disabilities differ by age, degree, and diagnosis. For example, a wheelchair user who is intellectually fit can do many things with their hands or, say, they can be an excellent software designer and very smart. The problem is, rather, with people with intellectual impairment. Although people with physical disabilities, especially wheelchair users, also have a hard time negotiating the architectural environment, those with intellectual impairment are yet to be faced with such challenges. This is a major issue for us and a group of parents of young people whose disabilities are less serious, who are adamant that they won't take them to day-care centres as they can and must work. Here, however, we are faced with the problem of the entire strategy of the state and the need for supported employment, sheltered employment, sheltered workplaces. Simple jobs, such as cleaning or arranging things, can be allocated for people with disabilities – for example, in the Varna municipal library a person with a disability, supported by a library employee, can arrange the books; arranging goods in supermarkets is also a suitable job for persons with disabilities. There are such job positions for persons with disabilities in the West. We've heard about them. In the last four years, after my son grew up and completed the school for visually impaired children, he has been going to a day-care centre for adults over 18, so I've met them, they are wonderful and truly have abilities, but someone must create jobs for them.

Could you please say something in conclusion?

What can I say? While there's life, there's hope and nature's above everything – nature triumphs and it's probably not we but life itself that determines how long someone will live and what they will do during their life.

Nevyana Feschieva

HAVING A VISION ABOUT THE FUTURE

An interview by Galina Goncharova

How did you get into social medicine?

There were both objective and subjective reasons for this. I've always been interested in the social sciences, but my original interests were in neurology and after completing my mandatory three-year-long internship in a village I moved to the city of Varna and started looking for a job. I was lucky to find a job in the field of neurology. While I was still doing my internship, however, I developed an allergy to penicillin – this was the most commonly prescribed antibiotic at the time and I had no idea how serious my condition was. Eventually, I realized that I had to change my job as I was unable to work with patients because of my allergy. Since I had already shown my interest in the social sciences, I was offered a new position, which was managerial but which I found to be very interesting – namely, director of health services at the district hospital in Varna. That's where I started combining management with the ideas of improving the population's health.

Later, when an opportunity came up for me to work solely at what is now the Department of Social Medicine and Public Health at the Medical University of Varna, I decided to quit my job at the district hospital. Initially, my position at the Department had more to do with management than with research, but it provided opportunities for identifying and studying public health problems. I constantly combined this with fieldwork – for example, at my initiative we researched the population's attitude towards the so-called at the time 'district doctors', i.e. primary care doctors who were the equivalent of GPs. Varna very often hosted various international events – for example, a World Congress of Sociology was held here in 1970, there was another very interesting congress on living conditions that was attended by scholars from all over the world – and this provided opportunities for establishing contacts and keeping informed about developments across the world. Various direct studies on health and factors affecting health were also published at the time [in the 1970s]. In the context of these congresses, we conducted initiatives on elderly people's health and their work, family and social life.

Can you make a comparison between the field of social medicine in Bulgaria before and after 1989?

What I told you about myself holds true for part of the other people working in this field – they were interested and eager to learn about everything going on in the world. Of course, there were also diehards. Here in Varna I was in a very favourable position – many people came here, I had an opportunity and a desire to establish contacts, I didn't feel restricted in any way except for the fact that I almost never went to congresses in Western Europe. Nor did I often go to congresses and other events in Eastern Europe as the system was centralized and international exchange was difficult. But the fact that many people came here was an important opportunity for contacts. It wasn't until quite late that I went to Moscow, Saint Petersburg, and Latvia; I also went to France several times in an official capacity. When travelling in a private capacity I needed to obtain permission to visit some medical facilities and I had to pull strings to get it. I managed to do so thanks to people I'd met here in Varna. I went to an interesting symposium in Berlin (in East Germany), organized by their institute for qualification of physicians and devoted to medical sociology, where I had an opportunity to meet many people. But all of us East Europeans were very keen to see for ourselves what was happening elsewhere in the world even though we were quite well-informed from secondary sources.

Let me say a few words about research before and after 1989. In the aftermath of 1989, I had the idea that we must do something to establish more serious regular contacts with key institutions in our field. In 1991, an anniversary of the Higher Medical Institute, as the Medical University of Varna was called at the time, helped me very much in this regard as we had the opportunity to invite people from different places. Thanks to this the first project on public health in Bulgaria was launched under the TEMPUS Programme in September 1991.

There are several reasons for the excessive prioritization of health management. This is a characteristic of the postcommunist transition because the ideas that a free market economy should be introduced into healthcare, albeit with certain constraints, played a very important role. However, there were also preconditions from the past, from the period before 1989. As we lived in a centralized state with a centralized economy, researchers placed a particular emphasis on the organization and management of healthcare – those were buzzwords. Of course, there was huge discontent with the underfunding and low salaries in healthcare, but management was seen and promoted as a panacea. There were international factors, too – for example, World Health Organization courses for qualification of physicians where the priority was on management. There were also congresses of the then ruling Bulgarian Communist Party that addressed issues of management. By and large, there was a preoccupation with developing management. After 1989 all of this was transformed into an excessive prioritization of health management, seen as a panacea. In the period before 1989, however, there were also some very interesting topics and a number of serious large-scale studies. I, for instance, intend to trace the development of research at today's Department of Social Medicine and Public Health at the Medical University of Varna – although I became Head of Department [in 1988 and held this position until 2000] towards the end of this period, I was an active participant in formulating the topics that were researched and developed. I will tell you what the general tendency was – for example, there was considerable research on morbidity involving temporary incapacity for work and, partly, on morbidity involving permanent incapacity for work, i.e. invalidity – there were a number of studies on the factors for such morbidity. Considering that a significant part of those employed at the time were employed at large enterprises, research on morbidity and the factors for it was a convenient opportunity to achieve important results. Although the studies on this subject conducted in that period weren't many in number and were limited to a particular kind of enterprises, families and incomes, such studies are very valuable – despite the fact that they were focused primarily on blue-collar workers and created the impression of a certain uniformity in the population's health status. This last was true to some extent – after all, the inequalities in people's health and social status appeared later. But there were interesting data and the researchers working on the project in Varna published a very important book about workers' health and capacity for work.

Does this mean that the then so-called 'invalidity' was thought of mostly in terms of physical disability?

No, I don't think so, but it was thought of in terms of what the health service could do and offer to society. For example, sufficient attention wasn't paid to people with disabilities, but this wasn't a specific characteristic solely of the health service. After 1989, to my mind, there were very serious changes in attitudes. In Bulgaria, there has always been a very good attitude towards people with disabilities, but before 1989 they were hidden in some way, this has something to do with the national mentality; the other thing is that until and shortly after 1989 the dominant model was the protective one, not partnership. The transformation in attitudes towards disability long remained insufficiently visible. Before 1989, too, there was an awareness that people with disabilities have their problems – for example, there was an organization of paramedics, an organization of people with multiple sclerosis. I remember taking students to a neurological ward and seeing a person with multiple sclerosis who had a handbook of multiple sclerosis that was translated from German which he was offering to the organization of which he was a member. Another turning point was the participation in the Paralympic Games, since in Varna there were enterprises of disabled persons which also enjoyed some protection from the state so that these people could strive for some independence in life. Despite these exceptions, however, I think that the major change took place during the transition, with the adoption of the ideas of independent living, of greater autonomy of people with disabilities. Back then they were called 'invalids', I don't know if 'people with disabilities' is an appropriate concept, but either way this is a sphere in which a major change took place and many initiatives were launched. As early as in 1991, many NGOs were established throughout Bulgaria – even if we look only at the things they've done in Varna, we can see how much progress has been made in this regard since 1989.

How were people with disabilities classified into groups? Were people with dementia or mental illness regarded as disabled? As far as I know, gerontology was a burgeoning field of research at the time, but has since apparently been abandoned.

There was even an Institute of Endocrinology, Gerontology and Geriatrics at the Medical Academy in Sofia, which conducted a lot of research. I don't know if anyone from that Institute is still alive… There used to be gerontological conferences and congresses (I attended some of them), which occasionally dealt not only with physiological but also with mental health issues… I remember that Assoc. Prof. Ignat Petrov had a dissertation on the feeling of happiness among the elderly – there were such studies and initiatives back then.

Why did this field of research wane?

Because many other topics appeared meanwhile and interest in gerontology declined. The former Institute of Demography used to conduct such conferences. I helped with their organization even though I couldn't attend all of them. The Institute of Endocrinology, Gerontology and Geriatrics had an international school for young researchers in the field of ageing. Most of the contacts were with the UK and there were some very interesting projects. There were two or three young researchers from Bulgaria, but they eventually abandoned this field because they were offered more interesting work. Prof. Naidenova and Assoc. Prof. Nevena Mihova, the organizers of the school, were trying to cultivate young researchers. It seems to me that geriatrics has been eclipsed by psychology and we don't have true gerontologists today. This holds true for other areas of research as well, which are eclipsed by something trendy because there are large-scale and better-paid projects in it. Thus, for example, now we will be talking about artificial intelligence and many issues will once again remain neglected. But then, new topics will certainly attract young people if research funds and other things don't provide adequate incentives, financing and opportunities for research in other, less trendy, areas. Regrettably, we have been in transition for thirty years now and we are still too easily besotted with trendy topics such as health management, which I think is overhyped.

There's something else, too – we've always been keen on clinical medicine; what's going on behind the hospital walls has always been of greatest interest to Bulgarian medical professionals as well as to the Bulgarian public. After 1989, I thought it would be worthwhile to study a particular tendency, so I assigned several final-year dissertations on the subject of what local healthcare authorities were doing and we conducted research in several small towns. It turned out that their main concern was to set the rent price for diagnostic and consultative centres (polyclinics) because the latter are municipal-owned facilities, and to decide how to vote at municipal council meetings on allowances for citizens in need of financing. There was almost no mention of risk factors and prophylaxis – of raising public awareness of risk factors. At present, for example, healthy eating has become mainstream – there isn't a Bulgarian family that doesn't discuss healthy eating, but that's at another level. Back in the past there wasn't too much state support either, but now the only thing municipal councils care about is how much money they will give to the hospital so that it can pay its debt and which buildings to allocate to doctors – prophylaxis is completely neglected. Nothing positive happens unless there's pressure on local healthcare authorities. In addition, there's a very frequent change of managements of healthcare facilities and they are concerned primarily with financing. Sometimes even entirely useless studies are conducted for the sole purpose of securing financing for them. I very often see dissertations – usually doctoral dissertations – that end with a couple of pages of recommendations to the ministry, to the relevant professional association, to universities training personnel, but they are entirely worthless. Absolutely nonsensical, hollow things that have nothing to do with reality. In reality, the only thing hospital managements are interested in is financing.

Can you tell me something about the socialist project on social hygiene, and more specifically, about prophylaxis in it?

It is associated with social medicine. Prophylaxis has gone through several stages and they are associated with scientific discoveries in medicine – they are even called revolutions.

By and large, the Russian school laid the foundation for the development of hygiene as a socially beneficial science already before the 1917 revolution. The organization of healthcare in Bulgaria came from the Russian, or more specifically, from the Soviet school – it had to introduce things that were non-existent until then, not to mention the time of the Second World War when healthcare organization was crucial. Although there were departments of social medicine, they were gradually renamed to departments of 'social hygiene' and healthcare organization. After the war, social hygiene became the leading subject in the Soviet Union. In Bulgaria, we had departments of social hygiene and healthcare organization. We didn't want this 'hygiene' – what I'm telling you is somewhat confidential – but we thought of ourselves as being different, as something more than 'hygiene', and that's how we developed the field of 'social medicine'. It has nothing to do with 'hygiene' in pure race theories, etc.

So it's interesting to see what was meant by 'social hygiene' under socialism?

Not just organization, but something else as well. We had an Institute of Social Hygiene and Healthcare Organization and that's where the first indications appeared of the inclusion of other specialists – of course, statisticians, who were also the first in the US – as well as laboratory specialists because of the need to diagnose the environment. The central institute in Sofia started employing not only statisticians but also psychologists and sociologists. I can say that in Varna, in particular, thanks to the initiative of young people and of the director of the hospital at the Medical University of Varna (who later became Head of the Medical Academy's Department of Social Medicine) to recruit other specialists – in disease management, organization of hospital work, organization of clinical work – important questions were addressed. For example, why should there be queues, could we make do without queues for services – those were very interesting studies conducted with the participation of mathematicians and statisticians; there were also sociological surveys, which were based on solid methodologies – unlike the present ones, which are solely questionnaire surveys and, moreover, use questionnaires that aren't very well-designed.

In Bulgarian medical universities in general, isn't there a slightly disparaging attitude towards sociology and history of medicine?

This is an interesting question that requires a long answer. When new subjects were included in the curriculum, the latter had to be revised to accommodate them. This was done at the expense of classes in history of medicine, the presumption being that those who were interested in the subject could study it individually. Since it so happened that I founded the degree programme in Health Management, which I now criticize and think is overhyped, we decided that we had to remove history of medicine from the curriculum and did so. Meanwhile, however, in Ruse – there's a degree programme in Midwifery there – I met people who wanted to introduce something similar as an elective course. I suggested that we design a syllabus in history of medicine. Reconsidering the global trend towards removing history of medicine from curricula, however, medical education experts have started concluding that this movement away from the humanities and social sciences is unfavourable for the profile of future doctors and other medical professionals. So they have started (re)introducing ethics, history of medicine, etc. History of medicine has been introduced as an elective or optional course at the Medical University of Varna, too. In fact, we didn't want to offer it because our students are overburdened, but someone asked about such a course and last year [2020] we introduced it as elective; we are offering it again this year [2021] because there's demand for this type of subjects. It's not a matter of disparagement – it's simply that if something has to be removed from the curriculum, it's this subject. As Head of Department, I agreed to removing history of medicine from the curriculum.

If you don't mind, I'd like to return to the question of attitudes towards disability in Bulgaria before and after 1989?

I can say very little about that. I'm not familiar enough with mental disorders. What I can say is that very little, if any, attention has been paid to these people. Before 1989, in particular, the attitude towards them was a bit like towards something that must be hidden. The only positive thing was the vocational therapy provided by psychiatric dispensaries – teaching patients vocational skills and helping them get a step closer to independent or less dependent living. My impression, however, is that the protective, paternalistic model prevailed – a paternalistic, condescending attitude towards the mentally ill, where the doctor is God and there certainly isn't any form of partnership. I think that the attitude towards people with disabilities in Bulgaria was unfavourable and pitying, even rejecting to some extent. Science didn't discuss the subject much because everything that was done about 'invalidity' consisted primarily of rehabilitation therapy. Some time ago

I tried to find my notes on invalidity to give them to a colleague of mine who is concerned mostly with the medical aspect, with medical evaluation. They were from Russian sources (I read them at a library in Moscow), the main idea being that there was no medical evaluation establishing invalidity if there was no rehabilitation therapy, if something wasn't being done to restore the person's ability to work. Before the transition again, attempts were made to utilize the remaining capacity for work of disabled people. There were successes in this regard, but when it comes to the general attitude of Bulgarian society towards people with disabilities, I think that it was only after the start of the transition that issues such as the need to raise public awareness of their problems and, very importantly, to bring them out of their homes were truly addressed. Of course, here I remember that the visually impaired and their organization defended the thesis that they felt much better when they were in special schools with fellow visually impaired children, while it was better for children with other disabilities to be in ordinary schools. I find it a bit difficult to make a comparison, but it seems to me that the transition, with the different international declarations, etc., played a role and set the ball rolling with regard to the issue of disabilities.

What do you think about the growing concern over dementia?

The key question here is whether old age is a disability; ageing is a process and old age brings limitations. This is where medicine comes in and says, for example, what can be done about joint pain. I'm a proponent of the idea that if we have a problem with ageing, then we must decide when to start dealing with the problem. My opinion is that this should be done in advance, through prophylaxis and promotion – we know that old age will set in, so we should find ways to prepare individuals for dealing with mobility issues or the diseases of old age. This should start from the age of 40, but needs to be popularized. Four years ago in Norway, I was very pleasantly surprised to see what was being done in this regard at the local level – not by medicine but by the community, by public organizations and municipal councils in a small town. They weren't doing things involving prophylaxis, rehabilitation, or medicalization – like, say, giving people pills or telling them to take ginkgo biloba because it prevents dementia. I saw people singing together and dancing easier dances at a certain age or dancing while they were still younger. I tend to be in favour of such advance actions and information campaigns conducted by local governments, while leaving the door open for self-organization or NGOs.

There are things that can be done at the local level with local resources at the initiative of local communities. And I'm happy to see things being done by people on their own – on their own and together; on their own because the initiative is theirs, and together because you can't do much on your own.

To return to the subject of disability: I think that before 1989, people with mental disabilities were more hidden from public view than those with physical disabilities because their family members were ashamed of them. Nowadays here in Varna there are several NGOs for disabled persons that are implementing various projects – for example, Sunny House, a day-care centre for adults with disabilities, which we visited recently. The change is visible, you can see the effects of social work, and this is a major achievement of the period after 1989.

Speaking of rehabilitation, I'm reminded of the accounts of mothers of children with disabilities from Varna. They said they used to spend months at rehabilitation centres. What's your view on these processes and on the now topical issue of psychosocial rehabilitation?

As doctors we have issued referrals for such centres and have seen the results, but they weren't for everybody. There were schools in some places, but not for the most serious cases, so that part of the parents could get some respite from round-the-clock care. There were such centres in Kotel, Momin Prohod and elsewhere, with schools for children with kidney disease, with heart disease, etc. – this provided temporary relief to parents but distanced children from their families. Still, their staying there for several months wasn't a bad thing. The question is whether they should be in an environment where they stimulate one another or should stay only in their families – to my mind, they should have a choice. Otherwise rehabilitation should unquestionably be both psycho- and social. It's a very tough journey. In my view, the parents, most often mothers, of children with disabilities are saints, but then one can't help wondering whether they should be so utterly selfless, a mere appendage. I remember a patient whose father always took him to the neurological ward. At some point I started thinking what would happen when the father died, because there was no one else to push his wheelchair. These are the sort of issues that need to be addressed. There should be facilities that provide temporary care. It's good that the parents are saints, but they too are human and need a break now and then. The German system, for example, provides temporary relief even for carers of elderly people. The elderly person is entitled to an assistant who is paid for by the health fund so that the carer can go on holiday. I mean, there should be some sort of facilities where people with disabilities can stay temporarily. This has to do with the issue of whether people with disabilities should be cared for solely by their families or there should also be social care services. I've always thought that there should be a balance between the two.

My last question: How do you see the future development of social medicine in general and in Bulgaria in particular?

First, it is necessary to train personnel who are ready to deal with the current issues – the current needs must be identified and addressed. This is the first condition. The other important condition is to develop a policy addressing the major public health issues – but not in a purely formal way. Reports on public health in Bulgaria are produced every year and everything in them is identified as a priority. But everything can't be a priority – it's important to set several specific priorities. I recently read interviews about child mortality in Bulgaria conducted before 1989. Back then the whole public took this issue to heart and it became a priority. When the transition came, it brought other priorities. Now everything is important and we have other priorities, but the top ones haven't been set – in other words, it's a matter of government policy. At the municipal level, local needs must also be taken into account.

It's also important what sort of research problems are formulated. Researchers sometimes fall into despair because they submit project proposals which, however, are rejected. There are two possible explanations for this – either the proposals themselves are weak, or they can't translate them into a comprehensible language. So what is necessary is high research criteria, effective research, translation into a comprehensible language. This will help ensure identification of future key issues.

If we take up a trendy topic when interest in it is on the wane, we will repeat what others have already said. If we see a problem when it arises, then we will be able to deal with it. I think this holds true especially for work in social medicine. In medicine, discoveries must be quickly implemented in practice, while in our science they pass through several cycles before they reach people. On the other hand, they must be translated into the language of politicians so that they can be placed on the agenda. We had to wait for Covid-19 in order to realize that the reforms in clinical practice haven't resulted only in something very good – they have also eliminated important actions and sections of work that would have been very useful now. Did we know that there are few virologists in Bulgaria? Yes, they don't have private practices, and everyone wants to become a surgeon or an obstetrician-gynecologist. In terms of management – we knew that somewhere there were medical specialties that would suffer a crisis because the older generation was retiring and there were no incentives for young medical professionals to take them up. This is what good politicians do, though – they provide incentives and support to preserve them. Problems that will hit us after some time must be identified in advance so that we can be prepared to deal with them – such as ageing, for example. We must be ready to deal with future problems and have the necessary resources and vision about how to cope with them. Having a vision about the future is very important in social medicine.

Vladimir Sotirov

ACCEPT YOUR DIFFERENCE

An interview by Galina Goncharova

Let's begin with the question of what attracted you to the field of psychiatry.

As a student, I worked as an orderly at the psychiatric hospital in Sofia. I had a fantasy back then. When the doctors and nurses on duty were in their offices, I was the one who stayed with the patients in the corridor – with the wandering shadows and ghosts that haunted and inhabited these spaces at night. Spaces which the professionals didn't inhabit, preferring to stay behind the locked doors of their offices. The patients were left to themselves and to some enthusiastic student, such as I was at the time, eager to talk with them for hours during the night. I fantasized that I had great, not power but possibility, to help. For instance, when I was on duty one night I discharged a patient, I opened the door and let him out. He managed to convince me that he was healthy enough – although he was mad, he wasn't so mad that he had to be locked up – he was healthy enough to be outside so I opened the door for him. Later, I told the nurse that he had simply taken the key while I was sleeping on the couch in the corridor in one of the niches where they gathered to talk and smoke – but in fact I had discharged him, so to speak, and I got away with it. And I actually decided that working with patients was very cool because I could do whatever I wanted to – I could talk nonsense with them, I could provoke them, I could listen to things that weren't to be listened to without having our conversation sanctioned by somebody, I could discharge them… In a sense, I could do whatever I wanted to. By this, I mean that I could interpret and think of them in whatever way I wanted, I could keep their own story in my mind and have this feeling of illusory power… That's when I started joking that psychiatry gives you great power. Not that this isn't true – it is. But I have something else in mind – I mean power of the mind, the power to do things in your mind and to conceptualize phenomena as you deem fit. Although this is characteristic of the doctor's profession in general – doctors have enormous social power and often aren't aware of it; they don't realize it and sometimes exercise it gladly, not to say sadistically – they forbid certain things, restrict, prescribe and, generally, determine their patients' destinies and lives as they deem fit and get cross when someone doesn't follow their prescriptions and orders. I had fun imagining that once I became a psychiatrist I too would become smart well-nigh in a magical way, automatically. In a sense, that is true if there is good training, if there is continuous, systemic and formative education – but there isn't such in Bulgaria. When I went to work at the psychiatric hospital in Kurilo I clashed with reality, which was a far cry from my expectations – the first psychiatrists I worked with there weren't smart, considerate, caring – they were absent, they weren't present, while I was at least present when I was on duty. They were boring, burnt-out, worn-out, not to say perverse; they abused patients at all levels – they tolerated abuse, they didn't merely tolerate, they patronized bad practices, so this reality frustrated me a lot. That's how I became a psychiatrist.

