

Ending institutionalisation:

An assessment of the outcomes for children and young people in Bulgaria who moved from institutions to the community

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Executive summary

The harm to children who grow up in institutions

Bulgaria has taken an important step towards reforming its care system for vulnerable children, moving from large residential institutions towards community-based care. As well as being expensive to run, institutions are harmful for children's health and development. Over 80 years of research from across the world has demonstrated the significant harm caused to children in institutions, who are deprived of loving parental care and who suffer life-long physical and psychological consequences.¹

Progress in Bulgaria

Bulgaria has made significant progress in deinstitutionalisation (the process of removing children from institutional care and moving towards family-based care) in a short space of time: the number of children in institutions has decreased by 78% since 2009² (from 6,730 in 2009 to 1,502 in 2015) and all 24 institutions for children with disabilities have been closed. This was achieved due to an ambitious programme of reform on the part of the Bulgarian Government with significant support from the European Commission and civil society.

However, the deinstitutionalisation (DI) process is complex. It involves not only closing down institutions and moving the children; new services need to be developed to ensure that all their needs can be met in the community, as well as preventing children from entering institutions. Placements need to be reviewed and the children monitored; financial mechanisms need to be modified to ensure the community-based services are sustainable. In addition, changes in the system need to be evaluated to ensure that new services meet the need for which they were designed, and their effectiveness evaluated. This assessment will help to inform the next steps for DI in Bulgaria and should be considered in the National Action Plan for 2016-2020.

Purpose of this report

This report shares outcomes to date for a group of 1,292 children and young people with disabilities who have transitioned out of large residential institutions (institutions) into small group homes (SGHs) in the community. This assessment was undertaken by Lumos in cooperation with State authorities from October to December 2015. The information gathered was compared with available data from an assessment of the same group carried out at the end of 2012 and the beginning of 2013, when the children and young people were still living in the institutions.

Research was also carried out by a group of five self-advocates from Lumos' children and youth participation group in Bulgaria, who developed their own questionnaire and set up a focus group to find out - from a peer-to-peer perspective – about life in the new SGHs.

It is hoped this report will be of use to:

- The Bulgarian Government in assessing the progress of reform and planning future initiatives
- The European Commission in assessing their investment in the system for caring for vulnerable children in Bulgaria
- Other stakeholders involved in the reform process in Bulgaria.

¹ Berens, A. & Nelson, C. (2015) The science of early adversity: is there a role for large institutions in the care of vulnerable children? The Lancet. 2015.

² For the 2009-2013 numbers please see: State Agency for Child Protection. (2013). Number of children in specialized institutions on 31.12.2013 in comparison to 2001-2013. [Data file in Bulgarian]. <http://sacp.government.bg/programi-dokladi/statistika/> The 2014 number is a Lumos calculation based on two sources: Personal communication with the State Agency for Child Protection. (2014). On file with Lumos. National Statistical Institute. (3 April 2015). Homes for Medico-Social Care for Children in 2014 [webpage]. <http://www.nsi.bg/en/content/5606/homes-medico-social-care-children>

Key findings

Independence

- The transition from institutions into SGHs led to a clear improvement in the independence skills of children and young people.
- However, an insufficient number of children and young people have any form of independence outside the SGH, which inhibits their inclusion in the community.

Health

- A majority of children experienced no change in their health. Where there were changes, they were mostly positive.
- However, there is a need to review diagnosis and prescriptions of medication. It is possible that in some cases medication is being used to control challenging behaviour.

Physical development

- The height and weight of children and young people have improved, with many showing some catch-up towards the norm measurements for their age.
- The use and availability of assistive equipment is insufficient, leaving some children and young people entirely dependent on staff to move around.

Communication

- There was some improvement in the communication skills of the children and young people assessed. However, many are unable to communicate in a conventional, verbal way.
- The lack of alternative communication methods places some children and young people in a non-stimulating environment where communication is entirely absent or is reduced to a minimum.

Challenging behaviour

- The number of children and young people with challenging behaviour has only slightly reduced in the SGHs, and there is a need for training and new models to address this.
- Staff members in SGHs and semi-independent living services need structured and regular support from trained professionals.

Eating and drinking

- As a result of the Childhood for All project, a number of initiatives and training sessions were provided which led to improved eating and drinking for children and young people with disabilities. In many SGHs this good practice has continued and was observed by the assessors.
- However, incorrect and harmful practices were also observed in some cases: feeding children lying in their cots, force feeding and use of inappropriate cutlery. This needs to be addressed as a priority.

Contact with family

- Despite some improvements, the overall level of contact between the child or young adult in SGHs and their families remains quite low.
- There is a lack of clear procedures in relation to making and keeping contact with the family of children and young people living in SGHs.

Support services

- Many more children are now accessing education in the SGHs than they did in institutions and there is good access to doctors and dentists.
- However, since the majority of the children and young people do not attend other support services in the community, access to professionals such as psychologists, physiotherapists and speech and language therapists has become more limited. This carries the risk of children and young people being deprived the full range of services they need.

Conclusions

The Bulgarian Government should be commended for the progress of reform achieved over such a short period of time, and for the monitoring and evaluation of this progress. The assessment shows that - in just two years - this first phase of reform has led to notable improvements in the health, development and quality of life of children and young people with disabilities.

Bulgaria has taken steps towards ensuring that all children have their basic rights met. It is to the credit of the Bulgarian Government that they chose to prioritise children with the most severe disabilities when planning and implementing deinstitutionalisation.

