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"Who Will Take Better Care of Him Than Me?!" Perpetuating Institutional Culture in Families of Children with Disabilities in Bulgaria

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Abstract: The right to live in the community is fundamental and is directly related to the possibility of independent living for persons with disabilities, a central principle of the UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Bulgaria in 2012. The opposite of these principles is living in an institution, and being compelled to reside in a space where one does not have the ability or one is not allowed to exercise control over one's life and day-to-day decisions. Through oral history and anthropological reconstructive analysis, with a special focus on the cultural contexts and social meanings of personal experience, we explore how families of children with disabilities are simultaneously victims of the local disabling legacies, environments and practices, and key agents that effectuate and perpetuate institutional culture. We highlight the dynamics and interactions of the traumatic images on the legacy of state socialism, the actual barriers during the transition period, the coping strategies chosen by families and, ultimately, the grim effects with regard to the affirmation and implementation of the idea of independent living for people with disabilities in Bulgaria.

Keywords: deinstitutionalization; institutional culture; independent living; postsocialism; families of children with disabilities

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1. Introduction

The right to live in the community is fundamental: it is defined as "a foundational platform for all other rights: a precondition for anyone to enjoy all their human rights is that they are within and among the community" [1] (p. 5). It is directly related to the possibility of independent living for people with disabilities, which is a central principle of the UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Bulgaria in 2012. The opposite of these principles is living in an institution, in an environment and culture defined by "rigid daily routines and rules" that do not allow for choice and control over one's personal life, nor over the necessary support [2] (p. 122). In this sense, deinstitutionalization should provide for "a shift in living arrangements for persons with disabilities from institutional and other segregating settings to a system enabling social participation where services are provided in the community according to individual will and preference" [3] (para. 25) [4] (p. 4).

The process of deinstitutionalization in Bulgaria can generally be defined as a process of constant substitution of the real meaning of this concept. The Bulgarian state officially launched this process in 2010. The event that provoked its intensification, three years earlier, was a BBC documentary on a social care home for children with physical and mental disabilities in the village of Mogilino, Bulgaria's Abandoned Children [5]. The appalling conditions revealed by the documentary, namely, sixty-five children totally deprived of individual health care, socialization and education, malnourished and sedated with drugs, some left in bed for years, brought the issue of deinstitutionalization in the country into the public spotlight. Eventually, the Bulgarian state was forced to take action to close down large institutions [6,7].

What happened subsequently, however, showed a particularly persistent entrenchment of the practices and attitudes characteristic of large institutions. Evidence of this began to appear soon after the official start of the deinstitutionalization process. In 2013, the Centre for Independent Living–Sofia documented the existence of "paternalistic attitudes of the staff, bloc treatment of residents, top-down decision-making, lack of choice on the everyday level, and isolation from the larger community" [8] (p. 1218). Key markers of community support, such as personal assistance, peer support, employment opportunities, and accessible housing, were missing [8,9]. In the following years, a series of reports from various organizations continued to document the failures and transformation of deinstitutionalization in Bulgaria into variations of reinstitutionalization [5,9] which, on top of that, was generously financed by European Structural and Investment Funds. One of the most recent reports is ENIL's Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union (February 2022), which shows that Bulgaria is among the countries that heavily rely on the proliferation of group homes and other segregated residential settings [10] (p. 11).

All of this is indicative of the persistence of the institution in Bulgaria, which can be defined as "any place in which people who have been labeled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size" [11] (p. 7). In such a local context, we should not be surprised by the conclusion that "institutional culture persists throughout all service structures designed to serve people with disabilities" [6] (p. 27), often including the family.

Until now, however, the attention of the various observers and human rights organizations has always been focused solely on the structures providing services in Bulgaria. What has largely been absent is a focus on families, and on the ways in which institutional culture is perpetuated and privileged in this space, which we are used to perceiving as private and as providing the best care by definition. This was recently affirmed in the very important Guidelines on Deinstitutionalization, including in emergencies, which states that "for children with disabilities, deinstitutionalization should be directed towards protection of the right to family life . . . For children, at the core of the right to be included in the community is the right to grow up in a family. An "institution", in the context of children, is any placement that is not family-based" [12] (IV, C, 43).

Thus, the aim of this analysis is to demonstrate how the family and the care for children with disabilities that it provides could also be a persistent generator of an institutional culture that does not produce mechanisms and opportunities to challenge the denial of independent living and life in the community. As we attempt to show, when situated in a specific larger constellation of factors, families reproduce some of the "defining elements of an institution, such as . . . no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; . . . rigidity of routine irrespective of personal will and preferences" [12] (III, A, 14).

Our intention here, however, is not to construct explanatory schemes based on abstract concepts of autonomous maternal/parental choice made in the isolated, intimate interiority of care, or on the even vaguer notions of a "local mentality" that is "patriarchal" in nature and drives families to sustain and affirm the relevant practices and attitudes, to value them, and even to feel ashamed and guilty if they want to leave their confines. On the contrary, we start from the understanding that the families of children with disabilities in Bulgaria are situated in a complex of legacies and current conditions that are deeply disabling in their very essence. As Sara Ryan and Katherine Runswick-Cole note regarding Western contexts, the complex and limited trajectories for navigating disability landscapes on the part of parents of disabled children and the strong stereotypes and assumptions that exist are in fact "a disabling set of practices" [13] (p. 201). These disabling environments and practices [13,14] have long been researched in Western contexts. In this article, we analyze them in a different context, a postsocialist one, with its specific intersectionalities, which produce specific local forms of disablement. It is these elements that drive families of children with disabilities in Bulgaria to almost invariably take on basic institutional characteristics.

In the next part of this article, we present the theoretical background, data, and methodology we used. The third part starts with a brief sketch of the local context, which combines heavy legacies and new challenges that reaffirm paternalist attitudes. The rest of it is devoted to data analysis and discussion, and is organized into four subsections that highlight the dynamics and interactions of the traumatic images on the legacy of state socialism, the actual barriers during the transition period, the coping strategies chosen by families and, ultimately, the grim effects with regard to the affirmation and implementation of the idea of independent living for people with disabilities in Bulgaria.

2. Local Context

Disability politics in Bulgaria is deeply marked by overlapping legacies combining the practices inherited from state socialism, the neoliberal-inclined postsocialist transformations after 1989, and the continuing weakness of disability activism and, particularly, of the self-advocacy initiatives by people with disabilities themselves [15].

