

A Dead End for Children

Bulgaria's Group Homes



DISABILITY RIGHTS INTERNATIONAL

DISABILITY RIGHTS INTERNATIONAL

A Dead End for Children: Bulgaria's Group Homes

Primary authors:

Eric Rosenthal, JD, LL.D.(hon), Executive Director, Disability Rights International (DRI)

Dragana Ciric Milovanovic, MA, Europe Program Director, DRI

Laurie Ahern, President, Disability Rights International

Co-authors:

Rachel Arnold, MA, Operations & Communication Manager, DRI

Donna Bouclier, MA, Family Advocacy Expert, DRI

Ruthie Marie Beckwith, Ph.D., Executive Director, TASH*

Marisa Brown, RN, Georgetown University Center for Child & Human Development, retired*

Robert M. Levy, JD, Columbia University Law School & New York University School of Law*

Melanie Reeves Miller, BS, Certified Disability Expert *

Matthew Mason, Ph.D., Senior Science Advisor, DRI*

*research team

Disability Rights International

www.DRIadvocacy.org

Disability Rights International (DRI) is a human rights organization dedicated to the protection and full inclusion in society of children and adults with disabilities. DRI documents abuses and promotes international awareness of the concerns of people with disabilities. DRI trains and supports disability rights and human rights activists and supports the empowerment of people with disabilities to control their own lives. DRI also promotes improved government programs and donor policies worldwide to ensure full community inclusion of people with disabilities. Through cutting-edge human rights litigation and legal advocacy, DRI protects disability rights and is dedicated to promoting the right of all children to live and grow up in a family.

DRI is based in Washington, DC with regional offices in London, Serbia, and Mexico. Over 25 years, DRI has investigated human right conditions and collaborated with activists in more than three dozen countries in Africa, the Americas, Asia, Europe, and the Middle East. DRI is run by people with disabilities and their families.

Staff

Laurie Ahern, President

Eric Rosenthal, JD, LL.D (hon.), Executive Director

Dragana Ciric Milovanovic, MA, Europe Program Director

Priscila Rodríguez, LLM, Associate Director

Rachel Arnold, MA, Operations and Communication Manager

Lisbet Brizuela, MA, Director, Mexico Office

Ivonne Millán, JD, Human Rights Lawyer

Board of Directors

John Heffernan, Board Chair

Alex Arriaga, Strategy for Humanity

John Bradshaw, DACOR

Holly Burkhalter, International Justice Mission

Ilene Cook, The Washington Post

Eric Mathews, University of Rochester School of Medicine and Dentistry (MD candidate)

Stephanie Ortoleva, JD, Executive Director, Women Enabled International

Kathy Ryan, Chernobyl Children's Project

Table of Contents

Executive Summary	i
Preface: Goals and Methods of this Report	xi
I. Observations: Dehumanizing Conditions	1
A. Segregation into facilities by disability	1
B. Pervasive inactivity, social isolation, and lack of habilitation	3
C. Regimentation.....	8
D. Difficulty motivating staff to engage with children	8
II. Observations: Dangerous conditions and mistreatment.....	15
A. Denial of medical care, physical and pain management.....	17
B. Lack of physical management and dangerous feeding practices.	18
C. Failure to protect against sexual abuse and violence	20
III. Structure of services: no choice or alternatives.....	23
A. New admissions.....	24
B. Gatekeeping: no alternative to group homes	27
C. Lack of foster care for children with disabilities	28
D. Isolation at day centers.....	30
F. Lack of support for parents in the community.....	33
G. Group home placement of adolescents without disabilities	35
H. A lifetime of discrimination ahead: transition to adulthood.....	36
IV. International Standards	37
A. Human rights obligations	37
B. Lessons from experience and research.....	40
V. Conclusions and Recommendations	42

Executive Summary

I just want to live like everyone else.

- young woman seeking to leave group home

While the buildings are better, everything else is the same.

- Former international NGO professional who trained staff for group homes

The main finding of this report is that **Bulgaria has replaced a system of large, old orphanages with newer, smaller buildings that are still operating as institutions.** While the new facilities are officially referred to as “family-like” residences or “small group homes,” DRI’s investigation finds that they are neither small nor are they family homes. In fact, they are mostly 14 bed facilities.¹ Many group homes are run by one local authority, leaving a few administrators responsible for dozens of children. In one case (9, 10, 11), DRI investigators observed three houses grouped together to create what was effectively a congregate living arrangement for 42 children. Some “group homes” are placed in the deserted corridors of the same old orphanage buildings that were supposed to have been closed (3, 12). **These institutions separate children with disabilities from society and contribute to their continued social isolation** – leading to a lifetime of segregation for a new generation of people with disabilities. As this report shows, placement in Bulgaria’s group homes exposes children to emotional neglect, inappropriate and potentially damaging models of behavior, and, in some cases, violence, bullying, and other forms of abuse that are common in institutions.

The world must see what is happening in our group homes. There will never be change here in Bulgaria unless people understand what is happening in our group homes.

- Director of three group homes

While extensive resources have been invested in moving from large to small buildings, little effort has been made to promote true inclusion in families or society at large. Bulgaria has failed to create a system of community supports, inclusive education, or transition to independent living, which will help children with disabilities remain with their families. As a result, many families have no choice but to give up their children with disabilities. There

¹ **Numbers in parentheses throughout this report refer to specific group homes visited.** All names and locations have been withheld to protect the identity of children residing in these facilities.

are still about 1,000 infants, toddlers, and young children with disabilities in large, old institutions. Bulgaria's foster care system is not equipped to take most children with disabilities. As a result of this broad failure to create family and community support, there is now pressure to expand Bulgaria's group home system. There are more than 600 admissions every year to Bulgaria's childcare systems, made up mainly of group homes and larger institutions. As a result, the government of Bulgaria has announced plans to create many more group homes – including facilities for the youngest children who are in greatest need of family care.

Money goes to the institution, not the family; and life, if you have a child with a disability, is life in poverty.

➤ Bulgarian Mother's Movement Foundation

His father was in tears when he left his boy at the home. If there had been any services in his village – or even a bus to take him – the family would have kept the child.

➤ Group home staff (20), describing recent placement of a five year old boy.

DRI urges Bulgaria to provide immediate support to prevent the break-up of families and stop new group home placement for all children – with or without disabilities.

There should be a moratorium on building new group homes. If families are given the support they need, the number of children placed outside the home can be virtually eliminated. Every effort should be made to reunite children with their families or to place them with extended family (also known as kinship care). If such placement is impossible, Bulgaria must create and expand supported foster care programs to ensure that children with disabilities can be rapidly moved from group homes into stable, new families. Bulgaria's top priority should be to protect infants, toddlers and young children with and without disabilities to remain with families – or to move from group homes into a supported family or foster family.

As a country that has ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), Bulgaria is under a legal obligation to protect the right of all people with disabilities to live in the community.² The UN Committee on the Rights of Persons with Disabilities (CRPD Committee) has said that that “[f]or children, the core of the right to be included in the community entails a right to grow up in a family.”³ To implement its legal obligations

² Convention on the Rights of Persons with Disabilities (CRPD), ratified by Bulgaria March 22, 2012. Article 19 protects the right of all people with disabilities to live and grow up with a family.

³ U.N. Secretary-General, *General Comment No. 5 (2017) on living independently and being included in the community*, U.N. Doc. CRPD/C/GC/5 (Oct. 27, 2017), para. 37. [hereinafter General Comment No. 5] (emphasis

under the CRPD, Bulgaria must shift the direction of childcare and social welfare policies away from a system based on group homes to a system based on family support. This approach is consistent with recent findings from scientific research showing that the stable, emotional bonds necessary for healthy development of the child can only happen in the context of a family – and will always be limited in a congregate setting, whether large or small.⁴ Thus, the UN Committee on the Rights of Persons with Disabilities has stated that:

Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. ‘Family-like’ institutions are still institutions and are no substitute for care by a family.

➤ UN Committee on the Rights of Persons with Disabilities (General Comment No. 5, 2017)

International law recognizes the evolving capacity of children and adolescents to make choices about their lives, including place of residence. With appropriate support and full information, some older adolescents should be able to choose their place of residence. But if there are no safe and appropriate family alternatives to the group home – as we found in much of Bulgaria – such placement cannot truly be considered a voluntary choice.

While Bulgaria has made valuable advances in closing down large orphanages, the creation of a system based on placement in group homes as the only option for many children – with and without disabilities – is not consistent with the requirements of international law. The living conditions observed by the DRI team leave children exposed to many of the same dangers they experience in larger institutions. While buildings are generally newer and cleaner than the old institutions, most of the conditions we observed in Bulgaria’s **group homes are strikingly similar to what DRI investigators observed in the institutions and orphanages the world over**: children sitting motionless on chairs, couches or benches, or on concrete floors sitting in pervasive inactivity, some rocking back and forth, hitting themselves, biting their hands or poking fingers in their eyes.

added). A family may not necessarily be the immediate biological family, but could include extended family, kinship care, foster care, substitute family care, or any family environment in which the child can establish stable emotional bonds. Throughout the world, there are successful models that demonstrate that all children – regardless of disability – can live and grow up with a family.

⁴ Mary Dozier, Joan Kaufman, Roger Kobak, Thomas G. O’Connor, Abraham Sagi-Schwartz, Stephen Scott, Carole Shauffer, Judith Smetana, Marinus H. van IJzendoorn, and Charles Zeanah, *Consensus Statement on Group Care for Children and Adolescents: A Statement of Policy of the American Orthopsychiatric Association*, 84 *American Journal of Orthopsychiatry* 219, 220 (2014).

In one facility children had shaved heads (14). In another facility we observed two cages for children, and immobile children were kept in cage-like cribs that isolated them from social interaction (9). Some children rarely ever go outside – except to a balcony (3, 5, 12) or a fenced-in yard (21). In two facilities children were kept in pens – a small space in the living room of a house surrounded by a wooden barrier – sitting or lying on the floor (4, 12).

In one facility visited by DRI investigators, a large, new house with high ceilings and modern furniture sits virtually unused (21). Visitors to the group home might never know that in the back of the house, down a dark hall reeking of urine and feces, children are kept on the floor, left in caged beds, not moving all day. One young person is locked naked in an isolation room. When asked why the residents are not moved to the well-furnished area, staff responded:

The children cannot stay in the nice room. They would ruin the house.

➤ Group home staff

Many children living in the group homes exhibit behavioral problems. Staff at group homes use commonly use restraints or high levels of medication – mainly as sedatives.

When children are sent here [from group homes], we see them so over-medicated that we wonder how they are still alive...They use medication as a substitute for care.

➤ Child psychologist, Children's Psychiatric Unit, Sofia

Cribs are often used as restraint devices for children with limited mobility (9, 12, 18, 21, 22). In some facilities (2,9,10,12,13), we observed children tied to chairs or strollers with makeshift straps or a scrap of fabric, despite – in some cases – the existence of modern, adjustable wheelchairs that could provide a child with needed support. Staff reported that appropriate wheelchairs were unavailable in Bulgaria – but we found such equipment nearby, unused and gathering dust (9, 10).

Instead of providing care suited to the needs and preferences of each child, staff care is regimented to meet the demands of staff. Due to the lack of attention to dress and grooming, it is often impossible to tell whether children are boys or girls. As one staff member stated:

The girls like to have long hair, but it is easier for us to shave their heads.

➤ Group home staff (14)

During the investigation, we observed children who were left to sit or eat in rooms that smelled of urine and feces (21, 9). DRI investigators observed children in wheelchairs

pushed toward the wall – left with no human contact (2). We found immobile children left on beanbag chairs with eyes pointed toward the ceiling so they could not interact with children around them (4). We saw rows of children as young as 5, 6, 7 or 8 years old with their pants down left sitting exposed before others on a potty (DC4, 21) – apparently for the convenience of staff.

Investigators met a girl who had been transferred to a group home from a foster family. The foster family had sent the girl to a specialized program in Varna (Karin Dom) to teach her communication skills. There she learned how to use a system of photographs to communicate (the Picture Exchange Communication System, or PECS). But staff at the group home said that she no longer used the system at the group home:

Here at the group home she does not need a system of communication, because she has nothing to communicate. All she needs to express is when she wants to eat, sleep, or go to the bathroom.

Professionals working for international NGOs to train group home staff expressed frustration that, even when group home staff have been trained to provide support or teach skills to children, they did not do so. Some experts explained that it was easier for staff to feed a child than to teach them how to use utensils. Others observed that staff insisted they be paid for each and every separate activity or they would not do it. An education expert on the DRI investigative team observed the following:

The tyranny of low expectations for children with disabilities is the most pervasive problem I observed throughout Bulgaria. Negative perceptions about children with disabilities are self-fulfilling. When it is assumed that children with disabilities can't do something, they are never given the opportunity to try.

➤ Dr. Ruthie M. Beckwith, Ph.D., Executive Director, TASH

Historically, stereotypes of single mothers and Roma as being “unfit parents” have also led to the over-representation of children in Bulgaria’s institutions.⁵ Today, many parents are still forced to give up their children because of such social marginalization, as well as poverty or disability, according to Galina Markova of the Know How Center.⁶ The government has

⁵ EveryChild, *Family Matters: A study of institutional childcare in Central and Eastern Europe and the former Soviet Union* 34, 43, (2005).

⁶ Galina Markova of the Know-How-Foundation added to this critique in an interview with DRI, saying that service providers and reformers “don’t know how to work with parents.” Interview with DRI, February 18, 2019. A small percentage of children separated from families are taken because of abuse by parents. National Scientific Council on the Developing Child, *The Science of Neglect: The Persistent Absence of Responsive Care Disrupts the*

invested extensive resources in new buildings, but it has not met the needs of vulnerable families. As a result, around 2,000 children are separated from their families each year.⁷ There are more than 600 new admissions to institutions for children 0-3 every year – largely made up of children with disabilities.⁸

Children placed in Bulgaria's group homes grow up without a family. Children without disabilities grow up and become independent at age 18. After that, they are on their own. But children with disabilities are likely to remain in the group home for life. Since young adults do not move out of group homes, the same facility may include a mix of young children and unrelated men or women in their twenties and thirties. Group homes are segregated by disability, with 145 homes designated for children without disabilities and 125 homes for children with disabilities.⁹

DRI had the opportunity to interview professionals in Bulgaria involved with every stage of planning and implementing reforms in Bulgaria: from assessing children in orphanages to planning new services and training staff in the group homes. These professionals report that reforms began with the best of intentions and the hope that children could return to families. It quickly became clear that after years of separation, it was impossible to get most children back to their families. From early on in the reform process, therefore, it was assumed that many children would have to be in group homes. After years of efforts to create a new model of care in group homes, including efforts to train and assist group home staff to create home or family-like environments, these experts reported to DRI:

Regretfully these group homes in a short time will turn into institutions. Instead of being centers for family-like care they are centers for the exact same kind of care. They have already become institutions in many places.