Can you give us some more context about psychiatric care in Bulgaria? You more or less witnessed the change after 1989, if there was a change at all, so I would like to ask you about the old generation of Bulgarian psychiatrists and, generally, about the way to circumvent the rules, if there was one?

What impressed me very much back then was that there were quite a lot of young men who were orderlies and students like me, many of them were quite genuine, empathic young people and they created a very pleasant atmosphere for the entire team at the hospital. There was a boy – a young man, actually – called Petar, who was gay. He cared for the patients in a way I hadn't even thought was possible – I didn't believe that a human being could care in this way, every day, for another human being who isn't a child. He looked after the patients who were in the worst condition – very demented, very disorganized psychotics, even aggressive ones – he was extremely tolerant and patient with them. He did the most unpleasant things possible, such as looking after the personal hygiene of those who couldn't go to the toilet, or bathing these people with rotting bodies, going inside the bathroom with them, getting wet in order to wash their hair – things no one else did. Manipulating the body in a purely orderly, caring way. No one taught us this. No one took notice of what he was doing, no one respected him. So my impression was that there were two levels of reality: one formal and insufficiently humane without being anti-humane; and another, informal one, which existed thanks to such enthusiasts or, I would say, marginal people operating on the periphery of the norms of society but who in fact were the pillars of care for these rotting, decaying bodies.

From what you're telling me, it seems that the atmosphere in the Sofia hospital and in Kurilo was quite different.

Not that much. But there were differences. In Sofia there was an academic atmosphere which I must admit I missed quite a lot in Kurilo, although it was present there too sometimes – thanks to the occasional visits of a hospital consultant, Professor Kiril Kirov, a fantastic specialist and person. It was actually thanks to him that I realized what caring for someone meant, and to the orderly Petar who helped me understand that there is a level of care that is very natural, that is close to people's natural needs. In the same way, Prof. Kirov helped me to see in patients something more than an opportunity for exercising power and to realize my need for power through patients, to see possible ways of connecting with these people – not possible ways of thinking but of connecting. With the exception of Prof. Kirov's specific perspective on people – the possibility of seeing the person in the patients, in the details that eluded us – we worked with clichés, everything was copy/paste and this gave us a sort of confidence that things were clear and recognizable. When you didn't understand something, you framed it in a way that's convenient to you and insisted: 'But this is clear, it's manic syndrome.' In fact, it wasn't clear at all – it looked like mania, it might be mania, but exactly what kind of mania, why mania – those questions remained unanswered. Prof. Kirov didn't work with such frames, he tried to see the person through the story and details of the person's life. With the exception of Prof. Kirov's visits, everything was routine hard work. In the Sofia hospital, by contrast, they put on airs and graces – they had plenty of time to do long rounds, to philosophize around the patient's bed and to amuse themselves in this way. In Kurilo, you had to work hard, to do everything in a hurry, you were pressed for time or you'd miss your bus and wouldn't be able to finish your tasks. You eagerly looked forward to Christmas, when you'd discharge your patients and be able to finish your paperwork. You didn't have time to do the paperwork – to write case histories, reports on consultations and daily rounds of patients. Holidays were the time to finish your paperwork and, in a sense, this was tantamount to psychiatric cynicism which I found somewhat amusing: 'Come on, please discharge the patients so that we can finish our paperwork.' We envied our colleagues with the big computers in the luxury clinics. The so-called database was a joke. There was simply a directory with files on patients who had already stayed at the hospital, and when they were admitted again you simply opened their old file and read their case history.

If you compare the Bulgarian psychiatric care system you found at the beginning of your career in the mid-1990s and the present one, do you think there's any difference?

I don't. There's no difference. I have colleagues who still work in Kurilo. Actually, part of my colleagues left Kurilo but then came back – I've kept in touch with them out of nostalgia, so I know what the situation is really like. The change will come when there's a change in mentality, a change of values that will lead to a change in the attitude towards patients. There is a need for new people, but these are the old ones, the very same people who meanwhile have become burnt-out and even more stressed, even more cynical and insensitive to human misery and suffering because you know how exhausting and distressing this job is – it stands to reason that people will develop defence mechanisms. As the saying goes, 'Cynic – more cynic – most cynic – medic.'

What about the banal difference between psychiatrists who employ solely medications and psychologists who employ psychotherapy?

But it's a matter of assessment – medications come after assessment. At the assessment stage, you have great leeway. You can ruin a person's life with an assessment – by saying, 'He has schizophrenia', but he actually doesn't, or by saying that someone is a psychopath but is legally sane to stand trial, yet that person has borderline personality disorder – but hardly anyone thinks along those lines. And no one can refute you because they don't have the tools to prove it – that's what you think, you yourself are the tool, so to speak. Being a tool used by those in power to qualify or disqualify people can indeed be intoxicating. That's why I say that psychiatrists have narcissistic needs and fantasies which they gratify through their profession – I'm talking about a large part of the young psychiatrists. They must be aware of these hidden motives I'm telling you about – somewhat intimate, personal, innermost things that make you vulnerable in a specific way – but recognizing your hidden motives is risky because someone you've told about them can reveal them to others, so it's better not to recognize your hidden motives at all.

Please tell us something more about the inside story of the Mental Health Centre 'Adaptacia', the outpatient psychiatric clinic which you co-founded in 2001 and whose director you are.

Yes, I dedicated myself completely to this. Someone must self-sacrifice – it's impossible otherwise. Toma Tomov, for example, who invited me and Irina Lazarova to co-found Adaptacia, is super cool, he's an all-round great guy – inspiring, leading, innovative, charismatic, transforming. I'm the director, a bureaucrat in a sense, which is an important job too – keeping things in a stable equilibrium – but it's nothing compared to turning things upside down and rearranging them in a new way. But Toma left in order to continue transforming things, while I stayed on in order to manage the centre so that it could stay. Because it has fantastic projects but there's no one to maintain them and to invest themselves in them. We founded this outpatient psychiatric clinic with the idea that it would serve as a model demonstrating here and now how things could be done in a good way. Setting up a one-stop-shop clinic, bringing together many specialists – having psychiatrists, a psychologist, a specialist in charge of the case, a social worker. Providing rehabilitation therapy in addition to psychiatric care. Enabling patients to meet other people, to become socialized, to learn the basic skills necessary for independent living which are taught in rehabilitation therapy programmes – art therapy, housekeeping, teaching social skills, teaching how to recognize the symptoms, that is, psychoeducation, as well as a healthy way of life, how to avoid gaining weight, etc. Health education in the broad sense of the word. This can be done in one multi-service provision centre. We tried hard for some time, but running such a centre is impossible without public funding. We had a contract with the National Health Insurance Fund (NHIF) and the first year we 'siphoned it off' – or at least that's what they assumed we did. Patients visited the centre for therapy almost every day, several days a week, which meant ten to fifteen days a month, we claimed payment for those follow-up checkups from the NHIF but they decided that something was wrong and set a limit: the maximum ratio of initial checkups to follow-up checkups was 2 to 1, and the trick no longer worked. We kept explaining to them why we were doing it and telling them that this was 'psychosocial rehabilitation' – they couldn't even pronounce those two words, they twisted their tongues. But because we were constantly arguing with them and explaining what we were doing, this term somehow entered into usage and even some gynecologists, random doctors who had turned into bureaucrats at the NHIF, who scolded us for 'robbing' the NHIF, began to use it. When I moved to Adaptacia I had the opportunity to take part in such truly formative attitudes and values, way of thinking and approach – an educational programme for young reformist psychiatrists which I had the chance to become part of and to be formed in the paradigm of community psychiatry, of social psychiatry. This somehow helped me not to lose my humanity by becoming part of the inhuman, institutional branch of psychiatry. That is also how Global Initiative on Psychiatry (GIP) – Sofia was launched. Influenced by the various courses, trainings and seminars, with one-year-long clinical practice behind us, we held a general meeting of Adaptacia to which we invited our patients' family members. We presented to them our activity report for that first year – a report of a business company, which was our legal form under the Commerce Act and which is required for all medical-treatment facilities that are not state-owned. We were a private business company that was not public and that was for-profit. We nevertheless presented a public report like non-profits designated for public-benefit activities. But the patients' family members were very enthusiastic about the opportunity to be together, to be in contact with one another, and said they wanted to continue together. That is how a self-help group, a group for support, emerged and then quickly grew into an association. So in 2001 we registered Adaptacia, and in 2004 the Adaptacia Society Association. But the latter is now defunct.

Why?

Because someone must work in a team. Someone who is a hyperactive psychopath like me, who doesn't have children to look after and who is ready to work for free – to work not with the kind of psychiatry that attracts big research projects and funds, but with social psychiatry – an absolutely marginal, despised field. There's no such person. Patients' family members have the best of intentions, but there are none among them who are not only capable, competent people with ideas, social experience, and knowledge as to how things are done, but who are also tolerant and can empathize and work with people who are somewhat difficult, who are desperate, annoying in their need to be listened to, who cling to your neck and want you to help them in every which way. You need someone who is not only competent and kind-hearted but who also doesn't want to profit from their knowledge and personal qualities, because someone with such qualities – resourceful, smart, good at working with people – can be a top manager earning BGN 10,000 [5,000 euros] per month.

In other words, there was no such person among the patients' family members?

There were desperate poor souls who relied on someone giving them something without their doing anything in return. But even if they wanted to do something, they couldn't. They were insecure, they were in a dependent position, so they were reluctant to stand in front, to speak for the organization, and to criticize – because this meant criticizing the system, exposing bad practices and existing deficits, which of course upsets the status quo. You are seen as a troublemaker, yet tomorrow your loved one will have to go to a hospital you have criticized – this stops people who are in a dependent position from becoming representatives, from being representative.

But we have as an example the very public protests of mothers of children with disabilities in Bulgaria since 2018. Why haven't there been such protests about the mentally ill?

Because generally these children sit quietly in their wheelchairs or lie motionless in their beds – they cannot go on the rampage, breaking furniture, smashing things, beating, hitting like the mentally ill do and, in this sense, they don't need emergency help and an ambulance to come and pick their children up and take them somewhere where someone else will temporarily care for them. They live with these children. Twenty-four-seven. I'm talking about the difference between the mentally ill and people with a physical disability, people with cerebral palsy – in wheelchairs, helpless, physically weak – and physically fit people who can be violent and who can really endanger the lives of their family members who therefore need help and care by the state, by the institution. This is a drastic difference, to my mind. Needing someone to come immediately, here and now, and to help you subdue your rampaging son or daughter is a matter of life and death. The need for external support in such cases is dramatic. Then you are bound to become very careful about criticizing those who are expected to help you. The families of children with disabilities live without any support anyway; even if they attack the state and tell it that it's absolutely good for nothing they have nothing to lose because they haven't received anything from it for years. But the mentally ill have received some sort of miserable psychiatric help in crisis moments and they will lose this help if they confront the state and will be identified as faces of the protest because speaking for the family members means speaking for the protest.

So I don't have to ask you why in Bulgaria there's no mental health activism?

Probably for the same reasons why mentally ill people's family members cannot become empowered, go to the frontline and declare war on the state – because the state will punish them by cutting down on the anyway scarce care services it has provided to them before. I have in mind hospital directors. They will say, 'Of course we won't admit this guy who's been lambasting us in court, saying such horrible things about us in the press and on television – let him go somewhere else…' But probably mental illness itself also matters. Most mental illnesses are cyclical in nature, and once you recover from a crisis it's only natural that you wouldn't want to return to your illness; you'd want to take advantage of this window of remission in which you're given the divine opportunity to feel well, normal – to live your life like most other people, not to connect with others through the story of your illness and to have this as your public image. People have a natural need to identify themselves with their healthy part, not with their ill part, and this is completely natural and human. Who would want to remain bound to their illness and misfortune in the broad sense of the word, and to keep thinking about it in order to represent themselves? Very few people, if any. Culture, in the sense of national culture, national psychology, also plays a role and explains why there's no mental health activism in Bulgaria. Probably because ours is a more provincial culture, whatever that means – more introvert and close, always preferring to 'keep things in the family' and trying to cope on our own instead of telling others. Ours is a culture that tries to keep things in the family, the tribe, the village.

During the interviews, someone said that having a mentally ill family member is worse than having a disabled family member.

That's right. If we're talking about the large group of people with disabilities, the mentally ill are discriminated against within this discriminated-against group. But the answer to the question of why there are such movements in the West but not in Bulgaria isn't psychiatric; it's sociological and has to do with the context.

What, then, do you think about the protests of mothers of children with disabilities?

I think that in them there is a core of people who have travelled the same path together, who have got to know one another well enough to feel comfortable together. They have been through various ordeals and have become friends, battle-tried comrades-in-arms. And my fantasy is that this core will succeed in their demands. They are a handful of people who are nevertheless numerous enough to send messages to Bulgarian society at large in a very categorical, consistent, timely and meaningful way. Including messages about the rights of nurses [who have been protesting in Bulgaria since 2018]. They fought for their own, trade union, rights, but despite this I think they are fighting for the same thing as the mothers of children with disabilities – for justice. I think that if you are fighting for a change in the status quo you must indeed be ready and willing to accept that you will be marginalized, banished from the herd, so to speak, and identified as dangerous. You must be willing to accept that your colleagues and other people will dissociate themselves from you, that you won't be part of your professional community, and that you are indeed different. This brings us back to the concept of the different people, including to my colleague, the gay orderly who cared for patients in a way no 'normal', 'ordinary' person did. If you yourself don't accept your difference, if you don't identify yourself with it and incorporate it into your self-concept, then you'll suffer a lot.

Over the years, have you ever met someone with real charisma who defends the rights of the mentally ill? I mean patients, patients' family members, or even carers of patients, who have declared, 'I will present myself as a defender of the mentally ill'?

Very rarely and, moreover, all of them quickly burnt out. In all the protests we talked about, marginalization isn't easy to bear, although there were such people who presented themselves as different. But I think that they burn out because of their illness. One such person that comes to mind is Sabina Naidenova, who years ago founded a patients' organization and a self-help group and tried to get publicity through Facebook and other media. She burnt out because she was alone. Because, as I told you, you must not be alone, you must have a team to back and support you in order to be able to resist, together with them, the pressure of the social environment and, generally, to meet the challenges posed by reality and to transform them not in an emotional but in a meaningful way.

I have another question. Have you observed any generational changes in attitudes towards mental illness in Bulgaria? You said that you don't see any change in the psychiatric care system but, in your view, have attitudes towards the mentally ill in Bulgaria changed since the end of socialism?

I don't know for sure, I think they have somewhat because nowadays quite a few Bulgarians wander around the world and come face-to-face with suffering, with human misery. For example, guest workers who sometimes live in total isolation and solitude and are in permanent depression. They have personal experience of depression in the broadest sense of the word. Quite a few Bulgarians have also become computer programmers. We know that programmers are slightly on the edge, maybe even beyond the edge of 'normal'. Many of them use substances to manage their stress – for example, smoking joints or snorting coke. This type of deviance has become part of the individual norm. That's because being deviant – experiencing strange states of consciousness, being quirky – is something that's tolerated nowadays much more than during the communist era, when everyone was expected to toe the party line. In this sense, nowadays the norm is broader and maybe that's why Bulgarians are now a bit more tolerant towards the deviant.

What about the generations of psychiatrists?

What I hear from others, including from patients – because I no longer have direct contact – is that things are much worse. Nowadays there's no longer any school of psychiatry. None whatsoever. First of all, psychiatric hospitals have become dehumanized – the psychiatrists working there are interested in the nervous system, in the brain of patients, not in their soul. And they treat patients impersonally, which I think is the main problem. I'm talking about the need for reflection and self-reflection – you must be aware of what's happening with the patient, how you are communicating with them; you must be reflexive and self-reflexive, a skill developed in the course of practice and training, which means that training should be focused on your personal experience, teaching you how to use yourself as a tool, to know yourself well and to be at peace with yourself.

This sounds quite depressing. That's because we know that psychiatrists in Bulgaria are few in number.

They *are* few in number. That's because the more or less decent psychiatrists have left Bulgaria. They have moved abroad. You know – to the West and all over the world. They have immersed themselves in other models, including axiological ones. They have succeeded somehow, while in Bulgaria the provincial mentalities – depressed, anxious, insecure, insincere – can by no means form an open-minded psychiatrist. Insincerity is a main characteristic of our provincial culture, along with pretence, hypocrisy and duplicity. Bulgarian psychiatry was more open to the world even during the socialist period because the world came here – even if just in the form of the school of psychiatric thought that was deemed to be ideologically correct. Quite a lot of literature also came here – via Russian and German psychiatry. But since Russian psychiatry was influenced by German psychiatry, German psychiatry was considered to be ideologically safe. There was significant exchange as well. In my view, now there's none. The world doesn't come here – psychiatry is called into question. Psychotherapy is a completely different ball game. Bulgarian psychotherapists succeeded in paving the way for psychotherapy in the country. While we psychiatrists have been left on our own – no one has adopted us, no one has recognized themselves in us, no one has recognized us as the younger pupil in need of care. And we don't say, 'We're young, we're orphans, please take care of us!' While the psychotherapists say it: 'Teach us!' But we say: 'We're great! We don't want anyone to teach us anything.'

It seems to me that before, back in the 1960s and 1970s, there were some timid attempts at individualizing patients, drawing up 'profiles' on them – what their reactions are to particular things, what their interests are, etc. – while now the priority seems to be on accumulating statistics and quantitative data.

This trend of dehumanizing psychiatrists, of turning psychiatrists into neurologists, comes from the pharmaceutical companies. They want the medications they sell and their effect on the neurobiology of the brain to be monitored. Hence in the last fifteen years or so Bulgarian psychiatrists have turned into researchers of the effect of medicines. This is a huge business, the pay is big as compared with the miserable salaries in clinics and hospitals, and quite a few people succumbed to greed. Besides this, Bulgarian psychiatrists invest a lot of time and effort in doing forensic evaluations. Instead of attending training seminars and developing as professionals, they make money – they do forensic evaluations, again using the copy/paste method, and appear in court to earn some paltry fees. And young psychiatrists would scheme and kill to get hold of such assignments. When a patient turns up, they are regarded as a potential source of an evaluation fee and psychiatrists do their best to prevent the patient's voluntary hospitalization because if the person is admitted as a voluntary patient they won't do paid evaluation, while if the patient goes down on record as refusing voluntary hospitalization, then they will do an evaluation and earn a couple of hundred leva. There are such bad practices.

Going back to your personal experience, what have been the most difficult and the most rewarding things in your psychiatric practice?

In principle, I cannot define or identify myself solely as a psychiatrist because my civic role is as natural and important to me as my psychiatric role. Besides this, I am a relative of a mentally ill person – my late brother-in-law, my sister's husband, had a severe mental illness, he was hospitalized several times, including at Kurilo, and died a few years ago. He was ill for a very long time, which affected me too – my sister and niece suffered together with him because mental illness always affects the whole family, including me since as my sister's brother, I too was involved and saw myself as his relative. It was a bit hard for me to recognize exactly what role I was in – of a relative or… I myself have been going to personal therapy for many years now. So I myself don't know exactly what I am, a relative or a patient…

So, what has been the most difficult thing for you?

In a sense, maybe what was the most difficult thing for me as a young psychiatrist now seems the most rewarding to me. What was difficult for me was that in a sense I banished myself from the herd, from the psychiatric community, and became independent. I am a deinstitutionalized psychiatrist, which, predictably, did not happen without a crisis. I worried for some time and kept going to meetings – to presentations by pharmaceutical companies, to scientific conferences, which are social rather than scientific events. Occasionally, there's something of scientific relevance, but the primary focus is on socializing – talking with colleagues, gossiping a bit, telling some stories, feeling that you belong to a group, to your group, to that of psychiatrists – this is what makes you a psychiatrist. And I felt a bit sentimental and kept going to such events, but eventually I realized that it was pointless and that I was engaging in a form of self-coercion. And maybe this was difficult, but now I'm proud of myself and boast of being an independent psychiatrist. It's a pleasure for me to say this.

Let's move on to the question of vocational rehabilitation of mentally ill persons in Bulgaria before and now. Do you know whether there were more job opportunities for the mentally ill under socialism?

I don't know for certain whether there were any social programmes for integrated jobs, but it's more likely that there weren't any. There were cooperatives of the deaf, of the blind, of people with disabilities, but there were no cooperatives or state programmes for integration of the mentally ill. They were segregated in hospitals, where most of them lived because there were very few residential care homes for the mentally ill in Bulgaria. The hospitals, however, had farms. For example, the best known farm was in the hospital in Radnevo, but there were also farms in some residential care homes for the mentally ill. Huge farms which were closed after 1989, but some still exist in some form. There was labour therapy for patients, they tended livestock, they had workshops and made things – brooms, string bags, envelopes, etc. They produced something. In this way people with disabilities or with severe mental illness had an opportunity to engage in a meaningful activity – to produce some product with their own hands – a practice which wasn't permitted after the changes and which even turned out to be illegal. It was declared that hospitals and residential care homes couldn't engage in commercial activities, hire and employ patients because this was tantamount to exploitation. There was still no alternative to labour therapy – no programmes, methodology, standards for labour therapy. It was conducted in an improvised manner, left to the discretion of the director of the hospital concerned. Labour therapy depended entirely on the initiative and enterprise of the director. And when the hospital farms and workshops were closed, patients began to roam back and forth as in a surreal show.

In other words, you think there

should be such practices?