Disability management in socialist Bulgaria can most generally be characterized as medicalizing and productivist oriented, ultimately resulting in strong paternalism [15–17]. The conceptualization of disability in this period was based on the idea of the inability to work and was treated through various forms of (re)insertion of disabled people into the process of productive labor (trudoustroyavané). This, however, was only possible after the so-called labor-expert medical commissions determined the degree of reduced capacity to work and issued work placement recommendations for the disabled person [17]. The strong paternalism and central role of medical professionals persisted after the collapse of the regime and can also be clearly seen in contemporary disability policies in Bulgaria.

These contemporary policies are implemented in a context in which the market paradigm, the idea of the minimal role of the state, and personal responsibility and enterprise are dominant and valued. On the one hand, this amplifies some aspects of the inherited productivism and forms a hierarchy of worth at the top of which are those people with disabilities who can be "productive"; on the other hand, it enables and legitimizes initiatives to curtail the welfare state, resulting in chronic under support of people with disabilities [15]: miserable "invalid pensions"; underfunding of health care, social services and community support; insufficient and inadequate assistive technologies; the real impossibility of people with disabilities to integrate into the labor market, etc. At the same time, the neoliberalization of social services, the imperative to generate profits, and the lack of strict quality control have had a very negative impact on the social services sector, as can be seen from the failures of the deinstitutionalization process noted above.

A closely related aspect that has played a crucial role in the specific profile of local disability activism is the absence of strong voices of disabled self-advocates. In the context of the disability rights movement in the West, it is precisely this type of mobilization that has a crucial impact. The slogan "Nothing about us without us", which in the Global North sums up the transformative political project, known as the social model, aimed at securing the rights, independence, and self-determination of people with disabilities, and calling for radical resistance to paternalistic and medical approaches, has never succeeded in permanently inspiring organizations in Bulgaria. Some principles of the social model, namely the integration, empowerment, and independent living of people with disabilities, have been mobilized by parental activism. This is another fundamental difference from the way disability activism has unfolded in the West where, in the history of disability rights struggles, parental organizations have been seen as a barrier to authentic activism by people with disabilities themselves [18,19]. In Bulgaria, the absence of vibrant, visible, and effective self-advocacy is the product of a constellation of factors: the stifling of citizen initiatives during state socialism; the traditional appropriation of the voices of people with disabilities by so-called “caring” professionals [20]; and the objective fact that there are simply not many adults in Bulgaria with certain types of disabilities, for example, people on the autism spectrum or with Down syndrome, who have received the appropriate support, enabling them to develop their full potential and to become leading figures in activist struggles. The latter is another unpleasant consequence of disability management in socialist Bulgaria, which segregated children with disabilities into the field of so-called defectology.

3. Conceptual Background

Conceptually, the present analysis is situated within a broad and burgeoning research perspective that is focused on the concept of “disablism” [13,14]. Carol Thomas defines disablism as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” [21] (p. 73). In this definition, we see that the focus is on people with disabilities themselves; hence, those who are closest to them, “husbands, wives, partners, parents, other family members”, are conceptualized as “agents of disablism” [22] (p. 48). Subsequently, however, Ryan and Runswick-Cole have problematized this, characteristic of Western disability studies and disability activism, as the unambiguous relegation of parents to the camp of those who exercise oppression, and insist that “parents, too, experience the psychoemotional aspects of disabilism” since they “experience directly and by proxy many of the discriminatory practices and attitudes their disabled children face” [13] (p. 202). This conceptual shift enables researchers to view the situation of parents and families of children with disabilities in a broader historical, social, and economic context, and to highlight factors, such as the lack, insufficiency or inadequacy of social services, information, and support networks [13] (p. 202). In other words, parents and families of children with disabilities operate in a disabling environment in which they have to navigate “a very narrow and often inflexible system of benefits, allowances and access to various resources”, permeated by “oppressive cultural ideologies of mothering” [13] (p. 206).

The conceptual background should also be complemented with a short explanation about the use of the term “institution” and “institutional culture”. The range of research perspectives that analyze institutions, their impact and effects on the identities and interactions of social actors within them, and the role of institutions in the wider context of social systems, is vast. One of the seminal analyses is Erving Goffman’s *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (1961), in which he examines total institutions and their impact on inmates’ identities, and defines them as “a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life” [23] (p. xiii). Later, a number of scholars turned their attention to the internal mechanisms of functioning and the interaction of the social actors involved in hospitals and asylums, and to questions on whether, and how, institutions depend on and are defined by their size. Many of them have concluded that size does not matter and that the characteristics of institutional culture are transferred to smaller-sized facilities, thus turning the latter into micro-institutions [24,25].

4. Materials and Methods

Proceeding from the intersection of these conceptual lines and applying oral history and anthropological reconstructive analysis [26], with a special focus on the cultural contexts and social meanings of personal experience, we explore how families of children with disabilities in Bulgaria can incorporate and perpetuate institutional culture themselves. We relied on thematic analysis [27] in order to identify the main themes within the data and to structure our analysis around them.

Our main source of data are the interviews and focus groups conducted in 2017 and 2018 (first round) and in 2020 (second round) for the project Generational Patterns of Coping with Life Crisis: Biographical, Social and Institutional Discourses, implemented by researchers from five academic institutions (Sofia University, the Bulgarian Academy of Sciences, the New Bulgarian University, and Plovdiv University). One of the authors was the leader of this project and both were involved in the interviewing process. The respondents are anonymized using pseudonyms. All respondents signed informed consent forms.