➤ International NGO staff

A former member of the State Agency for Child Protection who was active in planning and implementing Bulgaria's reforms concluded that **“the model from the institution was transferred to group homes.”** He said that EU funders asked for rigorous reporting on the

Developing Brian: Working Paper 12 (2012), posted at <https://developingchild.harvard.edu/resources/the-science-of-neglect-the-persistent-absence-of-responsive-care-disrupts-the-developing-brain/> (last visited June 18, 2018).

⁷ Source UNICEF <https://www.unicef.org/bulgaria/en/situation-children-bulgaria>.

⁸ National Statistical Institute web site <https://www.nsi.bg/en/content/5606/homes-medico-social-care-children>

⁹ Of the facilities for children with disabilities, 110 houses are designated for children and youth with disabilities, seven houses are only for children with disabilities and eight houses are for children with disabilities “in need for constant medical care.” Annual report of the Agency for Social Welfare for 2018, page 19. <http://www.asp.government.bg/documents/20181/115515/GODISHEN+OTCHET+ASP+-+2018+FIN.PDF/b171e9ad-0387-4085-8b18-5e0bbfda278e>

numbers of group homes and other programs created but never required an assessment of how the children were doing in those services:

If someone did an assessment now to compare how they are doing with how they were in the orphanage, we would have to tear up our diplomas.

➤ former Child Protection Authority official

Staff at some group homes appeared to investigators to be overwhelmed by the needs of the children in their care and unable to give the children the attention they needed. Many programs observed are not age-appropriate and are not tailored to the needs and potential of each child, resulting in a loss of skills and social functioning over time. According to one official involved in creating the group home system:

There is little individualized care in Bulgaria's group homes

➤ former Child Protection Authority official

The improper living conditions and potential for abuse is greatest among children with emotional difficulties, intellectual disabilities, and what are referred to as children with "behavior problems." These children are the most isolated:

The first mistake they make is that they are keeping children all the time in a group home which turns this into a small institution. They try to send them to school, but the school can't deal with them and returns them. This is especially true in the countryside where there are no services available to the children.

➤ Child psychologist, Children's Psychiatric Unit
Sofia

According to the child psychologist interviewed by DRI, there are only 14 child psychiatrists in all of Bulgaria. The larger problem, she explained, is that staff at group homes have no idea what to do to help or engage these children. Growing up without the love and care of a family, these are the children most easily ignored.

Life in a group home can also be demeaning and difficult for children and young adults who have fewer support needs and find themselves demanding choice and freedom. At one facility (7), the director of a constellation of homes reported that she was the guardian of more than 100 children and young adults. Human rights attorneys representing clients in Bulgaria's group homes have reported to DRI that this is the norm – with many group home directors serving as the legal guardians for dozens of children. In some cases, parents retain

guardianship over children they never see – leaving group home directors to act as the *de facto* guardians of many children. This concentration of legal authority in the hands of a very few group home directors creates a fundamental conflict of interest whenever a child's rights may be violated by a group home. As children with disabilities grow up, their choices can be limited by group home authorities even as adults. One young woman who uses a wheelchair wanted to have her photograph taken with the DRI investigators, but the director of the facility said it was against house rules.

It is humiliating for children who live here if people in the community learn that they live in a group home. So no one can take or post photos from here.

➤ Group home director

This young woman wanted to leave the group home to live on her own. **“I just want to live like all other people,”** she told us. But funding from her disability pension was not enough to afford a home in the community, even if she pooled resources with three of her friends. At three different group homes for children and young adults (7, 11, 14) we met young adults who grew up there who wished to live independently in the community. In response to one such story, staff informed us:

Don't listen to him. He is very manipulative. He has Gypsy schizophrenia.

➤ Group homes staff (11).

Lack of alternatives to group homes

There are major gaps in the community support system for children with disabilities – leaving group homes or international adoption as the only options for them. Parents do not receive the support they need and mainstream schools do not have programs for children with disabilities. While Bulgaria has greatly expanded its system of foster care, children with disabilities are largely excluded from this option.

Usually foster parents do not take kids with disabilities. Because there is no support for foster parents. It is very rare.

➤ Judge, Varna District Court,
responsible for group home
placements

I cannot speak about the whole country, but ... for our municipality foster care is something we have developed well. We can now find foster families for almost all children who need a place to go. Our goal is for all children to be in

families. **Despite this, we cannot take children with minor or severe disabilities.**

➤ Deputy Mayor, Gabrovo

Group homes may once have been seen as a stepping-stone to community integration, allowing children to go to school and daycare in the community. Bulgaria's education law allows parents (or group home administrators) to decide where to send their children to school. In practice, authorities at schools DRI visited reported that most mainstream schools are not fully accessible (DRI encountered some ramps) and educational programs are not adapted to children with mental disabilities.

A 16-year old boy with cerebral palsy living in a group home (14) reported that he enjoys going to the mainstream school in his neighborhood. Unlike at his group home, where staff decide when he can and can't listen to music – his great love in life – the school lets him listen to music all the time.

DRI: Doesn't the music bother the other children at school?

Boy: No. Because I spend the day alone in the basement.

Another man with a physical disability went to and graduated from a mainstream school that was physically not accessible, so he had to be carried in and out. He lived in a group home and said that there was "no expectation" and "zero assistance" to get a job after graduation. When he did get a job in Sofia as a result of his own efforts, he could not get a residence permit to move near his new job – and the group home still took 50% of his income. He told DRI:

There is 100% discrimination against people living in group homes.

➤ Former group home resident.

Despite the high hopes for group home placement when they were first created, professionals involved in their development reported to DRI that they do not function as a gateway to the community.

[Compared with] some of the smaller institutions in Bulgaria, children were better off than what we now have in the group homes. In the institution there were professionals who worked nine hours a day with the kids. Now they go to a daycare center where they may get 30 minutes of attention a day.

➤ International NGO staff.

DRI observations about treatment that is dehumanizing and emotionally dangerous are detailed in Section I. Physical dangers (inappropriate treatment, violence, and lack of access to justice) are described in Section II. Section III describes the structure of Bulgaria's service system that segregates children and young people with disabilities from society and leaves them destined to a lifetime in facilities that are effectively smaller new institutions. Section IV summarizes Bulgaria's obligations under international law, including the right of all children to live and grow up in a family under the CRPD. Section V describes how the requirements of the CRPD are based in the findings of research and experience showing that all children, regardless of disability, can and should live and grow up in a family.

Preface: Goals and Methods of this Report

The eyes of the world are on Bulgaria. A decade ago, media exposés, such as the 2007 BBC documentary [Bulgaria's Abandoned Children](#), documented horrendous conditions in Bulgaria's orphanages. Video revealed children detained in filthy, inhumane conditions – spending their lives in inactivity with little hope of having a family or people to love them. As a result of this international attention, the government of Bulgaria carried out reforms that closed most of the country's large, abusive orphanages.

After more than a decade of reform, Bulgaria is widely held up as a success story of deinstitutionalization – to serve as a model for other countries facing similar challenges. UNICEF has cited Bulgaria's "vision for deinstitutionalization" internationally as a "promising practice"¹⁰ to be emulated by other countries. At a recent "side event" of the United Nations General Assembly, Bulgaria was identified as a model for reform.¹¹ Bulgaria's Deputy Prime Minister, Ekaterina Zaharieva, proudly spoke of the country's success in bringing about a 90% rate of deinstitutionalization. She declared: **"every child should be in a family and not an institution or orphanage."**

The closure of Bulgaria's old orphanages is an enormous accomplishment that saved the lives of many children. There was a need for urgent action, and many well-meaning government officials, charities, and professional reformers created innovative approaches intended to protect children. But a system born out of crisis may not provide the most effective foundation for humane service delivery or rights protection. In recent years, there have been enormous worldwide changes in the recognition of disability rights and the growth of a new international disability rights movement. Throughout the world, children and adults with disabilities have shattered perceptions that they need "protection" in any form of residential care facility as they have lived, grown up, and taken control of their lives in fully integrated family settings. Extensive scientific research has now shown that placement in any form of residential care or group home is detrimental – especially for younger children.¹² The UN Convention on the Rights of Persons with Disabilities (CRPD),

¹⁰ UNICEF, "A vision for deinstitutionalization," 30-35 in *Compendium of Promising Practices to Ensure that Children Under the Age of Three Grow up in a Safe and Supportive Family Environment* (2015).

¹¹ The event in New York on September 25, 2019, "A Goal Within Reach: Ending the Institutionalization of Children to Ensure No One is Left Behind," was organized private a non-governmental organization Lumos, as a "side event" to the UN General Assembly gathering. Major international children's charities described Bulgaria as a model of reform.

¹² Dozier, *et. al.* (2014).

ratified by Bulgaria in 2012, reflects these new innovations and obliges Bulgaria to ensure that its service system complies with up-to-date human rights standards.¹³

This report assesses the new service system Bulgaria has put in place with international support. The report examines whether Bulgaria is keeping its promise to ensure that children grow up in families instead of orphanages or institutions. It evaluates whether Bulgaria is meeting obligations under international law to protect the rights of children, including the requirements of the European Convention on Human Rights (ECHR), the UN Convention on the Rights of the Child (CRC), and the CRPD. The CRPD protects the right of *all* persons with disabilities to live in the community with choices equal to others.¹⁴ When it comes to children, UN authorities have held that **“the core of the right to live independently and be included in the community entails a right to grow up in a family.”**¹⁵ The CRPD also prohibits public services that are segregated on the basis of disability and ensures the right of all children to education in an inclusive environment.¹⁶

As this report describes, at least half of the children transferred out of Bulgaria’s orphanages (about 3,300 children) are placed in what are called “group homes.” These are segregated facilities – about half of them are for children with disabilities and the other half are for children without disabilities. Young children, adolescents, and adults are mixed together and grow up in these facilities without the opportunity to have the love or care of a family. Children with disabilities are likely to remain segregated from society in these facilities for life. The main conclusion of this report is that Bulgaria’s new group homes are essentially functioning as smaller and cleaner – but not necessarily safer – new institutions.

Bulgaria’s childcare policies have been supported by the generosity and technical assistance of the European Union and international charities dedicated to helping children and bringing an end to the era of the orphanage. From 2010 to 2015, the European Union invested more than 100 million Euros in these reforms.¹⁷ Since 2016, more than 160 million additional

¹³ Eric Rosenthal, “The Right of All Children to Grow Up with a Family under International Law: Implications for Placement in Orphanages, Residential Care, and Group Homes”, 25 Buffalo Human Rights Law Review 101 (2019).

¹⁴ Convention on the Rights of Persons with Disabilities (CRPD), ratified by Bulgaria March 22, 2012, article 19. U.N. Secretary-General, *General Comment No. 5 (2017) on living independently and being included in the community*, U.N. Doc. CRPD/C/GC/5 (Oct. 27, 2017), paras 21-22. [Hereinafter General Comment No. 5].

¹⁵ *Id.* at para. 37. This interpretation of CRPD article 19 comes from the UN Committee on the Rights of Persons with Disabilities, an authoritative body established by the CRPD to advise and assist governments on the meaning and application of this human rights convention.

¹⁶ Article 24(1) of the CRPD states requires that governments “shall ensure an inclusive education system at all levels....”

¹⁷ Unicef: Situation Analysis of Children and Women in Bulgaria, 2017: The Action Plan for the implementation of the National Strategy “Vision for the Deinstitutionalisation of the Children in Bulgaria” provided investment of more than 100 million Euros. These funds come from EU structural investment funds (European Social Fund, European Regional Development Fund and European Agricultural Fund for Rural

Euros have been allocated for deinstitutionalization reforms through European Structural Investment Funds.¹⁸ In addition, there has been extensive private support for reform through private foundations, non-governmental organizations (NGOs), and international charities. If Bulgaria is to serve as a model of reform for other countries, it is essential to understand how those funds were used and what group home placement has meant for these children.

This report is based on visits to 24 group homes, five day care centers, four larger residential institutions for children and adults, two schools, and other programs throughout Bulgaria by a team of disability rights, child welfare, and medical experts from Bulgaria, Serbia, and the United States. In addition to interviewing staff, residents, and local and national government authorities, DRI investigators had the opportunity to conduct in-depth interviews with professionals who have worked in Bulgarian government and former staff of international NGOs playing key roles in implementing reforms.

Development) for the reform in the childcare system, and five national projects were implemented in the period 2010-2015

¹⁸ Opening Doors Campaign for Europe's children: Country fact sheet for Bulgaria, 2017.

Acknowledgements

We are grateful to the many people working in Bulgaria who met with us and welcomed us into their programs, offices, and homes. They generously gave of their time. We particularly appreciate the children and young people, as well as family members, who told us about their lives and their struggles. We met many professionals, staff, and direct care workers who were concerned about the welfare of the children they are serving and brought our attention to serious human rights concerns. We are particularly in debt to staff and program administrators who may have risked their careers to ensure us access to facilities.

It is not DRI's intention to blame any group as a whole or to disparage the efforts of the many dedicated staff who work to help children under very difficult circumstances. Many current and former staff, as well as activists working for reform, spoke out on the condition that their names not be used. Except for some leaders who have spoken out publicly, the report does not use names to protect sources and allow them to speak freely. Locations of specific group homes are not mentioned in the public version of this report to protect the identity of sources or children residing in these facilities. The numbers in parentheses throughout the report refer to specific group homes. Program names and locations have been provided to the Bulgarian Child Protection Authority to ensure that action can be taken to protect individuals.

DRI is especially indebted to many friends and colleagues in Bulgaria who helped us understand the service system and the human rights concerns of children. Kapka Panayotova, the Director of the Center for Independent Living for People with Disabilities, helped us understand the situation of people with disabilities. Tsvetelina Marinova, Myroslav Moravsky, and Maria Krasteva were our main guides, translators, and cultural interpreters in Bulgaria. Nadezhda Deneva provided invaluable background information about the operation of Bulgaria's social service system and the efforts of international organizations in planning and implementing reforms. Aneta Genova helped us identify locations to visit and people to meet and educated us about the human rights situation in Bulgaria affecting children and adults with disabilities. We have the greatest respect and admiration for them and their deep and longstanding commitment to human rights and social justice.

The authors are grateful to Steven Allen and Ann Campbell of Validity for introducing DRI staff to colleagues in Bulgaria. The Validity conference on human rights litigation held in Budapest in December 2018 brought together human rights and disability activists from countries throughout the region concerned with the problem of group home placement and played a key role in making this report possible. The gathering led to innovative strategies

to protect a generation of children and adults with disabilities from a new form of institutionalization.

Thanks to the many independent experts who volunteered their time and advice to make this research possible. These experts, as well as DRI Family Advocacy Expert Donna Bouclier, offered their knowledge and experience in helping us understand the potential and programs needed to help children with the most severe disabilities live, grow, and thrive within a family and community.