Maybe integrated jobs and specialized cooperatives, let's say, which are enterprises. There are some very encouraging and attractive programmes for people with physical disabilities – for example, subsidies for employers of disabled people amounting to the minimum wage and social and health insurance contributions for one year. This allows employers to save money from wages while having someone work for them and gives them enough time to see whether the employees can cope with the job regardless of the fact that they are hard of hearing, visually impaired, or have a chronic condition – heart disease, diabetes, hypertension, etc. Although they have health issues, such employees are less of a burden on employers than, say, a woman employee who goes on maternity leave for two years. This method works for people with physical disabilities but not for people with mental illness. People with physical disabilities need an enabling physical environment – for example, if the employee is in a wheelchair, the employer can apply for funding for a wheelchair lift or ramp. The problem with employing mentally ill people is that when they are in crisis, there must be someone who can fill their place. Their frequent absences, special conditions, oddities make them inadequate and incapable of doing their job – then there must be someone available to do it for them. A possible solution is to employ two or more people for one position who, however, are not to work simultaneously but to be mutually replaceable, standing in for one another in crisis.

But does a mentally ill or physically disabled person necessarily have to be a producer? Should there be such hierarchies – those who work are 'good', while the others are a 'burden'?

It would be a good thing because ours is a utilitarian society with utilitarian values. This is a very strong argument – that someone has some work capacity and can be employed to produce products, to bring profit, to be a producer, not a consumer. As the saying goes, 'better work to no purpose than stay idle'. This is a sacred principle for the Bulgarians. So it's good to demonstrate that people with mental illness have some work capacity that can be used for the public good.

But if they cannot work, doesn't this doom them to total marginalization?

Indeed, there are people with severe mental illness or physical disabilities who are incapable of working, and I think that they undoubtedly must be cared for and supported. We must be clearly aware that it is our moral duty to care for the unfortunate who rely entirely on us for support. This should be embraced as a personal cause – there should be benefactors who give meaning to their lives by caring for those who cannot care for themselves. It sounds condescending, but people must be allowed to help and to be proud of it.

My last question is, which are the most urgently needed reforms in the area of mental health in Bulgaria?

First, a major reform in the field of psychiatry education, but I have no idea who will do it. In the field of psychotherapy education, such a reform was done by foreigners who came to Bulgaria, designed the curricula and conducted the training courses. For years on end, the first Bulgarian psychotherapists regularly went for training abroad and, eventually, European and global best practices were introduced in Bulgaria. Perhaps something similar should also be done in the education of young psychiatrists. What's more, the reform should start from medical education, from the education of doctors. In the first two years of medical school, students shouldn't study biophysics, biochemistry, and other such fundamental sciences that no one ever uses; they should study ethics, human relations, relationship crisis management, how to communicate – such basic skills, and then the models of socialization which, in turn, should be full of personal, lived experience, not of clinical experience. Doctors should be mature, self-conscious and highly moral individuals and medical education should cultivate such personal qualities in future doctors. And second, elaborating mental health promotion programmes that overcome psychiatric stigma, and developing psychological culture – raising public awareness of mental health issues, including creating integrated jobs. This list can be continued almost indefinitely.

Milena Iakimova

MOTHER KNOWS BEST[1]

Vaccine Risk Taking in the Context of the Cultural Model of Good Mothering

Vaccine hesitancy is, as they say, a complex phenomenon. The forms it takes range from delay in acceptance or refusal of vaccines because of various fears and concerns to outright resistance and rejection of medical rationality. Apart from the complexity of vaccine hesitant behaviours, also complex are the networks in which they occur and are sustained – these networks are made up of heterogeneous elements, such as local communities (with complex symbolic universes), technological forms of knowledge exchange, religious organizations, experts, microorganisms and myths. The discursive 'pieces' from which they are assembled are heterogeneous as well. So by saying that vaccine hesitancy is a 'complex phenomenon' we in fact – rightly – take a slightly defensive stance. Here I want to look at one microsegment of this 'complex phenomenon'. Regrettably, micronization never reduces complexity. I want to focus on just several interviews in an attempt to see a knot of vaccine hesitancy among educated and affluent urban mothers in Bulgaria. This knot has not been tied by them and their specific life-stories or character idiosyncrasies, but by the position they are placed in and – more importantly – which they identify themselves with and see as a source of social pride, as a resource in their search for social recognition.

There are two political and administrative concepts of vaccination and they are not mutually exclusive: coercion and enlightenment. A doctor who worked as a district doctor[2] in the late years of state socialism in Bulgaria recalled – without any nostalgia, by the way – how vaccinations were carried out in the Roma neighbourhoods: by a nurse who went there accompanied by a policeman. The children who didn't live in those neighbourhoods were covered by the system of coercion in another way (vaccinations at school) and parents had no say. Neither do the enlightenment concepts and practices merit a triumphalist tone. Historically, the system of enlightenment has been associated with the cultural models of parenting in very different ways intertwined with overt or more subtle coercion, such as expert intervention in child-rearing methods – with strict routines and inculcation of conditioned reflexes, without hugs and kisses, with belts for good posture, and with the whole disciplinary repertoire. Both coercion and enlightenment exercised strong pressure towards intensification of motherhood, or what Sharon Hays (1996, p. 6) calls ‘intensive mothering’ – taking on care and responsibility for raising children, for their guidance, for their physical, emotional and moral formation in the family primarily by the mother, and ultimately centering the family around children and their physical, cognitive, moral and emotional development. Historically, the forms of this intensification have changed – from encouraging maternal warmth to medicalization of care and back to resistance against expert domination. The intensification and centering of care in the children themselves – raising children according to their (rather than their parents’) best interests – is the dominant model of parenting for the mothers whose interviews I will examine here. My purpose is to describe the figures of vaccine hesitancy and their context in a particular social group. The vaccine hesitancy and dominant model of parenting are entirely different in social groups with low cultural and economic capital, whose extreme case are the ghettoized communities. They would be the subject of an entirely different study. Here I will discuss data from semi-structured interviews with Bulgarian middle-class parents (mostly mothers) with higher education, permanent jobs, stable incomes, and a small number of children (usually one or two).

Why mothers and not fathers? And are there actually ‘mothers’ and ‘fathers’ in parenting among these social strata in which the boundaries between ‘motherhood’ and ‘fatherhood’ are being renegotiated in Bulgaria? There are – despite the move towards greater gender equality in the domestic division of labour in parenting. It is the mothers who, in addition to spending twice as much time on domestic work and child care, hold the interpretive power. And use it as a resource in seeking high social recognition. I will leave aside the purely inductive considerations that women look for health information much more frequently than men (according to data of Bulgaria’s National Statistical Institute) as well as the findings from the preliminary stage of this research project which included, among other things, observations at children’s playgrounds. There all mothers without exception chatted about their children, and about activities, institutions and experiences associated with the latter. The fathers who had taken their young children to playgrounds never conversed about them. They chatted about ‘work’. But from this we should not jump to the conclusion that Bulgarian society is conservative and patriarchal, with men taking on the social tasks while women remain confined to the home. Things are not only more complicated, they are in fact completely different. This holds true, I will stress once again, for the social category which the interviewees belong to.

The interviews suggested a hypothesis (which ought to be explored further in future research) that takes us back to Adrienne Rich (1995) and her thesis that although motherhood as institution is both a product and mechanism of male domination, motherhood as experience can be a source of power. Asked specifically about how decision-making about child care was distributed between the parents, in the interviews under study the mothers said that decisions were made ‘together’, ‘by consensus’, but that the fathers were confused about some issues and needed interpretive help, even though they took on their share of domestic work and of physical and emotional care for the children. ‘Motherhood as experience’ has been transformed into interpretive power – ‘I know.’ And hence, I help the other parent. The thing is, however, that our women interviewees are structurally placed in this position and, as we shall see, such a position causes significant anxiety.

Those who actually do not vaccinate their children are not many in number. The point is that they produce specific effects. They are part of the loud minorities discussed by PR expert Philip Lesly (1991) in the fourth edition of *Lesly's Handbook of Public Relations and Communications* in the early 1990s. It is not that they attract numerous followers, it is that they create an environment of uncertainty in a situation that is uncertain anyway. But they are also something like a magnifying lens on the concerns of the vaccine hesitant. This will allow us to hear and situate their concerns within the context of larger-scale and more stable cultural models. Besides understanding their anxieties without dismissing them as ‘unfounded’, this move also has a pragmatic task – stable cultural models cannot be attacked with campaigns.

In societies such as the Bulgarian one the system of coercion in matters of public health and in healthcare in general has lost much of its power (according to some, it has fallen apart as a system), but it has not been replaced by any system of enlightenment. Its function is performed in part by two structures: advertising and social media. Moreover, in a vastly changed technological environment of exchange of lay, professional, and most of all, semi-professional knowledge, enlightenment self-organizes from below with the significant sculpting participation of the loud minorities.

Because of the role of social media as amplifiers of the loud minorities' voices on many matters of public importance, social media platforms are increasingly willing to counter the disinformation many admit they are exposed to. But this cannot be enough nor, at the present stage, particularly effective. Social media platforms are simply corporate subjects guided by a desire to maximize profits, yet for the time being social responsibility brings them neither profits nor expectations for profits. It is not in their interest to restrict the circulation of content – of any content whatsoever.[3]

According to an investigation by the Center for Countering Digital Hate (CCDH, 2020) of 409 English-language anti-vax social media accounts, cited by Joshua Cheetham (2021) on the BBC,

> influencers with “anti-vax views” ... have gained nearly eight million followers since 2019. In all, 31 million people follow anti-vaccine groups on Facebook, and another 17 million subscribe to similar accounts on YouTube. The CCDH estimates that the movement is worth $1bn in advertising revenue for social media firms.

From this we cannot judge how many users and followers actually believe the content they use (nor do we know exactly how they use it), but which they frequently disseminate further even though they might not believe it entirely. The important point is that these groups are active as long as there is no one to counter them.

Another qualification is also in order: active minorities do not make up things out of thin air, they articulate existing concerns and fears.

My main task is to try to ‘hear’ and understand the concerns promoted by these active minorities, without dismissing certain opinions as ‘stupid’ even if they are such from an argumentative or expert point of view. These beliefs have some context in the lives of the people who hold them and make sense to those people. The main focus is on 12 interviews with mothers who have refused or delayed vaccinations for their children. At times their interpretations and concerns can be seen more clearly through the lens of anti-vax or, conversely, of pro-vax parents. It is mostly they who are quoted in such cases. But – as we shall see below – the problem is not in the battle between anti-vaxxers and pro-vaxxers; we share a common set of problems.

Who’s Worried? The 24/7 Mother

Some of the interviewees already have an opinion for or against vaccinations and use content selectively – picking out mainly content that supports their opinion. Thus, they trust opinions which they regard as their own personal experience and knowledge.

Others are hesitant and look for advice. We cannot explain those differences with the interviewees’ social status or with whether they perceive their children as sickly or healthy, therefore we will look for model trajectories towards anti-vaxxerism.

We must bear in mind that the vaccine hesitant are the main target both of anti-vax groups and of pro-vax campaigns. In other words, the campaigns compete for this group and should know its fears.

What common model can be identified in these 12 hesitant interviews?

Such a model is to be found in the notion of what it means to be a good mother. It means being completely dedicated, not allowing yourself to be absent:

> I can’t be without them for two hours, let alone a whole day, it’s we who take care of everything – of character formation, of joys and illnesses – whatever comes to your mind. And if I’m absent from this period, I feel incomplete – neither as a mother nor as a woman or as anything. (I1)

This is the dominant model in the interviews, called ‘intensive mothering’ (Hays, 1996). The available data do not show identification with motherhood as a biological destiny to which I freely and passionately wish to subject my individual freedom – what French feminist, historian and philosopher Elisabeth Badinter (2001, pp. 96-97) calls 'the tyranny of maternal duty', loving myself for sacrificing my freedom for my baby, answering 'the siren call of the natural' (ibid., p. 30). In our case the parent, mostly the mother, was interpellated in the responsibilizing discourse: all of us must manage risks, I am the one who assumes all the responsibility. What's more, this makes me feel complete. It reduces my life to avoiding danger.

Let me explain through a thesis that I have expounded in detail elsewhere. In short, there is a well-rooted and widespread general discourse of risk, i.e., of the future in terms of probability calculations.[4] The accelerated liberalization process strongly intensified this discourse which is quite ambivalent, albeit covertly. Risks are something that should be loved but avoided. This stems from an ambivalence in the meaning of risk – on the one hand, as stepping into the unknown, and on the other as a purely probabilistic category that sets a risk-producing machine in motion, whereby 'everything can be a risk' (Ewald, 1991), and hence, everything can be insured.

Risk calculations make everything that is non-existent real – potential, virtual – mainly through the insurance and advertising markets. Let me explain in a brief digression, using examples from Ian Hacking's (1990) book *The Taming of Chance*.

Probability calculations are based on a description of regularities. As innocuous as it may sound, this was a tremendous metamorphosis that took place over more than a century and ultimately changed the European concept of chance. From the nineteenth century onwards, chance stopped being regarded as 'the superstition of the vulgar' (Hacking, 1990, p. 1). Instead, it became a metonymy for the new conception of social law.[5] Determinism as a dependence on something immutable – the past, the universal – was replaced by the idea that 'the world might be regular and yet not subject to universal laws of nature' (ibid.), that this regularity might not be that of the laws of nature but of the enumeration and classification of units,[6] indeterminism but without chaos. Thus, the very idea of normality became ambivalent. The 'normal' in a deterministic universe is that which conforms to the invariable as its measure, while the pathological is in fact monstrous – 'unnatural nature', nature turned in excess against itself (Foucault, 2003, p. 100). The other meaning of 'normal' is the Galtonian 'mediocre' (Hacking, 1990, p. 178) – in any case its measure is ontological. In a regular but indeterministic universe, the 'normal' follows the laws of distribution and dispersion, loses all ontological connotations and turns into 'chance', a probabilistic category. For its part, 'pathological' comes to mean deviation from the norm – now without ontological connotations – instead of excess.

The laws of statistics are rules of administration of human multitudes and rules of order without the laws of nature. 'There is a seeming paradox: the more the indeterminism, the more the control', says Hacking (1990, p. 2); the assumption that both 'nature' and 'society' are at bottom stochastic immeasurably expands the scope of possible interference. With regard to the social world, such interference has a peculiar characteristic: statistical laws are self-regulating. That is how, according to Hacking (ibid.): 'People are normal if they conform to the central tendency of such [statistical] laws, while those at the extremes are pathological.'[7] The self-regulation of statistical laws in the social world is driven by the intentional behaviours of the 'units' – of individuals, who *want* to conform to the relevant central tendency because '[f]ew of us fancy being pathological' (ibid.) and thus strengthen the central tendency in question. The point, however, is that to us, probabilities do not exist ontologically. In the words of Claude Bernard, quoted by Hacking (ibid., p. 145), '[t]he statistician may report that 80 per cent of the victims treated in a certain way will recover, but the patient wants to know, "Will *I* survive?"' The concept of statistical regularity has eliminated the very notion of causality. In our everyday lives, however, we need causality – if not to foresee the consequences of our actions, then at least to find an explanation for what has happened to us. Cultural representations of probabilities solidify them into some sort of entities, events-objects about which we want to know – just like Dr Bernard's patient – whether they will happen to us or not. Naturalization – the solidification of probability calculations into designated events-objects – occurs at the level of cultural representation. In our everyday actions we operate with designated events-objects. That is to say, we routinely naturalize probabilities; through their cultural representations, formed and circulated by the insurance and advertising markets, we situate them in a deterministic universe, but without knowing the latter's causalities well enough – it is too complex.[8] Both insurance and advertising ontologize these probability calculations. This generalized discourse on risk, in which psychologized selves confront a mathematized future, is widely accessible through the media, and especially through the circulation of its symbols in advertising. Here by 'discourse' I mean only a regime of representation which functions as a cultural model of perception of things and events – as probable dangers. Dangers, unlike threats, do not presuppose intentionality; neither do they seem to involve metacommunication: when I walk towards you with flashing eyes and angry shouts, I am sending you signals how to interpret the signs – it's time to fight or flee. But I am just standing and sniffing, I might be upset, but then again I might be sick, should you shake hands with me, what if I've sneezed into my hands? But there are also some things that are worse than not shaking hands – your own behaviours have become risky, this is the normal regime of representation regarding the future and identities: What do you eat? Whom do you love (a cartoon shows us two young women chatting about their partners; one proudly tells the other that she and her partner are the perfect match, even their bone marrow is compatible)? What stories do you read to your children, won't they become autistic from too many puzzles, or hyperactive from too many movies? (By the way, there is an entire consumer industry around ADHD – fidget toys, of which the most impressive to me are the so-called pop its, essentially silicone-based trays in a variety of colours, sizes and shapes, of half sphere 'bubbles' that can be pushed in, making a popping sound; once you 'pop' all the bubbles on one side, you can flip the toy over and start again.) What apps do you download? Our own behaviours are culturally represented as dangers because we don't know what predispositions are dormant in us at the molecular level. And let me stress once again – the problem is not in probability mathematics, this is just one of the vectors; the other vector, however, is of the cultural representation of probability mathematics and it responsibilizes parents. As a result, mothers are overburdened with responsibilities but do not rebel against it, they identify with it. This is their model of self-realization. Petra Bueskens (2018) interprets this identification as a structural duality of contemporary capitalism that is played out at the level of individual identification as a contradiction – the contradiction between the autonomous self as a free individual and the maternal self constrained as a mother. It is precisely the autonomous self that chooses to constrain herself (ibid., p. 168).

The common model is of nuclear families with an insignificant social role of the extended family. The interpretive power regarding health matters is reduced to the nuclear family (in which there is interpretive matriarchy) which, in turn, opens up to the overabundance of information on social media. It is very difficult to say with certainty what the main effect of this overabundance is. There are two relatively stable facts that can give us an idea at this stage. First, we may claim with a great degree of certainty that false news spreads faster than true news on social media. And second, the claim to a privileged relationship with the truth has been heavily democratized (the truth about MY child).[9]

The second point will be discussed in the following paragraphs. As for the first, here is a brief summary:

In 2018 a team of researchers (Vosoughi et al., 2018) constructed a quantitative model to investigate the spread of something they termed purely technically as 'rumours' or 'news stories' – any story or claim with an assertion in it, regardless of its source and regardless of whether it is true, false, or mixed – and investigated the diffusion of these units on Twitter. To this end, they used the technical unit 'cascade' – the number of retweets of such a news story from a single source (i.e., if the same rumour originates from two independent sources, its retweets represent two independent cascades). I will not discuss the technical parameters – the depth, size, maximum breadth, and structural virality of the cascades. I will only say that every retweet increases each of those parameters. What did the researchers find?

False 'rumours' or 'news stories' were retweeted much more often and reached many more people. Of course, we should bear in mind the period covered by this study (2006–2017) – it included the years after 2012, when the internet and the media were flooded with propaganda messages. Despite this, the finding was unambiguous:[10] 'Whereas the truth rarely diffused to more than 1000 people, the top 1% of false-news cascades routinely diffused to between

1000 and 100,000 people' (ibid., p. 1148). Falsehood was retweeted by many more people than the truth. In addition, falsehood was much more viral – it spread through peer-to-peer diffusion, while the truth was much more centralized and spread from one account to others. 'It took the truth about six times as long as falsehood to reach 1500 people' (ibid.). In short, false news spread 'farther, faster, deeper, and more broadly than the truth' (ibid., pp. 1146, 1150).

Rumour cascades were also classified into seven topical categories, where the first place by all indicators was held by false political news, but false scientific news also ranked relatively high (moreover, in the years before the Covid-19 pandemic) – in third place.

What was this due to? One might suspect that it could be explained with the individual characteristics of users – that those who spread falsity had more followers, had been longer on Twitter, etc. In fact, the study found that the opposite was true – users who spread false news had fewer followers, followed fewer people, and were less active on Twitter (ibid., p. 1149).

What alternative explanation – verifiable by purely quantitative means, according to the design of the study – could be found for this finding, considering that it was not due to user characteristics? The researchers advanced the hypothesis that what diffused faster was novelty. Again, without describing their methods, I will point out that they found that false rumours were significantly more novel than the truth. As we know, retweeting novel information is prestigious – it suggests that we are 'in the know' or have 'access to unique "inside" information' (ibid.).

To our narcissism I would add the response we found in our interviews – there are too many things, I don't know how to judge about them, let someone else do so, it might be… This cannot be tested by the methods of the excellent study I am referring to here, but it was distinctly suggested by our interviewees. Vosoughi et al. (2018) also measured the emotional content of replies to true and false rumour tweets in terms of eight emotions and found that the false ones inspired significantly more surprise and disgust, while the true ones inspired sadness, anticipation, joy, and trust.

And one last point about the study in question: experimentally, to check the role of bots in this dynamic, the researchers identified and removed all bots before running the analysis. When they added bot traffic back into the analysis, they found that the results remained the same. Their conclusion (ibid., p. 1150): 'Although the inclusion of bots … accelerated the spread of both true and false news, it affected their spread roughly equally. This suggests that false news spreads farther, faster, deeper, and more broadly than the truth because humans, not robots, are more likely to spread it.'

So, let us return to mothers. Sockpuppetry is the most effective technique – someone pretends to be a doctor, expressing themselves articulately. The website should look 'specialized'. Quasi-scientificity lends added value, but it is often combined with the search for scientific or 'learned' authority that will only confirm what I think anyway. This must be underlined: such content is often used as self-therapy – to allay my anxieties. It is not used to learn something new but to confirm something old, to dispel uncertainty.

The 24/7 mother, who does not rebel against her over-responsibilization and expects high social recognition for it, is in sync with novelty. This cultural model of the smiling mother who, alone with her child in the nursery, calmly decides how to be both 'uncompromising' and 'caring', is a familiar advertising persona: the mother-sovereign. In this case, however, '[s]overeignty … is a fantasy misrecognized as an objective state: an aspirational position of personal and institutional self-legitimating performativity and an affective sense of control in relation to the fantasy of that position's offer of security and efficacy' (Berlant, 2011, p. 97).

What Do Mothers Worry About?

This type of advertisement actually prompts mothers to buy a projection of themselves, a 'self' they can never coincide with. And the Bulgarian middle-class urban mothers we interviewed identified themselves with it. In the real-life nursery, however, real-life mothers have to limit this omniscience that is ascribed to them by the cultural model, i.e., they must choose between two types of risk: placing their children in the care of others who know about children in general but not about this particular child (i.e., in the care of experts), or placing their children in the care of their own over-individualized and therefore always incomplete knowledge (my knowledge is so close-up and so specific that the only thing that makes events comparable is my way of reacting to them; what if now, right now, I'm wrong?).

Notions of Immunity

The mothers we interviewed think a lot about their children's immunity. What are their notions of child immunity? First, second and last, it has to be *strong*.