One of the goals of the above-mentioned project was to describe and analyze the individual and group, the formal and informal patterns, and discourse related to the care for people with disabilities and chronic health conditions in Bulgaria, where family patterns of care predominate. That is why we first approached leaders and members of parent associations and NGOs engaged in social and legal advocacy in support of people with disabilities and their families. The aggregate data on the socio-demographic profile of those among them, and among the people we contacted through them, who agreed to a biographical interview or to participate in a focus group, sixty-three people in total, clearly show that they are a highly homogeneous group and, moreover, not only because of their shared organizational and parenting experience. Most notably, almost all respondents were women (only three were men, two fathers and one grandfather),mostly mothers (and three grandmothers), which unequivocally shows the gendered nature of care in Bulgaria. The majority were born between 1960 and 1980 (a total of thirty-eight versus fifteen born between 1940 and 1960, and eight born in the late 1980s and early 1990s), that is, they belonged to one and the same generation insofar as their childhood or youth was spent during the period of late socialism, while their maturity and parenthood stage coincided with the first decades of the so-called transition, after the fall of state socialism. All of these common features took on a particular meaning in light of the specific and similar construction of the identity and acquisition of the new social and activist agency when faced with disability. Thus, without exception, all had experienced extraordinary hardship and suffering in caring for their children, and this had driven them to seek some form of social support and social services in the community, and to become advocates for disability rights. They were members of parent associations and other NGOs, users of social services and innovative therapies, participants in national and international projects, organizers of campaigns and protests. At the same time, they all shared the opinion that mothers are the only ones who understand and can respond adequately and well to the needs of children with disabilities. Hence, quite a few of them were personal assistants to their adult children and did not see a really good alternative to parental care. This dual identity, of carers for the social inclusion and integration of their children, and of primary and indispensable caregivers, can be seen as a direct result of the encounter both with the late effects of the socialist ideological and institutional framework of disability, and with the (ab)uses of EU directives and programs for free, dignified, and independent living. Accordingly, their life trajectories, with their various turning points, discontinuities, and ambiguities, as the interviews very clearly showed, have been marked by numerous social changes and shifts in leading paradigms since 1989. First, among them, is the process of deinstitutionalization and the attempts to replace the medical with the social model of disability, but also the transformation of a significant part of the nascent community services into small-scale institutions, or so-called reinstitutionalization mentioned above. As we shall try to show, mothers are direct witnesses of and (in)voluntary participants in the still-to-come transfer of support for people with disabilities from institutions to the community in Bulgaria.

5. Results

5.1. The Traumatic Memory of the Social Care Homes of the "People's Government"

Symptomatically, the female respondents' accounts almost invariably began with a recollection of the excruciating experience of choosing whether or not to leave their newborn child with a disability in a children's social care home. They faced this choice immediately upon receiving the diagnosis but reasserted it over many years, as it meaningfully organizes their whole biographical narrative. Thus, after hearing the "frightening" and "almost incomprehensible" medical terms describing their child's condition, mothers received the well-meaning advice from doctors and nurses to leave the "problem child" in a specialized institution in order to "save themselves the suffering", "to go on and have a healthy child", and to not "ruin the family" (Elitsa, 44, Plovdiv, electrician, personal assistant, caring for a daughter with hyperammonemia). To Teodorina (47, Pleven, psychologist, caring for a son with autism), such words "sounded like a verdict" that echoed in her mind when entering hospitals and doctors' offices. At one focus group, a respondent said that an acquaintance of hers with a newborn with Down syndrome had been told that "he'll never amount to anything" so she had better not take her baby home, while another respondent (from a parent association) reported a sad statistic: "More than fifty percent of our parents [members of the association] have been told, 'Leave them in a [children's social care] home'. Even recently" (focus group, Varna, 17 August 2017).

Despite the bleak and apocalyptic future predicted by medical experts and, as the respondents openly admitted, their hesitations and "temptations" fueled by these predictions, none of them chose to abandon or send their child to a so-called specialized institution, because this endangered the physical survival of children:

> *"From what I've heard so far, my impression is that if you left your child with such problems in a [social care] home, this was well-nigh tantamount to a death sentence for them—however much parents may have been reassured that their children would be cared for better there . . . "* (Tsvetana, 55, Varna, personal assistant, caring for a daughter with moderate intellectual disability).

This "impression", which undoubtedly had a direct impact on the mothers' decision "to go home with their child", was associated with or invoked a sinister image of socialist state-run institutions:

> *"During socialism, they kept them away from everyone, in various remote places, in homes with about a hundred, a hundred and twenty people, with terrible hygiene, they probably drugged them too . . . And no one knew what was happening to them . . . "* (Focus group, Plovdiv, 21 November 2017).
>
> *"While they were [kept hidden away] in the dense woods ten or twenty years ago, as I put it, and were regarded well-nigh as some disgusting creatures and were abused, now people are coming out of these woods . . . "* (Dimana, 45, Lovech, housewife, caring for a daughter with cerebral palsy and epilepsy).
>
> *"Few of them survived, part of them were placed in [social care] homes because the people's government encouraged the abandonment of children [with disabilities], saying: "We, the state, will take better care of these children in these homes". Then the homes became orphanages, of which Mogilino became a symbol. But now our care for people with disabilities has certainly prolonged their lives"* (Focus group, Varna, 17 August 2017).

It is no coincidence that the children's social care home in Mogilino was mentioned in the quoted excerpt, as well as in several interviews. In addition to the fact that the screening of the above-mentioned BBC documentary, *Bulgaria's Abandoned Children*, led to the first removals of children from institutions in the country, it also gave rise to some of the first protests by mothers of children with disabilities (including several of the respondents). Mogilino, thus, became a symbol of the most monstrous manifestations of the institutional practices of care for children with disabilities in Bulgaria, practices which had been hidden from, and neglected by, the public for many years. And, although they did not say so explicitly, the respondents saw a continuity between the practices in question and those in socialist institutions. Against the backdrop of the abuses in these institutions, care in the family appeared to be not just the better and more moral choice, but the only purely humane choice. To quote Polya (46, Varna, social manager, psychologist, personal assistant, caring for a son with multiple disabilities), "when you've seen how they are abused in Mogilino and in the other homes, you can't even think about other options except home care anymore".

5.2. In the Shadow of Postsocialist Institutions: Involuntary Confinement within the Family and Social Isolation

The mothers’ recollections of their earliest and most basic experience of disability, namely until their children came of age, reinforced their notion of parental care as the only alternative to care in state-run institutions. Moreover, they revealed temporalities and spaces of care within the family that constituted portals of postsocialist institutional culture, primarily by virtue of the unwavering influence of the medical model. In quite a few cases, the diagnosis turned into an indelible social stigma, constantly recalled by medical professionals and experts, and did not even allow parents and children to enjoy the comfort of the family home, let alone allowing them to have access to free social routes. The first months or years after childbirth were often marked by continuous and long stays in hospitals and visits to the offices of all kinds of luminaries and therapists, whom mothers had to plead with like “deities” and never stop thanking them when they identified the exact disability or prescribed the right medicines (focus group, Varna, 18 August 2017; focus group, Lovech, 25 April 2018).