However, current services are underfunded. In some cases, there are insufficient staffing levels. Staff do not have the necessary training and support and children and young people would benefit from further assistance and alternative models of care. There is a perception that better-resourced SGHs would be too expensive for the government to finance for the long-term. However, a financial analysis of the DI process demonstrates that, compared with budgets for institutional care in 2009, an annual saving is being made of approximately 13,313,905 BGN (6,807,024 EURO).³ These funds could be reinvested in making significant improvements to the SGHs.

Key Recommendations

- For the new care system to meet the needs of children and young people, community-based services – such as inclusive schools, accessible transport, support to gain employment and to access entertainment - need to be developed. This will ensure that children and young people are not only living in homes in the community, but are included in the everyday life of the community.
- Current services should be more accessible. This might include further development of Bulgaria's inclusive education strategy and the adequate provision of transport, *inter alia*. Training for SGH personnel is also necessary to support the children and young people's access to other services. This should be a key priority for the next programming period of European Union funding.
- Ensure the provision of inclusive education, or vocational training, for all children and young people who move from institutions to SGH, foster care, or back to families.
- Increase staffing levels, providing more carers to ensure the continuing presence of key figures for every child and young person who can respond to their individual needs.

Recommendations about the provision of care

- Apply flexible models of care, which respond to the specific needs of children and young people, such as challenging behaviour, multiple impairments and eating and drinking difficulties.
- An expert working group should be established to address the main challenges in the running of SGHs, based on the analysis and conclusions from this reassessment. In this way, existing good practice can be shared and solutions found for more complex issues.

³ Lumos (2015) Ending institutionalisation: A financial analysis of the financing of the deinstitutionalisation process in Bulgaria

- The over-reliance on medication to deal with challenging behaviours needs to be reduced. This can be achieved through a) increasing staffing levels: to ensure the continuing presence of key figures for every child/young person and most importantly for those with challenging behaviours; and b) providing regular training, supervision and psychological support for the care team.
- Undertake individual assessments of children and young people with disabilities and ensure the provision of assistive devices or alternative communication methods for all who require them.
- Training for dentists and doctors is needed in some areas to improve practices when working with children and young people with disabilities.
- It is recommended that the SGHs where adults and children are living together should be reassessed to ascertain whether more appropriate arrangements can be made.

Recommendations about working with parents and families

- The financial analysis by Lumos of the DI process shows that supporting parents to look after their children is the most economically efficient option.⁴ In most cases, it also provides the best outcomes for children.⁵ The government must ensure that sufficient prevention services and mechanisms are in place to provide consistent and purposeful support to families, so they can care adequately for their children in a strong and supportive environment.
- A fundamental right of children is to live with and be cared for by their parents and, if for any reason this is not possible, the authorities should in most cases ensure that contact with parents and relatives will be maintained.
- Regular reviews of placements should be mandatory and efforts should continue to reunite children with their family, including the provision of support services to birth and extended families. Children who are moved to families are likely to demonstrate even better results in terms of improved health, development and quality of life.

Recommendations about further assessment and monitoring

- The *Childhood for All* reassessment only documents children who moved to SGHs, not those who were placed in families (reunification with support, adoption or foster care). The authorities should reassess the development of all children who moved from institutions so that future reform is based on the best available evidence. Reassessments are also essential to ensure that each individual placement is working for each child.
- While the height and weight of the group assessed improved overall after they left institutions, average height and weight are still below the norms. The reasons for this should be further assessed and measures put in to place to address it. It should be noted that developmental delays are common among children who have been institutionalised. Those who have lived in institutions for long periods may never completely recover their delays.
- A unified information system should be created which will allow input and summary of information about individual children, in order to be better able to monitor progress.
- To better understand and reduce child mortality, it is important consistently to collect detailed information about each case so that this can be addressed urgently. A formal system of reviewing deaths in care should be introduced in order to reduce risk and improve the response to child mortality.

4 Lumos (2015) Op. cit.

5 Berens, A. & Nelson, C. (2015) Op. cit.

Recommendations about finance

- In 2010, the Government made a public commitment⁶ to ring-fence funds in the institutions and reinvest savings from reform in the new care system. As a priority, savings should be invested in increasing the number of high quality personnel for SGHs, and preventing mortality in baby institutions.
- Mechanisms for funding services should be developed based on the identified needs of individual children and provide tailored financial support, rather than using a general categorisation of 'need'. Bulgaria should consider models used by other countries to ensure that financing can be used flexibly and efficiently.

⁶ "It is necessary to develop a clear financial mechanism to ensure that the resources of currently existing specialized institutions will be transferred to the new services that will be developed under the Action Plan and will start operating as delegated by the state after completing the EU projects." National Action Plan for implementation of Vision for DI 2010 - 2015, page 33, <http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&id=601>

1. Introduction

1.1. The harm of institutionalisation

An estimated eight million children worldwide live in residential institutions and so-called orphanages that deny them their human rights and that cannot meet their needs.⁷ More than 80% of these children are not orphans and have at least one living parent.⁸ Around the world, children are placed in institutional care because their parents face extreme poverty; because the children have physical and intellectual disabilities; or because they are from socially excluded groups.⁹ Over 80 years of research from across the world has demonstrated the significant harm caused to children in institutions, who are deprived of loving parental care and who suffer life-long physical and psychological harm as a consequence.¹⁰ Babies in particular fail to develop as they should without one-to-one parental interaction, and research demonstrates the severe impact of institutionalisation on early brain development. According to numerous studies, children who remain in institutions after the age of six months often face severe developmental impairment, including mental and physical delays.¹¹

For children with disabilities the situation is even worse. They require close, sustained adult engagement to help them develop – including such skills as learning to eat properly. One study of children under three years of age who were discharged from institutions found that 28% of disabled children were in fact ‘discharged’ because they had died.¹² This mortality rate was 100 times higher than for children without disabilities.