This notion is intensified by the advertisements for all sorts of vitamins and supplements for 'strong immunity'. But they are not created out of thin air, they are built on mothers' consumer profiling.

This unanimous understanding of good immunity as 'strong' immunity includes a preference for the 'natural' over the 'artificial' – getting sick is natural and therefore healthy, illness makes you hardy: 'an organism becomes hardy by being ill… Everyone must go through diseases – through runny noses, coughs, fevers, everything' (I1).

Getting sick has become part of the complex aimed at improving child immunity, along with home-cooked food and the natural way of life – fresh air, sunlight, sports.

Thus, a professional laicism, something like folk knowledge, has been formed about immunity, but the mothers we interviewed tend to regard it as informed and quasi-scientific knowledge.

In any case child immunity must be high, it must be raised and prevented from waning – be it by natural illness or by vitamins, preferably also ‘natural’ (elderberry, fruit). This understanding is at the root of some of the fears causing vaccine hesitancy – how vaccination will affect immunity, how the child will deal with contacts with the environment in the days after vaccination provided that their immunity is lowered, what the child’s immunity is prior to vaccination. Not to mention the fact that such immunity has not been developed yet.

In the interviews, we found cases pointing to two scenarios in which vaccine hesitancy is fueled in the course of communication with the child’s doctor: 1) by pediatricians’ irritation and derisive attitude towards this professional lay knowledge of mothers, and 2) by GP pediatricians’ compliance with parents’ fears.

All interviewees understand immunity as something individual: ‘If everybody else is vaccinated, that’s to say, protected, the fact that my child will fall ill with something shouldn’t be a risk to them because they are protected, right? That’s to say, the risk is only to the child who isn’t vaccinated’ (I13). This quote is from an interview with a staunch anti-vaxxer, but it sheds light on the notions of all the rest. It must be noted once again that the interviews were conducted before the Covid-19 pandemic, which has popularized the idea of herd immunity among the general public.[11]

Immunity is a warrior who must exercise and become hardy.

Morbid Processes ‘Unlocked’

Of an entirely different type are the fears and concerns that something external made in a laboratory is introduced into children’s fragile organism. Another – similar but not identical – fear is of the components of vaccines (aluminum was mentioned regularly): we don’t know what’s in them, suppliers change but there’s always something, ‘there’s simply always some fine print somewhere which, you know, you can’t be a hundred percent certain [that it’s safe]’ (I14).

A third type of fears – also associated with children’s fragile organism – is that too many vaccines are given at once:

> My parents and grandparents have also been vaccinated. But they were vaccinated with monovalent vaccines. Monovalent means a vaccine that contains a single virus, be it alive or dead. They contained a single virus. But now if we look at our children’s cards, we’ll see that one vaccine contains at least five viruses. And how the hell is this fragile body going to cope with these three or five different viruses? When a child is behind schedule some doctors will even administer two vaccines at the same time. No way. How can this fragile organism cope? (I2)

This type of concerns includes the feeling that vaccinations start too early in life – from 'a piece of meat': 'Giving a piece of meat that's only just come out a jab in the first 24 hours. Two in the first 48 hours. That's way off to me' (ibid.).

But there is also a fourth type that probably contains the common denominator of the fears listed above: I can't know myself at the molecular level, that's okay as long as I'm well. I must avoid 'unlocking' factors. Vaccines can unlock all monsters that are stalking me from within, in my own protein chains. In their comparative analysis of the interviews conducted under this study, Veronika Dimitrova and Maria Martinova (2021) call this a 'hidden disease'. It is 'hidden', to my mind, in a broad cultural model that has three components: reduction of life to health terms, medicalization of the concept of health, and disappearance of the professional monopoly over medicalization. This 'molecularization' of life, as Nikolas Rose (2007) terms it, demands that we control ourselves at a level of our existence to which we do not have conscious access. But for parents who must make such decisions for the 'fragile beings' that are entirely dependent on them, responsibility for failure turns into pure guilt. Vaccine hesitancy is rooted in the avoidance of blame, not in half-educated stubbornness. Something else is also hidden in this 'hidden disease' – the cultural tension between the individualization of children and the model understanding of their biological and mental development. The individualization of children subverts the belief in universality – the universalist claim of science is dealt a strong blow: 'everyone is an individualist even in illness' (I7); 'What exactly is your constitution?' (I13); 'there's no point in reading websites, there's no point in reading everything the World Health Organization, pediatricians, and so on, say. I'm not denying their work at all, on the contrary; it's just that they have studied and do research on many children, not on mine specifically' (I6).

But on the other hand, diseases function in this cultural regime as models which however can remain latent. We parents, mothers, have to be careful not to 'unlock' them, we must keep them under lock and key, but we don't know where the keyhole is.

In this impossible situation, there is a need for techniques of consolation – because even when one resolutely refuses to vaccinate one's children, one still has lingering anxieties. A technique of consolation we found in the interviews is that 'these diseases affect young children and once they grow up somewhat, they are out of the woods'.

Perhaps paradoxically at first sight, another technique of consolation we found in the interviews is the search for bacteria – initially, mothers are afraid that their children may have contracted bacteria because 'you can't knock down bacteria', you'll have to resort to antibiotics, to chemistry. But bacteria are a source of certainty about what's wrong and what to do about it. Nasty, but clear.

Here is something that sustains homeopathy and alternative forms of medicine: 'who knows exactly what's right for my child?' Here there is a broader, general problem – the probability calculations that data about the safety of medications are based on. But, let me remind the reader, if probability calculations can show that the chance of something is 80 per cent, one wants to know, 'Will *I* survive?' (Hacking, 1990, p. 145), 'Will my child survive?'; from the perspective of the individual, there are just two possibilities – zero or one, yes or no: 'she [the pediatrician] has a book in which it is said that children on average should do this and that and take this and that, but she doesn't really know what effects this will have on my child – it's the same with vaccines' (I3).

And even more eloquently:

> You know they say in general, vaccines are – they test them on a particular group of people and, let's say, if there are four or five or a hundred children [with adverse side effects], to them this is a tiny percentage. But to a family this is a hundred per cent illness. If you're a family, it hits you in your most vulnerable spot. You love this tiny person so much that they destroy your whole world. To them, these are just numbers, but to a family this is a hundred per cent. (I2)

The categories we perceive in change the possible ways of action: 'People act and decide under descriptions, and as new possibilities for description emerge, so do new kinds of action' (Hacking, 1991, pp. 254-255). Once what we *think* is impossible has been thought of, it becomes actually possible.

The 'probable' and the 'possible' belong to different universes. But to us – as human beings who (to paraphrase Julio Cortázar) every day 'risk our lives to go pick up the newspaper at the corner' – there are no probabilities. To us, probability categories are ontologized. Things happen or don't happen, there are no probabilities. To us human beings, even if we are insurance agents, probabilities are not possible – they simply aren't an option for action. But probability calculations are a technique for controlling aggregates. Besides this, however, advertising ontologizes these probability calculations, producing from them categories of perception of social types, of differences. Advertising sells us probabilities in the form of normal pathologies – your liver isn't complaining, but heed it and start taking herbal pastilles. Probability mathematics plus consumer advertising – these are the components of the ontologization of risk, of the representation of objects in the world as designated dangers. And we responsibilized mothers have to manage risks. How else can we do so except by avoiding dangers?

When Is a Child Healthy?

Another problem – no longer a fear but a prosaic everyday worry, especially for parents of children who go to kindergarten or nursery – is the constant uncertainty about how healthy the child is, how to find an interval in which they are completely healthy, how can we be sure that they aren't already infected even if they have no symptoms yet: 'Sometimes children get sick but develop symptoms only a couple of days later' (I4). And if a child runs a fever after vaccination, how do we know whether this is a reaction to the vaccine, or whether the child was already infected with something that wasn't apparent at the time they were vaccinated: 'you pray after each [vaccination]: may she survive, may she stay alive, may she not… may nothing bad happen to her, nothing life-threatening or nothing that until the end of her life will… [cause] you as a parent to blame yourself for what happened to her' (I3).

(Our respondents reported four cases of 'unlocked' dermatitis.)

Leaving aside the staunch anti-vaxxers who already have beliefs (beliefs cannot be countered with arguments, it just doesn't work), a major factor for the vaccine hesitant is having someone to share the interpretive power as to how healthy the child is. Parents are weighed down by this over-responsibility – both power and vulnerability. Some of them – mostly mothers – identify with it the social recognition they expect to receive. Others don't, but all are plagued by the uncertainty of whether this child is healthy now, how can I know what's going on in his 'fragile organism'?

Here is a mother who is pro-vaccination:

> She [the doctor] is extremely careful in this respect because she explained to us that in fact um… the problems that appear upon vaccination are never connected to the vaccine itself, or in extremely rare, rare cases, well-nigh 99.99 of all cases, things um… the bad consequences are, come from the fact that either the parent hasn't given enough information about the child's health to the doctor, or the doctor hasn't examined the child in sufficient detail, because if an organism is healthy, completely healthy, there's no way it could have an adverse reaction to the vaccine… (I15)

This mother believes that the doctor can accurately assess the child's condition if the mother cooperates by providing accurate information. In this case she has someone to share her responsibility with.

But vaccine hesitant parents feel over-responsible without having someone to share the burden of this responsibility with. They are primarily concerned about judging whether the child is completely healthy upon vaccination:

> My GP, I've even told him, 'Let's get this vaccination done, I feel it's the right time!' [*raises her voice*] because it's terrifying, it's frightening. You worry for ten days before the vaccine about whether the child is healthy, you wait for ten days after the vaccine to see if everything will be fine, if he'll walk, jump, be healthy. This is a terrible ordeal for the parent, but the child doesn't realize it so much! The child is terrified by the pain, by the needle, and then God forbid any consequences. (I1)

A detail can be seen in this study, the validity of which cannot be inferred from such a methodology but which is conspicuous: vaccination is more frequently delayed in the case of a second child:

> When his older brother was being vaccinated, I had no worries whatsoever because I hadn't met the mothers from the park. I met the mothers in the park and they started saying: my child got vaccinated and her legs became paralyzed, my child got vaccinated and for a whole week after that had a rash, vomiting, headaches, and all side effects you can imagine. (I3)

> When it's your first child, you don't think twice, you say, 'okay, I'll go and get him vaccinated.' But then you start seeing cases of different things that happen subsequently, after vaccines. And by the time you have your second child you're worried sick and wondering whether to have him get this vaccine because it might do something to your child. (I5)

Doctors' Collaboration

Those who are pro-vaccination said they had good contacts with their children's GPs, and quite often, that the latter regularly reminded them when it was time for vaccination. The thing is, however, that those who are anti-vaccination select pediatricians who don't push them: 'That's the point, isn't it, when choosing the actual GP' (I2). And, generally, they have developed para-institutional strategies: choice of institutions to care for and educate children of preschool and school age, selection of a compliant pediatrician.

GPs – sometimes, but not always unwittingly – are complicit in mothers' power. Let me be clear: I am not talking about what GPs actually do but about what they do in the eyes of mothers. Certain maternal groups function as a sort of rating system for general-practitioner pediatricians. Second, there are GPs who support mothers' uncertainty about whether the child is completely healthy and delay vaccinations to avoid risks, including to themselves:

> Her attitude towards vaccines is positive, she is pro-vaccination, but she doesn't presume to encroach upon the private space of patients, in my view. She lets them know that, ultimately, nothing can be done by force, but she says, she expresses her professional opinion on the matter, which is often in favour; no, there are some vaccines about which she has concerns as well, she's cautious… She isn't inclined to break the rules, I mean, if a person, the patient doesn't want to, she lets him take the responsibility for his decision himself. (I6)

This interviewee's child has only been given the vaccines that are administered at the maternity hospital; all other vaccinations have been delayed.

> I'm thinking about changing pediatricians and I also know that there are pediatricians who don't give vaccines and note that a vaccine has been given. (I7)

Anti-vaxxers keep each other informed about such doctors' practices and networks:

> Well, then it was quite, I mean, it was difficult because of kindergarten vaccination requirements. And some people we know used [the services of] such a doctor who can certify that you've received the required vaccinations… At first, I mean, we knew that he would issue such a certificate, which you then show to your GP and tell him that your child's been vaccinated elsewhere. And the GP enters this [on the child's medical record]. (I17)

Another type of doctor was also identified in the interviews – that of the sinecural pediatrician you sign up with because they don't ask any questions, they accept certificates and enter what's required in the documents. But the results of this study should not be turned into a persecution against GPs, these are their images in conversation with parents of their patients. A network is formed around these types – paperwork wizards and sinecural pediatricians – and this network spreads information about them.

Is There Someone to Share Responsibility With?

It is undeniable that distrust and fear are often intertwined, inducing each other to the point where it is difficult to distinguish between the two. But in addition to being distinguishable analytically, we can also distinguish them in the interviews at certain points: parents basically distrust the process of recording and reporting information on children's health status and the effects of vaccination in Bulgaria. In short, our respondents know that there are no unified information registers, which of course intensifies their responsibilization. In their eyes, informed consent is simply a technique of relieving all units of the healthcare system of responsibility. This distrust has grown into a distrust as to whether there is any system in the Bulgarian healthcare system at all. One of the mothers said that six months ago she had filled in and submitted a report about an adverse reaction of her child to a vaccine, but hadn't yet received any institutional response.

Here we should bear in mind that trust is less an attitude of the individual human being than 'a feature of social relations themselves; by implication, trust consists of placing valued resources and outcomes at risk to the malfeasance of (trusted) others' (Tilly, 2004, p. 6). From this perspective, responsibilization – which, in the particular case of this study, can be defined as intensive mothering – structurally represents a contraction of trust. Risks are being increasingly taken individually rather than entrusted to other parties. The mental effects of this structural circumstance are stressful – my own behaviour turns into a source of risk and this undermines my trust in myself. Such is the paradox of what I call 'over-responsibility' – the interpretive power through the child as a form of seeking recognition, which follows from the individualization of risk taking. This is a general problem that transcends local contexts. In addition to this, however, in Bulgaria there is simply no trust in the system of control, not just in its efficiency but arguably in its very existence: ‘to this day I haven’t received any response from her [the GP of the vaccinated child whose mother reported an adverse reaction], neither have I been contacted in any way – I simply feel that this filling out [of the report form] is purely formal, it’s just such a waste of time, it’s just to note for the record that you’ve done something’ (I8).

Distrust in the system of control over vaccines and vaccine production and supply chains as well as over the acts of the institutions in these chains is decisive and does not stem from the moods of mothers. The latter feel over-responsible but cannot rely on too many things to share the risk they feel they are taking. Hence any campaign mounted by these same structures, which are not trusted to exercise effective control, is bound to be futile.

Here is part of the problem: the paradigm of coercion has been replaced by the paradigm of informed choice, i.e., of enlightenment. But in reality there is no enlightenment. The niche has been occupied by information circulating online – with all the risks that this entails, some of which we have seen above. The universality of science is called into question, scientific dissensus is more interesting than scientific consensus. I assume full responsibility for this child, who is at the centre of my universe. And, very curiously – despite this over-care and over-responsibility for children, a possible point of view of the children themselves is not mentioned at all, there is no thought about ‘what will my children say to themselves when they grow up, would they want things to be the way I’ve chosen for them?’

How People Become Anti-Vaxxers

No one is born an anti-vaxxer. The problem is that there is no adequate social support in Bulgaria for families with very young children, which need help in raising them.

Here are the trajectories towards anti-vaxxerism which we identified in our interviews. One type is that of young mothers who find themselves in such a milieu. What they are looking for is social approval, rational arguments do not necessarily come into play – you may just want to win the approval of such people or ‘to be at their level’. In other cases, there is some initiating event: after vaccination, your child develops complications or a disability, you start reading, delay the other vaccines, look for the right doctor and, hence, find such a milieu again; you and your child suffer severe complications, the only support you get is from fellow sufferers, and you set out on the path of para-institutionalism:

> After the vaccine, my younger son fell seriously ill and we’re omitting [his other vaccines]. And they [the health authorities] aren’t insisting [that he be vaccinated]. [Interviewer: What complications did he actually develop?] Guillain-Barré syndrome, he was in a coma for two days, on artificial respiration… (I12)

Parents suffering a traumatic post-vaccine experience in Bulgaria have no form of support whatsoever, they just follow the bureaucratic path through the healthcare system. They do not feel supported and are initially in shock. But there are also more severe cases – I stress again, we cannot tell from this study whether these disabilities are related to the vaccines given to the children, but when there is a traumatic event parents will look for an explanation. And there is no one they can particularly rely on because the interpretive power, this sovereignist fiction, has been left to them and they have identified with it. And if the traumatic event does not end but worsens, this leads to an overwhelming feeling of guilt. Parents are left on their own with this feeling, sometimes families break up and the mother is left on her own with her disabled child and her immense guilt.

The vaccine hesitant reveal how important it is to feel you are supported; this in turn opens up an important perspective on anti-vaxxers: they need support as well. They find it in the feeling of community and network. Their para-institutional strategies survive because there is a system of validating children's institutional stays. In the contemporary technological and communication environment, however, this cannot be countered by a return to the system of coercion. The results of this study show that if there is someone to share the responsibility of the responsibilized mothers, they will become less vaccine hesitant.

But the saddest interviews are those of anti-vaxxers who have experienced very traumatic and sometimes terrifying things with their children who are returning to the embryonic stage (Goncharova, 2018). People with such experiences seek support, but they can find it only among fellow sufferers 'simply on the basis of the different parents, right, who are around me and who don't vaccinate [their children]'[12] and among some obscure 'doctors', 'groups', and assorted conspiracy theorists.

These mothers need to find an explanation for what has happened (without being able to rely on a system that enjoys at least a minimum of trust in its capacity to exercise control) and they need to emancipate themselves from a situation of perpetual pregnancy. The fact that they cannot find an explanation and keep looking for one, that the relevant institutions are incapable of integrating children with developmental problems, traps these parents in their own interpretive and para-institutional self-help bubble. And they are preyed upon by all sorts of charlatans.

In the light of these interviews, it isn't anti-vaxxers who have a problem, it's all of us who have a common problem: relieving parents of over-responsibility, i.e., risk sharing. Who should share risk with us? Moreover, some risks are unbearable if they are not shared.

But the Bulgarian medical community does not appear to our respondents to be unanimous. It doesn't speak publicly enough, it doesn't convey a message of scientific consensus, its authority is also at risk, its public image is rotten for a number of reasons, including flaws in the healthcare system. In short, without overcoming systemic deficiencies there can be no good campaign, even if efforts are made. Whether efforts are being made is quite another matter. And the action taken to counter vaccine hesitancy should be complex – debunking the untruths in anti-vax films, posts, etc. as well as the conspiracy theories of part of the loud minorities should be just one of many measures. It is far more important to enable these mothers to see themselves through the eyes of those who are manipulating them: as vulnerable and manipulable. With a vulnerability that is used as a tool – they aren't offered a cure for it, they aren't offered any relief other than looking for an explanation and culprit for their suffering. Even if this explanation is implausible, it cannot be defeated by debunking. In other words, the effort to regulate content on social media can only be a supplementary measure. The key to the problem lies elsewhere. The key lies in supporting the vulnerable against their vulnerability, in enabling these mothers to emancipate themselves from that vulnerability.

Some doctors claim in public that the problem with vaccine hesitancy is a lack of information. No, there is abundant information, there are no interpretive authorities, and you are naked and alone, a fragile sovereign against a reality which contemporary culture represents as being full of dangers.

NOTES

[1] This title was inspired, first, by a subheading in Sharon Hays's book on intensive mothering, *The Cultural Contradictions of Motherhood*, which reads 'The Doctor Knows Best' (Hays, 1996, p. 39); and second, by Mother Gothel's ironic song of the same title in Disney's 2010 animated feature film *Tangled*. This article presents results of the research project *Childhood Immunizations: A Challenge to Contemporary Bulgarian Society (Studying Pediatrician-Parent Communication Problems to Identify Adequate Measures to Improve Immunization Coverage in Bulgaria)* (No. KP-06-OPR03/15 of 19 December 2018) financed by the Bulgarian National Science Fund at the Ministry of Education.

[2] During the socialist period, the so-called 'district doctors' were primary care doctors who were the equivalent of GPs.

[3] In my view, this is confirmed, not negated, by Facebook's proud announcement that they had already appointed 60 people to monitor disinformation and misinformation about Covid-19. Sixty people for billions of users in 80 languages. This is at best a demonstration of social concern, but it is by no means content regulation.

[4] Although this has become a commonplace, see Furedi, 2002, pp. 14-19.

[5] I would like to stress the word 'metonymy' here. The statistical conception of society, the introduction of an order of regularities into chaos, is never pure nor unified or uncontested. Incidentally, some of the most brilliant contestations cited by Hacking (1990, pp. 143-145, 159) to which – I must admit reluctantly – I hadn't paid attention until now – are by Auguste Comte (unsurprisingly), and by Emile Durkheim for whom statistics visualizes an underlying quasi-natural law.

[6] Here we should remind the reader that Auguste Comte, 'who denied any metaphysical underpinning for our idea of laws of nature' (Hacking, 1990, p. 144), continued to insist on a universal positive law and regarded statistical regularities as pure fetishism (ibid.).

[7] Here one can hardly avoid referring to at least several studies by Michel Foucault, although Hacking manages to do so even though he discusses works by physicians, who are at the centre of *The Birth of the Clinic* (Bichar, Broussais, Bernard), for instance. It seems to me that the differences between the two are rather 'programmatic' – Hacking severely criticizes social constructivism which, in turn, copiously refers

to Foucault.

[8] To my mind, herein lies part of the 'truth' of conspiracy theories – they are deterministic in the most primitive sense: someone does something they want to do and thereby do not merely provoke, they *cause* consequences. I am mentioning conspiracy theories because they are one of the main tools on anti-vax social media.

[9] The role of activist structures and of loud minorities in this democratization, whose flip side is the erosion of expert authority, is the subject of analysis in various discussions, but here I will refer the reader to Nichols, 2017, and Furedi, 2002, pp. xiii, 21. I too have discussed it, see Iakimova, 2021.

[10] The study referred to almost until the end of this paragraph is by Vosoughi et al., 2018.

[11] This, however, has not led to an increase in public trust in vaccines, as found by a number of studies of social media, including the ones cited here. Popular coverage of debates around the pandemic seems to have strengthened the impression that there is a lack of scientific consensus. As we know, weakening of the public impression that there is consensus among scientists inevitably weakens trust in science.

[12] This is also the network that shares information about compliant doctors.