This research was possible thanks to support from Oak Foundation, the Nick and Holly Candy Foundation, the UBS Optimus Foundation, the Blaustein Foundation, a major anonymous donor, and many individual donors and family foundations.

I. Observations: Dehumanizing Conditions

Any analysis of the current situation of children in Bulgaria must start with recognition of the progress that has been made in shutting down the large abusive orphanages of the past. Urgent action was needed. Bulgaria's orphanages and institutions for children with disabilities were inhumane and dangerous places. As one international NGO worker, engaged in that reform process for a decade, observed, **"whatever the shortcomings, many lives were saved."**

While acknowledging the importance of closing down Bulgaria's old orphanages, it is necessary to take a full measure of the conditions in the congregate living arrangements where children are now living. **DRI's observations make it clear that children in Bulgaria's group homes are still widely exposed to emotional neglect and physical danger.**

From what the DRI investigators observed, the physical conditions in one group home for adolescents without a formal label of disability (15) was far better than what the team witnessed in all other homes for children and young adults with disabilities.¹⁹ Even so, there are dangers to raising *any* child in a congregate setting, and these are described further in section III-E below.

The structure of Bulgaria's group homes for children and young people, built on a system of segregated environments for people with disabilities, constitutes a form of *de jure* discrimination on the basis of disability. There is extensive evidence in the research literature showing that raising children with disabilities and behavioral problems in a group or segregated environment contributes to negative behavioral models that are mutually reinforcing and emotionally dangerous.²⁰ DRI's observations powerfully reinforce what we know from extensive research and from disability experience worldwide: instead of contributing to patterns of social interaction and behavior that will assist them in developing skills to live independently and integrate into the community (contributing to what is known as social "habilitation"), the segregated environment of group homes reinforces and contributes to increased disabilities and even more serious behavioral disorders.

A. Segregation into facilities by disability

¹⁹ DRI also visited one group home for eight young adults with disabilities who had grown up in orphanages (23). At this facility, all adults had their right to legal capacity respected and adult residents were free to come and go -- some to employment in the community. The atmosphere appeared to be humane, family-like and respectful. DRI observers did not identify any visible concerns at this adult facility during our visit.

²⁰ Dozier *et al.* (2014) at 220.

Social service and government authorities interviewed by DRI commonly reported that the “biggest problem” they face is caused by placing people with disabilities together in group homes:

We have children with behavioral problems in group homes, and **they endanger the other children in group homes**. Also, there are really young and old mixed together in one place. We would like to be able to separate these groups.

➤ Gabrovo Deputy Mayor

The large differences in ages among unrelated children and adults placed in group homes adds to the physical and emotional dangers facing children. Since there is no place for children to go after they grow up in a group home, the current policy is to allow them to stay at the facility. Group homes are simply renamed and become group homes for children and youth. DRI investigators were informed that the current definition for a “youth” is a person up to age 35 – making it possible for young children to be mixed with unrelated adults in their early 30s. At one group home we visited, the residents ranged in age from 8 to 30. In another, the range was age 6 to 29.

We visited one group home (20) where a five year old child with autism was recently placed with young adults and no peers his own age. His parents were reportedly heartbroken when they dropped him off at the facility and staff reported that they would have kept the child if there were any services or respite care in their small village. The child now has no peers or children near his own age, and group home staff reported that the chaotic atmosphere of the older children and adults was very difficult for him to endure (including sensitivity to sound or touch that is common among people with autism). Even though we observed this child able to move about on his own, he was placed in a crib in the center of the common living area “so he could get some privacy” while still being observable by the limited group home staff.

In one group home (21), DRI encountered a 16 year old deaf girl who does not go to school because she is “too disabled.” None of the staff or residents at the group home where she was placed use sign language. She was delighted when she discovered that one of the DRI investigators could communicate with her in sign language, and she demonstrated that she did not have a significant intellectual disability and is very much able to communicate. There was only one 15 year-old boy near her age in the group home who she was trying to teach to sign so she could talk to someone. While he is also intelligent and verbal, he showed signs of social aggression – and she appeared to be mimicking his behavior during our visit. All other

residents of the facility appeared to be non-verbal, so this boy and girl had only each other to communicate with.

The Deputy Mayor of Gabrovo observed that this situation is particularly bad for children with physical disabilities who are forced to live with children who have mental disabilities or behavioral problems. **“We cannot ensure the best development of the child because of this mix,”** she observed.

The group homes were built before the individual assessments were made. So kids had to fit into what was available rather than the other way around.

- International NGO staff

B. Pervasive inactivity, social isolation, and lack of habilitation

There is nothing to do all day but sleep. I am never allowed outside the gate of the facility.

- A 15 year old boy (21) who was communicative and playful with DRI investigators. The boy was recently placed in the facility because his father is serving a long prison sentence. His father still writes to him weekly.

Investigators met a girl who had been transferred to the group home from a foster family. The foster family had sent the girl to a specialized program in Varna (Karin Dom) to teach her communication skills. There she learned how to use a system of photographs to communicate (the “Picture Exchange Communication System” or PECS). But staff at the group home said that she no longer used the system at the group home “because she has nothing to communicate” about. This is one of the ways investigators observed that group homes foster dependency and lead to a loss of existing skills.

The most consistent observation in group homes is one of pervasive inactivity. Even in the cleanest and most well-staffed facilities, DRI investigators observed children and young adults with disabilities sitting motionless for long periods of time in chairs, at tables, or on couches in almost every facility we visited. In some facilities, DRI investigators observed children and young adults rocking back and forth on mattresses or on the bare floor in some of them (e.g. 9, 10, 17, 18, 21, 24). At other facilities, investigators observed children sitting on potties for hours or lying on beds or cribs without any form of attention during the day (e.g. 21). Many of the children observed by investigators appeared to have little or no social

interaction with others. This is a particularly serious problem for children considered to have so-called “severe” disabilities who do not go to school and spend their entire life in the group home.²¹ This total lack of active treatment and habilitation is common throughout the group homes visited by DRI. There appears to be little or no continuous or consistent implementation of any program of support to preserve and enhance self-care, socialization, or independence. Indeed, staff members interviewed appeared to be unaware of what such a program might entail.²²

At a group home (13)

DRI investigator: Please tell me about this boy. What does he do all day?

Group home staff: He’s 16. He sleeps. He can’t talk.

DRI: After that?

Staff: He sits by himself. He likes to hear the sound of tearing paper. That’s all he does. He likes to listen to the wire vibrating on the clothes line outside.

DRI: Does he like to do anything else?

Staff: He likes to go outside and tear the leaves from the bushes. But because of his allergies, we don’t let him go outside.

People don’t seem to understand that children need to do something other than watch TV and put together puzzles.

➤ Child psychologist, Sofia Child
Psychiatric United

²¹ The term “severe” disability is widely used to describe by staff or social service authorities for children who are believed to be unable to live in a family or go to school, but the term does not appear to be consistently used or defined in any meaningful way. As with the 16 year old deaf girl considered to be “too disabled” to go to school (21), investigators were unable to discern any disability other than for the fact that she was deaf and had perhaps not had the benefit of formal education suitable to her needs.

²² At one facility (22), there was a chart on the wall to rate the behavior of all children in the facility. Each child could earn a yellow, red, or black dot three times a day for behavior that was good, bad, or in need of improvement. When interviewed, staff indicated that there were no specific activities or behaviors identified for each child, and rewards were given based on a general impression. Children who were more disabled consistently received dots indicating improved behavior was needed, but staff could identify no activities or support they were providing to achieve better results.

Group homes are often physically isolated in remote locations. But even when they are in the center of a town, we observed buildings that are set apart from other residential areas and surrounded by locked gates and fences (4, 7, 8, 9, 10, 11, 13, 14, 17, 18, 21, 22). In some locations, these fences go so high up the building it looks like it is surrounded by a cage (7, 8, 13).

While physical conditions are generally clean and well-furnished, many common areas and bedrooms are barren and largely devoid of personalized decorations or personal possessions. In a number of facilities, walls in bedrooms have become filthy and some beds are left without sheets (9, 10, 14). At one facility, we observed filthy conditions, little light or furniture, with an overwhelming smell of urine and feces in the areas where the children were kept (21). At one group home (14), we observed a bed covered in hard plastic and at other facilities (9,10) we found soiled sheets and paint peeling around beds.

Sometimes we do not use sheets because they wet them.

- Group home staff (14)

While staff worked hard to engage a small handful of children during our visits, most children sat motionless. This was especially true for the more disabled children, who were often curled up in corners or sitting quietly by themselves.

The girls like to have long hair, but it is easier for us to shave their heads.

- Group home staff (14)

Instead of going out in the community to get a haircut or for the girls to get their hair cut and styled, a barber came to the home and simply shaved everyone's head. In several group homes, it was impossible to determine the gender of the child because of identical closely cropped haircuts and drab clothing of an androgynous nature.

Children who could easily be toilet trained are often left in diapers, and overworked staff cannot get to them. At one facility, food was served in a room that reeked of excrement (9). In another facility, we observed four children sitting in a row on small plastic potties. Their pants were pulled down in front of other children and they remained motionless there for more than 30 minutes while we were in the room (DC4). In one home (19), a man soiled his clothing with urine during our visit. Despite the fact that there were guests in the room, the staff simply removed his pants in public and walked him to his room half-naked.

With little support for communication or social interaction, placing children together in a congregate setting contributes to their further isolation rather than the creation of a “family-like” environment:

The severely disabled children here hardly ever communicate among themselves. Everyone lives in his own world. The most important thing to know is that they don't make trouble.

➤ Group home director (13)

Even the apparently clean and bright decorations in group homes can undermine emotional development and habilitation.

A large colorful mural looked festive from afar. But it depicted a disconcerting scene of a dinosaur being shot dead by a huge pistol. In another scene dancing strawberries looked more like menacing monsters.

➤ DRI investigator on visiting a group home (18).

Teenagers and young adults are kept in areas decorated for little children and are left with only stuffed animals. In the facility where three group homes were grouped together (9,10,11), paint and plaster had been chipped on the wall next to a bed. At another facility (14), a teenage resident in a wheelchair complained that he could not choose what music to play and controls were kept out of his reach.

On arrival at one group home (run by a private international NGO with public and international funds) (2), we found a child in a wheelchair, alone, pointed toward the wall at the end of the dark corridor. Many children sit in inactivity with little stimulation from other residents or staff. On the walls of this facility, staff had posted statements from the children about “my daily rhythm.” Two of these read as follows:

My daily rhythm...is monotonous, but that doesn't worry me because I like peace and quiet.

My daily rhythm...is also monotonous. I can't see and for everything I need help.

These statements, likely written with the assistance of staff and in English, reinforce low expectations about children with disabilities as well as stereotypes of them as passive and entirely dependent on the care of others.

Children who cannot move by themselves often lack physical activity or movement of any kind with long periods of confinement to a bed, a chair, or a particular area of the living quarters. In one facility (4), for example, the team observed children left in beanbag chairs staring at the ceiling. Even though there were other children in the room, these immobile children were placed in a manner that denied them the opportunity to make eye contact to see what was happening around them. In the same facility, DRI found one young man (age 21) sitting on the living room floor surrounded by a two-foot high wooden fence or pen. He was moved from this penned-in area to another pen adjacent to him as room was made to detain another child. At no time during DRI's visit did either isolated child interact with other individuals in the home. Although DRI was initially told that one boy leaves this area during meal times we later witnessed him being fed by one of the staff members over the fenced side of the pen.

The use of prolonged physical restraints can be dangerous and has come to be understood as a form of degrading treatment or even torture. The various forms of restraints and isolation used also have an impact on generating even further exclusion and social disconnection. In one group home, we found a 15 year-old boy, too small and thin for his age, strapped in a small wooden chair from which he was released as soon as a staff person noticed us approaching them. The team observed children strapped to wheelchairs, strollers, swings – ostensibly to keep them upright, occasionally to stop self-abuse, but almost always limiting mobility and further human interaction. Other children and young adults with cerebral palsy who require chest supports and seat belts to maintain optimal posture were instead seated in chairs that did not provide these needed supports. This leads to pain, increased spinal deformities, breathing problems, and aspiration pneumonia from improper feeding positions.

Many children (and young adults) we encountered are not able to move freely. They rarely have any activities outside of the group home and do not attend school or daycare centers. Some children are registered to go to daycare centers or school but staff report that they do not always go. Even when they do go to daycare, conditions of isolation are reproduced in these other locations. Group homes, daycare, and schools are all segregated by disability. These conditions combine to create a lack of access to socialization and the opportunity to form relationships with age appropriate, non-disabled peers outside the facility. There are children and young people who stay in group homes and never leave.

The girl in a wheelchair looks about eight years old:

DRI: How old is she? Does she go to school?

Staff: She does not go to school because she is 26. She is not going anywhere, she stays

only here.

DRI: Is she included in any activity?

Staff: From time to time, there were projects, but on a regular basis there is no one working with her.

DRI: What does her usual day look like?

Staff: After breakfast we move her to another chair. She likes sitting on the bench. She

likes sitting at the table and banging with her hands making sounds. We give her different things, she likes to throw them on the floor. She has lunch. She goes to bed. They take her outside. When the rest come from school we don't have time for [her] [With all the kids around] we need to take care of their things and give them lunch. So we place [her] somewhere safe.

C. Regimentation

In the group homes visited, DRI investigators observed many of the negative characteristics of institutions, such as a restrictive environment, separation from the community, and lack of interaction and engagement from carers. At most group homes, there are clearly marked schedules that maintain routines that have been set in place for the convenience of staff. In two group homes we visited (7, 8) there was a strict routine of a two-hour nap immediately after lunch. We witnessed children being rushed to bed without any free time between a meal and sleep. A teenager with Down syndrome (7) wanted to watch television after finishing his meal but was told to "go upstairs".

Even adults are "sent to their rooms." We met two young women who were rushed to their room immediately after finishing their lunch. They are both students and briefly attempted to live independently but were forced into a group home due to financial reasons. Despite their independence they had to leave the living room of the group home and go to their room "to rest."

D. Difficulty motivating staff to engage with children

Professionals who were involved with hiring and training staff at group homes reported tremendous frustration in their effort to get staff at group homes to interact with or support the children in developing or maintaining skills.

In the guidelines for each child, there was a recommendation that he feed himself. Staff [should] help him hold his spoon. We knew [the child] could do it. We trained them. We took video to prove it. Apparently the staff in the group homes do not follow these recommendations. **My fear is that the [the children are] fed the same way as in the institution. My fear is based on experience. I see this all the time.**

➤ International NGO staff

DRI investigators encountered numerous children and adolescents fed with baby bottles. At one facility (21), staff said that this practice was used because the children had become dependent on this practice growing up in the orphanage.