Then, came the long years in rehabilitation centers and in auxiliary schools, where children were treated only “en bloc”, i.e., the support consisted of giving them the opportunity to interact only with children in a similar condition and with specialized staff, and to develop not according to their personal potential but according to medically defined “disabilities” and deficits. Thus, when Tsvetomira (71, Plovdiv, housewife, caring for a son with moderate intellectual disability) said she wanted her son, who had 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!” Also, on the advice of doctors, Polya went for rehabilitation with her 10month-old son Ivo, who has cerebral palsy, autism, and a spastic lung, to a sanatorium hundreds of miles from the town they live in. As the sanatorium was overcrowded, they were put up for a week on the top fourth floor, where the rooms for children from state-run homes were located. Polya still cannot forget the sight of the hungry little children who were crying “Mummy” and clustering around her as they expected her to give them food, and who were later literally hosed down in heaps by the staff. On top of this, she felt extremely isolated and disoriented because neither the staff in question nor the doctors exchanged any words with her other than “commands”. Despite the nightmarish situation, in the next eight years she and Ivo spent a few months in a sanatorium at least twice a year, because this was the only chance to fulfil the most important medical prescription and a cherished maternal dream: “that he would be able to stand upright and, in the best case, learn to walk”.

Contrary to the expectations formulated in the visions and programs of NGOs in this period, the family home proved to be just as prone to the risk of becoming, albeit a smaller and less hostile environment to the child with disabilities, yet nevertheless a closed institution with a rigid, monotonous, and repressive routine. In the interviews and focus groups, members of the Varna Parent Association repeatedly mentioned and referred to the 2015 TV documentary by well-known Bulgarian journalist Mirolyuba Benatova, titled *Zalozhnitsi na detsata si* (Hostages to their children) [28], in which three of them participated together with their families. Not only does this documentary employ implicit messages and aesthetics that are similar to those in the BBC documentary about the Mogilino home, but also uses the most notorious footage from the latter in the opening section, showing children in a terrible physical condition rocking back and forth and making unintelligible sounds. This is followed by footage of youths in wheelchairs or in bed glancing at the camera in despair and distress or performing special exercises on equipment or on the floor under their mothers’ commands in the family home. Parallel to this, the mothers themselves talk about their “descent into hell”, about financial problems, about countless visits to various officials and departments just to qualify for a miserable pension or to get a wheelchair totally inappropriate for their child’s condition, while having to hear offensive and derogatory remarks. With tears in their eyes, they admit that they feel imprisoned and often think about suicide because “there’s very rarely someone to help you”, “even just to go out”, and because instead of being acknowledged for not leaving their children in a home, they are in fact “condemned” to live a wretched and unbearably difficult life. The main, explicitly articulated, message in this documentary is that a “veritable genocide” is taking place that must, but cannot be, stopped because of the monstrous indifference and repressive, bureaucratic system of the state.

The same bleak storyline and messages appeared in the respondents’ biographical narratives, especially in their accounts of their desperate search for support and elementary help to meet the most basic needs of their children at an early age, something which they never found, or which constantly eluded them. Relatives and friends refused to give mothers even an hour’s respite, fathers often left their families, administrative staff did not give them the necessary information, behaved “extremely coldly”, or responded only when there was a risk of a scandal, and employers politely refused to employ mothers of children with disabilities. Entering and remaining in ordinary kindergartens and schools became a heroic act; the respondents were often persuaded to keep their child at home or were constantly summoned to “take matters into their own hands” at the slightest unusual behavior by their child.

This structurally determined impossibility for children with disabilities to be outside their home led to the descent into an extremely regimented, disciplined, and oppressive daily routine and, in fact, to the convergence of the symbolic and moral boundaries between the depersonalizing world of institutions and the confined, intimate world of the family. As Polya said, “care is 24/7”, between feeding, washing, and toileting, and lifting, and pushing wheelchairs, mothers had to cope with epileptic and autistic crises, severe bouts of illness and communication difficulties, while they themselves suffered financial hardship, depression, divorce, exhausting bureaucratic procedures, and the need to quit their jobs. If the fathers had not left their families, they were working as long as possible to earn the necessary money and were no less constantly tired and exhausted. For their part, the children suffered all sorts of insults at school or in urban spaces, made incredible, but often unsuccessful efforts to learn to read, write or speak, and stayed indoors because their mothers were afraid to let them out into a world that seemed too hostile. In the words of the leader of one of the organizations for people with disabilities, herself a person with a disability, parents did not have the courage to separate from their children out of “fear that something may happen to them” and under the pretext that “it’s too dangerous outside”. As she said, “the children are locked at home all day... That’s how they cripple this child for life...”

But outside the home, children with disabilities (and their parents) suffered, and continue to suffer, exclusion by the community. After listening for years to “thousands of absurdities” about herself and her son, who is blind and has Down syndrome, Vanya (59, Varna, construction technician) continued to suffer offensive comments when taking the now 25-year-old Georgi for a walk in the neighborhood:

> *“And some grandmother rushes towards us, starts making the sign of the cross, pulling him; I tell her, “Now wait a minute, he isn’t contagiously ill, he doesn’t have leprosy or the plague.” Walking away, I’ve heard comments such as “Where’s this mother taking this child, why has she brought him here to scare our children?!””*

The respondents generally blamed abstract and over-personified social actors for all of this, the motif that “the state is a stepmother to our children” is recurrent both in the above-mentioned TV documentary and in the interviews, but behind this sentimental accusation there is in reality an almost complete lack of forms of community support:

> *“When there is no care for the children, the parents take on double, triple and even more [work], and they thus do much more for this country and society, but nothing is done [to care] for them. For overwork, despite the emotional aspect, there is nothing in return”* (Focus group, Sofia, 16 May 2018).

5.3. Paternalistic Model and Sanitized Womb Capsules

There is another, no less powerful, factor for social exclusion and the impossibility of acquiring independent living skills in Bulgaria, and that is the paternalistic reduction and contraction of family care to predominantly maternal care which, moreover, should cover the entire life cycle. Returning home with their newborn, mothers were greeted with words like "*You* gave birth to her, *you* will look after her" (focus group, 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 registered deviations from the medical or social norm. Tsvetomira (70, Plovdiv, housewife, caring for a son with intellectual disability), said her husband told her almost every night: "The child's your problem, you deal with him, I want you to give me something to eat and drink, make my bed for me to sleep in—and nothing else".