The European Union has also recognised the harm caused by institutionalisation. The introduction of an *ex-ante* conditionality on social inclusion (9: 9.1.), in the Regulation 1303/2013, includes an investment priority of “...the transition from institutional to community-based services”. This effectively prohibits the use of European Structural and Investment Funds (ESIF) for the maintenance or renovation of existing, and the construction of new, large residential institutional settings. It also encourages Member States to prioritise programmes that support the transition to community-based services.

1.2. What is deinstitutionalisation?

Deinstitutionalisation (DI) is the process of reducing reliance on large residential institutions and shifting a system towards the delivery of community-based services. It is a complex process that involves:

- Developing community-based services and approaches that prevent admissions of children to institutions
- Transferring all children currently resident in institutions to families or family-type placements that respect their rights and meet their needs. No child should be left behind
- Ring-fencing the resources (financial, human and material) in institutions and transferring them to cover the costs of the community-based services that replace institutions.
- Developing and deploying sufficient professional capacity and expertise to manage this complex process of change
- Changing attitudes, policies and practices
- Empowering children and families to take a lead role in the process of change.¹³

7 The number of residential institutions and the number of children living in them is unknown. Estimates range from ‘more than 2 million’ (UNICEF, Progress for Children: A Report Card on Child Protection Number 8, 2009) to 8 million (Cited in: Pinheiro, P., World Report on Violence against Children, UNICEF, New York, 2006). These figures are often reported as underestimates, due to lack of data from many countries and the large proportion of unregistered institutions.

8 Csáky, C. (2009) Keeping Children Out of Harmful Institutions: Why we should be investing in family-based care London, UK: Save the Children. p7. Better Care Network. (2009). Global facts about orphanages.

9 Faith to Action Initiative. (2014). Children, Orphanages, and Families: A summary of research to help guide faith-based action. pp6-7.

11 Michael Rutter (1998), Development catch-up, and Deficit, Following Adoption after Severe Global Early Privation, Journal of Child Psychology and Psychiatry, 39 (4).

12 Browne, Kevin, C. E. & Hamilton-Giachritsis, R. (2005), Mapping the number and characteristics of children under three in institutions across Europe at risk of harm. Birmingham: Birmingham University Press (in collaboration with EU/WHO), p22.

13 For more information see: Mulheir, G. & Browne, K. (2007). De-Institutionalising and Transforming Children's Services: A Guide to Good Practice. Birmingham, UK: University of Birmingham.

Crucially, DI should not be seen as a cost-cutting exercise. It should involve the reinvestment of resources in services that result in better outcomes for children.

All of these elements are essential to the process of change and Bulgaria has made significant progress in some areas. However, further monitoring and development is needed to ensure that the change is sustainable, high quality and guarantees the best outcomes for children.

1.3. Institutionalised children in Bulgaria

Like many countries in the region, Bulgaria had inherited a system of care for children that relied heavily on residential institutions with little focus on community-based alternatives. At the beginning of 2010, there were 6,730 children living in institutions.¹⁴ Compared with other countries in Europe, this represented an extremely high rate of institutionalisation.¹⁵ Annual rates of admission were also high; in 2009, more than 3,000 children were admitted to institutions.

1.4. Mortality rates

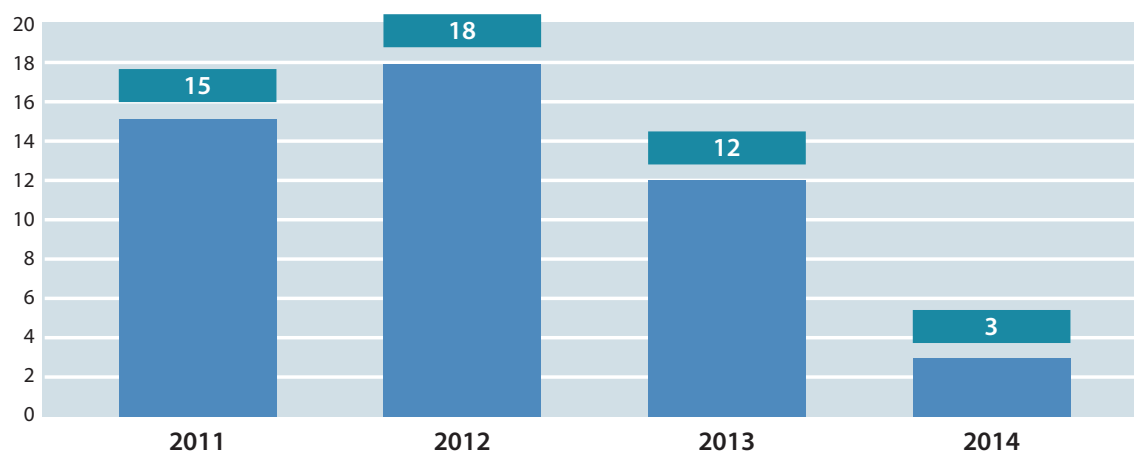
Before the reform began, conditions in the institutions were poor and mortality rates were high, particularly in the institutions for children with disabilities (see below). This is common in other countries with large number of children with disabilities in large residential institutions: they are often under-resourced and the children's needs neglected.

A report by the Bulgarian Helsinki Committee in 2010 following inspections of disability institutions found that 238 had children died between 2000 and 2010.¹⁶ The report suggested that at least three-quarters of these deaths were preventable. The Bulgarian Government was also criticised by the UN Committee Against Torture and urged to address the situation with a number of recommendations, including acceleration of the DI process.¹⁷

Lumos was asked by the government to help intervene in two disability institutions with high mortality rates. This work in Krushari and Rudnik reduced the mortality rates dramatically. Since Lumos' intervention began at the end of 2010, only two children have died in Krushari, which previously had the highest mortality rate, and none in Rudnik.