Similarly, former NGO workers who trained staff report the lack of support for communication in the group homes:

Another example: in group home[s] we trained staff to use simple signs to communicate with non-verbal children. We put up posters. We worked with the staff so we know they knew what to do. But then we found they never did it.

In part, the lack of initiative is caused by the fact that staff are overwhelmed by demands. According to a staff person from an international NGO, in the original plans for the group homes “there were supposed to be three day care people per shift in group homes. But [in practice] the day care staff also have to clean the place, wash the dishes, do the laundry. In some places, they have to cook. So they don’t have time to work with the kids.”

The problem is low salaries. So you don’t get the best people. They are people who can’t get any other kind of job. They don’t have a clue about disability. They don’t understand the reasons why they are there.

➤ International NGO staff

E. Neglect of children with emotional difficulties and behavioral problems

The maximum they got outside of group homes was for two hours of treatment. Many never got out at all. The great majority. That is how it still is now.

➤ Former international NGO staff with years of experience training staff in group homes

Staff at almost every home I visited did not know what to do with children who have autism or behavioral problems. Staff have apparently never been trained to support children with these needs, and they were desperate for information or advice as to how to help these children.

- Dr. Matt Mason, DRI Science Advisor and child psychologist.

Throughout Bulgaria's group homes, DRI investigators observed signs of emotional neglect and inactivity. We observed a five year old boy with autism whose face was black and blue from self-abuse (21 – according to staff, his bruises were caused by self-abuse; we also observed another child hitting his peers in the group home). We observed children with open wounds from biting themselves (12). Rocking behavior and self-abuse are widely understood to be produced or exacerbated by emotional neglect. Group home staff acknowledge that they have no programs to respond to children with behavioral issues.

He rests in the crib or on the floor. He's self-aggressive. If you try to get him to do anything he gets stressed and more self-abusive. So we leave him alone.

- Group home staff (13)

If the problem is serious, we have to send the child to the [___] psychiatric hospital for treatment. But that is care for children...and they are even more likely to act out if that happens. It would be much better if we could provide treatment here...

- Group home director

Children who are neglected or have behavioral problems, are aggressive or self-injurious can't be handled by staff at the group homes. So they are sent to hospitals. **They use medication as a substitute for care.**

- Child psychologist, Children's Psychiatric Unit, Sofia

There is a lack of any form of behavioral support or children who are self-abusive. In addition, the lack of alternative communication methods to support choice-making and to facilitate communication is insufficient and places children in a non-stimulating environment where communication is entirely absent or is reduced to a minimum thus increasing self-stimulatory, self-harming, and challenging behaviors. According to a child psychologist interviewed by DRI at the Sofia Hospital Department of Child Psychiatry, children with "challenging" behavior are either medicalized or restrained:

Medication is not for these children. They don't have psychiatric problems. We have seen children brought here [from group homes] so over-medicated that we wonder how they are still alive.

The problem of over-medication has been identified by other organizations that have evaluated outcomes for children transferred from old orphanages to group homes. One study found that the use of neuroleptics has increased substantially *after* children were transferred to group homes from institutions.²³ The same study, published in 2015, found that the percentage of children and young people with “challenging behavior” remained approximately the same in the institutions and group homes.²⁴

Despite extensive international assistance and training of staff, not one facility we visited had a program to respond to the problems of dangerous self-abuse other than sedatives or physical restraints. **We observed one child left with his arms in splints so he could not use his hands or even feed himself.** (10) We also saw this boy tied to a chair. Staff explained that they tied him down so he would not bite his hands. At the adjoining group home (9), we observed a girl gouging her eyes with her fingers. Staff members did not respond in any way – as if this were completely normal behavior. When asked about staff could do to protect her, staff responded:

A child psychiatrist [from an international organization] visited us, and she said that there was nothing we could do. She said that it was not dangerous, and we should leave her alone.

➤ Group home staff (9)

At the same facility, the team encountered a boy laying on the ground in front of the group home systematically smashing his face against the concrete ground. A staff member sat and watched, apparently so accustomed to this behavior she did not seem to notice anything unusual. At one point, she handed him a tree branch that he used to hit himself.

Professionals involved for many years in establishing group homes for an international charity observed that “the outside professionals were not prepared. The service providers did not know how to help kids with severe disabilities. **They would say it is impossible to work with this child.**”

²³ Ending Institutionalisation: An Assessment of the Outcomes for Children in Bulgaria, Lumos (2016).

²⁴ According to the Lumos report (2015): “Although there are some instances of positive changes in the behaviour of children and young people, overall the percentage of children and young people with challenging behaviour remains steady at around 30%. The number displaying challenging behaviour has reduced slightly from 345 (32%) in institutions to 329 (31%) in SGHs.

As a result of the way they were trained, these perceptions were passed on to the local professionals. According to former international NGO staff, “it became the perspective of the professionals. And it was self-fulfilling. They believe nothing could be done for these children.”

According to DRI Science Advisor and child psychologist Dr. Matt Mason:

The behavioral problems observed in group homes are likely to be exacerbated by the lack of love and care of a family experienced by these children. Without the option of getting these children into a stable family, it would be extremely difficult for even for the most highly trained professionals to get these children the care they critically need.

F. No planning for family or community integration

They will be here forever.

➤ Staff, group home (9)

DRI investigators heard different views as to whether group homes were or were not intended as a stepping-stone to reintegration into the community. Some reformers observed that group homes were built with no room for staff to live because they would be going home to their own families. According to NGO staff involved in reforms, the “original idea was that kids would go to the group home just to sleep. They would go do different services in the community from there – schools, day centers, specialist services.” In practice, however, “the problem was that there were no such services. **They had a lot of buildings and not enough services. So the result was that the kids were left to sit in the group homes and do nothing.**”

In some cases, what are called “day centers” are located in the same isolated buildings as group homes, so children never go outside. At one location we visited (12), a group home and daycare center are located in a former orphanage. Staff at the group home say that **some children never go outside – except to sit on the balcony.** Other children go to school or day centers in town, but as described below, these are usually segregated locations and do not lead to further social ties in the community or employment.

In practice, staff at every group home we visited recognized that the facility was the permanent residence of the child:

I have never even heard the word “re-integration” in any plan for any child.... Of course family environment and preparation for individual life was always the “ideal” of the officials and specialists. But this was never aim for government, for the locals, or the real plan. Due to intervention by foreign specialists, we reached out to biological family.”

➤ International NGO staff

There was never any expectation that these children would go to a family. Most biological families did not want the kids back.

➤ International NGO staff.

Some idealists from abroad talked about how the group home staff would become foster parents. But that is because they did not know the kind of people who would be staffing the group homes.

➤ International NGO staff

Local staff and authorities describe how international assistance often contributed to the idea that group home placement is the only option for children with disabilities. The Director of group homes in one town (14) described how she was brought to visit programs in the Netherlands. There she saw children with “severe” disabilities in group homes. “It is the same as Bulgaria. All children with more severe disabilities in Europe are placed in group homes. Even if the disability is intellectual and not psychological.” On the other hand, DRI also interviewed group home staff (17, 18) who derived the opposite lesson from their international experience. One such staff person reported that, based on her trip to the Netherlands, she understood that all children could eventually be returned to families.

G. Incentives for new admissions

There was EU money [for group homes]. That money needed to be spent. Getting that money meant profit.... It was not about the children. It was about the money. How fast you build and how much money you spent.

➤ Former Bulgaria Child Protection official

The current system of financing is laden with incentives to keep children in residential care rather than placing them with families or foster families. A number of service providers reported to DRI (1, 2, 3) that they must operate at full capacity of 14 to 15 residents in a group home, or raise private funding, to be able to sustain their services.

A former Child Protection Officer involved in planning and implementing reforms observed that the availability of EU funding for group homes became one of the major motivating forces by municipal authorities to build new facilities – whether or not there was a local need for such services. He described the process in detail to DRI. When buildings were being construction, he said, the amount of funding any municipality would receive would depend on the size of the group home, so there was incentive to build group homes as large as regulations would allow – which was generally 14 beds (though group homes could be arranged in clusters to allow additional efficiencies for the operators). Municipalities competed with one another to build group homes quickly so they could obtain EU funding before a deadline for its availability. Since some funding came from an EU project to assist less developed areas, remote locations had an incentive to build group homes and worry later about how to bring in children from other parts of the country. The practice of placing group homes in remote locations makes it even more difficult to hire well-educated staff. It also makes it harder for children to remain in contact or reunify with family members. At two group homes located in a remote area (19, 20), staff reported to DRI that they were aware of family members who wished to remain in contact with children but could not because of the difficulty of transportation.

According to the former Child Protection Authority official:

In June 2013, they decided to pay per day per child. So, if the group home is less than full, they get less money. This is when the incentive to fill the group homes started. A hysterical effort began to search for children to fill up each group home.

According to the same former Child Protection official, there had been a careful process of assessing the needs of each child in the orphanage before transfer. But this process fell apart as a result of the financial incentives given to municipalities:

All they cared about was filling the group homes. The process of preparation was destroyed. As a result, the new services suffered. They were not prepared to deliver the necessary services for the children who came.

In addition, there was one flat amount of payment per child with a disability, so every municipality receiving disability funds had an incentive to accept children perceived to be less disabled and with the fewest support needs because they were less costly to serve. Former international NGO staff described how some children with the most severe disabilities died in institutions because they could not get any group home to accept them.

In a number of localities, former international NGO staff members reported that the capacity of group homes was greater than the number of children in need, so there was a financial incentive to fill the beds. In many cases, international NGO staff report that municipalities had discretion to decide what kind of group home they operated and which children would be admitted. In the facilities for children with disabilities, some desperate local authorities would take anyone – including children from juvenile justice authorities. Other local municipalities sought out “healthy” children for placement.

II. Observations: Dangerous conditions and mistreatment

While most of the group homes DRI visited were clean and new, some of them were filthy, run-down, and overtly abusive. At one facility (21), children and young people were kept in locked rooms off a dark hallway that smelled overwhelmingly of urine and feces. During a visit that lasted most of the day, one man was locked naked in a cell the entire time, and two residents never moved from a bed and a crib – creating a dangerous risk of bedsores, respiratory problems, and bowel obstruction. For hours, some group home residents sat on potties with their pants down while others rocked back and forth on the floor, repeatedly banging their heads and hitting themselves.

Among the group homes we visited, one facility was outfitted with two different cages (9). In several facilities (5, 9, 13, 19, 21, 22, DC4, DC5) DRI investigators saw metal or wooden cribs with sides so high that they effectively functioned as cages for children with mobility issues. In at least two group homes (4, 12) we found children placed in pens, sitting or lying on the floor. In another facility (17), investigators were informed by staff that a child kept in such a crib had recently died. There were bite marks on the side of the crib where the child had clearly been left to gnaw on the wood.

The two cages observed by DRI (9) were new and made so nicely they could blend in with the group homes’ furniture and decor. But they functioned as cages nonetheless. Staff informed us that they were used for the “safety” of the children when staffing was low. One child was placed in the cage because he “often” jumped out the window. Another child was placed in the cage because of epileptic seizures.

Physical restraints are still commonly used to hold children in to ill-fitting wheelchairs or strollers. We observed such restraints in several facilities (4, 9, 13, DC1, DC4). In one facility where we observed a child tied into a stroller, staff informed us that adapted wheelchairs could not be obtained (9). Yet in that same facility, and two other group homes (9, 10,13) we found a row of sophisticated, new wheelchairs that could be adjusted to provide the exact kind of support a child would need to preserve the use of his or her arms and legs. These wheelchairs were unused and gathering dust.

Leaving a child improperly tied down to an ill-fitting chair can be dangerous, leading to atrophy of arms and legs and of their muscles, increased spasticity, painful constipation, ruptured bowels, and eventual organ damage.

➤ Marisa Cenci Brown, RN, DRI
expert/investigator

United Nations authorities have observed that the use of prolonged restraints or placement persons with disabilities in cages causes severe physical and emotional suffering, amounting to inhumane and degrading treatment or torture in violation of international law.²⁵

We saw numerous children left improperly in cribs and wheelchairs in a manner where their bones could be easily broken by getting caught in openings (9, 12, 14). We observed one woman in an ill-fitting wheelchair (24) contributing to problems with her back and posture. Staff reported that this woman is ambulatory but was **placed in the wheelchair because she was blind and staff found it easier to move her around in the wheelchair.**

At one group home (14), investigators encountered a 16 year-old boy with cerebral palsy in a wheelchair that was ill-fitting and broken. Due to his spasticity, his arms were caught under the chair arms and the metal was digging into his skin. When the DRI team member assisted him to remove his arm, it was dark purple with scratches and indentations. The boy was yelling that his legs were caught under the footrest. The DRI investigator assisted him to free his feet and he stopped shouting.

Investigators observed children in beanbag chairs left to stare at the ceiling (4, 7) and children in wheelchairs pointed toward the wall (2).²⁶ Leaving children isolated in these positions **inhibits social interaction and contributes to social isolation and emotional damage.** Cognitive deprivation from treatment in Bulgaria's group homes leads to further developmental disabilities. Many children do not eat adequately because of lack of support and assistance with eating. Children who are malnourished are not put on special high calorie diets. As a result of this lack of support, these children are left with serious health

²⁵ UN Special Rapporteur on Torture Juan Mendez has stated that prolonged use of physical restraints on persons with mental disabilities in institutions is a form of torture or ill-treatment. (A/66/268, paras. 67-68, 78).

²⁶ HC Pro, "Complications from immobility by body system" (2012), posted at <https://www.hcpro.com/LTC-286850-10704/Complications-from-immobility-by-body-system.html> (last visited October 21, 2019); Hillrom "Complications of immobility" <https://www.hill-rom.com/international/Clinical-Solutions/clinical-programs/progressive-mobility-program/Complications-of-Immobility/> (last visited October 21, 2019). who

problems. Investigators also observed children left without dental care and who did not have teeth at all. This also limits their ability to eat healthy food. **These conditions are identical to those DRI has commonly observed in institutions.**

A. Denial of medical care, physical and pain management

In a number of facilities, investigators observed the denial of essential medical care and treatment. In some group homes investigators observed a pervasive lack of dental care and children with missing teeth – including dangerously decayed roots (12). Investigators observed children with disabilities placed in chairs and wheelchairs without appropriate support in a manner that is dangerous. As noted above, investigators observed numerous children and young people who were dangerously thin and malnourished (e.g. 12) but had never had any consultation with a nutritionist and were not receiving any special assistance or high-calorie food to help them gain weight (19, 20, 21).