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Veronika Dimitrova and Maria Martinova

TYPES OF HESITANCY ABOUT MANDATORY CHILD VACCINATIONS IN THE DOCTOR-PATIENT INTERACTION FRAMEWORK[1]

In recent years, doubts about the effectiveness of vaccines and fears of side effects have become increasingly widespread. This has prompted the European Centre for Disease Prevention and Control (ECDC) and the World Health Organization (WHO) to define a new social problem, vaccine hesitancy, one that addresses the increasing hesitation of parents and their delay or refusal of childhood vaccination.[2]

In Bulgaria, two nationally representative surveys have been carried out on this subject, showing the discrepancy between the evident need for vaccinations, on the one hand, and the levels of vaccine confidence and vaccine hesitancy, on the other (Trend, 2019; de Figueiredo et al., 2020). The issues of vaccine hesitancy, elements and factors of hesitancy, and Bulgaria's position in a comparative perspective have been examined in detail by Stoitsova et al. (2021) on the basis of a systematic review of quantitative studies. The studies show that a growing proportion of the Bulgarian population is vaccine hesitant and that the vaccine hesitancy spectrum is expanding. That is why we think that qualitative studies on the same subject are also necessary in Bulgaria in order to reconstruct parental attitudes, knowledge, and behaviours towards vaccination.

Although the topic of vaccine hesitancy can be examined from multiple perspectives – ethical, legal, public-health, epidemiological, etc. – here we will concentrate on the specificities of the Bulgarian case and the way vaccine hesitancy is situated in the already institutionalized and existing physician-patient relationship. Our specific focus is empirical: identifying the types of and reasons for vaccine hesitancy. Studies show that parental decisions are influenced the most by trust in general practitioners (GPs) as sources of information (Mohanty et al., 2018; Casiday et al., 2006; Tafuri et al., 2014). Hence the main theoretical perspective we will use is the service relation model proposed by Erving Goffman (1963, p. 326), and deviations from the ideal-typical model upon mandatory vaccination. The detailed reconstruction of parental motives, knowledge, and behaviours will, in turn, allow us to see how parental perspectives are situated in the doctor-patient interaction framework as well as to identify their consequences in distorting the model in Bulgaria. The doctor-patient relationship itself has a broad capacity for impact on public health, therefore we will try to identify both the problematic points and potentials.

The Model of the Medical Service Relation

Erving Goffman claims that professional services are given enormous weight in contemporary societies and have therefore become a model of relations. The service relation model is a framework for contact that ‘can be at once a source of identity, a guide for ideal conduct, and a basis of both solidarity and divisiveness’ (Goffman, 1961, p. 323). Personal services may be defined as situations in which a professional performs a specialized personal service where the service requires direct personal contact with the person being served and expert knowledge (including competencies that cannot be easily acquired). That is also why provision of medical services ought to be regarded precisely as a type of service relation. The framework of interaction itself includes a practitioner, object (in the field of medical expertise – the body), and owner (the individual) (ibid., p. 326). In the process of performance the medical server switches from a realized face-to-face interaction in which the other is a subject to an interaction with the other as an object based on professional expertise. The success of a service depends on keeping those two essences apart and means that doctors should divide their activity into a verbal and a mechanical part, which will create a number of difficulties (ibid., pp. 341-342). Although the process of switching is ritualized and routinized, it entails a substitution that can be a source of conflict.

From the perspective of the person being served, the service itself should look like a service for the benefit of others (and not, for example, for the benefit of some bureaucratic organization). The realization of the service relationship will require voluntary entry into it and placing oneself in the hands of another, that is, it will require trust in the doctor as a carrier of professional expertise and faith in the rationality, empiricism and mechanisms of medicine. Voluntary entry will mean that each of the two parties will be able to withdraw if the relationship turns out to be unsatisfactory. Upon provision of a service, both parties will have to show respect for each other.

Interaction, in turn, is structured in three phases: 1. Technical – the giving and getting of relevant information (in medicine, history taking – patient-reported symptoms and signs of the disease); 2. Contractual – stating the approximate costs, time, consequences of the intervention, etc.; 3. Sociable – exchange of courtesies and civilities, signs of deference (ibid., pp. 328-329).

All this allows us to identify several key issues in the interviews conducted by the research team in Bulgaria: trust in the healthcare system, medical science, and GPs; access to services and factors for choosing a GP; communication by and interaction with GPs about mandatory childhood vaccines; construction of the child's body; the role of parenting; vaccine risk perception; attitude towards vaccines and hesitancy about mandatory childhood vaccinations (including rumours and the way they are spread). These issues, in turn, contain aspects that have the potential to disrupt the physician-patient relationship. For example, the bureaucratization[3] of medicine may distort the view of a doctor's motives in administering mandatory vaccines.

Description of the Interviews

For the purposes of the study, 25 semi-structured interviews were conducted with Bulgarian parents who had at least one child under the age of eight; within the sample, the age of children ranged from a few months to eight years, with some of the interviewees having other children over the age of eight. Eleven of the families had one child, and 14 had two. The average age of the interviewees (24 women and one man) was 33 years. All interviewees were from big cities in Bulgaria (mostly from Sofia), and one of them lived abroad. Just three of the children were in private day care/school, the rest were in state nurseries, kindergartens or schools, or did not yet attend such an institution. As regards vaccine hesitancy, the interviewees fell into the following groups: four vaccine refusers (anti-vaxxers)[4] – current and former; seven vaccine delayers; seven hesitant acceptors (the interviews with six of them are analysed in detail; the interview with the seventh was not recorded by the interviewer and is documented solely in the interviewer's report); five non-hesitant acceptors (control group). Two of the interviewees were exempt from vaccination due to a medical condition developed by their child after vaccination (paralysis; Guillain-Barré syndrome). Their interviews are not analysed in this article.

What follows is a typological description of these groups of parents through the lens of the issues of relationships, understandings of health and their relevance to vaccination, and the role of different forms of coercion to vaccinate, our purpose being to highlight the issue of vaccine hesitancy, its reasons and meanings to the interviewees.

Non-Hesitant Acceptors

The number of *non-hesitant acceptors* in the total sample is five. These parents are characterized by a common healthy lifestyle approach to their children's health that was observed among all interviewed parents – healthy nutrition, outdoor walks, sports, etc., but also avoidance of external interventions in the child's body. In mild cases of illness, they try treatments they described as more gentle (they avoid antibiotics and 'artificial' supplements, and use homeopathic[5] products) and prefer various natural remedies to improve their children's immunity. In these interviews, there was no discernible fear of external interventions; we may say that there was fear of premature interventions (treatment with medication) but, in general, medical interventions seemed acceptable. These interviews revealed a fear of infectious diseases:

> At the same time, we shouldn't protect them too much, but neither should they find themselves in an environment where there are sick people. (I18)

> [J]ust as every parent of a child, regardless of the child's age, I too worry that he might catch a cold, get the flu, get some virus, run a fever, about absolutely… everything… related to his health and his life that can worry me. (I19)

The fear of infectious diseases is one of the reasons for the lack of hesitation – for this group of parents, vaccines protect against ***severe and serious infectious diseases***:

> To me, vaccination is what helps avoid contracting very serious diseases later on. (I15)

> [I]n my view, we're in the twenty-first century, medicine is very advanced, there are a lot of diseases, viruses, flus, etc., and I prefer my child to be vaccinated, to be protected in some way, because vaccination reduces the percentage and risk of falling ill and, what's more, with very severe diseases and disabilities. (I19)

This group includes two parents who said they were not interested in vaccines, they vaccinated their children by default because they trusted the doctor (I17) or because it was mandatory (I18). The importance of vaccination was also explained, on the one hand, with the less safe environment due to migration, and on the other, with faith in the progress of medical science – the eradication of some infectious diseases and the decrease in child and infant mortality.

The parents in this group do not worry about side effects, although some reported short-term indisposition and fever after vaccination. For them, the main source of information is the GP (and other physicians), they follow the advice of doctors, and their accounts suggested that they trust medicine in general.

> In our family we've had a slight fever [as a side effect], in the case of both children, nothing other than that. (I15)

> Running a fever or something else, yes, that's normal because antibodies are being produced and this is a process that's stressful for the organism, but if you're completely healthy everything will be fine. (I16)

> Mostly expected reactions such as sleepiness, running a fever. But, on the whole, there haven't been any adverse reactions. (I18)

Here the side effects are attributed not so much to the vaccines as to carelessness on the part of GPs:

> But everything happens after the relevant medical examination, after a detailed conversation with us about the possible effect this vaccine could have upon the child's organism. If there was even a mild cold a week or two before vaccination, the vaccination is postponed. She [the doctor] is extremely careful in this respect because she explained to us that in fact the problems that appear upon vaccination are never connected to the vaccine itself, or in extremely rare cases, well-nigh 99.99 of all cases, things, the bad consequences are, come from the fact that either the parent hasn't given enough information about the child's health to the doctor, or the doctor hasn't examined the child in sufficient detail, because if an organism is healthy, completely healthy, there's no way it could have an adverse reaction to the vaccine… (I16)

These interviews also showed a much higher level of parental trust in GPs, which was described as 'one hundred percent', the reasons for that being different – trust due to a long-term relationship with the GP, the GP's competence, the GP's good professional attitude. Only one parent in this group expressed dissatisfaction with the GP.

> I trust her very much because in those three years she's proven she's a very competent doctor who subjects each of her decisions, i.e., bases it on the relevant research, she never makes a decision simply because she feels it's right … [A]s for the pediatrician, [I trust him] one hundred percent, after all he has ten years of education and more than 25 years of work experience. (I16)

> I don't only think, I'm one hundred percent certain and claim that I trust the doctor whom I've chosen to be my child's pediatrician. (I19)

On the subject of trust, there are two cases that differ from the others. In the first, the mother's experience (understood as instinct or intuition) is pitted against expertise. This case is more limited compared to the similar accounts of hesitant acceptors, as the doctor prescribes treatment and the mother does not feel competent to self-medicate her child; that is why if the child falls ill, she takes him to the doctor straight away. In this case faith in science, scientific knowledge and medical expertise shows the mother the limitations of her own competence:

> [Interviewer: Do you trust him completely when it comes to your child's health?] Yes and no. I trust him but I always take what he says with a grain of salt and think for myself. I rely very much on my instinct. And I've never been wrong when I've followed my intuition. My maternal instinct and intuition. … We take him [to the doctor] almost straight away. I don't attempt to self-medicate him because I'm not competent about what to give him although I have experience with my older son. I have some knowledge and instinct. But I prefer the doctor to tell me what to do. (I17)

In the second case, the respondent is not satisfied with the services provided by the GP, whom she thinks of more as an administrator. If the treatment prescribed by the GP is ineffective, she takes her child to another physician:

> I'll change him in December. I'm not satisfied because when I go to [my child's] GP, he expects me to say what should be prescribed for my child. He wavers. I as a parent may have an opinion, but ultimately I want the doctor to be confident in his decisions. Otherwise I don't feel I can trust him… I usually follow his recommendations, but I give myself a time limit to see if it [the prescribed treatment] will work – about a week. If it doesn't, I stop doing it and go to another doctor. (I18)

In other words, this group trusts GPs, doctors, medical expertise in general, but also institutions:

> If they prove that these complications are due to the vaccines, I don't think that the authorities will allow them to be administered. Besides this, the diseases and consequences caused by their non-administration are quite serious. (I15)

Questions regarding 'coercion' to vaccinate were answered by the respondents in three main ways. First, by noting that mandatory vaccination contravenes the right to choose, and to some extent, the role of the responsible parent. Second, by denying that the decision to vaccinate or not is a matter of choice at all (emphasizing the mandatory nature of vaccination); third, by acknowledging the limits of parental competence – when the parent is not an expert on an issue, they should leave the decision to experts.

> In fact, in our country you don't have the right not to vaccinate, unless you can afford the luxury of caring for your child at home. I even think that it's now mandatory for children to be fully vaccinated in order to attend schools. (I18)

> I'm interested enough to keep track of what the younger mothers think, it's interesting – at least this is my impression – that the younger generation tends to be against, while our generations, which have completed and complied with the immunization schedule without being asked, 'Do you want [to be vaccinated] or not?', those of us who have completed the immunization schedule are more inclined to accept that it's mandatory and not subject to debate – it's not a matter of choice, it simply must be done. (I15)

> When it comes to some things, yes, naturally, parents' personal opinion matters. … However, hardly everyone is competent about these vaccines to, you know, simply decide for themselves. (I17)

It should be noted that the decision to vaccinate is determined not just by faith in the effectiveness of vaccines but also by their mandatory nature. When there is a clear awareness of the benefits of vaccines as well as faith in science and institutions, parents are more inclined to accept that their competence is limited. Although only one of the interviewees explicitly spoke of the limitations of parental competence, they were implied in the interviewees' attitude towards GPs, doctors, institutions and medical science. In other words, we may say that these parents are more inclined to delegate some of their decisions to experts because of their greater trust in them.

Hesitant Acceptors

The number of *hesitant acceptors* in the total sample is seven.[6] These parents follow the already discussed healthy lifestyle approach to caring for their children's health: healthy nutrition, outdoor walks, physical exercise, avoiding external interventions in the child's body. That is why when their children fall ill they try to cope through 'more gentle' treatments and prefer various natural remedies to improve their immunity. According to the respondents, 'natural' immunity is the best protection against infectious diseases:

> Now I've decided on some vitamins that can't be bought from pharmacies and [aren't] chemical – I have some friends who make homemade elderberry. (I1)

> The AquaSource products are natural products based on green algae, essential fatty acids – I've included them too, but not so much to treat a specific disease than as a background. (I1)

> [T]here usually are various immunostimulants based on colostrum and some others of this kind, but they aren't serious vitamins or immunostimulants. (I11)

External interventions in the body – such as the premature administration of medicines, 'chemicals' – seem unacceptable when the child is in good health, but are acceptable if the child has more serious symptoms. However, the very environment in which the child resides seems unsafe. Thus, the issue of fear of infectious diseases appeared spontaneously in the accounts of all respondents in this group. It was formulated in different ways – with a focus on the contagious nature of the disease and the child's ability to infect others, on fear of viruses and orientation of practices towards it, on the severity of some infectious diseases, on the insecurity of some public spaces such as playgrounds (an important aspect when it comes to younger children):

> [W]e are wary mostly of viruses and that's it. Nothing much has happened to us yet, so we don't think about such things… Her dad got sick, but she's

> healthy for the time being. She's already had two vaccines, I don't know if that's the reason or it's just that the virus was different. We followed hygiene rules quite strictly, making sure we didn't kiss and hug her until the virus was gone. (I7)
>
> What worries me the most is that I'll take her to a playground and, as people constantly take their children [to playgrounds] when they're sick, I, too, will take her home sick. (I36)

Arguably, it is the fear of infectious diseases that underlies the view of vaccines as providing 'protection of the organism'. Despite this, there were hesitations among the respondents and they were driven primarily by fear of side effects. The respondents' position was defined as 'for and against', 'case', 'question', etc. This makes it difficult to generalize their statements as they did not comprise any distinct position that defines their narratives but included accounts of various feelings, opinions and pieces of information. In this group the benefits of vaccines outweigh the risks, with the former seen as twofold: health benefits (despite the fear of side effects) and administrative benefits – possibility of enrolling the child in kindergarten. The respondents in the **first group** (i.e., those who assign higher priority to health benefits) have retained some sense of parental control, which is concretized in the parent-GP relationship. That is the reason why side effects are attributed to GPs' inattention to the child's health status at the time of vaccination.

> Let me tell you that my N. after the first vaccine – no one can possibly know what caused it – developed a rash, atopic dermatitis. … After the first vaccine I was very frightened, because like every parent the first thing [you say to yourself] is 'What's it going to be?', while every mother tells you, 'It's frightening, be careful!', 'It's crippling children!', yet vaccines have always had negative effects not because they themselves are negative but because people didn't have that much access to information. At present we read everything, reports, TV – well, children used to die before too, suffered [adverse] effects from them before too. What's bad here isn't the vaccine, it's bad if the parent and the professional aren't a team – this is my opinion. If your child's sick, if they feel unwell, then for God's sake, don't take them to be vaccinated! The organism has to be extremely healthy, you know; even if fear is the main thing stopping you from doing it. My GP, I've even told him, 'Let's get this vaccination done, I feel it's the right time!' [*raises her voice*] because it's terrifying, it's frightening. You worry for ten days before the vaccine about whether the child is healthy, you wait for ten days after the vaccine to see if everything will be fine, if he'll walk, jump, be healthy. This is a terrible ordeal for the parent. (I1)
>
> Oh… [*sighs*] now on this point I'm in two minds, I'm both for and against vaccination, I think it's good to have this general immunity that's always

> talked about, but then it's not entirely certain that the child will develop such immunity from this immunization, and to what extent the diseases that are included in the immunization… what the immune response will be, you know, so that's why; they also have quite a lot of harmful components which aren't very pretty either [*laughs*], and, generally, I'm in two minds. It's good to develop some immunity and to be protected from these diseases but, in general, if such immunity isn't created and all that's left are some harmful, um… harms of immunization, which's isn't very nice, but I think that if the child's healthy enough there shouldn't be a problem with any immunization. … Well, I've read a lot of information on the internet and I've talked with many relatives and friends about opinions and so on, but I can't say that I dare to trust [anyone] well enough because there's a lot of speculation on the internet. Different opinions, different articles… some are positive, others negative. Some provide even what I think is false information, others provide true information. I don't think you can trust anything, no matter how much information you read. Everything's a matter of personal… personal decision, personal feeling… I've thought about it a lot, already while I was pregnant vaccines were quite a pressing issue, but we ultimately decided that we'd be the kind of people who vaccinate their child even if there's a slight risk; I think that just as a, um… not positive response to some vaccine is dangerous, so too the disease itself is dangerous, so these are… both cases are risky, but at least [in one] there may be some positive outcome, an immunity for the child… possibly. Even if it's not to everything, even if it's for one vaccine, to one thing, having immunity is a plus. (I11)

To the **second group** of respondents (i.e., those who assign higher priority to administrative benefits), the mandatory nature of childhood vaccination means that parents should resign themselves to their lack of control and hand over their child completely to the institutions and GPs (the respondents accept that in certain situations their parental authority is limited). Most of them are parents who described their vaccine hesitancy in the past tense. In this group too, fear of infectious diseases ultimately prevails.

> In general, we were a bit against vaccines, we've heard all sorts of things, some conspiracy theories that they are absolutely unnecessary, that they make children sicker, that they mark [children] in some way (which is a bit over the top, I'd say). How much of this is true and how much isn't, I can't know. How true these things are, we can't know. I won't be able to forgive myself if something goes wrong and she gets sick because I didn't want to vaccinate her. (I7)

> Well, when it comes to vaccination, my opinion is very ambivalent because there are some sources that denounce vaccination and other sources that warmly welcome it. But for the time being, I vaccinate my children because there's no other way. (I8)

In the first group, hesitations persist over time because of a perceived side effect of vaccines. Although in the respondents' accounts the benefits outweighed the risks, emotions ultimately prevailed – there was a stronger sense of coercion, focus on the risks of vaccination, etc. Current hesitations encompassed the whole narrative, but also filled it with fear, with feelings of restlessness, of being 'on edge', with a sense of coercion and frustration about the fact that parents are not allowed to make decisions about their children. Here parents' limited control over their children looks problematic.

> In the beginning, I thought that since they've invented them [vaccines], children must receive them. As regards some of them, I indeed agree that they should exist. … The fact is that my daughter developed dermatitis after the vaccine against tuberculosis, the BCG vaccine. Since then I'm a little bit afraid of these vaccines, of the BCG vaccine in particular. But I eventually said to myself, 'So what, after all, every child has this specific reaction to a vaccine,' so I didn't think there was anything to be afraid of until the moment she received the 6-in-1 vaccines first, and then the one against staphylococci – I think it was 16-in-1, on the second month. I struggled for over 24 hours to bring down a fever of 38.5 and 6 and 8 C, but I couldn't bring it down with anything. Neither with homeopathy nor with Nurofen or Panadol or wet sheets, etc. Absolutely nothing worked and I've been on edge ever since. (I36)

This respondent's experience led to fear of future vaccinations:

> What reassured me was that my child wasn't the only one to develop dermatitis. … Some statements are very extreme and this is something which I strongly dislike. Such as the one that if the child has had one reaction, she will inevitably have another as well. This is simply a very extreme statement. But I'm terribly worried about the fact that the MMR vaccine [against measles, mumps, and rubella] isn't due yet for her [respondent's daughter], but it too will be due soon, this March or April. Even if I wanted to, I couldn't delay it for long, even if I could delay it for two years, eventually they'll call me again and I'll have to vaccinate her. If I want my child to go to nursery and kindergarten, I simply must do it. But what worries me the most are these reactions… we're talking about more severe reactions, we aren't talking about a skin rash that will go away, we're talking about severe reactions caused by this particular vaccine. (I36)

These hesitations have been compounded by doubts about the composition of vaccines, the pharmaceutical sector, and the responsible institutions:

> My main [concern] was the composition and the fact is that in quite a few of the vaccines until a year ago, even before she was born, when there was this… the flu vaccine, I managed to find its composition on this website.

> Eventually, I found out, in this [Facebook] group, that its composition wasn't exactly what [the leaflet] said it was. Um… since then I've been wondering if the full composition of the vaccine is listed, because recently, you know… [*respondent's tone becomes earnest and she starts picking her words more carefully*] Recently, after she was born, I read about aluminum, about some dead embryos and so on, however brutal and disgusting this may sound. Okay, but in the package leaflet itself this thing isn't listed in the composition of the vaccine. It's just not there, nothing… It wasn't there at that time, I haven't read [the leaflet] recently, I haven't had to. But until then this aluminum, for example, wasn't listed. So at some point I start wondering what in fact I'm voluntarily letting my child be jabbed with, basically… (I36)

> Now we're in the twenty-first century, I hope they aren't poisoning us with various things needlessly, because children are the future of this world. I hope it's not just a money game – I don't want to think about it! … If I speak not as a sensible and rational person but as a fearful mother – well, I'll be trembling in terror! So when she goes into the consulting room, every mother sits and stays silent, she turns to the other side and says, 'Give [him or her] the jab and let's be done with it!' Now hold on! Your role is to also check if this is the right vaccine, is it within expiry date, is it clean. The nurse that checks it is human too! Imagine she's had, say, a bad night and purely emotionally is unfit for work – it can happen to anybody. But you're a parent! Before giving it to your child, check the package. Now, with the risk of offending the professional… But no, the nurse doesn't take offence. She even says, 'Thanks, let's check together!' After all, the responsibility isn't hers alone. No one's forbidden you to ask, to have access to information – if you want to, even go buy it yourself! Get it yourself! Your GP can't oblige you to use his [vaccines]. The minister of health has appointed some people to check these vaccines, but you never know! The chain that leads to your child isn't made up of a single person, it consists of the GP, the nurse, everyone. (I1)

In three of the cases, there was a perception of a serious side effect that aroused the concerns of the parents. It is interesting when and how parents establish a causal relationship between vaccine and side effect, since the parents who accept vaccines without such hesitations perceive side effects as well, but this does not cause them to seriously question the safety of vaccines. It is likely that when the perceived side effect persists in time (as in the case of the most commented side effect, dermatitis) and if there is a severe side effect that arouses fear that the child may die, parental concerns increase and may lead to delay or refusal of vaccines. This raises the issue of the role of GPs in suspected cases of vaccine side effects, but also of the role of other institutions in this sphere. Interview 36 is key because the respondent hadn't received any institutional response in a suspected case of an adverse reaction of her child to a vaccine.