Nationally, the picture is not as positive, although there has still been a significant reduction in deaths in the institution for children with disabilities, as the following table attests.¹⁸

Deaths in institutions for children and young people with disabilities



14 State Agency for Child Protection. (2013). Number of children in specialized institutions on 31.12.2013 in comparison to 2001-2013. [Data file in Bulgarian]. <http://sacp.government.bg/programi-dokladi/statistika/>

15 Lumos (2015) Op. cit.

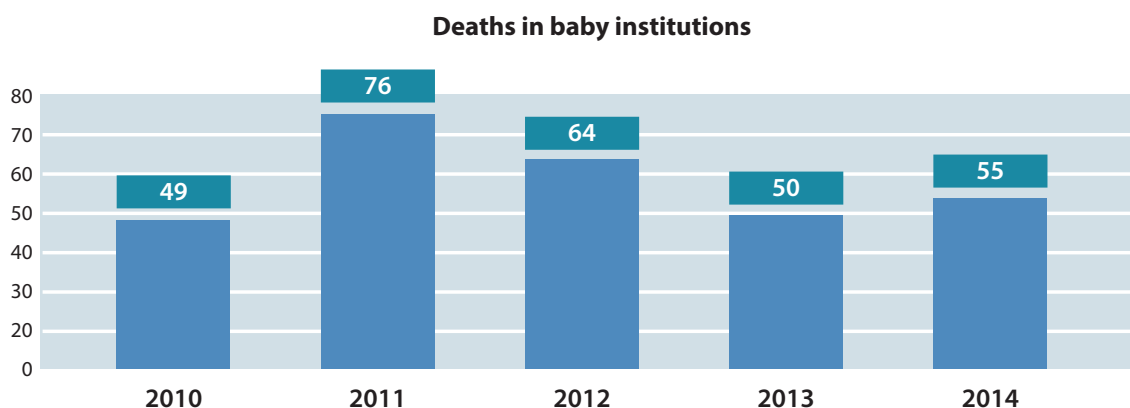
16 Kukova, S. (2011). Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities: desk report Bulgaria. Commissioned by the European Union Agency for Fundamental Rights. Bulgarian Helsinki Committee. http://www.bghelsinki.org/media/uploads/special/bg_fra_mh.pdf.

17 Committee against Torture, Forty-seventh session, 31 October–25 November 2011, Consideration of reports submitted by States parties under article 19 of the Convention, Concluding observations of the Committee against Torture, Bulgaria

18 Personal communication with the State Agency for Child Protection. (8-12 June 2015) On file with Lumos.

The overall mortality rate in institutions for children with disabilities has dropped from 3 to 1 deaths per 1,000 children in institutions since 2011, which is important progress.¹⁹ However, it is worth noting that the numbers have been reducing over the course of *Childhood for All* and there has been a moratorium on admissions to these institutions since the start of the project (see the Bulgarian Reform Programme, below).

According to the Bulgarian Helsinki Committee report, the number of deaths in baby institutions has increased slightly since 2010, from 49 to 55 in 2014. At the same time the rate has doubled - from 9 babies per 1,000 children in institutions in 2010 to 20 in 2014.²⁰ This is of some concern considering the overall reduction in the number of children in institutions.



There is a need for closer monitoring and investigation of deaths in institutions or in other forms of care. There can be a tendency to assume automatically that the death of a child with disabilities in care is due to their disability. However, this is not always the case and a formal system for reviewing deaths in care should be introduced.

1.5. About the assessment

The information for this report comes from the recent reassessment of a group of 1,291 children and young people with disabilities who moved out of large residential institutions (institutions) into small group homes (SGHs) in the community. This process was undertaken by Lumos in cooperation with State authorities between mid-October and the end of December 2015.

To monitor progress and to understand how life outside of institutions has influenced the development of this group, the information gathered in the reassessment was compared with available data from the assessment implemented at the end of 2012 and the beginning of 2013. At that stage, the children and young people were still living in the institutions. It measured changes in key areas of each individual's health and medical history, physical, communication, social and emotional development as well as school attendance, the child's relationships and contact with their family.²¹

For further information about the scope of the reassessment, see Methodology and Limitations.

This document presents the outcomes for the children who have transitioned out of the large residential institutions into homes in the community *so far* in the process. It shares both progress and challenges and provides recommendations for the future.

It is hoped this will be of use to:

- The Bulgarian Government, in assessing progress of the reform and planning future initiatives
- The European Commission, in assessing their investment in the system for caring for vulnerable children in Bulgaria
- Other stakeholders involved in the reform process in Bulgaria.

¹⁹ Calculation on file with Lumos

²⁰ Calculations on file with Lumos

²¹ In addition to the Form there is a questionnaire covering different features of the residential service itself, such as organisation of its work and daily activities, meal time, furniture, staff, staff training and support, etc.

2. The Bulgarian Reform Programme

2.1. Overview

In 2010, the Bulgarian Government, with significant support from the European Commission and civil society, embarked on an ambitious programme aimed at transforming the system of caring for vulnerable children and improving their quality of life and developmental outcomes.