And, just as the professionals invoked their authority and medical expertise, husbands, relatives or neighbors invoked the sacred authority of the familial community to dissociate themselves and to establish insurmountable "healthy" distances from the world of disability, imputing excessive biological and social responsibility to the mother of the disabled child. Thus, Asya (39, Varna, social worker, caring for a daughter with intellectual impairment) said the following:

> *"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".*

As much as the paternalistic sanction of parental care caused pain and bitterness, as the above excerpt shows, the majority of respondents accepted their prescribed identity and internalized their role, both as destroyers of sound family relationships and laws, and as sole guardians of life with a disability. Bogdana (68, Varna, insurance agent, pensioner, caring for a daughter who has Down syndrome) strongly believes that "the truth is that it's mothers who are the primary carers of these children" and, like many other members of what she calls a "parental cooperative", it is she who took her daughter to therapy appointments, negotiated with school staff, dealt with red tape, and argued with social workers and labor office employees in order to "secure a dignified life for her daughter". In her case, as in many others, the acceptance of "the truth" led to the almost complete subordination of the mother and the child to the intimate consolidation and social legitimation of their symbiotic bond:

> *"We were like stickers"* (Denitsa, 43, Varna, social manager, caring for a son with hydrocephalus).
>
> *"We were inseparable from each other"* (Krasimira K., 40, Varna, social manager and occupational therapist, caring for a son with cerebral palsy).
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> *"I'm not thinking of my daughter only. I look at them—curled up in a fetal position and staring at nothing. And I go crazy"* (Magdalena, 41, Sofia, administrator, caring for a daughter with Cornelia de Lange syndrome).
>
> *"I never thought I would ever work, I thought I would care for this person all my life, I've tried to start work several times, but caring for my son has pulled me back—it's like having a rubber band around your ankle or a stone tied to your leg that prevents you from*

> *flying"* (Polya, 46, Varna, social manager, psychologist, personal assistant, caring for a son with multiple disabilities).

The above quotes show very accurately how the structural, disabling conditions of past experience, namely the socialist institutions, the local culture of paternalism, and the social and economic crises of the transition in Bulgaria, compelled mothers and children with disabilities to withdraw into a protective, sanitized womb/capsule [29] (p. 9) that would denounce the system and save them from society or from the "stepmother state", but that would also affirm their hegemonic legacies.

5.4. Deautonomization of People with Disabilities

Although they acknowledged the existence of an inseparable, symbiotic bond between mothers and their disabled children, in the present too, most of the respondents believed that they had done everything in their power to resist being confined to the family home and assuming a fetal position. Like Dimana, they were convinced that the "dense woods" were far behind them or that the greatest difficulties in obtaining social support were long past. By virtue of belonging to the generation of the transition in Bulgaria, they witnessed and were directly exposed to/targeted by the late negative social effects of postsocialist institutional culture, as well as by the new social policies on disability and community services that were slowly and precariously making their way in the country. What is more, with their selfless commitment to motherhood, after 2010, when their children started or finished primary and/or high school, they eagerly embraced even the slightest opportunity to receive support and to test (within international programs or NGOs' agendas) the emerging social services.

Especially emblematic in this respect is the case of Polya, who spoke directly about a period of "coming out of institutions" and "opening a window to the world". This was the time when she actually began her activist work in advocacy for the rights of people with disabilities. Together with other mothers, she was involved in various public initiatives, campaigns, and international projects, closely followed all the legislative changes and projects, and was not afraid to seek media publicity, and spearhead protests on "difficult causes". Meanwhile, Polya acquired many scientific, professional, and social competences that she believes helped her to provide, in her words, a better quality of life for her son and for people with similar disabilities; she obtained a Bachelor's degree in social work and a Master's degree in psychology, and took part in various training courses (for social work associates, on working with people with intellectual disabilities, for cognitive therapists, etc.). Last, but not least, Polya began to monitor and participate in the implementation of so-called community services, which were widely introduced in Bulgaria after 2012. She actively helped run a day-care centre for young people with disabilities and visited and interacted with staff at sheltered housing and family-type residential centers.

Regarding the development and implementation of such, let us call them, ambitious strategies for coping with the personal and social situation of disability, a number of contemporary researchers have drawn attention to the fact that mothers tend to take on excessive responsibilities as carers, to prolong the period of care as much as possible, and to "extend their caring role to broader community or societal concerns" [13] (p. 205). Thus, the opportunities for "coming out of the dense woods" provided by deinstitutionalization have turned into a space for the unlimited expansion of the womb/capsule and its transformation into a "parallel world", as one of the parent associations in Plovdiv has tellingly named itself, namely a world in which both mother and child feel more protected and supported, but which continues to separate them from the society of "normal" people. It has turned out that the efforts to improve the lives of children with disabilities have also "opened windows" for establishing greater control over them. Entering the day-care centre, Polya's son Ivo relied for years on the attention and help of his grandmother, who worked there as a carer; Polya was (and is) his paid personal assistant and unpaid teacher, therapist, and the organizer and initiator of most of the public events he was involved in (such as trips to the city centre or charity campaigns by the parent association). Especially telling in this regard is the oscillation between the combination of autonomizing and deautonomizing practices and discourses on family care, which found particular expression in the conducted focus groups where, as a rule, various self-censorships, and ideological framings of lived experience were relaxed more quickly. For example, a participant in a focus group (Lovech, 26 April 2018) spoke in a definitely approving manner about the various current opportunities for social inclusion; notably, however, she did so right after she had unequivocally defended the imperative nature of motherhood:

> *"But I want me to take care of him instead of hiring someone and going to work. It's a conscious choice, it's a priority for me, to keep him alive, healthy, and [to help him] develop as much as he can, we work [on his development] at home, I'm doing my best. I can't just leave him sitting with someone".*
>
> *"We use an auxiliary school, we also use the services here, and when he was younger we also took him to speech therapists for private treatment. I rely on the way he is taught and the way he interacts with people to help him in his development".*

In a similar vein, another participant (Focus group, Pleven, 25 April 2018) was indignant about the fact that due to the absence of a day-care centre for adults in the city, "it gets worse because such a young person has to stay home with his parent, he has nowhere to go to anymore". At the same time, she ruled out any possibility of living with disability outside of parental care, regardless of the extreme self-sacrifice this requires:

> *"I have to let my child be looked after by someone like a foster parent, for example, so how will that child feel? Who will take better care of him than me?! No one. How can I go to work when I'm with him. It's simply that one of the family is doomed. One parent has to do everything".*

Striving to justify their belief that they alone are the bearers of true knowledge about their child's specific characteristics and special needs, some of the respondents went as far as to reproduce medicalized and dehumanizing images of living with disability:

> *"This is the most dreadful thing: you have to constantly keep an eye on what he is doing, because he doesn't realize the risk. He may be ten years old, but intellectually he is three. You look after a baby all your life and that's your main preoccupation"* (Focus group, Pleven, 25 April 2018).
>
> *"She's mobile, but she's like a rag doll—she can dress herself, she can work on the computer, and we've made progress—she can stay home alone for a few hours, she can go buy something when I write her a [shopping] list, she can take out the trash, she can work on the computer. She's twenty years old"* (Velislava, 47, Plovdiv, private business manager, caring for a daughter with cerebral palsy).