In a specialized “medical” group home designated for children in need of “continuous care,” investigators encountered a child with hydrocephalus, leading to a dangerously swollen head because of the accumulation of fluid. This condition can be treated by insertion of a shunt to drain fluid from the head and relieve pressure, a medical procedure which is available in Bulgaria. We received various conflicting explanations for his lack of treatment from staff – that parents refused to authorize it, that it was “too late” because the child was already so disabled, or simply that doctors never really explored the possibility. Staff said that the doctor at the child’s former institution was responsible for not getting an evaluation. Yet investigators were told that the same doctor worked at the group home where the child was placed for more than two years and apparently never obtained a full evaluation or treatment during that time.

The experience of advanced stage hydrocephalus – where a person’s head is so large they can barely move it or sit up – is extremely painful. Yet staff informed us that the child received no pain medication for his hydrocephalus. Leaving a child with untreated hydrocephalus and an enlarged head is known to be extremely painful, and the **denial of pain medication has been ruled a form of torture by international human rights bodies.**

This case also revealed a number of other dangerous practices on the part of the group home. We were told that the child with hydrocephalus had to be kept in total isolation from other people because he was at risk of infection – and had just returned from the hospital for treatment of pneumonia. When staff described feeding practices, they indicated that they spoon fed him while lying on his back. This improper feeding practice exposes the child to

aspiration pneumonia. Despite this, the child's total isolation from adults and children behind a wall of glass cannot be justified by his condition.

B. Lack of physical management and dangerous feeding practices.

In many of the group homes DRI visited, investigators observed improper feeding, physical management and lack of support for eating, creating serious health dangers. As described earlier in this report, children are often left in ill-fitting wheelchairs or strollers without support – even though, in some cases, adaptive wheelchairs were found in the same facility. As observed by one DRI investigator:

Children with moderate to severe physical disabilities such as cerebral palsy, spina bifida, muscular dystrophy, developmental delay, etc., fail to develop postural control and require special seating systems or wheelchairs designed at providing an appropriate level of postural support, as well as offering comfort, skin protection, and stability to enable daily functional activities to be carried out at home and at school. Specially fabricated and professionally-designed therapeutic devices and services protect children from harm and regression. Appropriate physical management, including physical and occupational therapy services, should be designed and provided with the goal of enhancing the child's capacity to function (i.e., enhance the ability of the child to move, sit upright, and participate in daily life activities) and to prevent loss of function and further deformity. **Such practices were almost universally absent in the group homes we observed in Bulgaria. The skills required to provide this support could easily be provided through training and support of family members.** Communication with the child is essential. For children who do not speak, understanding their needs may require long periods of close attention to non-verbal cues, very difficult to communicate to staff in the kind of rushed and chaotic environment we observed in group homes.

➤ Melanie Reeves Miller, certified disability expert

In many facilities, staff fed children in a manner that was rushed in such a way that could cause aspiration or choking risks, and did not promote the independence of the child. In some locations, food was pureed or ground to accommodate rate of eating or possible swallowing difficulties without supportive intervention. DRI also observed lack of appropriate and adequate cutlery to promote independent eating.

At two group homes (4, 7), DRI investigators witnessed harmful and dangerous feeding practices:

DRI found one boy (in group home 4) sitting on the floor surrounded by a two-foot high wooden fence. At no time did he interact with other individuals in the home. Although DRI was initially told that he leaves this area during meal times we later witnessed him being fed by one of the staff members over the fence.

At another facility (group home 7), a boy with Down Syndrome was seated at a kitchen table and given a bowl of stew. A male staff person walked up to him and rapidly fed him stew from the bowl. The whole operation took less than a minute. Then he ordered the boy to his room for his afternoon nap.

➤ Observation at group home (7)

DRI visited three group homes (3, 5, 12) designated for children in need of constant medical attention. At one group home (12), staff had little awareness of basic practices needed to keep children safe – or avoid the extreme levels of pain that come with untreated hydrocephalus. As noted above, this is the facility where a child with hydrocephalus was not provided essential treatment and pain medication. At the same facility, investigators observed numerous other practices that are dangerous – but that could be remedied with simple training (including training that could be provided to family members to perform at home). DRI investigators observed:

- at least two children with bed sores from lack of assistance with movement;
- all children in diapers; staff reported they provide no training with regard to toileting;
- a child who was recently brought back from the hospital for pneumonia; staff informed us that the boy was fed laying on his back, a practice which is likely to lead to the child developing aspiration pneumonia;
- children lifted from the armpits/shoulders by carers; this practice creates a risk of dislocation and injury;
- staff standing behind children kicking their feet to replicate walking; this is not a technique that will help the child develop strength or motor control to actually engage in walking behavior; there are numerous techniques for support that would help the child develop this skill;
- a child severely contracted to the point that her rib cage was protruding from her right side and her spine was highly arched; there were no foam contour devices to support her body;

- no engagement or interaction from the carers or any meaningful activities provided to the children.

The medical care we observed for medically fragile children at this particular home could have been provided within the context of a family with visits and consultation with outside medical professionals. Several of these children had severe contractures. A few of these children were also receiving nutrition through feeding tubes (nasogastric, gastrostomy, or jejunostomy). With training, families can learn to provide such care necessary to support the child living at home.

DRI investigators visited a group home for children designated “in need of continuous medical attention” operated by a private NGO (3). At this group home, children received considerably better services than other medical group homes we visited. DRI’s investigative team did not include medical personnel for this visit, but some of the care at this facility raised concerns. DRI investigators observed one child struggling to breathe as a result of spinal stenosis. Such a condition could be immediately life-threatening. This is likely a treatable medical condition and care for this child should be possible in Bulgaria. The staff of this NGO informed us, however, that the child was fully assessed but nothing could be done for him in Bulgaria. We are deeply concerned about this child.

The larger concern at the facility (3) is whether all children need to be living permanently in a group home to receive the care they need. Down the corridor in another room at this facility, investigators observed three children lying awake in cribs. One of the children was celebrating his ninth birthday. His family was present for the celebration. The family members informed DRI investigators that they visit weekly and would have him live at home if adequate services were available in their small rural community. Staff stated that the boy receives two hours of physical therapy per day. The remainder of the day he stays in his crib. According to staff, this boy could live at home if services could be brought to the family.

C. Failure to protect against sexual abuse and violence

Systematic research...suggests that children in congregate care settings are at increased risk for maltreatment compared with children placed with families....Sexual abuse was higher in residential care than in either foster care or the general population.²⁷

As this report shows, the group homes of Bulgaria are much more like institutions than families. In the congregate setting of group homes, where staff cannot keep an eye on

²⁷ Dozier et. al. (2014) at 222.

children and adults mixed together from ages 5, 6, or 7 to their mid-thirties, there is an ever-present risk that children will be subject to abuse.

At one home visited by DRI investigators (19), we observed a large 16 year old boy physically abusing much smaller children in the group home. At one point, the boy pushed over a boy with cerebral palsy who appeared to be 10 years old. A member of the group home staff observed this act of violence and did not intervene. The 16 year old also made another child dance for him. Later on, the boy attacked a member of the DRI investigative team, twisting the investigator's arm behind his back and trying to force him into a bathroom. During a subsequent interview, the boy bragged about beating other children and hitting staff members with impunity. He said that because of his "severe mental illness" he could not be treated anywhere else so would never be removed from the group home.

At the same facility (19), DRI investigators encountered a 16 year-old girl who was "dating" a 23 year old man outside the group home. Staff acknowledged that they knew about this relationship and gave the girl "sex education" but did not try to stop her.

DRI heard from numerous staff and government authorities that children with behavioral problems – including violence toward other children – cannot be removed from group homes because there is nowhere else to accommodate them. A former official from Bulgaria's child protection system, three former international NGO staff members, and group home staff said that this situation exposed children to serious dangers. According to the Deputy Mayor of Gabrovo, the placement of children with behavioral problems in group settings "endanger the other children in group homes. Also, there are really young and old mixed together in one place. We would like to be able to separate these groups."

DRI observed the problem of oversight and protecting children at three group homes that were grouped together (9, 10, 11) behind one fence. At this facility, there were three 14-bed group homes with open doors among them, combining 42 non-related people together, ranging in age from 9 to their early 30s. DRI investigators encountered one girl who held and attempted to kiss many of the investigators on the face. Later during the visit, one of the DRI investigators observed the same girl in a bedroom down the corridor in bed with another teenage girl kissing and holding one another. Staff did not appear concerned when the DRI investigator mentioned this incident to them, as if such an occurrence were routine. Staff reported to investigators that they did not have any process in place to determine whether "abuse" had taken place in the life of their residents. "If any abuse happened, I'd know it," the group home director reported.

At one group home (14), there had previously been an incident where staff were documented on video physically beating children. This was posted online and thus brought to public

attention. DRI investigators asked staff at the home about this incident, and they confirmed that the abuse had taken place. Staff described the abuse and the situation in the group home as “a horror.” They assured investigators that, since it was exposed, the staff members had been removed and the abuses had stopped. A criminal case against the perpetrators is now pending. According to the attorney from Validity, there has been no compensation to the victims of the abuse.

Many of the children placed in group homes, especially for non-disabled children, are removed from their parents because of violence, abuse, or neglect in the home. DRI investigators asked staff at almost every home whether there were any screenings or special programs for children who have experienced trauma. Most staff appeared to have no idea what we were talking about. Bulgaria’s group home system and services for children are not in any way “trauma informed.”²⁸

At one 60-bed facility for non-disabled children authorities reported that many children had been abused in their homes, yet no programs were available to screen for or assist children who experienced to trauma. Staff reported that there was no behavior to suggest children were having a hard time coping with this history. The director of the facility reported that there had never been an attempted suicide. When asked about the practices of cutting (documented to be linked to a history of child sexual abuse), authorities said that it never happened in the facility.

DRI investigators observed a lack of oversight and awareness about the dangers of violence and trauma at an adult facility that raised broader concerns about protections that may be lacking in the social service system as a whole. At an adult social care home, DRI observed a woman who was kept locked in her room. An official from the Directorate for Social Services of the district, who was accompanying DRI’s investigators, explained that the woman had been physically abused by a man at the facility. This man lived across the hall from her and was standing outside her door during our visit. When we opened the door, she ran into the hallway and began screaming at the man. We asked why the man was not removed. The official explained that, because he was mentally ill, there was no other place in the

²⁸ Children and adolescents with intellectual disabilities – and any person separated from his or her family as a child or adolescent – are likely to have a high risk of abuse and trauma history. “Trauma-informed” care refers to care that is sensitive to this experience and builds resilience for individuals who have survived abuse. Trauma is one of the core factors leading to behavioral problems observed in children with intellectual disabilities. Even if no disability or mental health issues can be observed, coercive treatment or conditions that reproduce the earlier abusive experiences – such as placement in institutions or residential care, treatment by unfamiliar staff, and exposure to others with erratic behavior and a similar history of trauma – can trigger a further trauma response. See Jessica Dym Bartlett and Kate Steber, [How to Implement Trauma-informed Care to Build Resilience to Childhood Trauma](#) (May 2019). See also resources available from [Eurochild Carepath: Helping Europe’s Children Access Trauma-Informed Leaving Care Support \(2019\)](#).

municipality that could serve him. In practice, she said, there was no other place he could go. We asked whether this situation had been reported to higher municipal or law enforcement authorities. The official explained that, if she caused trouble by raising this issue, she would be in danger of losing her job. As a result, the alleged abuser in this case roamed freely about the facility while the victim was locked up. There appeared to be no awareness or concern about the emotional impact of continuously exposing the woman to her abuser.

DRI did not observe any programs to inform children of their rights and allow them to complain about abuses to outside authorities independent of the group home. At facilities where DRI inquired about this topic (19, 20, 21), group home staff stated that children would have to ask staff for help in raising any complaints. At one facility, a box for complaints existed but it was outside the reach of children, who would have to ask staff to help them. The director of three group homes (21, 22, and 23) said that “if there is any system in Bulgaria for children to complain about treatment in group homes, I am unaware of it.”

III. Structure of services: no choice or alternatives

Many of the children formerly detained in Bulgaria’s orphanage system are now residing in the country’s new group homes. As of 2009, there were more than 6,700 children residing in orphanages.²⁹ While Bulgaria closed most of its large orphanages, about half of these children (the official count is approximately 3,300) now live in group homes.³⁰ Today, there are still an estimated 1,000 children living in large institutions.³¹ This includes hundreds of babies and toddlers with disabilities. To complete the process of deinstitutionalization, Bulgaria has recently announced plans to build twenty new group homes for nearly 300 of the youngest children with disabilities.

DRI encountered a five year-old boy with a diagnosis of autism who had recently been placed in a group home by his foster family. Staff at a day center where the child was served during the day said that the group home placement was extremely difficult for the whole family. The

²⁹ Lumos, “Ending Institutionalisation: An assessment of the outcomes for children and young people in Bulgaria” (2015). Of the original orphanage population, many of the children have aged out of the child welfare system. Some children were placed in other long-term institutions. Lumos conducted a study 2,115 moved out of institutions from 2013-2015. In this sample, 150 children died (7% of the total). The largest portion, 1,378, were placed in group homes. Nearly 5% were re-institutionalized (probably in adult facilities), 3.6% (78) were reintegrated into families, and 3.6% (77) were placed in foster care. Lumos (2015) at 15.

³⁰ The Audit Report № 1000100416, for an audit on the compliance in the implementation of the Action plan with the Vision for deinstitutionalization for the period 2009 - 2015

³¹ There are 14 institutions under the Ministry of Health for children ages 0-7 designated for children with disabilities (though it is likely that some children without disabilities are also placed in these facilities). UNICEF web site <https://www.unicef.org/bulgaria/en/situation-children-bulgaria> In addition, almost 200 children in conflict with the law and children with delinquent behaviour remain in institutional care while (excluded from the official statistics of children living in residential care. UNICEF web site <https://www.unicef.org/bulgaria/en/situation-children-bulgaria>

father who brought the child to the group home was in tears. The family lived in a small village where there were no supportive services. Without any assistance, someone from the family had to stay at home constantly to care for the child.

If there had been any services in his village – or even a bus to take him – the family would have kept the child.

➤ Group home staff

Disability services are often made available only in a group home setting, creating what are effectively small segregated facilities for children with disabilities. Today, according to one source, there are 3,325 children living in “group homes” or what is called “family-like” residential care.³² According to the Bulgarian Helsinki Committee, there were 3,116 children in 282 “small group homes” at the end of 2017.³³ Of these group homes, 145 were designated for children and young people without disabilities and 129 homes limited to children and young people with disabilities. There are also 8 homes for 64 children and young people who are officially designated as “in need of permanent medical care” (according to our observations, most of these children could easily have been served at home with a family).