This involved reducing the numbers of children living in institutions and replacing institutions with high-quality family and community based services. Based on the *Vision for Deinstitutionalisation of Children in the Republic of Bulgaria*, an inter-ministerial, inter-agency Working Group drafted the National Action Plan for Deinstitutionalisation. This outlined five programmes for implementation focusing on different parts of the DI process, including:

- Transferring all children with disabilities out of institutions to community-based services, known as the *Childhood for All* project (see below). Data from this project provided the source data for this assessment
- Introducing a pilot reform programme in eight baby institutions
- A foster care development programme
- Strengthening social services
- Introducing regional planning

EU funding was essential in launching the reforms, and an innovative approach of using two types of European Structural and Investment Funds was successfully carried out before the ex-ante conditionality on social inclusion was in place. For the first time, the European Commission's Directorate-General for Regional and Urban Policy (DG REGIO) and Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL) pooled their funds to launch the DI process in Bulgaria, starting with children. The determination and commitment of the EC to meaningful reform has led to a massive change in the country and has set an example both of how the EU funds could be used for transforming the child care system and of achieving a cross-sectoral approach within the EU executive body.

2.2. Initial challenges

Although efforts over the years had already led to some reduction in the numbers of children in institutions, there were considerable challenges when the programme began in 2010, including:

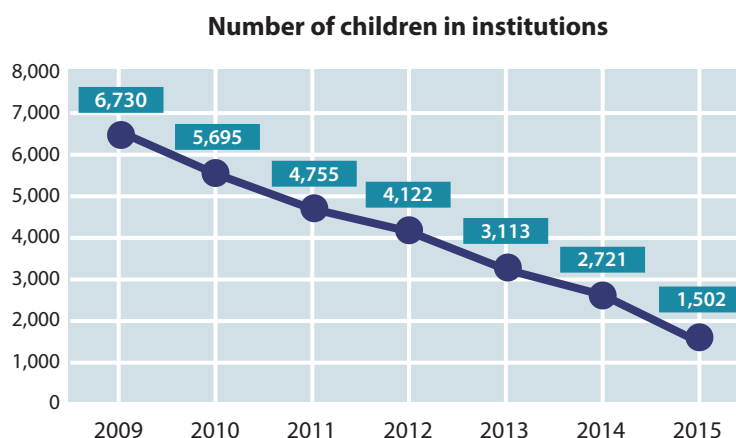
- Difficulties in developing the foster care system. Bulgaria had found it particularly difficult to increase the numbers of foster parents
- Extremely poor conditions in the institutions. In particular, the disability institutions experienced unusually high levels of child mortality
- A general belief that reform was too expensive and that the country could not afford to run a system of community-based services. There was an erroneous belief in 'economies of scale' – that gathering children together in large groups in institutions must be the most financially efficient way to care for them.

2.3. Progress during the reform programme

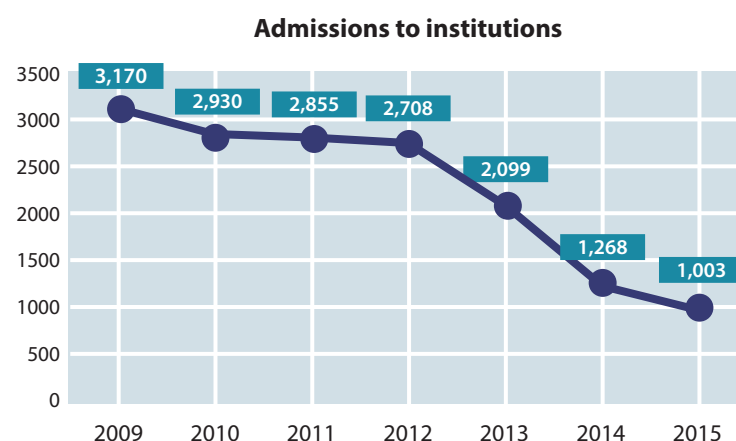
a. Number of children in institutions

The Bulgarian Government has made considerable progress in reforming its care system.

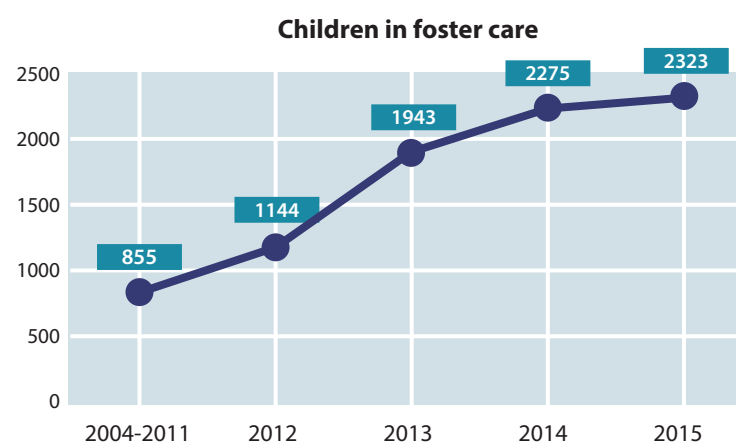
The number of children in institutions has decreased by 78% since 2009.²²



The number of children admitted to institutions annually has also reduced by 68%.²³



There has also been a significant increase (272%) in the numbers of children cared for in foster families.²⁴



This represents significant progress in a short space of time.