Last, but not least, the respondents often unintentionally symbolically equated parental care with the total supervision of the individual and their personal life in closed institutions:

> *"For the time being I control everything, I mean, I manage to control things, but later on … God knows, we'll see how it goes"* (Focus group, Lovech, 26 April 2018).

This often toxic bond between mother and child was also observed and discussed by social workers, what is more, it was pointed out as a barrier to their work with service users. In a focus group with professionals from the Global Initiative on Psychiatry–Sofia, one of the NGOs in Bulgaria that operates both as a service provider and is engaged in advocacy, a participant recounted her encounter with such an impenetrable "capsule":

> *"Only once have I ever told a family that came [to see me] to leave immediately. They kept referring to "the child", but "the child" was in fact a woman of forty who had never seen a psychiatrist, never undergone treatment, never worked—she just sits and colours all day long … 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 helps that you withdraw from the world and create a whole new reality—I don't know if you can grasp the scale of this".*

A specific high point in the exercise and an assertion of such over-responsible parenting were the 2018 protests by mothers of children with disabilities in Bulgaria. They showed, very well, how the withdrawal into a womb/capsule was initially justified by the adverse structural, historical, and cultural conditions described so far, but then gradually turned into something like a conditioned reflex or routine act against any change in the environment. What is more, this withdrawal contributes to change, often being thought of in terms of the benefits and harms it will bring to the family, without drawing or maintaining the line between private and public interests, namely between the demand for (financial) support for the provision of parental daily care and the quest for justice regarding the lack of community support for people with disabilities. The central demand of those protests was the adoption of a Personal Assistance Act to guarantee independent living for people with disabilities and their inclusion in the labor market [30]. Initially, this demand of theirs seemed to be entirely consistent with the social model of disability and the CRPD paradigm based on the latter, but once the newly adopted Personal Assistance Act was enforced, it became clear that it would not be used to expose the systemic violation of the rights of people with disabilities and to provide the conditions for autonomy. Instead, and as a result of the strong and unambiguous pressure from the protesting mothers, it actually facilitated the reinforcement of the family institutional culture of disability. They insisted, and ultimately achieved, that they be guaranteed the choice to be personal assistants to their children and to receive the desired, much-needed financial support to cover their various and specific needs, but again within the family.

6. Discussion

The purpose of this analysis is to explore the combination of various factors that are specific to the Bulgarian postsocialist context and that produce the same disabling effects on families of children with disabilities. One such effect, in our view, is the reproduction of institutional culture within families, or, as we call it here, the “Who will take better care of him than me?!” effect, that is, the confinement of children with disabilities mainly in the home, not letting them acquire autonomy and coping skills, the emotional and physical symbiosis of the mother and child that lasts until the latter’s maturity, the subjection of the child to a strict daily routine, and the unequivocal preference mostly by mothers (more rarely by fathers or other relatives) to be personal assistants, something which is unacceptable and deeply damaging from the perspective of the philosophy on independent living. As one quite recent piece of analysis claims, “the over-reliance on family members to provide personal assistance in familialist contexts has contributed to the ‘institutionalisation at home’ of disabled people . . . ‘Institutionalisation at home’ has also been fuelled by the persistent lack of adequate formal supports in the community” [31] (p. 13). Locally, there are occasional critical voices, for example, from the Centre for Independent Living–Sofia [32] and some service providers who are trying to affirm the principles of the CRPD, but this is far from enough in order to provoke real change.

The project team revisited two of the cities where the interviews and focus groups were conducted and met again with the respondents from Varna and Lovech in the summer of 2020, after the first COVID-19 lockdown. When we asked them again how they saw the future of their, now adult, children, they all replied that they hoped they would be strong enough to continue to provide them with full care within the family. Asked whether they saw an alternative in the new social services and family-type residential centers, they painted a picture that is very close to the extremely critical assessment given in various reports on deinstitutionalization in Bulgaria. Polya told us how the day-care centre attended by her son followed all the worst trends in the social services sector: constant staff turnover; division into people with mild disabilities and those with severe disabilities, “wheelchair-bound” and “autonomous and others”; the infantilization of users, namely treating 30-year-old men and women like little children; speaking in diminutives; tabooing the subject of sexuality; and not infrequently neglecting care for personal hygiene, the need for rest, etc., for the sake of attaining “learning outcomes” in skills acquisition. The chairperson of a large NGO, on the other hand, told us how she had suffered complete failure in her attempt to give autonomy to her over-30-year-old daughter (with cerebral palsy and other disabilities) and to place her in a sheltered home close to their apartment in Lovech; the staff in the home accused her of abdicating from her maternal role and of "wanting to get rid of the poor girl", since she had enough financial resources to provide her with a good standard of living in her own home. Finally, a carer at a sheltered home in Varna told us she could no longer bear to see how "the boys" there were "living as in the barracks", how she had to beg the manager to buy them phones or nicer clothes, how they were forbidden any contact with members of the female sex under threat of expulsion from the home, and how at certain hours they were not allowed "to make the slightest sound" in order to not disturb the staff. All three respondents quoted above complained that to all this the COVID-19 measures were added, which led to the lockdown of all the day-care centers for almost a year and to the complete restriction of visitors to sheltered homes. Summing up, Polya noted the completion of a cycle of deinstitutionalization in Bulgaria, which reached a dead point and, in the final analysis, had not liberated them but returned them to the grip of postsocialist institutions: "We've returned to those hateful times when we stayed at home all day and could only look through the windows at how normal people were living outside" (Focus group, Varna, 29 May 2020).