In these three cases of vaccine hesitancy, it is also characteristic that the child is constructed as too young and fragile to handle 'the condensed immunization schedule' and 'multicomponent' vaccines:

> Or at least not until she's old enough, because she's too young for vaccines for so many things at once. She's too young. (I36)

Parental concerns are associated primarily with fears of side effects, but the hesitant acceptors think that side effects are caused mostly by inattention on the part of physicians (i.e., they are medical errors). The hesitations in this group are not associated with doubts about the healthcare institutions, the pharmaceutical sector, and science. In the case of Interview 36, in which there was trust in the GP, GPs are seen as administering vaccines, while the responsibility is shifted onto more abstract subjects such as science, the pharmaceutical sector, and the healthcare institutions. That is to say, the explanation serves to exonerate the physician's error.

In the case of the parents who described themselves as vaccinating their children because the state obliged them to (the second group), the main argument for vaccination was that it is required for enrollment in nurseries and kindergartens. Some of those who described themselves as 'former' anti-vaxxers pointed out that they wouldn't be able to enroll their children in kindergarten without the mandatory vaccinations:

> At the very least, if the child isn't vaccinated, they won't be admitted to any educational institution; there's no way you could deprive them of this. You can't falsify things, documents, and so on. (I7)
>
> But for the time being, I vaccinate my children because there's no other way. (I8)

These parents noted the mandatory nature of vaccination and their sense of coercion, but since their experience with vaccines has been mostly positive they do not view immunization itself as problematic. The parents who 'perceived' side effects were very emotional in their accounts, spontaneously repeated the subject several times, and thus created the impression of tension:

> [I]t is very difficult to decide whether to vaccinate your child or not, first, because the institutions themselves also require it. If you want your child to attend kindergarten or school, you must present this immunization card. (I12)
>
> But I'm a single parent and I have no choice! [*respondent's tone and facial expression show frustration*] I have no choice because I can't afford to look after my child at home until she turns six and has to start school. From a purely financial point of view I couldn't possibly afford it. I live alone with her, my maternity pay will become BGN 380 [approximately EUR 190 a month] in the second year. After that I won't be paid anything. After the second year I

> simply have no choice but to send her to a nursery or kindergarten, where she won't be admitted without the [mandatory] vaccinations. My dilemma lies exactly in this. … Above all, the percentage of cases of [adverse] reactions, I want to see exactly what these reactions are, etc. But this is it, as I said, I'm a single mum, I have no right to choose. … Whether I like it or not, that's how things are. The state simply doesn't give me a choice. (I36)

It is likely that some life-situations (related to incomes, opportunities for alternative forms and support in parenting) intensify the tension of parents because they mean lack of desired control to them.

The case of Interview 1 is interesting and different in that there was a perceived side effect, but the parent and the GP have delayed the vaccine together, the GP's reaction being rather to 'limit' coercion:

> This year they had even said that unvaccinated children wouldn't be admitted anywhere and you could be exempted only by a commission. My GP said, 'Well, let's be exempted by a commission if that's what they want', because… my D. had one vaccination left, we were behind schedule because of illnesses… (I1)

It is likely that the GP's attitude plays a key role in making parents feel that they are being coerced into vaccinating their children.

Coercion, which involves the public appropriation of the child's body, in turn conflicts with the role of the parent along several lines. On the one hand, it conflicts with the view that all decisions should be based on *informed choice*. Obligation generally conflicts with the attitudes towards parenting – the latter is seen as a series of *choices* which parents must make and which are crucial to their children's wellbeing. On the other, along the same line of reasoning, coercion conflicts with the responsibility for *choices and consequences* that are within the remit of parents, not of institutions. In this sense, coercion is inconsistent with basic requirements and practices characteristic of the way the participants see their role as parents.

> I'm both a grown-up and a sensible woman, but I'm also a fearful parent. But despite all fears and difficulties, everyone is an individual and everyone must bear the consequences of the choices they make. For example, if you decide to vaccinate your children, you have to accept that if anything goes wrong you'll have to suffer the consequences. The same holds if you don't vaccinate them. But once you've decided to become a parent, that's how things are. … By law, parents are responsible for their children until the age of 18. Because if children could say 'no', every child would say 'no' out of fear. (I1)

> I think you've touched on absolutely all issues that currently are and have been quite controversial – really very controversial in the whole of society, not just in one Facebook group, or two or three. Because I'm not the only

> mother in the group of mothers we hang out with. We're about a dozen mothers and all [have children] of my daughter's age – between eight and ten months. Regardless of whether they are for or against vaccines, all of them are of the opinion that there should be a choice. I mean, one has to have some choice. Ultimately, it's not for the state to determine what's best for their child, it's for the parent to decide. Like I said, I'm not against all vaccines, I'm against some of them, really. (I36)

The changed structure of responsibility raises doubts about the institutions, the pharmaceutical sector, or the whole chain of social actors involved in the mandatory immunization schedule.

In this context, it is also interesting to consider interactions with GPs and the relationship with parenting. The relationship with GPs in this group is mostly positive if GPs are responsive and understanding:

> He's like part of our family! I don't need to rush to his consulting room urgently and immediately – he's on call 24/7. I can call him on Sunday, on Saturday, at 10 pm… Of course, not about everything. … We chose him because we can trust him about everything at any time. (I1)

> Well, [we get information from] doctors, pediatricians, we avoid looking things up on the internet. (I7)

> We fully trust the pediatrician and have no problems in our relationship. We often have to go [to her], but basically we see her for a consultation every month – apart from that, if we have any health concerns, we see her more than once a month. (I11)

The parent-GP relationship is charged with tension in a single instance – when there is a perceived conflict between the GP's expertise and the parent's experience. GPs are conduits of expert knowledge and it is precisely as such that tension may arise against them and their practices. For their part, parents have experience – of specific treatments administered to their children, of knowing 'their own child', of their children's reactions to particular medicines, of their illnesses and the latter's course. This means that there is a potential for confrontation between doctor and parent – the parent's experience, knowledge of the child, 'maternal intuition', tried and tested remedies (which often apply medical practices, e.g. swabbing [I1]), can all be opposed to the doctor's expertise and decisions. This is expressed in the desire to individualize the decisions about the particular child – which may be contrary to the universally accepted principles of medicine. It should be noted that the issue of individualization of decisions about the particular child was more pressing in the interviews with vaccine refusers, that is, here we can speak of degrees of expression of a certain tension.

> Everyone's an individualist even in sickness. I didn't mention by chance that my children have their weak spots – with N. it's the throat, with D. it's fever – and whatever they may tell me, it's never universal. There's nothing that's like a magic wand you wave and say to yourself, 'Come on, just do it and your child will get well!' In this case, the particular impasse you've found yourself in makes you choose a GP's opinion, the GP's a professional... we absolutely have to get tested. I don't wait long before I approach my GP. If I feel something's wrong with [my child's] throat or snot, I go to the lab straight away to test a throat swab, a nasal swab, to see if there's any bacteria. Because if there's bacteria, you can't knock them down – there are medical solutions to deal with bacteria. (I1)

> I trust her insofar as her opinion and practice overlap with my opinion. The fact is that there are many things I've done and think are right, which she definitely wouldn't have approved of. … But I abide by the things that I, too, think are right. As I said, I agree, I'm in no way downplaying her work or all the years during which she has studied and practised. I suppose she has continued to inform herself in some ways to this day, but she has studied about all children, not about my child in particular or your child in particular, and so on. (I36)

It is interesting that this conflict between parental experience of a child and expert knowledge was very pronounced among those who have perceived side effects that have changed their stance on vaccines. This means these criticisms of medical expertise probably express a loss of parental control over the child and a desire for more parental autonomy.

> In general, I trust my GP very much, even though following my intuition and knowing my children, in some instances I've ignored some of her recommendations. (I12)

But in addition to mothers' own experience (most of them claimed that they had mastered certain practices), the experience of other mothers can also be relevant. And in this sense, the claims of other mothers seem to be equivalent to science.

> I trust [medical professionals], but I always take things with a grain of salt and check them out as a mother… (I8)

> I've read this website too, BG-Mamma, where childhood vaccinations are discussed too much. … This is the experience of mothers. This is real life, the example! … Well, there's always some doubt about everything that's said. But by and large, mothers are not so inclined to lie – she may not understand and explain things correctly, but I don't think a mother would be likely to lie. (I8)

Vaccine Delayers

The group of *vaccine delayers* consists of seven parents. What their different accounts had in common was the decision to delay vaccination at some point that does not have to do with a current physical ailment of the child or a medical condition that presupposes exemption from vaccination. Some of these parents had decided to delay only one, specific vaccine, while others were delaying all vaccinations for a specific period.

In their attitude towards children, the parents in this group apply a variety of practices, with a primary focus on healthy eating, establishing a daily routine, frequent outings in nature, taking care not to overdress the child. Although they are keen on providing a good environment and nutrition for their children, the avoidance of foods considered to be unhealthy (e.g., bread, sweets) is an attempt to reduce rather than to eliminate the consumption of such foods. The vaccine delayers share other parents' affinity to deal with health problems by avoiding unnecessary intake of medicines, but are relatively open to accepting the need to use medication and to give their children medicines.

> [I]f my child has a runny nose and fever, I'd prefer a homeopathic product, or if she has a cough – a homeopathic syrup, instead of directly giving her antibiotics or products with corticosteroids and, you know, everything… chemistry that… we try to avoid chemistry. … [A]t first, she prescribed me homeopathic remedies, products which eventually turned out to be ineffective, so I asked her to give me something with an antibiotic to make sure the infection wouldn't get worse. (I5)

> I don't experiment, but neither do I like them taking a lot of medicines. (I4)

Although mothers in this group are the primary expert on the child and the leader in decision-making, among vaccine delayers the responsibility for decisions about the child is often shared with fathers.

As regards parental response to illness, the usual approach for vaccine delayers is to take their child to the doctor if they decide that the symptoms are serious enough and last longer than expected. Although they rely on their own experience and judgement, they will readily consult the child's doctor if they deem it necessary.

> I take him to the doctor if I see that his throat really hurts more or if I'm worried that the infection may get worse or spread to his ears, to his chest, but I decide to do so on a case-by-case basis depending on how he feels and how quickly he gets better. (I3)

> [S]ometimes I manage on my own. If it's just a cough, I give them syrup, if it lasts longer or if they have a fever that doesn't go away, or other symptoms, I go to the GP, he's a pediatrician, or get a referral for another specialist and consult them. (I4)

As regards the issue of trust in GPs, this group of parents demonstrated both trust and some distrust. The mothers generally acknowledge the importance of GPs' experience and competence, but question some of the solutions offered to them. One reason for this is the perception of medical knowledge as scientific, supported by information about humans as a whole, but not tailored to individual specificities. However, the fact that the parents in this group may question a particular aspect of the prescribed treatment does not necessarily mean that they will consult people outside the medical profession; they may consult parents they know, or simply another professional (doctor, pharmacist).

> Well, at first I trusted her about everything because she's a competent person to whom I've entrusted my child and I thought that I must do whatever she says, you know … first I examine my child and then make a decision whether to do what she's told me or not. … I don't think that everything she says is right because she has a book, she has the basis. It doesn't specifically say what will happen to my child, which medicines he should take, what he should be fed. No, she has a book in which it is said that children on average should do this and that and take this and that, but she doesn't really know what effects this will have on my child – it's the same with vaccines. (I5)

> I first check when she prescribes me a medicine, I first ask at the pharmacy what the medicine is, how strong or weak it is, is it suitable or not, because in some cases she's prescribed us medicines which, according to the pharmacist at the pharmacy, aren't suitable for babies so I didn't give them to my baby. … I question and check everything she tells us. … Yes, I'd check for myself [not just for the child], I wouldn't buy something just because the doctor told me to. And I don't mean the specific doctor, I mean in general. (I21)

Thus, the general tendency is towards accepting the doctor's recommendations, while being aware that they are precisely recommendations; automatically following every bit of advice does not seem warranted. On the contrary, parents in this group feel obliged to make their own judgements and decisions, albeit supported by the professionals and their arguments. An important tendency among all parents is the search for treatment options that are sufficiently gentle on the child's body and that can avoid the intake of medicines.

> [A]fter all, I don't have a medical education and don't think I'm more competent, so when the children have serious symptoms I take them to the doctor. Well, of course every time he prescribes me an antibiotic I ask if it's necessary, if it's really necessary, I try not to stuff them with medicines, but if it's really necessary I don't object. (I4)

The approach of the parents in this group is to check and seek reassurance that the recommended treatment or action is the right and necessary one, and not to refuse or disregard the doctor's recommendation. However, in this group trust in doctors depends on several factors other than faith in medical science. In their relationship with GPs, parents appreciate openness to discussions and accessibility, the feeling that you can count on help when you need it. Factors for this are: explaining the situation, what is recommended and why, what can be expected; accessibility in the event of a problem, referring patients to specialists; respect for and discussion of parental concerns and questions.

> I trust her about almost everything. She's proven that her decisions and actions are the right ones, I'm satisfied with her, I listen to her advice, she tries to be objective and doesn't overdo things, she doesn't make me panic. I like this. (I3)

> I always prepare myself before going to my GP and we talk things over; … in general, I trust him but I don't always agree with him. To be honest, so far I haven't had any problems with him and I'm very satisfied with him, he's conscientious and helpful, whenever I've asked him to do something he's never turned me down – whether for advice or for a checkup or for a referral, he's always been cooperative and has helped me. (I4)

> [S]he's never turned us down – she's never refused to help us in any way on any day at any time. (I13)

In our interviews, we encountered a few possible reactions to negatively assessed communication: an already realized change of GP due to lack of proper communication; considering such a change as there is a current conflict with the practitioner; finding another professional to turn to for help instead of contacting the GP.

This notion of physician-parent communication corresponds to the respondents' decision to delay vaccination. All respondents in this group share the opinion that vaccination makes sense. However, they are concerned that vaccines can not only protect but also seriously harm health.

> Like every parent, I want my child to be fully protected, but I wouldn't want the minuses to outweigh the pluses. For the moment, I've decided to delay them. (I3)

> The plus is that they protect and prevent people and especially children from contracting serious and dangerous diseases, and the main minus are the side effects that may occur – I'm speaking from experience. That's my biggest fear. (I4)

> Well, I think it's good to vaccinate your children so that they can sort of be protected against some diseases, which they might suffer from in a milder form or not contract at all. Which are dangerous to their life. And that's why

> I'm in favour [of vaccines], but having seen how many drawbacks they have, that they may cause much longer-term disabilities, I'm against. It's normal to be afraid for one's child. … I know that it's for his own good, generally. However, my fear is stronger! (I13)

The respondents who have delayed at least one mandatory vaccine are anxious about vaccination, recognizing it as a way to protect their children against potentially lethal diseases but also fearing possible side effects. Some of them identified the higher awareness, the availability of more stories of parents whose children have become ill after vaccination, as a reason for parents' heightened sensitivity to vaccination and its effects on the child's body. The hypothesis about the connection between vaccines and autism was also mentioned by some of the vaccine delayers.

> When his older brother was being vaccinated, I had no worries whatsoever because I hadn't met the mothers from the park. I met the mothers in the park and they started saying: my child got vaccinated and her legs became paralyzed, my child got vaccinated and for a whole week after that had a rash, vomiting, headaches, and all side effects you can imagine. (I5)

> Well, it's a public secret that vaccines are the number one cause of autism. In addition, the child's organism can't take so many vaccines and [children's] natural immunity is much stronger. (I9)

> When you don't know, when you aren't informed about some things, it's somehow easier. You vaccinate your child and you're sure that they are receiving this vaccine to be healthier. But when you start seeing some cases on the internet and on TV very often, you start fearing for your own child and don't know what to do. You start floundering. You simply flounder. Because one mistake and your life and your child's life depend on it… (I13)

The vaccine delayers are equally afraid of illness ('It's a shame in the twenty-first century for your child to fall ill with something when there are vaccines that protect against it, as the GP says – and he's right' – I4) and of the possible side effects. Although their strong anxiety about vaccination is related to severe, long-term health consequences, the occurrence of mild side effects is interpreted as a sign of a problem, probable 'rejection' of the vaccine, or as a possible preindication of a severe condition, which frightens parents and serves as a reason for delaying vaccination. With the following somewhat longer quote, we can trace precisely this sense of floundering, of the action 'freezing' between two alternatives:

> Our case is very um… they were going to fine me because I was refusing to vaccinate one of my children. For a long time! I put it off and off, let's say, for a year, but it's just that I… when it's your first child, you don't think twice,

> you say, 'okay, I'll go and get him vaccinated.' But then you start seeing cases of different things that happen subsequently, after vaccines. And by the time you have your second child you're worried sick and wondering whether to have him get this vaccine because it might do something to your child. So I put it off time and time again, and in the end I was told that they would fine me if I didn't vaccinate him and that they wouldn't let him go to kindergarten and nursery and any other educational institution … which is pressure, and in the end I vaccinated him. But for a very long time, I kept postponing it or thought he had a runny nose – you start getting things into your head, you know – but the child has to be a hundred percent healthy to be vaccinated. I personally put it off for quite a long time and in the end they pressured me into vaccinating both children at the same time. (I13)

Among the reasons for delaying vaccination is previous experience of a perceived side effect or illness after vaccination.

> So, yes, I must confirm – I do have hesitations. They arose when the first vaccines were administered and my child had acute adverse reactions on the skin and with digestion, which lasted quite a long time. I checked and found out that this is very typical, typical consequences after vaccination, but regrettably I couldn't find an opinion that was documented, so I myself had to assume responsibility for their delay. (I3)

> The last but one time I took my younger daughter to be vaccinated against measles, and when we came home – I always watch them to see if everything's normal after vaccination, to make sure they don't have any side effects; I worry a lot in general and want everything to be okay – a few hours later I noticed she had spots on her face, a rash on her face only, not on her body, but I was literally on the verge of a nervous breakdown, worried sick that something might have gone wrong. … Some time later we again had to go to the doctor for vaccination and I felt a bit afraid, I kept thinking certain things again, I read quite a few things on the internet where there were all sorts of cases and I was scared stiff that she might get a rash again, for instance, or God knows what – I was afraid, I must admit. I mean, I felt hesitant and was wondering what to do. (I5)

For the parents in this group, even the side effects that are considered to be mild (skin rash, indisposition, swelling at the injection site) become a cause for anxiety and possible delay of the next vaccines. The respondents also focused on an issue of utmost importance to them – the child's overall health status before vaccination. They are afraid that vaccinating children when they may already be ill or may soon fall ill is a risk to their long-term health. Hence the special attention paid to the issue of 'the appropriate moment' for vaccination. In the context of this issue, the situation of families with more than one child is complicated because of the frequent illnesses in the family, leading to delay when someone else in the family has any symptoms. Also important in this regard is communication with the GP, where a more sympathetic attitude on the part of the latter and willingness to delay the vaccine until the moment the parent is certain that the child is healthy and can be vaccinated more safely, proves to be important for parents' future attitude towards vaccination.

> I think the way vaccines are administered makes them much more dangerous than they actually are and that, I think, turns parents off. It's likely to turn me off. Although I think that they are beneficial, that vaccination is beneficial, but not when the child isn't healthy … because we received such a vaccine. (I21)

> Well, when I know that my child's due to be vaccinated, the GP examines his lungs, throat, she asks me if he's fallen recently and other things she wants to know so that she can judge whether he can be vaccinated. When I mention that he had a cold that went away two days ago and that I want and prefer not to have him vaccinated right now, she complies with me because that's my decision. She doesn't insist, she doesn't say that he must be vaccinated right now, at this very moment. (I5)

Furthermore, the GP's behaviour upon the occurrence of an adverse reaction (caused by or ascribed to the vaccine) is important. Acknowledging that the vaccine may be the cause for a particular condition (for example, a skin rash) and informing parents in advance about possible reactions increases parents' sense of respect by and trust in GPs. Denying that there is any connection between the adverse reaction and vaccination was criticized as an insufficiently responsible attitude.

> His lymph nodes were swollen, the child wasn't in a good overall condition … Naturally, the GP kept silent… When we got to the private consulting room, the other doctor said that this was just a reaction to the vaccine, which faded away later. … So I delayed revaccination with the vaccine that caused a strange reaction because I didn't dare lest I cause a similar or more severe reaction. (I10)

Concerns about the general effect on the child's immunity (such as being temporarily weakened by vaccination) and the idea of a hidden disease that may get worse because of vaccination have driven some of the parents to practise a specific type of vaccination delay – refusal to have their children vaccinated with two vaccines within a short period of time, on the same day, or at the same time, delaying one of the due vaccinations.

> Administering two vaccines at once just for the sake of keeping the immunization schedule I don't think is right. To my mind vaccines should be ad-

> ministered when the children are healthy and when everyone in the family is healthy. Not if a member of the family is ill. … [W]e asked them to administer one vaccine a month, not two at a time, i.e. instead of administering them – they are six vaccines – in three rounds, to administer them in six rounds. (I21)

Parents in this group are also concerned about the polyvalent vaccines which, in their view, are more likely to cause an adverse reaction. Like the group of vaccine refusers, some of the parents in this group think that monovalent vaccines are probably more gentle on the child's body.