In addition, there are approximately 1,000 children in larger institutions. According to the Ministry of Labour and Social Affairs, there are 633 children in 20 remaining social care institutions,³⁴ as well as 482 children in baby homes under the Ministry of Health (as of the end of 2018).³⁵ There are also 113 children in 18 crisis centers, and 96 children and youth in 17 “transitional homes” for children³⁶ and, according to UNICEF, an additional 200 children in conflict with the law are detained in institutions.³⁷

A. New admissions

Bulgaria does not have early intervention programs to prevent abandonment of children. There should be neonatal teams in the hospital

³² ANED 2018-19 – Country report on Living independently and being included in the community – Bulgaria <https://www.disability-europe.net/downloads/1016-year-4-2018-19-policy-theme-il>, pg.22: “Neither the number nor any other characteristic of the actual users or activities of the services are mentioned in the annual reports of the Social Assistance Agency which is the only state authority which publishes regular reports on the development of social services and assistance. These annual reports do not provide data on the current state of occupancy level of each type of service”

³³ Bulgarian Helsinki Committee, Annual human rights report for 2017, https://bghelsinki.org/media/uploads/annual_reports/annual_bhc_report_2017_issn-2367-6930_en.pdf.

Validity (2019) reports that there are now 3,338 children in 268 group homes.

³⁴ DRI’s meeting with Ministry representatives held on February 21, 2019

³⁵ <https://www.nsi.bg/en/content/5606/homes-medico-social-care-children>

³⁶ Bulgarian Helsinki Committee, Annual human rights report for 2017

³⁷ <https://www.unicef.org/bulgaria/en/situation-children-bulgaria>

to support mothers. There are no such services in Bulgaria. The models are proven by effective pilot programs, but they have not been continued. The Bulgarian Association for Persons with Intellectual Disabilities runs a pilot program. For Our Children runs such a program.

➤ Child psychiatrist, Sofia Children's Hospital

According to Galina Markova of the Know How Center, "planning for deinstitutionalization of orphanages was not associated with prevention of new separation of children and families." As a result, "no investment has been made into building capacity for preventive work at the national level. No such services have been established. No further training has been carried out, no campaigning, not even guidance by the Child Protection Departments about the work needed to reorient toward prevention."

Professor Markova has also drawn attention to a cultural and historic problem within Bulgaria's child protection system that was traditionally focused mainly on the prevention of child abuse. Social workers within the Child Protection System have long assumed that marginalized families (especially Roma but more generally poor families) are likely to be bad or inadequate parents. According to Professor Markova, the social work profession acculturated to believe families are abusive or inadequate and children are better off in the care of the state.³⁸

As a result, as of 2019, the number of children living outside of families (in institutions and group homes) has not decreased significantly in recent years – and neither has the number of new admissions. According to data provided by the National Statistical Institute³⁹ there were 630 new admissions to homes for medico-social care for children in 2018 (including large institutions operated by the Ministry of Health), of which a great majority (557) were children under 1 year of age.

According to staff at the Our Children Foundation, newborn children are abandoned and kept in neonatology wards of hospitals for up to one year until they can be legally placed in social service. DRI has not been able to corroborate this. If true, this would be a very great concern – and we ask the government of Bulgaria to disclose these practices and allow independent monitors access to investigate this issue. Leaving an infant or baby without a parent is likely to be damaging to the child, contributing to irreversible psychological damage and

³⁸ "The child protection system is reluctant to see that the DI essence is to invest in parents' capacity. Rather, they see the essence of the process in the setting up and developing substitute care services. Most respondents openly share their understanding that there will always be groups of children for whom home families are the worst option." "DI – The Case of Bulgaria 2 Know-How Center for Alternative Child Care, NBU; Key Findings (January 2018): Galina Markova, Evgenia Toneva, Natalia Mihayilova, Kristina Slavova, Iliana Maliniva, Zlatka Angelova, Lora Sarkisian, Elitsa Gerginova, Kostadinka Samsorova

³⁹ <https://www.nsi.bg/en/content/5606/homes-medico-social-care-children>

developmental disability. DRI has similar concerns about children placed in “baby homes,” the remaining large institutions under the Ministry of Health. **We are deeply concerned about plans to build 20 new group homes as well as 8 new specialized centers for children with medical problems.**⁴⁰

Until the break-up of families is addressed, and new admissions are stopped, there will be pressure to keep open institutions and create group homes. The children who will be most at risk are the youngest children who will be placed in these new group homes. These are the children who are in most immediate need of a family and who are most easily and permanently damaged by placement in congregate settings.

DRI investigators were not given permission to visit any of the baby homes under the Ministry of Health. In Varna, we did walk around one institution, however and we looked in the windows. We were able to see that institutional conditions remain at these facilities. We saw young children in cribs and strollers with no adults present.

DRI investigators did visit one highly regarded program in Varna, Karin Dom, that provides a broad range of services to help parents in the community keep their children with disabilities. It is a private non-profit center that helps parents of children with disabilities with prevention programs for children 0-3 years and provides support for families of children with disabilities between the ages of 3 and 8. Among the many valuable programs at Karin Dom, the DRI team observed training for children and families in the use of supported communication, such as the Picture Exchange Communication System (PECS). This system allows children with little or no verbal communication abilities to use pictures or symbols to express him/herself or request a desired item through exchange of a picture card.

The program also runs separate schools for children with and without disabilities. The staff observed that the children without disabilities had to be kept out of the same classrooms from the children with disabilities because the program is privately funded and parents of non-disabled children do not want their children forced to learn with children who have disabilities. Staff reported to DRI investigators that they were disappointed not to be able to offer integrated educational services where children with and without disabilities could

⁴⁰ Updated Action Plan for the implementation of the National Strategy “Vision for Deinstitutionalisation of Children in the Republic of Bulgaria”, 2016. In theory, the 20 homes are for children who require “specialized medical and social care,” and the 8 specialized centers for children with “high-risk behavior and need for special health care.” These children, like all other children, have a need to live and grow up with a family. If they need specialized medical or mental health care, it should be provided within the context of a family placement. DRI investigators observed group homes for children designated as needing the highest level of continuous medical care. With very limited exceptions, the care we observed could have been provided in a family setting.

study together. Such a program, they observed, would send a powerful message about the potential for inclusion throughout Bulgaria.

While various “islands” of good service and support for families exist in Bulgaria, it was clear from interviewing family members in many parts of the country that the need for support is vastly greater than the services that are available. DRI visits to group homes also made clear how such programs are *not* likely to benefit children already separated from families. Staff at group homes simply have no interest in providing continued support to help children maintain the skills they might develop in the program.

Many other programs – for which there is expertise and training in Bulgaria – have not been implemented in the group homes we visited. DRI investigators observed the same problem at group homes with physical therapy activities designed to promote movement, increased mobility, and strength training were provided in daycare or other programs. As a general rule, the group home carers had received training to appropriately continue the exercises and training throughout the child’s daily life – but they choose not to do so. All activities and training provided at specialized centers cease when the child leaves for the day.

There are 135 Community Support Centers in Bulgaria which are intended to provide preventive activities. However, they mainly focus on families affected by poverty, families in rural areas, and Roma families, with very limited activities for families of children with disabilities. While their main outreach was to Roma, the Centers we visited had no Roma professional staff. We were concerned by generalizations about Roma families by some staff that appeared to be based on prejudice about the lack of responsibilities these groups take for their children and the danger of Roma having too many children.

B. Gatekeeping: no alternative to group homes

All children will be in families. Except for children with disabilities who are the exceptional cases.

- Director of the Directorate for Social Affairs and Health Care, Municipality of Veliko Tărnovo.

National government authorities at the Ministry of Labor and Social Welfare reported to DRI that children with “severe” disabilities *have* to be placed in institutions or group homes and could not live with biological families or foster care. They said that each placement is based on an individualized decision, by professionals, who examine the needs and the best interest of the child.

DRI's observations throughout the visit demonstrate the opposite. **Decisions are not based on the individual needs of the child but on the care that is or is not available in the service system.**

DRI interviewed two judges from the Varna District court who are responsible for the legal order as to where a child will reside. They described the "heroic" efforts of social workers to find placements for children. Out of great respect for their work, the judges almost always back up the social workers' recommendations. However, the best the social workers can do is to examine what services are available to families and what are not. When supports are not available to families, the social workers must recommend – and the judges must approve – group home placement.

Often we know that parents could keep a child [if they had] more resources. But there are no more resources. The only place that is available is the group home.

➤ Judge, Varna District Court

Everyone knows this happens. Because there are not enough resources for families, we have to place children in group homes.

➤ Judge, Varna District Court

C. Lack of foster care for children with disabilities

While extensive resources have been invested in group homes, the foster care system remains under-developed – especially for children with disabilities. In part, this problem is a product of Bulgaria's historical lack of any foster care system. Historically, there has been a cultural resistance to foster care in Bulgaria based on traditional views about the importance of biological families and the perceived dangers of relying on families receiving government support to keep children.⁴¹ DRI interviews with government authorities and service providers revealed that this suspicion of foster care is very much alive today. The current system of foster care was established in 2013 when the first contracts were signed with foster families.⁴² According to the National Association for Foster Care (NAFC), there were 2,000 foster families in Bulgaria by 2018 – but the system only serves 178 children with disabilities. At the same time, the foster care system for non-disabled children is under-

⁴¹ EveryChild (2005) at 51.

⁴² Audit report no. 1000100416 on the implementation of the Action Plan with the Vision for deinstitutionalization for the period 2009-2015, Adopted by the Decision no. 202/18.07.2019. by the Court of Auditors (Protocol no. 27).

utilized. According to NAFC, 515 of 2,172 approved foster families are not sent *any* children.⁴³ \

In Sofia, we visited a group home run by a private NGO (1) that houses children for a short time until they can be placed in a family in the foster care system. Staff reported that although 2 million people live in Sofia, they have only been able to find seven foster placements for children with disabilities. In Varna, Bulgaria's second largest city, municipal authorities reported to DRI that there are only 11 children with disabilities in foster care.⁴⁴ In a number of locations, DRI investigators were told that children with disabilities were placed in foster care. When pressed for details, however, former international NGO staff explained that "kids in these programs have minimal disabilities with few support needs. Anyone who really needs a lot of support can't be in foster care."

A number of officials, such as the Director of the Directorate for Social Services of one municipality, reported that "foster families do not want to take children with disabilities." Many of them seem to assume that the problem lies with the families who refuse to accept children with disabilities – rather than understanding that the problem may be the lack of support. But others report that it is nearly impossible for foster families to take children with disabilities given the lack of extra support available to accommodate the child's disability:

There is effectively no system of foster care for children with disabilities in Bulgaria.

➤ International NGO staff

Usually foster parents do not take kids with disabilities. Because there is no support for foster parents. It is very rare.

➤ Judge, Varna District Court

At the Foundation for Our Children (1), staff report that payment to foster parents taking children with disabilities is higher than for children without disabilities. But this payment is simply not enough to cover the cost of taking in a child with a disability who has significant support needs. There is not enough funding for respite care or other sources of support. Additional forms of support, education, and counseling would also be valuable to help foster parents take responsibility for children with disabilities. As a result of this lack of support, a judge of the Varna District Court observed that well-meaning foster parents who try to take

⁴³ National Foster Care Association, *Every fifth foster family does not have accommodated child*, December 30, 2018. <http://www.napc.eu/vsjako+peto+priemno+semejstvo+u+nas+e+bez+nastaneno-novini/1/MNKjIVKrcZOHMdijcxeDYxenc5erYpafYJebYReLI9evIJOPMVKPMZKTcleDIBKb?fbclid=IwAR3Rj7wfOPW-IJ2zEMbDM6OHcqaVkpLysnYYcMKWNPBIupKP7XbFgXV6tKU>.

⁴⁴ Data obtained in the interview with local officials in Varna

a child with a disability are forced to give up. Former international NGO staff provided an example of this:

There was a lady who was part of special staff [at an institution] for children with the most severe disabilities. She had a special affection for one child. She followed him to a group home. She loved him. She became his foster mother. But now she's burnt out. She reached the end of her capacity. She has no supportive services. She can't leave him for two hours. She has to be with him all day long even though he's now 16 years old. By the way, this is the only child [from the group home] who gained any weight. He gained 5 kg in one year because of the affection from this one lady.

➤ former international NGO staff

D. Isolation at day centers

We are not teaching them things to get a job. No one gets jobs.

➤ Day care center staff (DC3)

In theory, group homes were intended to facilitate children's further integration into the community by allowing them to go to day centers or schools. During our investigation, DRI visited one mainstream school, one special school for children with disabilities, and five day centers. Apart from the mainstream school, all of these facilities were essentially segregated by disability. The mainstream school had ramps but was not physically accessible in some areas. The school also reported that it does not have accommodations for children with so-called "severe" disabilities. All other facilities we visited are limited to children with disabilities. None of these programs systematically lead to further social integration or jobs in integrated settings.

Day care centers were set up to supplement the educational system, but many of the children DRI encountered in these facilities have no schooling and this is the only place they go outside the group home. The day centers do not provide a meaningful alternative to schools. According to staff at the Our Children group home (1), daycare is really for the convenience of the parent and not the benefit of the child:

Day Care Centers are made for parents not children. They're like institutions, except that children don't sleep there. They should be in a school. I don't think you can find a school with severely disabled children in Bulgaria.

Day centers DRI visited maintain fixed daily schedule. In addition to regimented conditions, each of the five facilities DRI visited reported that they were over their official capacity,

limiting the amount of individual attention any child could receive. All day centers DRI visited (except DC4) had nearly twice as many children as allowed by their official capacity. For example, at one day care center (DC1) with capacity for 17 children accommodated 31 children, while a day care center (DC5) with capacity of 35 accommodated 50 children and youth.

According to staff at the day centers, the majority of children attend either mainstream or special schools or kindergarten – but some children receive no education. At one group home, staff report that four children stay at the daycare for the whole day. This daycare program is better staffed than a group home, staff report, but it still cannot accommodate the needs of all children, especially those who need individual attention and support to engage in activities. While there is individual treatment provided to one child at a time, only a limited number of children benefit from any form of attention on any given day.

At one day center (DC5), staff report that children from families receive much more individual attention and are more engaged than children from group homes. When asked why this was the case, staff explained that **“their parents fight for them. There is no one to fight for those abandoned in group homes.”**

At one daycare center, staff said that it was easy to tell the difference between children living in families and children from group homes:

The ones from families are much more free. Much more happy.... You can tell they are raised with love. They have a normal social life. Because they spend time with family and interact with others.

As a former staff member of an international NGO observed “most of the services will be used by children from families. Because parents fight for their children. For kids coming from group homes, it is just a formal requirement [that they go to the day center]. **The staff see that they go. But it’s not their concern what happens there.**” As a result, DRI investigators were told that “children from families get services for a whole day. Children from group homes just get a few hours.”

DRI visited a daycare center (DC4) located on a corridor of a huge former baby-home. The facility looked much like a hospital with lines of metal cribs. DRI investigators observed children in this daycare sitting on “potties” from the time the team arrived until we departed over 30 minutes later. Staff picked up other children from their cribs and placed them on “potties” alongside the others. There was no recognition of privacy or respect. The children appeared to be conditioned to this practice as none attempted to get up from the seat. When asked, staff reported they were provided no training with regard to toileting.