This complex dynamic of reinstitutionalization in Bulgaria has dangerously found in recent years support in the attitudes of the general public, which increasingly frames the notions of rights and self-determination as foreign and harmful principles imported from the West, and appeals for a return to the "original" patriarchal, family, and traditional values: a process often described as illiberalism [33,34]. It threatens, additionally, to perpetuate and normalize the already powerful normativity of the "capsulation" of families of children with disabilities and the refusal to release now grown-up children from the burden of "self-sacrificing care". Thus, "disabled people will remain confined in institutions or at home, while independent living will remain abstract, distant, and even menacing 'Western stuff'" [35] (p. 29). If in the late 1990s mothers of children with disabilities in Bulgaria could choose only between saving their lives by confining them to the family or sending them to almost certain death at a state-run institution, nowadays they can choose from different sorts of social programs and services that are meant not only to end their isolation, but to set them on a path to exercising freedom and independence, and yet which prove to be a kind of "Potemkin villages", that is only officially adopted and formally regulated. What is more, the continuing influence of socialist institutional culture and the enduring persistence of paternalistic, gendered patterns both of informal and formal care, are intersecting dangerously with the neoliberal standards for good performance [36]: the replacement of the productivist ideology with an ideology focused on "achieving results", the heavy bureaucratization of the procedure for placement in sheltered housing, and the specialization of day-care centers by type of disability, etc. And, all of this against the backdrop of a national lockdown during the COVID-19 pandemic and the subsequent economic and social crisis, which ultimately aborts any attempt at serious public discussion or critique of the status quo, and which makes both highly relevant and purely rhetorical the question, "Who will take better care of him than me?"

Certainly, there are measures that could be taken to counteract this deeply entrenched institutional culture. The most radical is, of course, changing the Personal Assistance Act to prohibit parents or relatives from being personal assistants, but such measure would likely backfire and be harmful rather than helpful. Other, "softer", measures could be aimed at increasing parents' trust in social workers and personal assistants, which requires improving the quality of their education, training, attitudes, and last, but not least, a wage increase. It is necessary also to popularize locally the key tenets of the CRPD, the value of independent living and personal assistance, as well as to work towards increasing the social prestige of personal assistance as a vocation. In this regard, however, the role of disabled people themselves and their organizations are decisive. They should work and cooperate with parents and demonstrate to them how fulfilling an independent life with disability could be.

7. Limitations of the Study and Implications for the Practice

This study has three important limitations. The first one is that it does not include the voices of the disabled people themselves and their reflections on the issues discussed, both people who use personal assistance provided by a close family member, and those who use personal assistance provided by a non-family member. This is a particularly important aspect that would enrich the picture and perhaps generate new and unexpected findings, internal tensions, and new challenges that should be further researched. The second one is the absence of alternative models, families that have embraced the struggle for independence of their children through, for example, choosing a personal assistant who is not a family member. The third one is the scant presence of the perspective of the experts or the "caring" professionals, who are often faced with the exact challenge to "tear off" the children from their families in order to be able to work effectively with them. All these aspects should be further studied, since they have crucial implications for the practice.

The implications of this study in its present form for the practice are related to drawing attention to the quite palpable absence of attention in policies, institutions, and organizations on people with disabilities, to the affirmation of independent living as a central value, which is also enshrined in the human rights model of disability, which Bulgaria should follow as a state that has ratified the CRPD. The Convention's extremely strong emphasis on the right to self-determination, the right to direct participation in all decision-making that affects persons with disabilities, and the dangers when third parties appropriate the voice of people with disabilities, is in practice swept under the carpet locally, precisely because of the power of institutional culture, which is easier to perpetuate than to radically transform. In this sense, research could assist in improving the formal forms of care, in designing training that forms skills for independent living, and programs aimed at working with parents to convince them of the importance of their child's autonomization and the benefits of the latter for the parents themselves.