Given their desire to delay and their experience with side effects, parents are suspicious of institutions and dissatisfied with some aspects of the coercion to vaccinate. The possibility of being fined and especially of being denied access to kindergarten is often what drives them to stop delaying and to vaccinate their children.

> Well, the people at the kindergarten saw that we hadn't given her one of the vaccines yet and they asked me about it, so we went and got her vaccinated urgently. Since my husband travels a lot and I've started going to work, the only option we have is to send the children to kindergarten and to follow the rules accordingly. But I was quite hesitant, to be honest. (I4)

> [H]e can't go to kindergarten, you can't receive child benefits, he can't go to school, he won't be admitted to educational institutions, um… there's plenty of things you can't do. Your child will be kicked out… from the institutions because the parent has decided that she doesn't want him to receive this vaccine. So it turns out that the state exerts pressure on doctors who, in turn, exert pressure on us parents to accept these vaccines. You have no right to choose. Yes, you have the right to delay it for a month or two, but not forever… (I5)

> So I put it off time and time again, and in the end I was told that they would fine me if I didn't vaccinate him and that they wouldn't let him go to kindergarten and nursery and any other educational institution… (I13)

All interviewees in this group said they felt pressured to vaccinate their children. We may advance the hypothesis that the possibility of finding an alternative solution to the child's care and education, knowledge of informal practices, and exposure to a particular type of milieu help to differentiate the group of the vaccine hesitant into delayers and refusers.

To summarize, the group of vaccine delayers includes parents who want to be well-informed about the different aspects of child rearing and character formation, which include healthcare.

> As a parent, I have to be constantly informed, to know that they are developing normally, to constantly watch out for possible deviations so that I can react adequately. (I4)

They actively seek expert advice on their concerns about their children and the latter's wellbeing. Their concern and uncertainty about whether to follow a particular piece of advice or not are based on their position of an expert on the particular child about whose individuality medical expertise has limited knowledge and understanding. Although they generally agree that vaccines are beneficial to the individual and society, these parents are anxious about vaccinating their children after a perceived reaction. As regards vaccines, they place special emphasis on side effects and the possibility of administering a vaccine when the child is ill, which is interpreted as particularly dangerous for the child's health. That is also why it is particularly important to them that GPs show understanding about the need to find an 'appropriate moment' for vaccinating the child.

> If she contracts a virus or if the doctor hasn't seen that she has a sore throat or that her chest is wheezing and injects the vaccine, she's injecting poison into my child, she's killing her, i.e., as a parent [you pray after each] of these vaccines which are seven, eight, I no longer know how many they are, more than five vaccines are given to your child, and you pray after each: may she survive, may she stay alive, may she not… may nothing bad happen to her, nothing life-threatening or nothing that until the end of her life will… [cause] you as a parent to blame yourself for what happened to her. (I5)

So the solution for parents in such a position is to delay, to postpone mandatory vaccinations, because they are aware of the benefits of vaccines and despite their concerns, fear and profound uncertainty.

Vaccine Refusers (Anti-Vaxxers)

The study includes four interviews representing the views of *vaccine refusers*. Some of them include the accounts of parents who refused vaccination in the first months or years of their children's lives, but subsequently changed their minds. One of the interviews, I22, shows how the two parents gradually came to disagree about vaccinating their child. All are a useful source for identifying the basic notions of vaccination, of the child's body, of the relationship with institutions and GPs, which frame the experience of anti-vaxxers. Parents whose children have medical exemptions from vaccination are not included in this group. The accounts of vaccine refusers are important for our study as they reveal fragments of the communication and interaction with institutions, which are not experienced by the other parents.

Like the other groups of parents, vaccine refusers are very interested in the issues of children's health and healthy practices. Although all parents focused on healthy nutrition, this group seemed to be much more passionate about it.

> Well, you can't buy [anything suitable for] lunch from the tuck shop, generally. You have to bring something to eat from home. And we cook for them, which is pretty hard. … Often it's sandwiches, unfortunately, but sometimes

> there's also cooked food, maybe fifty percent. … I would like it to be a hundred percent [cooked food], though. (I23).
>
> Our family has almost stopped eating bread. But he eats [bread] at school, unfortunately. (I22)

More importance is also given to tempering children:

> Taking them to the mountains. … This is very important. … In November we bathed in the sea. (I22)

This focus seems perfectly understandable if we consider the dominant notion of the child's body in this group. In the view of vaccine refusers, children (and especially infants) are extremely fragile. The small size of the child's body as well as the perception of vulnerability to everything external justify their attitudes not only towards vaccines but also towards medicines in general. This is also shown by the greater responsibilization (Foucault, 2009; Rose, 1999) of parents – the decisions made by parents in the present will have an impact on children's development in the future. Parents in the anti-vaxxer group are the most committed to finding alternative solutions ('grandma's cures', 'homeopathy') and postponing 'conventional remedies with antibiotics'. Although they do not categorically denounce medication, they seek to avoid or minimize the intake of medicines, and if possible, to postpone it until it becomes absolutely necessary.

> I treat my children homeopathically; but, you know, from this point of view, I've given my child an antipyretic, Nurofen, just once, you know, I mean… Everything else… And I think this also matters. I don't use any… conventional remedies with antibiotics. … I mean, in this direction – fluids and anything. (I24)
>
> I can't deny that I've taken or given my child something like Analgin or Aspirin at times, but these were absolutely exceptional cases provoked by the desire for a fast reaction or absence of something else at hand at the wrong moment. I'm not extreme in my attitude towards ordinary medicines, I simply avoid them and, when possible, I'd always opt for homeopathy or some grandma's cure! (I6)
>
> And she had to take an antibiotic, she took an antibiotic for the first time now, at the age of six. That's still better than taking it at the age of six months. … [N]ow that my daughter had pneumonia we left her in their hands and [gave her the prescribed] antibiotic. We decided she wouldn't have to take most of the [prescribed] medicines, we only gave her the antibiotic. … [W]hen my son has a cold, the doctor directly prescribes an antibiotic. … For my part, it's never even occurred to me to take it. If I'd treated him the way they've wanted so far, he would have taken more than ten antibiotics by now. (I23)

In this context, we may summarize that this group of parents perceives the child's body as particularly vulnerable and aims to minimize the 'interventions' in it, to reduce them to 'external' influences rather than internal 'intake' of medicines, for example. Hence, tempering, good food, homeopathy, grandma's cures, fluid intake when the child is ill are welcomed and regarded as natural ways of coping with illness, while the use of medication evokes concern and a sense of failure. Conversely, avoiding and minimizing medicine intake is considered to be a good way of coping with illness. The child's body is a vulnerable, delicate but separate, closed body, and it is the parent's task to regulate its relationship with the environment.

All those points were articulated much more clearly when the parents in this group discussed the issue of vaccination, which they see as a radical intervention in the child's organism. In this context, infants, the little babies, are again seen as the most vulnerable, the practice of intervening in the infant's body being the most incomprehensible and unjustified.

> Giving a piece of meat that's only just come out a jab in the first 24 hours. Two in the first 48 hours. That's way off to me. (I22)

> In general, I think… both of us think that now that they are older it's not so dangerous. … Well, I'd read that vaccines contain various toxic elements. Aluminum and things like that. Which, you know, are very dangerous in such a little baby's body. … [P]eople normally take things orally, but this is injected directly into your blood so… things can very easily go wrong. (I23)

The understanding about the meaning and purpose of vaccination is not uniform and systematic across the group, and some of the descriptions were fraught with hesitations. Still, the emphasis was placed on the risk of vaccines, thought of more specifically as a danger to children's health. In this sense, the effects on the child's organism, the possibility of temporary or longer-term problems caused by vaccination, were at the core of these parents' accounts, while the uncertainty as to what those problems might be and how they might occur naturally intensified their fear and anxiety. Moreover, the interviewees juxtaposed this notion with the idea that the mandatory vaccines are actually against diseases that are considered to be extinct, alien to their current environment and also curable.

> I haven't vaccinated my child, first, because I think that many of the diseases targeted by the 'life-saving' vaccines have been completely curable and I'd say extremely rare for decades, so we don't have to deliberately take poisons into our bodies for whatever purpose. (I6)

In the accounts of parents who are refusing or have refused vaccines, the hypothesis that vaccines cause autism occupied a special place. It was precisely her professional experience with children with special needs that had led one of the parents to decide not to vaccinate her own child.

> I think that what more or less cemented the situation for me was the work that I was doing at the time, working with an awful lot of children with special problems, for me it was very much a tipping point, you know. Because in their case it was really very obvious. You know, you see the child, you see them after the vaccine, right – the [before and after] dividing line was very, very sharp. (I24)

It is interesting to note that the respondents who had reconsidered and changed their attitude towards vaccination were familiar with the studies refuting the link between autism and vaccines. Reflecting on the issue of vaccination and weighing the reasons why parents are for or against it, we ought to bear in mind the dynamic of the popular theses about vaccination and their reasoning, the probable existence of fads in the way vaccination practices are questioned, and the contexts in which vaccination is situated.

The image of vaccination and its relationship to immunity at the same time refers to the already discussed view of the child's organism as specific, different from the adult organism, and as containing potential risks that may become manifest depending on parental behaviours and decisions.

> I don't get it. I still don't get it, you know. Why are you injecting – in a normal organism – things which will… you know, will still provoke something it will have to cope with. An organism is sufficiently adaptive in any situation, isn't it? (I24)

> And actually I can't understand what's the idea of this chemical injecting. … But the main idea is that … you have a nucleus, a whole one, then you inject something, whatever it may be, because the components of each of the vaccines are different, and you want to destroy this nucleus, right. That is, to make it feel more… adaptive. … And, say, for people who have hereditary diseases. If they have more, a large percentage of allergies, right. … [B]ut in fact if you have hereditary diseases, then the situation is much… worse for your child, right. [Vaccines] activate, for instance… the first vaccine activated dermatitis. … But with each one it's simply… you additionally activate, right, I mean, things you have in your body. That is, if you're prone to something, you aren't stopping it, you're continuing in that direction. That is, you're intensifying… intensifying the very symptoms of the particular thing. (I24)

> And we all know that the organism is itself capable of building immunity against certain diseases once it has fought them off. Vaccination can only cripple this capacity and in some cases – unfortunately not so rare, as I've seen several times – the vaccination itself can cause permanent problems. (I6)

Thus, in some of the accounts vaccination was represented as unwarranted testing of, and impact on, the organism's natural capacity to interact with its environment.

The respondents' accounts also revealed their notions of the overall impact of vaccines on immunity (not just on the specific disease targeted by the respective vaccines).

> I wouldn't say I've ever regretted [refusing vaccination], thank God I haven't had a reason to! My child's healthy. Of course we haven't avoided all seasonal viruses and a cold now and then, but I think that's perfectly normal. And I think my child quickly gets over them. (I6)

> I haven't noticed my children getting sick. I mean… much more often than the others or whatever. (I24)

In this context, the reasons why parents have changed their attitude towards vaccination – and have caught up or want to catch up on missed opportunities for vaccination – are interesting. Here the topic of the environment and the parent's control over it clearly stands out. The concept of the child's health and treatment only by natural, mostly external means, is associated with the task of controlling the environment. If while the child is very young parents can exercise control, determine the ways of rearing, nutrition and communication, choose the group of acquaintances, restrict or encourage certain interactions, as the child grows older they encounter obstacles, inevitably coming up against undesirable elements of the environment (e.g., travelling, socializing with a wider range of children, etc.).

A comparison with the vaccine hesitant groups (hesitant acceptors and delayers) allows us to propose the hypothesis that **vaccination refusal is directly related to the degree and duration of retained parental control over the child's environment – including choice of kindergartens and schools, occupation of the respondents, and so on**.

That is also why a frequently mentioned topic in the interviews was that of travel and mobility in a global world, which cannot isolate children from 'all sorts of' other people, including people travelling from places where the causes of infectious diseases that have been eradicated in Europe still exist.

> We were flying to Barcelona. N. was six months old. And when we saw how many people, I mean people of colour, [all sorts of] different races there are, and I told him [the child's father who is against mandatory vaccinations], 'You see, here, for example, if he hadn't received these vaccines, he couldn't have come here.' (I22)

> There's too much mobility across the world. People fly back and forth constantly and these diseases really exist. They are there. … There's no way [to

> avoid them for certain]. Even if you live in the countryside, a tourist will come along, something will happen, and you're done. (I22)
>
> For example, at some point there was an outbreak in Plovdiv… I think it was measles. … And we were going to go to Plovdiv, but we decided that… it's risky and didn't go. We waited [for the outbreak to pass] and went the following year. (I23)
>
> And perhaps we should give [our children] some of them [mandatory vaccines]. … And trips… and yet, you know, both are in new schools and… … The schools are bigger, [there are] more children. (I23)

The group of vaccine refusers is also distinguished by its multifaceted distrust of health-related institutions. While they are not alone in their concerns, they display a more complex distrust of health authorities and experts that includes GPs as well as a large part of the medical community, the pharmaceutical industry and, more generally, the 'system' involved in healthcare. Let us look at the main aspects of this distrust.

> My child isn't vaccinated and there are a number of reasons for that. I'll start by saying that perhaps my overall attitude towards the industries at the moment is negative. They are just money machines manipulating through elementary techniques and numbers, brainwashing people and profiting mainly from their ignorance. I think the pharmaceutical companies aren't an exception. I personally feel that they are making us feel more and more sickly and helpless, spewing all sorts of medicines that can cure an endless list of ailments. To my mind, vaccination works on the same principle. Most parents are paranoid when it comes to their children, and so am I [*laughs*]. And because the belief that vaccines are absolutely mandatory and irrevocable is well-entrenched, almost all children are vaccinated. (I6)
>
> [B]ecause, you know, I mean, I personally don't feel secure going to the doctor. In general. I don't know. … Because experience shows – you go and he tells you, 'You need surgery!' I mean, this is mandatory … because of the clinical pathway. And you actually start wondering, 'Okay, is the clinical pathway the thing that, you know, is motivating?' (I24)
>
> [W]hether these things against which [children] are immunized occur at all in reality. I suppose the Health Insurance Fund has an interest in having more vaccines so as to take more money from people. (I23)

The reasons for distrust include both specific examples of commercialization of the physician-patient relationship (for example, a focus on clinical pathways rather than on patient needs; media-publicized examples of unnecessary procedures performed for commercial purposes; etc.) and distrust of the competence of most doctors (recounted through examples of medical errors, change of specialists, lack of respect for the patient, 'automatic' prescription of antibiotics, etc.).

For some of the interviewees, the crucial factor in choosing a GP was precisely the attitude towards vaccinations, where there were two types of situation: the choice of a GP who is against vaccinations, or of a GP who is willing to accept vaccination certificates (which are practically false – the children are not vaccinated). This issue is relevant in the interviewees' social milieu and they said that many of their acquaintances also do not vaccinate.

> Our contact with the GP was established on the basis of the different parents who are around me and who don't vaccinate. They actually, you know, put me in touch with this doctor as well. Who doesn't mind [accepting false vaccination certificates]. (I24)

> Besides this… yes. We asked her [the GP] at the beginning whether we could bring certificates [of vaccination instead of having the child vaccinated by the GP] and she said yes. This was the main [factor for] choice of a GP. (I23)

The experience with GPs varies across this group. In one of the cases (of a former anti-vaxxer who changed her mind and 'caught up' on her child's vaccinations), the GP's support for vaccines was one of the factors for vaccinating the child, along with the fact that they are mandatory. However, some of the respondents in this group said they saw GPs as having a purely administrative role and consulted them mostly for paperwork (sick leave certificates, for example); if they had a real medical problem, they sought help from other professionals – physicians with a relevant specialty, homeopaths, microbiologists, etc. Interaction with GPs was also described in the accounts of vaccine refusers through the lens of the key issue of vaccination and the difficulties in refusing 'mandatory' vaccines. The main strategy for dealing with the situation has been noted above – seeking a GP who is supportive of the decision not to vaccinate, which allows formal interaction and consultations on other health issues to occur unproblematically. In this role, however – as doctors who are supportive or not, who agree or refuse to sign up a patient if the parents do not want to vaccinate the child, GPs are recognized as part of the bureaucratic system that serves the health sector and are seen primarily as administrators, not as medical professionals.

The accounts of vaccine refusers also included stories of difficulties and misunderstandings with doctors when the children were ill. Some cases involved delayed diagnosis, others a dismissive attitude and lack of dialogue, and still others hasty, from the parent's point of view, prescription of medication. The interviewees' choices and concerns were based on real situations in which contact with health professionals and institutions was unsatisfactory – hasty or delayed treatment, lack of clear information, refusal to explain treatment decisions, imposition of a sanction ('fine') for early discharge from hospital, etc. At the same time, the actions of health professionals were often ascribed to motives other than the interest and health of the particular child: keeping the immunization schedule, prescribing medication according to pharmaceutical companies' campaigns, following clinical pathways, and in some cases, purely financial motives. Thus, parents look for a 'suitable' specialist in whose goodwill, expertise and worth they do not have such a strong distrust. In some cases this means getting a second, third, etc. opinion on the specific health issue.

On the topic of physicians, the group demonstrated a sense of familiarity with a wider range of medical professionals. Whereas the dominant perception in the other groups is that doctors are generally and unanimously in favour of mandatory vaccinations, the accounts of the refusers showed that there are also different positions within the medical community itself. Hence, for them the issue of vaccination is a matter of finding a doctor who is supportive of their position against vaccines.

> [T]he other thing is that there's quite a large percentage of doctors who don't vaccinate their own children. Which… … The point is that, you know, there's simply always some fine print somewhere which, you know, you can't be a hundred percent certain [that it's safe]. That is, everything's just an estimate, roughly speaking. … Um… nowhere does any doctor tell you that… vaccinating is dangerous. Actually, I have a doctor who says this and she categorically refuses, you know, to vaccinate, actually. … [The GP is] against vaccines. … That's [the factor determining the] choice of GP, you know, but there's quite a large percentage of doctors who… what's the word, formally, you know, there are some who categorically refuse and don't vaccinate, others who disagree but register [vaccinations that weren't actually given] and still others who are in favour. (I24)

The parents in this group also use more alternative approaches in caring for their children's health (for example, purely homeopathic treatment, microbiological testing, detoxification, etc.). We may tentatively conclude that vaccine refusers perceive their way of thinking and actions as alternative to society at large. Perceiving others as blindly following a system they consider irrelevant and unjustified, they assume that their own behaviour as parents is more conscious and informed; in some ways they conceive of themselves as a group that is informed, well-read, more conscious in their decisions about their children. Accordingly, they commented on topics such as how vaccines are delivered, they are aware that doctors' views differ (and do not expect a unanimous opinion from everyone), etc.

> Apart from that, I suppose there some vaccines arriving in Bulgaria that aren't of such good quality in general. … And… this doctor who issued [false

> vaccination] certificates had told us actually that there is, say, a [vaccine]… Pentaxim [administered] at a certain age, which is very heavy, and he's told us that there's a lighter one which is more expensive and therefore isn't covered by the Health Insurance Fund – he said we could buy it and vaccinate [our child] with it. It, for instance, isn't 5-in-1, it's 3-in-1. (I23)

The critical attitude and distrust towards institutions are reflected specifically also in the vaccine refusers' attitude towards the educational system, which they expressed unambiguously.

> Everyone has some sort of… option of their own. We simply didn't succeed with the state forms [of day care] and that's why we… … We tried sending our older daughter to nursery and actually that was… a complete disaster. And that was it [*laughs*]. (I24)

The requirement of vaccination for access to public education forces parents who refuse vaccines to look for different options of dealing with the situation – falsifying documents, admission to forms of day care or education where vaccination requirements are circumvented, caring for the child at home. Compared with the hesitant acceptors who are under similar pressure, the refusers, faced with the same conflict, find ways to include their children in what they see as an appropriate form of day care or education without having them vaccinated with the mandatory vaccines.

> Well, they again look for an alternative form [of day care, for instance]. Yes. Looking for an alternative form, that's the option. Or falsifying [documents]. … Those are your two options, there aren't really any others. Actually, falsifying documents, by a doctor at that, you know, actually that's what has to be done. … And they simply look for an alternative form. I think a large percentage of the people who are with an alternative form haven't vaccinated their children, roughly speaking. I may be wrong, I don't know. (I24)

Hence, in this group there is a strong feeling of coercion to vaccinate. The mandatory nature of vaccination was strongly criticized.

> Well, it's good to have a choice. Because ultimately we… You have the right to an own opinion on the matter. In other countries the mandatory vaccines are much fewer in number. … While here, for example, you can't send your child to kindergarten if you haven't vaccinated them with absolutely all [mandatory] vaccines. … They made other false cards. … But the system is such that it forces you to do things. (I22)

The parent's decision is regarded as determinative; interventions against the parent's position are seen as problematic.

> I by no means condemn parents who vaccinate their children, on the contrary, I think it's even commendable as long as it's a thought-through decision and not the typical following of… conventional wisdom. … As I said earlier, I respect every mother's right to personal choice and don't aim to propagate extreme anti-vax views. (I6)

Following this line of reasoning, vaccine refusers generally think of vaccination through the lens of the particular individual child and his or her health. Inasmuch as the issue is understood solely in terms of the particular individual, we may say that there is no hidden intentional opportunism in the behaviour of the refusers. They do not expect the others to take on the risk of vaccinating their own children so that they can benefit from it indirectly; they think of care for every individual as being independent of the decisions of and about the others.

> It's still a taboo subject, few people say it, you know. Because it's like, you know, the people around me with vaccinated children worry that my child may infect them, you know. And what's the logic of [your child] being infected, you know, if your child's been vaccinated and has already adapted to… whatever. But they are very extreme, you know. I mean, I've noticed that those who are with vaccines are more extreme than those who don't vaccinate. (I24)

Parents in this position are aware that their decision is somewhat frowned upon by society at large – it is an opinion and behaviour that often needs to be defended from critics (mostly relatives, but also other parents, physicians, and so on).

> [B]ecause a large percentage of doctors moralize, you know: 'If you don't vaccinate your child, they will suffer, blah blah blah.' (I24)

In this sense, vaccine refusers are often urged to reconsider their position. However, this pressure has probably also led to the formation of a group of like-minded people who identify themselves as different, more knowledgeable and more careful than the others, which allows parents not to be in a constant state of tension about the decision they have made for their child. It is noteworthy that the group of vaccine refusers is characterized by a particularly high degree of responsibilization.