E. Lack of Education and Inclusion

Bulgaria has a progressive education law that permits all children with disabilities to attend the school that their parents pick for them. In theory, they could go to mainstream school. In practice, the one mainstream school we visited was physically accessible only on the ground floor. In addition, the curriculum was not adapted for people with intellectual disabilities. There was at least one deaf child at this school. But investigators were told by school authorities that its program was not adapted to children with what they called “severe” disabilities.

In its 2018 report on Bulgaria, the UN Committee on the Rights of Persons with Disabilities found that a “segregated education system still remains” in Bulgaria and that “children with disabilities are not allowed to enroll in mainstream schools.”⁴⁵ The CRPD raised concerns about the lack of information provided by the government about the number of children with disabilities who do not go to school at all. The Committee called on Bulgaria to “[r]eplace segregated education systems with quality inclusive education.”

While a system of segregated schools for children with disabilities does exist, government officials and staff report that there is very little or nothing in the way of education available at these schools. According to the Deputy Mayor of Gabrovo, the school for children with disabilities “is not really a school” at all. It is of some value, she said, because “there are teachers and some education there.”

Many children living in group homes do not go to school at all (e.g. 21). At one day center, they boasted having the only speech therapist in the area. They said children cannot go to the neighborhood schools because “they have no speech therapist and can’t talk.”

One center DRI visited had small “protected” classrooms and different therapy rooms around the building. Here, children from families were provided with hourly individualized treatments (which could be provided to a small number of children compared to their total number) or “educational” activities. Some children only came for individualized treatments while others attended a half-day program. These centers are used as a “replacement” for real education although they provided some occupational training. However, it fostered segregation and exclusion of children from the community.

⁴⁵ **Committee on the Rights of Persons with Disabilities**, Concluding observations on the initial report of Bulgaria, Adopted by the Committee at its twentieth session (27 August–21 September 2018), CRPD/C/BGR/CO/1

In contrast, in the mainstream school we visited children with disabilities were well integrated and indistinguishable from other children. However, according to staff at the school (SC2), schools don't feel equipped to accommodate children with more complex disabilities and usually accept children with "physical and minor learning disabilities."

The lack of inclusive education puts pressure on parents who keep their children with disabilities with them at home. Some parents have to take their children long distances to go to school. One mother said she is able to take her child to the mainstream school, but he effectively gets no education there. The day care center he attends also does not help in developing any skills. She said the child's grandfather was able to teach him how to read. Her child clearly had potential to develop important new skills, but neither the school or the day center made any meaningful effort to facilitate learning.

F. Lack of support for parents in the community

We are poor. Instead of helping us, you are punishing us by taking our children.

- Paraphrase of statement by a parent, quoted by the Director of the Know How Center

The parents [of children with disabilities] are overwhelmed. Mothers have to give up their job. They need a lot of help to keep the child.

- Judge, Gabrovo District Court

There should be more services in the community for children to support the families. It is better to put money into services than buildings.

- Child psychiatrist, Sofia Children's Psychiatric Ward

Parents interviewed by DRI shared their concern that even if there were "great community services for children," at 18 years of age everything stops.

One activist mother interviewed by DRI said that "disability is directly linked to poverty you have to pay everything by yourself. Families become poor because they have a child with disability. 80% of families with children with disabilities get divorced. We have many single mothers or fathers [in their program]. Mainly they don't work or other children are taking care of their disabled sibling."

Families reported to DRI that they feel under pressure to place their children in institutions. The pressure is primarily economic. When one family member has to stay home to take care of a child, "it impoverishes the family." In addition, families must also cope with stigma and social pressure in the community against disability inclusion. Another parent activist (R.B. parent advocate) reported to DRI that children could get more support services in institutions than in the family, so family members feel pressure to give up their children. And when children turn 18, support from the government stops entirely, leaving young adults even more at risk of institutional placement.

Even though deinstitutionalization for children has advanced, part of the problem is that most of the supports cease entirely once the child turns 18, leaving young adults and their families, little choice but to apply for institutional care. [As children get older], six of the children's institutions simply became adult institutions, with the same residents."

- Family activist for children with disabilities

There is unfortunately no strong, independent organization of family members working for the rights of children with and without disabilities. At Karin Dom, staff report that many small parents groups do exist, but these are usually focused around the specific diagnosis of their children and they focus their efforts on getting the government to provide the kinds of services their children need. There is no national coalition that can hold the government accountable on big-picture policy issues. According to the director of Karin Dom, many family activists are angry and frustrated at government authorities and service providers. "Even though Bulgaria is moving in the right direction," she says, "**change will not happen fast enough to help their children.**"

According to Kapka Panayotova, the Director of the Center for Independent Living for People with Disabilities, some family-run groups have been able to get government contracts to provide services. This reliance on government funding leaves them unable to challenge government policies if and when those policies fall short.

In addition, some non-governmental organizations made up of families have supported institutions or group homes because they are easier to raise funds for than community programs. A mother running one such organization explained:

"We gather volunteers and brings them to group homes to provide treatments or to renovate. It is easier to persuade donors to invest in institutions (group homes); it is easier to put donations into buildings. NGOs have an interest in maintaining group homes because of cash flow."

G. Group home placement of adolescents without disabilities

The availability of positive, stable supports has been identified as one of the most important factors in promoting resilience in traumatized individuals studied across the life cycle. Researchers have long been aware of the importance to infants and young children of a healthy, secure attachment to at least one adult. Attachment is also critical to healthy development as children enter middle childhood and adolescents....[E]ffects of housing with peers who have behavioral and emotional problems can increase an adolescent's susceptibility to deviant peer influence.⁴⁶

DRI investigators visited one group home for five adolescent male and female teenagers. The group home was in an apartment indistinguishable from others in a large building. It was well furnished and as "home-like" in appearance as it could be. During our short visit, the staff and residents in the home appeared to have a mutually respectful relationship. The residents of the home go to school, engage in community activities, and they come and go independently. The director of the group home described an impressive program to help all residents find jobs or continue with higher education.

DRI's concerns about this home do not derive from anything we observed at this home but from scientific research on mental health and child development about the placement of adolescents in homes of this kind. While these adolescents have no visible disability, they have all likely experienced the difficulties and traumas of losing their parents or coming from abusive families. While sibling relationships are very important, the best role models for these individuals are stable adults and not necessarily other adolescents going through these difficult situations. Even well-meaning and highly committed staff are not the same as true family members who will remain bonded with the individual throughout a lifetime.

Among older adolescents, such as the ones we observed in this home, the right to make informed decisions about place of residence is important and must be respected. In theory, these individuals should have been relatively easy to place in foster care at an earlier age. In practice, DRI is concerned that these teenagers may never have been provided an opportunity to live in a safe and consistent foster home. Without this option available, it would be impossible to say that the decision to live in the group home is informed and voluntary.

⁴⁶ Dozier, et. al. (2014) at 220.

H. A lifetime of discrimination ahead: transition to adulthood

Group homes can keep people into their 30s. The expectation is that when the last person turns thirty, it becomes an adult home. No one ever leaves. There are no new admissions until someone dies.

- Child psychiatrist, Sofia Children's Hospital

One of the challenges facing children with disabilities and their families is that discrimination against adults with disabilities is pervasive in Bulgarian society. While there has been extensive international attention to the deinstitutionalization of orphanages, institutions for adults with disabilities remain.

Some sources have observed that demand for community and institutional placement is now growing faster than the provision of services, so the challenge of community integration is becoming greater over time.⁴⁷ While there are some limited resources to help parents of children with disabilities keep their children at home, parents describe a “cliff” when the child turns eighteen and such programs come to an abrupt end.

For people with disabilities, reports the Director of Sofia's Independent Living Center, “housing is a big problem; rental housing isn't adapted for people with disabilities to live there. As a result, there are long waiting lists in institutions for placement because there are no alternatives, no personal assistants, and institutions are the only option.”

DRI interviewed four people who used to live in big institutions. Two of them now live independently – one after years of living on the street. All reported to DRI that they wanted to avoid group homes so they “can be like other people” or “live independently like others.” They all report that the law and the social service system create multiple obstacles to living independently.

Once they are in the social service system, people with disabilities report that their place of residence is linked to a particular institution or small group home. If they want to leave, they are unable to obtain identification documents showing residence in another location. As a consequence, they cannot receive social support in any location other than the group home.

⁴⁷ ANED 2018-19 – Country report on Living independently and being included in the community – Bulgaria <https://www.disability-europe.net/downloads/1016-year-4-2018-19-policy-theme-il>, page 24: “Deinstitutionalisation of adults is lagging. There is no report yet on the implementation of the Action Plan for Deinstitutionalisation of Adults (2018-2021). However, the number of residential, day care and personal assistance services is gradually growing while waiting lists for placement in institutions are also longer each year. The demand for community-based services is much greater than the current provision”.

The State decides for them where they can live and get access to services. They are forced to choose between their independence and access to necessary services and benefits to which they are entitled.

The stories of three people DRI met were similar – starting with early abandonment, spending their entire life in institutions, forced to stay in small group homes they didn't choose. Two of them tried to live independently and were forced to go back to the group home because they could not afford to live on their own. While they maintain some independence and freedom of movement outside the facility, they are still forced to follow the strict rules of these institutions.

Two young women living in a group home spoke to DRI extensively about their situation. When the investigators were leaving, they wanted to take a picture in their room with us. The director of the group home interfered and told them they were not allowed to take photos in their room “because it is a social care institution.” Despite the express consent provided to DRI investigators minutes earlier, the director claimed that “the girls do not like to have pictures of themselves in an institution because it affects their self-esteem.”

Some of the people DRI met are still fighting for their independence. Their future is uncertain due to the unsolved issue of their place of residence. A young man we spoke to reported that even if he were able to obtain a permanent residency status, 50% of his income would still go to the “protective home,” leaving him little resources to live independently and have full autonomy over his life.

DRI has recently learned that new group homes are planned for adults, building on the reputed success of the group homes for children. In one municipality, local authorities showed us an empty field where they said they hoped new group homes for adults would be created. The field was not located near any population center, but it was right across the fence of the local psychiatric facility – conveniently located for quick transfer as the need arises.

IV. International Standards

A. Human rights obligations

This report evaluates Bulgarian compliance with binding human rights treaties to which Bulgaria has committed itself, including the European Convention on Human Rights (ECHR), the UN Convention on the Rights of the Child (CRC), and the UN Convention on the Rights of Persons with Disabilities (CRPD). It also refers to non-binding standards, such as the UN Guidelines for the Alternative Care of Children.

DRI observers documented treatment practices in institutions that violate the protection against torture and the right to life included in the ECHR. The use of physical restraints and cages constitute inhuman and degrading treatment and can rise to the level of torture. The failure, mentioned previously, to provide treatment to the child with hydrocephalus is a practice that causes a slow, painful death. Such practice should also be considered a form of torture. Leaving children without medical care is a violation of their right to life. The children we observed left in cribs with arms and legs atrophying through immobility, tied to wheelchairs, or left in cribs that inhibit their interaction with others should also be considered a form of inhuman and degrading treatment. These practices, in some cases, may threaten the individual's life.

The United Nations Committee on the Rights of the Child has recognized that children with disabilities, like all other children, are “best cared for and nurtured within their own family.”⁴⁸ The CRC Committee also recognizes the “role of the extended family” which is “one of the best alternatives for child care” which should be strengthened and empowered to support the child and his or her parents or others taking care of the child.”⁴⁹ Article 23 of the CRC calls for the creation of the social supports and special care necessary to allow children with disabilities the “maximum possible” social integration.

The CRC has been interpreted to allow for placement in residential care where it is in the best interest of the child.⁵⁰ The U.N. Guidelines for the Alternative Care of Children provides guidance to governments in implementing this provision. The Guidelines specify, however, that governments must protect families by adopting “policies that ensure support for families in meeting their responsibilities toward the child and promote the right of the child to have a relationship with both parents.”⁵¹ The Guidelines state that for the youngest children (under age 3), care “should be provided in family-based settings.”⁵² Any placement of older children in residential care “should be limited to cases where such a setting is specifically appropriate, necessary, and constructive for the individual child concerned and in his/her best interest.”⁵³

⁴⁸ U.N. Comm. On Rts of Child, *General Comment No. 9: The rights of children with disabilities*, UN Doc. CRC/C/GC/9 (2000), at para. 41.

⁴⁹ *Id.*, para. 45.

⁵⁰ See discussion of the CRC's requirements in Rosenthal (2019) at 112. See also Nigel Cantwell and Anna Holzscheiter, “Article 20: Children Deprived of Their Family Environment,” A COMMENTARY ON THE UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD (2008).

⁵¹ UN Guidelines, para. 32.

⁵² *Id.*, para. 22.

⁵³ *Id.*, para. 21.

This report shows that Bulgaria has not met its core obligations under the CRC and has not developed services consistent with the UN Guidelines for the Alternative Care of Children. Bulgaria has *not* created the community-based services for children with disabilities that would allow maximum possible social integration. Children who could clearly benefit from family integration or placement in foster care are not able to live and grow up in a family because those services do not exist. The lack of options for children with disabilities to live in a family also means that no individualized determination of best interest is made. Rather than making individualized determinations of best interest or appropriate care, children are placed in group homes because there is simply no place else to go.

The CRPD provides stronger protection for the child and his or her right to live and grow up with a family.⁵⁴ The right to live in the community under CRPD Article 19 applies to all children and adults with disabilities – regardless of their level of disability.⁵⁵ Thus the common practice of placing children in institutions or residential care on the basis of disability – and the widespread perception that children with so-called “severe” disabilities cannot be accommodated within a family – runs contrary to the requirements of the CRPD. If children cannot stay with their immediate family, they must be served “within the community in a family setting.”⁵⁶ The term “family setting” could mean placement in foster care or kinship care (placement with other relatives). The CRPD Committee, the authoritative body established to interpret and help governments implement the convention, has made clear that “within the community in a family setting,” however, means a family and not residential care or a group home:

for children, the core of the right to be included in the community entails a right to grow up in a family.”⁵⁷

The CRPD Committee goes on to explain that:

Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. ‘Family-like’ institutions are still institutions and are no substitute for care by a family.⁵⁸

⁵⁴ See Rosenthal (2019).

⁵⁵ General Comment No. 5 states that: “Persons with intellectual disabilities, especially those with complex communication requirements, inter alia, are often assessed as being unable to live outside of institutionalized settings. Such reasoning is contrary to article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirement.” CRPD General Comment No. 5 at para. 21.

⁵⁶ CRPD article 23(5).

⁵⁷ General Comment No. 5, para. 37.

⁵⁸ *Id.*, para. 16(c).