²² For the 2009-2013 numbers please see: State Agency for Child Protection. (2013). Number of children in specialized institutions on 31.12.2013 in comparison to 2001-2013. [Data file in Bulgarian]. <http://sacp.government.bg/programi-dokladi/statistika/> The 2014 number is a Lumos calculation based on two sources: Personal communication with the State Agency for Child Protection. (2014). On file with Lumos. National Statistical Institute. (3 April 2015). Homes for Medico-Social Care for Children in 2014 [webpage]. <http://www.nsi.bg/en/content/5606/homes-medico-social-care-children>

²³ The 2014 figure was provided by the SACP: Personal communication with the State Agency for Child Protection. (28 July 2014). On file with Lumos. For the 2012-2013 figures, please see: Rogers, J. (2014) Deinstitutionalisation of children in Bulgaria – How far and where to? Sofia, Bulgaria: UNICEF, p33. http://www.unicef.bg/assets/PDFs/De_I_Review_Report_EN_small_size.pdf For the 2009-2011 figures, please see the first and second monitoring reports, available on the SACP website: State Agency for Child Protection. (2011-2012). [First/ Second] Monitoring Report on Implementation of the Action Plan For Implementation of the National Strategy "Vision for Deinstitutionalization of Children in Bulgaria" [report in Bulgarian]. <http://sacp.government.bg/deinstitutionalizaciya/>

²⁴ Agency for Social Assistance. (5 June 2015). Official letter to Lumos, no. 62-122. On file with Lumos.

b. Childhood 2025

The coalition Childhood 2025 is playing an important role in Bulgaria's social care reforms. It is a group of civil society organisations and networks from across the country working in fields related to DI. Its priority is the development of individual community-based care for every child, respecting their rights and meeting their needs. Founded in 2013, it set out to support a successful and sustainable DI process regardless of political changes.

The Coalition members are representatives of a broad range of organisations – service providers, donors, advocates, advisors, researchers, parent groups and lobbyists. To achieve its goals, the Coalition works with all stakeholders – government bodies, regional and municipal administrations, the media, international donors, the European Commission and others.

In recent years, members of the Coalition have participated and provided expertise in working groups with all ministries involved in the DI process. At the time of writing, the members are engaged in the development of the new National Plan on DI for the period 2016-2020, ensuring that the main priorities and needs will be addressed effectively. These are:

- The closure of all residential institutions for children and ensuring that they are no longer needed
- Establishing a network of support services for families to prevent separation and well-developed methods of alternative family care for children who cannot remain with their families
- Supporting families and providing every child with the opportunity to grow up in a family setting
- Increasing the effectiveness of multidisciplinary teams, the quality of work in the child protection system and the network of related services
- Coordinating and unifying the efforts of governmental bodies and civil society during the reform process so as to avoid any inaction or delay that might harm a child during the transition period.

2.4. Children with disabilities – the *Childhood for All* project

Embarking on its reform process, the Bulgarian Government took the forward-thinking step of prioritising children with disabilities. This group is one of the most vulnerable but is often left behind when it comes to DI: people with disabilities are frequently undervalued and their inclusion in the community mistakenly deemed too difficult or of no clear benefit.

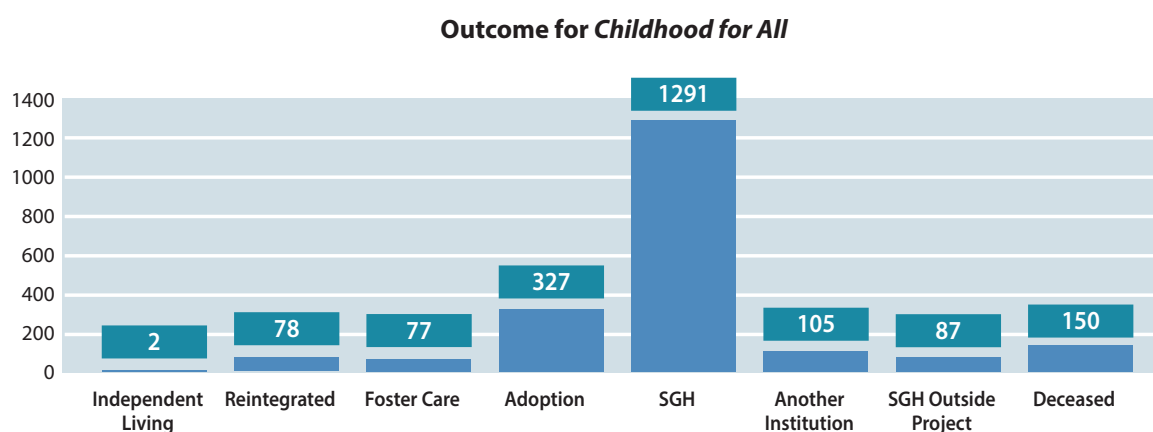
The *Childhood for All* project, initiated by the State Agency for Child Protection, set an ambitious target of removing all children and young people with disabilities (aged three or over) from institutions in Bulgaria. At that time the project started in 2010, there were:

- 24 institutions that accommodated a total of 1,290 children and young people with disabilities. Twenty-three of these institutions were for children with intellectual disabilities; the other housed children with physical disabilities
- 31 institutions for medical and social care for children aged 0 – 3 where 507 children with disabilities were placed.

The total target group of the *Childhood for All* project involved 1,797 children and young people. However, during the course of the project, 318 children with disabilities from the baby institutions automatically entered the target group once they reached the age of three. Therefore, a total of 2,115 children and young people transitioned out of institutions to new placements.

At the end of the *Childhood for All* project in November 2015, outcomes for the children and young people were as follows:

- 1,291 were moved from institutions and placed in SGHs
- 327 were adopted
- 105 children and young people were moved to another type of institution (homes for children 'deprived of parental care' and homes for elderly people with disabilities)
- 87 were moved out from institutions and placed in another existing service outside of the project, including SGHs developed before Childhood for All and vocational training centres for children with disabilities
- 78 were reintegrated with their families
- 77 were placed in foster families
- Sadly, 150 children and young people died during the course of the project.



Lumos was unable to access further information about the 150 children who died during the project. The death of any child is a tragic loss; to better understand and reduce mortality, it is important to collect information about the age of the child, the nature of the disability and the cause of death so that these can be assessed. Based on previous investigations. It is likely that a number of these deaths could have been prevented. Consistent recording and assessment would highlight where the Government should focus its resources, including (for example) improved staff ratios and training.