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References

1. Council of Europe Commissioner for Human Rights. *The Right of People with Disabilities to Live Independently and Be Included in the Community*; Council of Europe Publishing: Strasbourg, France, 2012. Available online: https://rm.coe.int/the-right-of-people-with-disabilities-to-live-independently-and-be-inc/16806da8a9 (accessed on 10 April 2013).
2. European Expert Group on the Transition From Institutional to Community-based Care (EEG). *Common European Guidelines on the Transition from Institutional to Community-Based Care*; EEG: Brussels, Belgium, 2012. Available online: https://enil.eu/wp-content/uploads/2022/03/Guidelines-01-16-2013-printer.pdf (accessed on 10 April 2013).
3. UN Office of the High Commissioner for Human Rights (OHCHR). *Thematic Study on the Right of Persons with Disabilities to Live Independently and Be Included in the Community*; UN: Geneva, Switzerland, 2014. Available online: https://digitallibrary.un.org/record/792502 (accessed on 10 April 2023).
4. European Union Agency for Fundamental Rights (FRA). *From Institutions to Community Living, Part II: Funding and Budgeting*; Publications Office of the European Union: Luxembourg, 2017. Available online: https://fra.europa.eu/bg/publication/2017/institutions-community-living-part-ii-funding-and-budgeting (accessed on 10 April 2023).
5. BBC. Bulgaria's Abandoned Children. December 2007. Available online: http://topdocumentaryfilms.com/bulgarias-abandoned-children/ (accessed on 1 July 2023).
6. Validity Foundation. *Deinstitutionalisation and Life in the Community in Bulgaria: A Three-Dimensional Illusion*; Validity Foundation: Budapest, Hungary, 2021. Available online: https://validity.ngo/wp-content/uploads/2021/09/Deinstitutionalisation-and-Life-in-the-Community-in-Bulgaria-FINAL.pdf (accessed on 10 April 2023).
7. Angelova, L. *Patyat kam Mogilino: Ideologiyata na Normalnostta i Izostavenite Detsa na Balgariya [The Road to Mogilino: The Ideology of Normality and Bulgaria's Abandoned Children]*; Centre for Independent Living—Sofia: Sofia, Bulgaria, 2008. Available online: https://cil.bg/wp-content/uploads/2020/03/Putqt_kum_Mogilino-1.pdf (accessed on 10 April 2023).
8. Mladenov, T.; Petri, G. Critique of deinstitutionalisation in postsocialist Central and Eastern Europe. *Disabil. Soc.* **2020**, *35*, 1203–1226. [CrossRef]
9. Deneva, N.; Petrov, R. *Zhivot na Volya ili po Chuzhda Volya! Politikata na t. nar. "Deinstitutsionalizatsiya" (DI) v Balgariya i Posleditsite za Pravoto na Nezavisimiya Zhivot na Horata, s Uvrezhdaniya, Koito sa Obekt na Tazi Politika [Living at Will or by Another's Will! the Policy of So-Called "Deinstitutionalization" (DI) in Bulgaria and Its Consequences for the Right to Independent Living of People with Disabilities Who Are Subject to This Policy]*; Centre for Independent Living—Sofia: Sofia, Bulgaria, 2016. Available online: https://cil.bg/wp-content/uploads/2020/03/Report-DI-Final.pdf (accessed on 10 April 2023).
10. European Network on Independent Living (ENIL). *Shadow Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union*; ENIL: Brussels, Belgium, 2022. Available online: https://enil.eu/enil-submits-shadow-report-on-the-implementation-of-the-crpd-in-the-european-union/ (accessed on 10 April 2023).
11. European Coalition for Community Living (ECCL). What Does Exclusion from Society Mean? ECCL: Brussels, Belgium. Available online: https://fliphtml5.com/qcfn/ejtg/basic (accessed on 10 April 2023).
12. UN. Committee of the Rights of People with Disabilities. Guidelines on Deinstitutionalization, Including in Emergencies: Committee on the Rights of Persons with Disabilities. 2022. Available online: https://digitallibrary.un.org/record/3990185 (accessed on 6 July 2023).
13. Ryan, S.; Runswick-Cole, K. Repositioning Mothers: Mothers, Disabled Children and Disability Studies. *Disabil. Soc.* **2008**, *23*, 199–210. [CrossRef]
14. Reeve, D. Psycho-emotional disablism: The missing link? In *Routledge Handbook of Disability Studies*, 2nd ed.; Watson, N., Vehmas, S., Eds.; Routledge: New York, NY, USA, 2020; pp. 102–116; ISBN 978-1-138-36530-8.
15. Mladenov, T. *Disability and Postsocialism*; Routledge: London, UK, 2018; ISBN 978-1-138-23446-8.
16. Dinu, R.H.; Bengtsson, S. (Eds.) *Disability and Labour in the Twentieth Century: Historical and Comparative Perspectives*; Routledge: London, UK, 2023. [CrossRef]
17. Mladenov, T. Disability Assessment under State Socialism. In *Re/Imaginations of Disability in State Socialism: Visions, Promises, Frustrations*; Kolářová, K., Winkler, M., Eds.; Campus Verlag: Frankfurt, Germany, 2021; pp. 91–116; ISBN 978-3-593-51348-5.
18. Carey, A.C.; Block, P.; Scotch, R.K. Sometimes Allies: Parent-Led Disability Organizations and Social Movements. *Disabil. Stud. Q.* **2019**, *39*. [CrossRef]
19. Carey, A.C.; Block, P.; Scotch, R.K. *Allies and Obstacles: Disability Activism and Parents of Children with Disabilities*; Temple University Press: Philadelphia, PA, USA, 2020; ISBN 9781439916346.
20. Russo, J. Psychiatrization, Assertions of Epistemic Injustice, and the question of Agency. *Front. Sociol.* **2023**, *8*. [CrossRef] [PubMed]
21. Thomas, C. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*; Palgrave Macmillan: Basingstoke, UK, 2007; ISBN 978-1-403-93637-0.
22. Thomas, C. *Female Forms: Experiencing and Understanding Disability*; Open University Press: Buckingham, UK, 1999; ISBN 978-0-335-23296-3.
23. Goffman, E. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*; Anchor Books: Garden City, NY, USA, 1961; ISBN 978-0385000161.
24. Hide, L.; Bourke, J. Cultures of Harm in Institutions of Care: Introduction. *Soc. Hist. Med.* **2018**, *31*, 679–687. [CrossRef] [PubMed]

25. Fylkesnes, I. Institutional talk and practices: A journey into small group-homes for intellectually disabled children. *Disabil. Soc.* **2021**, *36*, 999–1020. [CrossRef]
26. Thompson, P.; Bornat, J. *The Voice of the Past: Oral History*, 4th ed.; Oxford University Press: New York, NY, USA, 2017; ISBN 978-0-19-933546-6.
27. Mihas, P. Qualitative, Multimethod, and Mixed method Research. In *International Encyclopaedia of Education*, 4th ed.; Elsevier: Amsterdam, The Netherlands, 2023; pp. 302–313. [CrossRef]
28. Benatova, M. Hostages to their children [Zalozhnitsi na detsata si]. 1 February 2015.
29. Goncharova, G. The Generation of the Transition in Bulgaria and the Sentimental Narrative of Disability. *Crit. Humanism* **2021**, *55*, 83–101. Available online: https://hssfoundation.org/wp-content/uploads/2022/02/body-KX-55eng-20220216-fin.pdf (accessed on 10 April 2023).
30. Dimitrova, I. Impasses of Disability Alliance Building in Bulgaria: Successful Phantom Activism and Toxic Grassroots Mobilization. In *Disability Alliances and Allies: Opportunities and Challenges*; Carey, A.C., Ostrove, J.M., Fannon, T., Eds.; Research in Social Science and Disability 12; Emerald Publishing Limited: Bingley, UK, 2020; pp. 67–85. [CrossRef]
31. Mladenov, T.; Cojocariu, I.B.; Angelova-Mladenova, L.; Kokic, N.; Goungor, K. Independent Living in Europe and Beyond: Past, Present, and Future. *Int. J. Disabil. Jus.* **2023**, *3*, 4–23. [CrossRef]
32. Deneva, N. Za Churcheto, Mamcheto i Programkite [On the Weenie, the Mommy and the Little Programmes] [Online]. 2018. Available online: https://cil.bg/blog/za-churcheto/ (accessed on 10 April 2023).
33. Graff, A.; Korolczuk, E. *Anti-Gender Politics in the Populist Moment*; Routledge: London, UK, 2022; ISBN 978-1-000-41329-8.
34. Krizsan, A.; Roggeband, C. Towards a Conceptual Framework for Struggles over Democracy in Backsliding States: Gender Equality Policy in Central Eastern Europe. *Politics Gov.* **2018**, *6*, 90–100. [CrossRef]
35. Mladenov, T.; Petri, G. Independent living in Central and Eastern Europe? The challenges of postsocialist deinstitutionalisation. In *EU Social Inclusion Policies in Post-Socialist Countries: Top-Down and Bottom-Up Perspectives on Implementation*; Fylling, I., Baciu, L., Breimo, J., Eds.; Routledge: London, UK, 2019; pp. 16–34; ISBN 978-0-429-43454-9.
36. Thomas, G.M. Dis-mantling Stigma: Parenting Disabled Children in an Age of 'NeoliberalAbleism'. *Sociol. Rev.* **2021**, *69*, 451–467. [CrossRef]