Summary (Hesitancy)

We can summarize key components that proved significant in parents' accounts. Parenting as a personal responsibility may conflict with the manifestation of trust in an expert (the GP, for example) and is difficult for a large part of the participants. Non-hesitant acceptors cede control of decisions about their child's health most readily, in contrast to vaccine refusers who almost dismiss this possibility. An important aspect of parents' attitude towards the expertise and relevance of doctors' recommendations is their own personal experience, intuition and knowledge about the particular child. This was often pointed out, especially by mothers of older children justifying their criticism of doctors' positions as being overly general, conforming to statistics or norms, but without knowledge about the specific individual about whom the parent has more experience. In this respect, a juxtaposition of the types of knowledge about the child and the child's health can be observed, with expert knowledge being just one of the possible types of knowledge.

As regards child rearing, all interviewed parents feel that a healthy diet and other practices guaranteeing the child's safe growth are important. Although they are concerned with the same issues (cutting on bread and sweets in favour of fruit and vegetables; exercise, outdoor walks, sports, etc.; avoiding overdressing), there are nuances in the views of the different groups. A common enemy is 'chemistry', associated primarily with medication in general and antibiotics in particular, but parents' readiness to give their children medicines when they are sick varies from one group to another. Vaccine refusers are the least inclined to 'resort' to pharmaceuticals.

With the exception of the control group of non-hesitant acceptors (in which fear of diseases is dominant), for the other groups vaccination is about balancing between fears – of the disease and of its side effects. This means focusing on different ideas about and experience with vaccines (when a reaction occurs), which underlie the differences in behaviour – vaccine refusal, delay, or hesitant acceptance. The vaccine hesitant are more inclined to problematize the child's body not only as individual but also as specific – fragile, vulnerable, and therefore in need of protection from external intrusions.

Coercion to vaccinate and parents' right to choose are important issues for all groups. Only some of the non-hesitant acceptors said they were in favour of coercion in the child's interest. The other groups were of the opinion that parents should have the right to choose and should not be coerced into vaccinating their children. An important factor in this respect are the administrative sanctions and restricted access to institutions (nursery, kindergarten, school). The role of GPs – as experts expressing a particular position on vaccination, giving advice, accepting and discussing parental vaccine hesitancy or not, exercising pressure on parents or not – is particularly important. Let us summarize our findings about the parent-GP relationship through the lens of the service relation model described above.

Distortions of the Service Relation Model

Ervin Goffman (1961) builds his model of the medical service relation on two premises: 1. Voluntary (we can safely say – private) entry into a relationship; 2. Realization of the relationship in a non-bureaucratic framework (often called bedside medicine). That is why we think that this ideal type is suitable in examining the relationship between parents and GPs precisely in the latter's capacity as the-doctor-at-the-patient's-bedside, but with the caveat that GPs in Bulgaria are representatives of the healthcare system, entry into a relationship with them is voluntary (insofar as GPs are chosen by patients), but the relationship with them is binding (insofar as GPs are a sort of 'gateway' to the healthcare system). That is also why the relationship itself may be a source of distrust.

First, because the reasons for choosing a particular GP may be different (from trust in the GP and their professional expertise) – location, willingness to register new patients, etc. The analysis of the interviews shows that coercion of parents to vaccinate their children – in short, 'If you want me to be your GP you must vaccinate your children' – is an important factor in this regard. That is, the notion of good medical competence influences the choice of GP, but in doing so limits the possible positions of parents and GP-parent negotiation in some areas. This, in turn, creates subpopulations of refusers who use the services of GPs who are against vaccinations and do not vaccinate children. In this case, GPs are chosen precisely because of their anti-vax attitude and regardless of their professional competence.

Second, although the particular GP may be trusted, in performing certain services they may be seen as a representative of bureaucratized medicine (given the relatively high levels of distrust in healthcare institutions in Bulgaria), and hence the parent-GP interaction raises doubts about the doctor's motives – personal gains, obligations, etc. This means that the framework of personal contact is transcended in the case of certain activities performed directly by the GP. We may say that in the case under study the parent-GP relationship remains mostly personal – that is the reason why respondents who have concerns spoke of side effects as physician's errors. The personal contact framework is transcended only in situations of perceived longer-term side effects (or side effects that have generated fear of the child's death), which give rise to subsequent concerns. These emotions are graded in the different groups – from refusers (with the strongest doubts in the entire chain) to delayers and hesitant acceptors. In this case the GP is seen more as an administrator, which gives rise to a number of practices of checking the GP's administration. These checks may appear to GPs to be a sign of distrust, but they should be understood rather as exercise of parental control over the situation that is seen as precarious.

Third, by virtue of the mandatory nature of the relationship with the GP (as the 'gateway' to the healthcare system), the GP themselves may be seen as a carrier of professional expertise (or at least of segments of it) that the patient does not trust. It should be noted here that medical knowledge continues to be esoteric, but recent years have seen an 'opening up' in medicine not only because of the effort to raise public awareness of certain topics but also thanks to new technology and its wide access. This means that there are likely to be significant discrepancies in the interpretations of science by GPs and parents. The analysis of the interviews shows that there are serious disagreements about medicine as a science (although it is accepted in some cases) only in the group of vaccine refusers. However, these disagreements about vaccines should be understood as incompatibility of the practice of immunization with parents' notions of 'unnecessary intervention' in the work of the child's organism, with their constructed image of children and wishes for a healthy lifestyle. The characteristic construction of children as fragile and commitment to a particular type of healthy lifestyle increase the desire for parental control, individualization and responsibilization of decisions about children. Decisions seem to invariably responsibilize parents for their child's future condition. To the greatest extent, this conclusion holds true for the refusers, while for the other groups of vaccine hesitant parents the mothers' experience of the 'particular' child is pitted against medical expertise. It is in this light that the doctor's decisions can be reviewed and challenged. Hence also the construction of children (more specifically, infants) as more vulnerable upon vaccination – this notion is particularly salient for the refusers, while for the other groups it seems that the primary concern is making sure that the child is completely healthy upon vaccination.

Fourth, the very act of placing the child's body in the hands of another can generate tension. Here we should say that in the case of mandatory childhood vaccinations the service relation model is distorted by the fact that the interaction involves three parties: GP, parent (subject), child (object). The very objectivation of the child can be a source of anxiety because of, on the one hand, the parent's strong identification with the child, and on the other, because of the child's construction as fragile and vulnerable. As noted above, the interviews show that the parental role is strongly responsibilized – every decision in the present may have an effect on the child's future development. Disagreements may also arise in the parent-GP relationship on the issue of what is 'good' for the child. It is quite likely that parents' and medical professionals' notions of the child's body themselves differ and that is precisely why placing the child's body in the hands of the medical professional is problematic for parents. The interviews confirm this tension caused by the act of placing the child's body in the hands of another. Not just because the child is constructed as too 'fragile' and 'young' to be vaccinated but also because all external interventions are undesirable. This attitude is also graded – it is strongest among refusers, while among hesitant acceptors and delayers it is manifested under specific conditions – the perception of side effects – and hence the interventions through vaccine administration themselves are problematized. Still, it should be noted that it seems that in the case of refusers the risks outweigh the benefits of vaccination, while in that of hesitant acceptors the benefits outweigh the risks. But these are not stable positions, as we usually think they are; they are dynamic and vary depending on the definition of the situation. The less safe the environment around the child seems, the older the child himself or herself seems, the more inclined the parents are to vaccinate their child.

In the structuring of the parent-GP interaction upon vaccination there are a number of distortions of the service relation model as well. **First**, the premise that entry into the relationship is voluntary is violated – many of the vaccines on the immunization schedule in Bulgaria are mandatory. Hence the next phases of negotiation cannot possibly take place. The provision of information is a formal aspect of the vaccination procedure. The mandatory nature of vaccination in turn creates the possibility that, even if there is a high level of trust in medical science and the particular GP, the act of vaccine administration itself may be seen as part of bureaucratized medicine – that is, there may be a switch from personal relationship to a relationship with a representative of institutions. This aspect of parent-GP interaction raises concerns that are formed rather on the basis of trust in healthcare institutions. It is likely that the very administration of mandatory vaccines gives rise to a conflict both for the server and the served. As noted above, GPs are seen as administrators (representatives of bureaucratized medicine) most often when the respondents have serious doubts, that is, as exonerating doctors (this is especially visible in the case of hesitant acceptors). On the other hand, the fact that the relationship with the GP is binding thwarts patients' resistance, but at the same time causes a growing sense of frustration with state child-rearing institutions in general. The sense of obligation and coercion by institutions is strongest among the respondents whose children have experienced adverse reactions.

Second, as regards prevention the parent-GP relationship is dictated not so much by the occurrence of a condition (e.g., injury) as by the risk of illness. Hence it is very likely that there is a fundamental incommensurability between parents' and GPs' perceptions of risk. We may presume that a high risk perception motivates parents to engage in the relationship. But we should also say the opposite – in the absence of a perception of risk any intervention can seem unnecessary because there hasn't been an event that requires it. Vaccines are something like preliminary interventions, without reaching the threshold level for medical intervention. The explanations of parents who have no perception of risk may vary greatly. On the one hand, the environment may seem safe; on the other, the disease may seem mild. That is, in the absence of an epidemic (or when a particular disease is no longer visible), the decision-making parent cannot judge how severely ill their child would be without vaccines (Goffman, 1961, p. 331; 343). And since these interventions are preliminary, we can say that the very cycle of recovery from which the medical profession derives its recognition and prestige is compromised. Even in the event of effective prevention – that is, the child never contracts a particular disease – proper tribute cannot be accorded. This further increases the likelihood that the intervention will be condemned, since only distrust and non-acknowledgment are possible here. We can expect, then, that the most discussed issue upon immunization will be that of the possible side effects, and that every, even the mildest, side effect will raise doubts about the server and their expertise. We can confirm that it is precisely the perception of risk that differs in the different groups – to vaccine refusers, the diseases seem mild and curable, and the environment itself safe (including because of the practices of the parents themselves); hesitant acceptors are very afraid of infectious diseases and this fear prevails in decision-making; non-hesitant acceptors perceive diseases as severe and serious. Here, however, these perceptions are modified as a result of the perceptions of parental control over the environment. This again means that the period of vaccine hesitancy is usually limited in time. The side effects, in turn, do not always lead to denial of the GP's expertise even though the dominant model of explanation is precisely physician's error – which calls expertise into question. The GP's expertise is not denied when there is a good and trusting relationship with the GP and when the respondents feel they are 'playing together' with the GP.

Third, public health and GPs' practices in this field is something of an add-on function of the medical profession and goes against the logic of the service relation model because it is serving not so much the individual as the population, the 'public mandate' of medicine (Goffman, 1961, p. 339). This contradiction is revealed most clearly through the thematization of the surrendering of the child's body to the GP and acceptance of the limitations of parental competence. We can say that all parents (except for the non-hesitant acceptors) stressed that vaccination should be a matter of choice, not 'coercion', since even if we assume that the benefits are for society at large, the risks and consequences (i.e., side effects) are for parents. Overall, vaccination is in conflict with dominant trends in the perception of the parent's role – in the view of the respondents, responsibility for children is personal, not collective.

The analysis of vaccine hesitancy, proposed here, examined significant aspects of Bulgarian parents' thinking and practices regarding the mandatory vaccination schedule. Important points were identified, such as the notion of the child's body, of the interaction with institutions, of the role of parents with regard to child health and prevention. The key interaction in this context is with the GP, and the analysis through the lens of the service relation model and the deviations from it allowed us to note key points generating hesitancy or uncertainty in the interaction.

NOTES

[1] This article presents results of the research project *Childhood Immunizations: A Challenge to Contemporary Bulgarian Society (Studying Pediatrician-Parent Communication Problems to Identify Adequate Measures to Improve Immunization Coverage in Bulgaria)* (No. KP-06-OPR03/15 of 19 December 2018) financed by the Bulgarian National Science Fund at the Ministry of Education.

[2] See https://www.ecdc.europa.eu/en/immunisation-vaccines/vaccine-hesitancy (accessed 23 August 2021).

[3] Actually, the bureaucratization of medicine is often called 'deprofessionalization' since it is a major source of tensions in the medical profession (Light, 2010; Ritzer and Walzscac, 1988).

[4] Here we use the term ‘anti-vaxxers’ descriptively, not pejoratively, to refer to parents who are against vaccines and refuse to vaccinate their children.

[5] We use the word ‘homeopathy’ in the most general sense, as it was used by the interviewees. Only a single interviewee confirmed that she uses classic homeopathy (homeopathic dilution). To the rest, the term probably means various remedies other than medication – for example, various herbal and other natural remedies as well as products labelled as homeopathic.

[6] The interview with one of them was not recorded by the interviewer and is not analysed in this article.

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ABSTRACTS

Teodor Mladenov

THE SOCIAL MODEL OF DISABILITY, THE INDEPENDENT LIVING, AND THE IDEA OF 'CARE'

This article discusses the relationships between three concepts that are key for contemporary disability policies: social model of disability, independent living, and care. The first part explores the impact of the social model and independent living on the UN Convention on the Rights of Persons with Disabilities, as well as the conflict between the social model and independent living, on the one hand, and the idea of 'care', on the other. This conflict is addressed by making recourse to studies of the 'ethics of care' and by introducing a distinction between 'paternalist care' and 'egalitarian care'. In the second part of the article, these concepts are used in an analysis of contemporary Bulgarian disability policies. This includes a critique of the barriers to the independent living faced by disabled people in Bulgaria, and more specifically, of the continuing institutionalization of disabled Bulgarians, the lack of adequate personal assistance, the difficulties with providing access to inclusive education for disabled children, and the medical assessment of disability. The conclusion emphasizes that the approach of 'paternalist care' still dominates in Bulgarian disability policies. This significantly complicates the attempts to apply the 'ethics of care' in the Bulgarian context in a way that affirms disabled people's rights.

Keywords: social model of disability, independent living, ethics of care, UN Convention on the Rights of Persons with Disabilities, Bulgaria

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'NOTHING ABOUT YOU WITHOUT US!' THE SOCIAL PSYCHIATRY PROJECT IN SOCIALIST BULGARIA

This article analyses how social psychiatry in Bulgaria was framed and mobilized by the psychiatric elite under state socialism and argues that it functioned through a dual stake. Social psychiatry was asserted and promoted by the psychiatric community; in practice, however, it was reformulated for the latter's practical needs. This resulted in a convenient inversion: it was not the social that penetrated into the psychiatric system so as to subvert it from within; it was the psychiatric system – as a medical undertaking at that – which was to penetrate into the whole social body so as to keep it healthy, treat and cure, closely monitor, and never abandon it. The author argues further that this was a case of appropriation of an emancipatory, in its essence, project, which was reworked for local purposes and reduced to an adjunct of the medicalized paternalistic model. Just as social psychiatry was medicalized and 'paternalized' to the benefit of the psychiatric field itself, so too it may turn out nowadays that the UN Convention on the Rights of Persons with Disabilities (CRPD) serves primarily the expert professions, while service-users remain mostly in the passive dependent position of objects of care.

Keywords: socialism, social psychiatry, CRPD, paternalism, activism

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(UN)DESIRED IMAGES: EVERYDAY ATTITUDES TOWARDS PEOPLE WITH COGNITIVE IMPAIRMENT AND MENTAL ILLNESS

This article examines everyday practices in the public representation of two groups of people in Bulgaria: children living with cognitive impairment and adults living with mental illness. It traces the way the images of these two groups are present in the Bulgarian public sphere and the extent to which the social attitudes projected on these images ensure their integration into or exclusion from the life of the community. The article contains quotes from biographical and expert interviews with parents of children with disabilities, and with social and health professionals, as well as from news stories related to both groups.

Keywords: social attitudes, media, care, mental illness, cognitive impairment

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ADDING LIFE TO DAYS

This article presents the results of a pilot study on pediatric palliative care needs in Bulgaria consisting of an online questionnaire survey of public opinion, and a series of in-depth interviews with professionals and parents. The results have proved that there is a huge need for further research on this subject. Approximately five to eight thousand children in Bulgaria need palliative care. At the same time, there are vast differences of opinion, including among professionals, as to what pediatric palliative care consists of and how it ought to be organized.

Keywords: palliative care, children, policies, institutions

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THE GENERATION OF THE TRANSITION IN BULGARIA AND THE SENTIMENTAL NARRATIVE OF DISABILITY

This article analyses the cultural and historical background of the sentimental narrative of disability in Bulgaria. By 'sentimental narrative' the author means the narrative of living with disability which portrays the disabled either as heroes who overcome physical/mental limitations and social barriers and succeed in certain professional fields, or as martyrs and victims doomed to endless social suffering without any hope for a 'normal' future. This narrative is constructed and reproduced by the generation of the post-1989 transition in Bulgaria, which has lived through various economic and social crises and met the challenges of deinstitutionalization and the move away from the medical model of disability. Despite its key role in raising public awareness of the problems of people with physical and cognitive limitations/impairments, this generation has failed in its attempt to construct a consolidating, emancipatory narrative of disability in Bulgaria.

Keywords: generation, transition to democracy, sentimental narrative, over-responsible mothering, disability activism

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CARE WITHOUT LIMITS? THE EXPERIENCE OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

This article focuses on certain ethical issues that are evident in the images of children with autism spectrum disorders, drawn from semi-structured interviews and focus groups conducted with their parents. The main subject of study is to what extent, why, and how parents' images adopt, modify, contest and/or combine different normative models of dealing with their children's condition. Parental care is examined in the context of ethically relevant concepts, such as normality and disability, normative moral agent, and ultimately, good life. The analysis addresses the ethical limits of care experienced, as a burden, but also as an aspect of mutual growing. The ethical conceptions of vulnerability and autonomy are discussed, as well as the moral problems of stigmatization and social exclusion. The study uses biographical research methods and approaches from the field of bioethics and ethics of care, critical disability studies, and social studies of autism. A conclusion is reached that parents strive towards medical and social normalization of their children, but also respect their difference, thus attaching ethical value to it.

Keywords: autism spectrum disorders, care, parental images, ethics of autism, neurodiversity, normativity and (ab)normality, vulnerability, burden, moral agency

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Niya Neykova

THE ‘MALE’ VOICE IN CARE

This article examines the ‘male’ voice in the field of care through life-stories and aims to go beyond the stereotypical gender discourse in which men are represented mostly as ineffective in providing care because they cannot emulate (or take over completely) the role of women. Interpreting the family as the central institution in a period of crisis, the main question the article seeks to answer is what are the gender-specific roles of men and women in it. More specifically, the male voice is found to be not only different and complementary to the female voice; it voices a specific way of thinking ‘outside the system’ and even a sort of resistance against the traditional notions and state policies of care.

Keywords: families of disabled children, gender-specific roles, men’s involvement in care, father-child relationship

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Stoyan Stavru

‘LAWS FOR TRASH’: CARE IN THE AUTUMN OF LIFE (THE BULGARIAN CONTEXT)

This article examines the three bills on older persons that were introduced in the 44th National Assembly of the Republic of Bulgaria (2017–2020). A detailed comparison is made between the different approaches taken in the bills in regulating the legal status of older persons. Also examined are the objections that led to the rejection of the bills by the parliamentary majority in Bulgaria. Special emphasis is placed on the importance of the issue of the elderly's special needs and situation in the context of growing intergenerational tensions.

Keywords: older persons, bills, Bulgaria, old age, rights, care, autonomy, dignity

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Desislava Vankova

HEALTH-RELATED AGEING – DETERMINANTS AND DEBATES

The aim of this article is to analyse health and ageing in their interdependence and to debate some myths about 'the significant others', the people over the age of 65, as the fastest growing group in modern societies. The investigation of the demographic ageing and the health determinants is performed from the position of a medical doctor and a public health researcher. Data from large-scale sociological studies are presented as proof that healthy habits greatly improve health-related quality of life and prolong life. On the other hand, there is age discrimination in healthcare, which, together with poverty, determines the gloomy picture of our ageing society. In the context of the historic political changes after 1989, the term 'fourth value transition' is introduced, which unites themes of sustainable societal efforts to achieve a better health-related quality of life in opposition to the banalized and socially demobilizing myths regarding old age and population ageing.

Keywords: health promotion, health determinants, ageing, bioethics, quality of life, integrative approaches

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(IN)FORMAL CARE IN A HISTORICAL FRAMEWORK

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Milena Iakimova

MOTHER KNOWS BEST

Vaccine Risk Taking in the Context of the Cultural Model of Good Mothering

This article outlines the figures of childhood vaccine hesitancy among affluent urban mothers in Bulgaria and the context of these figures. This context is dominated by the intensification of parenting and the centering of care in the children themselves – raising children according to their (rather than their parents’) best interests. This pattern of parenting prevails among the mothers whose interviews are analysed here: semi-structured interviews with middle-class well-educated parents (mostly mothers) with stable incomes and one or two children. The primary task is to listen to and take seriously their hesitancies, concerns and anxieties, which are encouraged and directed by certain active minorities on social media.

The mothers are interpellated in the responsibilizing discourse, they identify themselves with the position it places them in and, through this position, seek social recognition. Against this background, the article outlines their notions of ‘immunity’, of ‘life’ reduced to ‘health’ terms, of naturalness, of questioning the universalistic claim of science.

Keywords: vaccine hesitancy, intensive mothering, immunity (strong, natural, individual), mother-doctor relationship, responsibilization

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Veronika Dimitrova and Maria Martinova

TYPES OF HESITANCY ABOUT MANDATORY CHILD VACCINATIONS IN THE DOCTOR-PATIENT INTERACTION FRAMEWORK

This article is devoted to parental hesitancy about the mandatory childhood immunization schedule in Bulgaria. The term 'hesitancy' describes the growing uncertainty and actions to delay or refuse childhood vaccinations. In the specific analysis based on semi-structured interviews with parents, the issue of vaccine hesitancy is examined through the lens of the doctor-patient interaction framework. The focus is on outlining the types of vaccine hesitancy and the reasons for them. New parenting styles and parental responsibilization, in turn, undermine parents' trust in GPs; parents are becoming experts on their children. It seems that the doctor-patient relationship has become more horizontal. This kind of parental 'expertise' in turn leads to the emergence of a common enemy of the overall construction of the child's body – 'terrible chemistry', unnecessary interventions in the body, where vaccines are among the 'risky' and 'dangerous' interventions. Thus, vaccination turns out to be a process of balancing between fears – of the disease and of its side effects. Hence, respondents also raised the issues of 'coercion to vaccinate' and 'parents' right to choose', which contradict their understanding of parental role and responsibility.

Keywords: immunization/vaccination, trust, hesitancy

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