There are children who may be terminally ill and appropriate services, such as palliative care, need to be in place for them.

It should also be noted that children should, as far as possible, never be moved from one institution to another as part of reform. Moves are stressful and children who move to other institutions are likely to suffer trauma and a deterioration in health, development and quality of life.

2.5. Challenges in the reform

Lumos firmly supported the decision to prioritise children with disabilities and worked closely with the State Agency for Child Protection and the Agency for Social Assistance from the beginning of the reform. Lumos invested additional resources in childcare staff training, assessments of the children, research into the parents' attitudes to keeping in touch with their children and case conferences for each of the children and young people. Methodological and technical support has also been provided for the creation of guidelines for transitioning from institutions to other placements, as well as procedures for making decisions in accordance with the best interests of each child.

However, the government's desire to change the system quickly for children with disabilities resulted in too narrow a focus on residential alternatives. The format and capacity of the small group homes increase the risk that an institutional culture will prevail.²⁵ A desire to 'fill the homes up' to their maximum capacity of 12 has been observed, on the grounds of efficient use of resources. However, the greater the number of children in a home, the more difficult it is to provide individualised care.

At the beginning of the project, it would appear that few people believed it would be possible for children to be placed in families and few resources were put into the development of supportive services, to make sure children could go home and enjoy life in the community. In spite of this, more than 20% of the children did go to family placements. If a greater focus had been placed on community services and family support, it is possible this number could have been greater.

However, it is not too late to address this and the reassessment process is an opportunity to clarify how to best deal with these concerns.

Some good results are already evident and with this reassessment Lumos will continue to support the government authorities to ensure that the new placements are meeting children's needs, to review progress and help overcome the challenges. The children and young people moving out of institutions should not be viewed as the end of a process; rather is it the beginning of the improvement of children's lives, their full inclusion in the community and their full enjoyment of their human rights.

2.6. Next steps in the reform programme

It is important to build on the successes of the past five years, assess where further reform and support is needed and ensure this is taken into account in the National Action Plan for 2016-2020.

Institutions are expensive and harmful to children's health and development. In all but the most complex cases, children have the right to grow up in families. Considerable savings are already being made due to the deinstitutionalisation process, and it is vital that the money is reinvested in the system. Deinstitutionalisation involves not only closing down institutions and moving the children: new services need to be developed to ensure that all their needs can be met in the community, as well as preventing children from entering institutions in the first place.

A set of recommendations is provided at the end of this report. It is hoped these will be of use in planning the next stages of ending institutionalisation in Bulgaria, in line with the objectives set out in the Vision document.²⁶

²⁵ Institutional care' is understood to be any residential care where institutional culture prevails. The size of the institution matters, but is not the only defining feature. Children are isolated from the broader community and/or compelled to live together. These children do not have sufficient control over their lives and over decisions which affect them. The requirements of the organisation itself tend to take precedence over the children's individual needs. This usually includes large residential units (more than 10 children) but also smaller units with strict regimes, units for children who have committed minor offences, residential health facilities, and residential special schools. For further information see: European Commission. (2009). Report of the Ad Hoc Expert Group on the Transition from Institution to Community-Based Care

²⁶ Bulgarian Government 2010: Vision for Deinstitutionalisation of Children in the Republic of Bulgaria

Widespread public support

A national public survey, commissioned on behalf of the State Agency for Child Protection from July to August 2015, showed overwhelming support for the country's progress on DI:

- Four-fifths (80%) support the values of the DI process
- Almost three-quarters (74%) approve of the DI process so far, and only three per cent disapprove
- 84% agree that new services offer better care than the old institutions
- The report concludes that this is the only social reform in the history of Bulgaria (post 1989) to enjoy such a high level of public support five years after it began.²⁷

3. Methodology and Limitations

3.1. Methodology

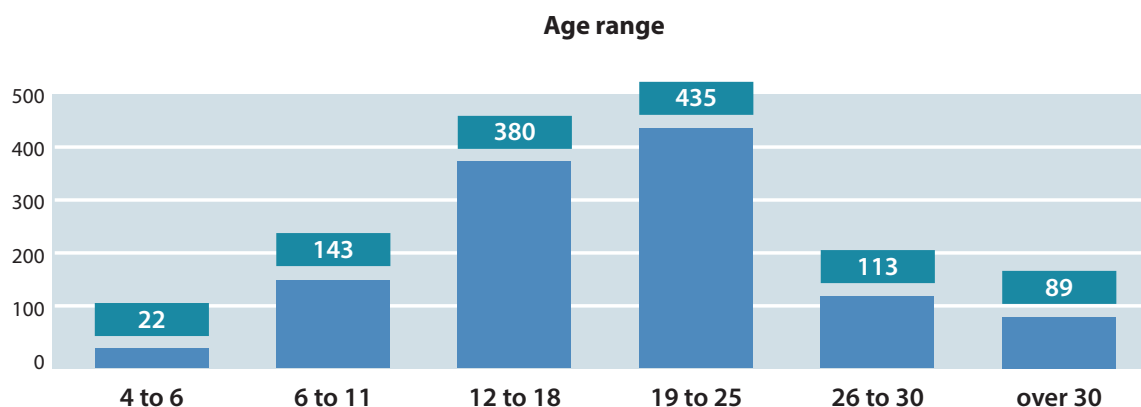
The information in this report comes from the recent reassessment of a group of children and young people with disabilities who moved out of large residential institutions (institutions) into small group homes (SGHs) in the community. This process was undertaken by Lumos in cooperation with State authorities.