As interpreted by the CRPD Committee, the CRPD does not allow for residential care placement and insists that all children receive the protection they need to grow up in a family. The CRPD was adopted 30 years after the CRC, which assumed that some children with disabilities would have to be placed in institutions or residential care. As described below, the CRPD is based on extensive research on the dangers of group homes – and experience which has shown that all children with disabilities can be supported to live safely within a family.

Based on this analysis, the UN Special Rapporteur on Disability Catalina Devandas has observed that “[a]ny placement of children in a residential setting outside a family must be considered placement in an institution...”⁵⁹ Thus, under the CRPD, an “institution” for children must be defined as any placement outside a family. **Under the CRPD, group homes and residential care are legally considered a form of institutional care.** This differs from the terminology used in the Guidelines for Alternative Care of Children which distinguishes between institutions and residential care.

In this report, DRI uses the more traditionally-accepted language, referring to “institutions” as large facilities and “residential care” or “group homes” as smaller facilities (the report avoids the commonly used term “small group homes” because most of the facilities DRI visited house what would be larger than a normal family, and at 8-14 beds or more are generally not what could be called a “small” home in Bulgaria or most other places). This use of language allows the report to identify situations where residential care and group homes clearly create “institution-like” conditions. Bulgaria’s system of group home placement, on its face, violates the requirements of the CRPD. To meet its obligations under the CRPD, Bulgaria must establish a system of family support and foster care that will allow all children with disabilities to live and grow up with a family.

B. Lessons from experience and research

While treatment can occur in a family, family cannot occur in a facility.

➤ Nancy Rosenau⁶⁰

⁵⁹ UN Human Rights Council, Report of the Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas, *Rights of persons with disabilities*, UN Doc. A/HRC/40/54, (Jan. 11, 2019), para. 19. [Hereinafter UN Special Rapporteur on Disability (2019)].

⁶⁰ Nancy Rosenau, *Do We Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities*, University of Minnesota Institute on Community, Integration Policy Research Brief 7 (2000).

It was once believed that some children with disabilities would have to be placed in some form of residential care. Experience now shows that, with appropriate support, children with “every kind and severity of impairment [are] currently living successfully with a family.”⁶¹

A report of this kind is no substitute for the scientific knowledge that has been gained over the years from long-term studies of child development. This research has allowed a careful study of outcomes from children living in families, foster families, institutions, and group settings. These studies have shown that raising children in any form of congregate setting affects brain development and results in often irreversible psychological damage and developmental delays. As researchers Charles Zeanah, Nathan Fox, and Charles Nelson have observed “[d]ecades of research have clearly demonstrated that children fare better in families than in institutions.”⁶²

These researchers describe the factors that distinguish between families and institutions:

First, in most institutional settings child-to-caregiver ratios are far greater than they are in families. Thus, children are deprived of the socioemotional, cognitive, language, and sensory stimulation that is essential for the proper development of the brain areas promoting healthy development. Second, institutions are staffed by caregivers who work in shifts. This limits opportunities for young children to experience them as consistently available, which is necessary for formation of healthy attachments. Third, care is typically provided on an institutional schedule rather than a particular child’s needs, making it impersonal and insensitive. Fourth, perhaps because of all these factors, institutional caregivers are often less emotionally invested and committed to the children in their care compared to biological or foster families.”

As described in this report, DRI teams have observed each of these factors – staff ratios, caregivers working in shifts, and lack of emotional investment in children – in Bulgaria’s group homes. These findings are consistent with the views of researchers who have found that group homes and family-like residences are fundamentally more like institutions than

⁶¹ *Id.*

⁶² Charles H. Zeanah, Nathan A. Fox, and Charles A. Nelson, “The Hazards of Institutional rearing for Children’s Brain and Behavioral Development,” in *A Goal Within Reach: Ending the Institutionalization of Children to Ensure No One Left Behind* (2019) at 21.

like families or foster families.⁶³ An international consensus of child researchers, including professor Charles Zeanah, reviewed the research literature and came to the conclusion that:

...group settings should not be used as living arrangements, because of their ***inherently detrimental effects on the healthy development of children, regardless of age.***⁶⁴

For these reasons, the main recommendation of DRI, based on our findings, is that a fundamental shift in approach is needed. The detrimental impact of group homes will not be overcome simply by better staff-to-child ratios or less regimented schedules, or with more funding for highly trained professionals, better buildings, or even strict oversight of conditions. **The key factor that cannot be provided in a group home is the long-term emotional bond with an adult that is formed only in a family.**

V. Conclusions and Recommendations

Based on observations in group homes, **DRI finds that group home placement can be emotionally and physically dangerous for children and is likely to result in increased disability.** Placement in group homes is dehumanizing, socially isolating and does not contribute to habilitation and the development of skills that contribute to further inclusion in society. Treatment – or the lack thereof – results in increased disability, endangers children's health, and can be life threatening.

DRI was not allowed access to what are called “baby homes,” institutions for children with disabilities 0-7 under the authority of the Ministry of Health. These are the children *most* vulnerable to the dangers of being raised in any form congregate care outside the family. DRI has been informed that these facilities will soon be replaced with new group homes. Based on the dangers DRI’s team observed for older children – and everything we knew about the need of all children to grow up with a family – **DRI urgently calls on the government of Bulgaria to stop construction of new group homes and work to reintegrate these children into families.**

More broadly, **DRI recommends a fundamental shift in policy and programming – moving away from group homes as a placement for any child and moving toward family placement for all children with and without disabilities.** Bulgaria’s new policies

⁶³ Dozier, et. al. (2014) at 220. Another study compared children who attained permanence in a family setting to those who did not. Permanence was associated with decreased risk of incarceration; food, housing, and income insecurity; unemployment, educational deficits; receipt of public assistance, and persistent mental health disorders. Katie K. Lockwood, Susan Friedman, and Cindy W. Christian, *Permanency and the Foster Care System*, 45 *Current Problems in Adolescent Health Care* 306-15 (2015).

⁶⁴ *Id.*

should be based on a recognition that all children have a right and a need to live and grow up with a family. Such a shift in policy is consistent with the findings of child welfare research and disability experience – and it is required by Bulgaria’s obligations under the CRPD.

This shift in approach is justified by Bulgaria’s own experience. Perhaps no country in the world has received such intensive support for its reform, including the training and support for a system of group homes. A detailed study in 2015 by Lumos, an independent non-governmental organization promoting reform in Bulgaria, found many of the same problems endemic in group homes that DRI observed in this report in 2019.⁶⁵ The Lumos report found that only 28% of children and young people had “some degree of independence” (up from 14% in institutions). The study found that children and young people are left “in a non-stimulating environment where communication is entirely absent or is reduced to a minimum.”⁶⁶ Researchers found that some children never left their bed. Compared with the old orphanages, “challenging behavior has only slightly reduced in the SGHs [“small group homes’], and there is a need for training and new models to address this.”⁶⁷

The 2015 Lumos analysis attributed many of the failings of the group homes to “insufficient staffing levels” and poor training. Instead of calling into question the group home model, the major recommendation of the report was for more resources for group homes.⁶⁸ DRI was genuinely impressed by the sincerity of many of the trainers who attempted to engage group home staff. Four years later, after extensive attention to training and support to group home staff, DRI’s team has found conditions that remain dangerous for children. These findings are consistent with those of international researchers who have studied the problem – and concluded that group homes *cannot* be improved to the point where they meet the emotional needs of children.

Placement in families is the most urgent intervention for these children and has demonstrated substantial gains in their development, including formation of secure attachments. Further, when children are removed from institutions and form secure attachments with their foster parents, they are less likely to experience subsequent psychopathology or problematic peer relations.⁶⁹

⁶⁵ Lumos, Ending Institutionalisation: An assessment of the outcomes for children and young people in Bulgaria who moved from institutions to the community” (2015).

⁶⁶ *Id.* at 38.

⁶⁷ *Id.* at 38.

⁶⁸ *Id.* at 40.

⁶⁹ Dozier, et. al. (2014) at 223.

DRI, therefore, recommends *against* using new resources to improve staffing or care at group homes, except to protect against immediate, life-threatening conditions. This is consistent with the requirements of the CRPD, as interpreted by the UN's Committee on the Rights of Persons with Disabilities, which has stated that:

No new institutions may be built by States parties, nor may old institutions be renovated beyond the most urgent measures necessary to safeguard residents' physical safety.⁷⁰

The provision applies to group homes as well as larger institutions. As noted above, the CRPD recognizes the right of all children to live and grow up with a family and considers group homes another form of institutionalization. As noted below, international law does recognize the evolving capacity of the child to make choices about their life. Given the known dangers of raising a child in a group setting, the duty to protect younger children against harm would not make this a reasonable option in the best interest of a young child. In theory, older adolescents who are given a meaningful choice (a safe and appropriate option for family placement), full information, and support in making a decision, may choose to live in a group home. In practice, DRI investigators did not see that option available for most children – and certainly not for children with disabilities.

DRI recommends that the Government of Bulgaria:

- 1. Immediately stop plans to build new group homes** – especially for babies, toddlers, and children in medico-social institutions under the authority of the Ministry of Health. These children should receive the highest priority for placement in foster care (and supported foster care for children with disabilities) or return to biological families where possible.
- 2. A broad commitment to enforcing the right to family life for all children** – to be supported by the EU and international donors – to ensure that every child has the opportunity to grow up in a family and *not* in residential care or group home. Dangerous stereotypes of children with disabilities (including so called children with “severe disabilities” or “behavior problems”) as unable to live in families must be addressed through education and training – and as a matter of enforceable law and policy. Immediate training is needed for policymakers, judges, and service providers about the rights and full potential for family inclusion of all children with disabilities;
- 3. Expansion of supported family, kinship, and foster care** – Parents with disabilities should be able to keep their children and will need improved financial assistance and

⁷⁰ General Comment No. 5 to CRPD, para 49.

support to do so. Foster care programs also must be made fully accessible and appropriate for children with disabilities and behavioral problems. For children with intellectual disabilities, models of supported foster care have proven effective in other countries. For children with behavior problems, models of therapeutic foster care have proven effective. It is not acceptable for authorities to accept that families are “unavailable” or “unwilling” to take children with disabilities until a full range of supportive and therapeutic services are available to help families and prospective foster parents;

The amount and kind of financial assistance and supportive services provided must be based on an individualized determination based on the needs of the child and the family. The vast majority of family support does not require professionals and need not be costly. Programs to help foster parents care for children with a broad range of disabilities may require as little as 25-40 hours of training. Families, children, and people with disabilities should be given a choice as to the kind of supports they do and do not need. Funding should be provided for a broad array of family supports, including education and training, as well as respite care.

- 4. Support for prevention of family break-up and new placement** – Bulgaria’s top priority should be the support for families to prevent break-up before it happens. Financial and other forms of support for families of children must be at least as high as the support given to foster families out of recognition of their common challenges – and to avoid incentives for further family break-up. Programs should be specifically targeted to help those families most at risk – including families of children with disabilities, single mothers, and children living in poverty. Special outreach efforts should be made to ensure that Roma and other ethnic minorities receive the services and supports they need to avoid unnecessary family break-up.

Effective support for families must also include:

- **Early intervention** from birth to support mothers and families of children at risk;
- **Ending all segregated programs** – providing professional support in the home or school and never requiring a parent to separate from or send away a child to receive services;
- **Inclusive education** – Specialized schools or day centers for children with disabilities are just one more form of segregation that constitute a dangerous form of discrimination. Education must be fully accessible throughout the

country. School programs must also be adapted to be appropriate for children with intellectual and psychosocial disabilities.

- **Support for and empowerment of family advocacy** – Parents of children who are at risk are the best informed and best positioned to advise government and service providers on the needs of families to avoid break-up and protection of young children. Funding should be made available to civil society organizations and non-governmental organizations (NGOs) run by parents working to bring about full inclusion. Parents should be involved through representative organizations in policy-making and programming on matters that affect them and their children (it is essential that some of this funding go to independent NGO's that are not also service providers – so that they can represent the interests of parents and children without having a financial stake or conflict of interest).
 - **Peer support networks by young people and families with disabilities.** Providing education and training for peer support networks made up of other family, children, and people with disabilities, as well as other members of the community is one way that family-based community support can be provided at relatively low cost. Parents, youth, and adults with disabilities can be trained as trainers to share knowledge and skills with their peers.
 - **Full inclusion of children and adults with disabilities throughout the life-cycle** – Policies focusing on children must be closely aligned with programs to ensure full inclusion of children throughout the life-cycle. The best family supports for children will be undermined if adults face re-institutionalization or pervasive discrimination in society later in life. For this purpose, **support for advocacy and full consultation with disability rights groups is essential for any effective child protection and reform program.**
5. **Support for choice, self-determination, and self-advocacy** – Both the CRC and CRPD recognize the importance of choice and advocacy by children and adults with disabilities. This must include participation in decisions about what services to receive as well as where and with whom to live. Any meaningful choice, however, depends on the availability of a real set of options. Until good, safe, stable family placements are available for all children, there will effectively be no meaningful choice. For children and adults with disabilities, support must be provided so that information and choices are made available meaningfully in a manner they can understand.

Given the evolving capacities of children, it is impossible to say at exactly what age a particular child has the ability to fully understand the decision to live in residential care rather than in a family. Given the dangers that have been documented by this report and by research literature, this is a decision that only adolescents in the best of circumstances – with full support and a range of choices – can be expected to make. Policies on choice should be made consistent with the statement on the right to family life adopted by a coalition of international disability rights groups:

The Convention on the Rights of the Child recognizes that all children have a right to be heard in decisions that affect them and for their views to be given due weight in accordance with their age and maturity. This means that children’s views about where they live must be taken into account and children with the capacity to make a decision about where they live, may make that decision, including choosing community-based supported living arrangements that are not family-based. Such a choice must be informed and voluntary, however, and the child must be provided support to make an informed decision and after being provided the opportunity to observe, live in, and experience a safe and stable family-based setting with support services appropriate to his or her age, gender, and disability.⁷¹

- 6. Stop torture and abuse in group homes and community programs** – No effort to stop torture or abuse should be used to justify maintaining group homes. Indeed, the CRPD Committee has said that funds should be used to support community integration rather than fixing up institutions. The narrow exception to this is immediate steps necessary to correct life-threatening conditions and stop torture. As required by CRPD Article 16, all programs for people with disabilities must be regularly monitored to prevent violence, exploitation, and abuse.

All residential care, including group homes, as well as community programs and foster care should be subjected to independent monitoring. Oversight and enforcement mechanisms should be age and gender appropriate and should include participation of people with disabilities. Rights protection and monitoring programs will be more effective if they rely on forms of peer support by formerly institutionalized children, including children with disabilities. Independent advocacy groups should be given access to visit all institutions and residential programs.

⁷¹ [UN Disability and Child Rights Groups On Behalf of Children without Parental Care, “Key Recommendations,” September 12, 2019.](#)