To monitor progress and analyse how life outside institutions has influenced the development of this group, the information gathered through this reassessment was compared with available data from the assessment implemented at the end of 2012 and the beginning of 2013. At that stage, the children and young people were still living in the institutions. It measured changes in each individual's health and medical history, physical, communication, social and emotional development and independence skills, as well as school attendance, the child's relationships and contact with their family.²⁸

From October 15 2015 to the end of December 2015, assessors visited SGHs to meet personnel and to observe and engage with the children. The specific activities undertaken depended on the nature of each child's health and their level of understanding and communication skills. Where the children and young people were attending school or a community-based non-residential service, such as a Day Centre or Centre for Social Rehabilitation and Integration, the consultant set up additional appointments in the school or service.

3.2. Ages of the reassessed children and young people

The ages of those being reassessed ranged from four to 49 years old, encompassing children, young people and adults. The adults in the group had all grown up in institutions.



The wide age range is not uncommon in institutions for children with disabilities: it is a result of the lack of services, not just for children, but also in transitional, 'leaving care' services and services for adults with disabilities. However, a key principle of high quality DI, which the Government of Bulgaria has supported, is ensuring that no one is left behind. This is encouraging, but it has led to a number of challenges for the SGHs and service providers as the law specifies a maximum age of 29 for receiving certain services.

²⁸ In addition to the Form there is a questionnaire covering different features of the residential service itself, such as organisation of its work and daily activities, meal times, furniture, staff, staff training and support, etc.

3.3. Participation in the research by children and young people

A key part of the research involved the active participation of children and young people as researchers. This group, made up of five young people aged 16-27, with intellectual disabilities, carried out their own research and set up a focus group to find out what life in the new SGHs felt like from a peer-to-peer perspective.²⁹ The children and youth participation group made the decision to focus on how they could effectively support their counterparts in the SGHs during their planning session for 2016.

They developed a questionnaire and surveyed the children and young people about living in their new environments. This project was called the *Peer to Peer Support Project*. One young Lumos self-advocate was also involved in giving advice to professionals on how to communicate with the children in SGHs during the national reassessment process.

Once the reassessment data was available, Lumos personnel discussed the findings in an accessible way with the focus group. Each member of the group chose to develop and share their opinion on one or two topics that were close to their own life experience. A questionnaire was prepared based on proposals from the group. The young people had the opportunity to ask a number of experts, local policy makers and practitioners about the lives of children after the placement in the SGHs. They were also able to share the children's opinions, thoughts and suggestions during these meetings. The conclusions of this group are contained in the Assessment Findings section of this document.

Through this work, the young people have become confident self-advocates, attending numerous national and international conferences, events and training.

3.4. Limitations

1. The reassessment data collected only covered the SGHs in which the children and young people with disabilities were placed under the *Childhood for All Project*. It is essential that *all* children, including those who were reintegrated into their birth families or placed in foster families, are also reassessed.
2. Information from the reassessment forms only allows analysis of specific areas of their lives. It is also still early in the process of reform. It is likely that further development and changes in behaviour will be observed if children are reassessed annually.
3. The group of children and young people subject to reassessment:
 - only includes children and young people who were moved from institutions into SGHs
 - has an age range of four to 49 years old; the adults in this group grew up in institutions.
 - includes 1,182 children and young people
 - excludes 120 children whose assessments from 2012 that were missing. These cases have been removed from the data comparison.
4. Most of the analysis relates to the whole group assessed, with the exception of data concerning access to education and height and weight. In the latter, the 'normal' range correlated to expected norms up to the age of 18.

²⁹ The Lumos child participation group in Bulgaria was set originally up as part of a previous EU funded project Turning Words into Action. Many of the participants are still actively engaged in the work.

4. Assessment findings

4.1. Overview

The data collected at the end of 2015 and the conclusions drawn from it have been compared to the initial assessment in late 2012/early 2013 when the children and young people still lived in the institutions. The reassessment focused on the following key areas:

- **Independence** - assistance with household responsibilities; care of personal belongings and personal hygiene; ability to make choices and decisions; level of independence outside the SGH
- **Health** – changes in health; diagnoses and treatments³⁰
- **Physical development** - height and weight; mobility
- **Communication** – the development of language and communication skills
- **Challenging behaviour** – the number of children and young people with challenging behaviour and strategies used for dealing with this
- **Eating and drinking** – the number of children and young people who eat independently and those fed by carers; number of children and young people who eat in bed/in a lying position
- **Contact with parents and family** – number of children and young people who keep contact with family (weekly, monthly or infrequently) and the number of those who have no contact
- **Support services** – access to healthcare, education and community-based services (day centres, centres for social rehabilitation and integration etc.)

As might be expected these skills vary with different children and young people depending on their age, developmental level and disability. However, the majority of developmental milestones presented below should already have been reached within the age range of the group of children and young people assessed.

Overall, the findings demonstrated encouraging results in these key areas. This is particularly positive considering the early stage in the process at which the reassessment took place; these trends could be expected to continue. However, the findings also raised some areas of concern which need to be addressed.

4.2. Independence

“She has developed skills for making simple choices regarding daily functioning – food, clothes, place and activities.”

SGH, Dobrich

Some of the most significant changes in children and young people after they moved out from the institutions relate to the development of independence. Overall, when in institutions only 14% of children and young people had some degree of independence; this rose to 28% in the SGHs. For some children and young people, decision-making skills involve simple choices: which socks to put on, which clothes to wear according to the weather outside. For others it is about more complex choices and decisions, such as organising a visit to the hairdresser and choosing their hairstyle for themselves.

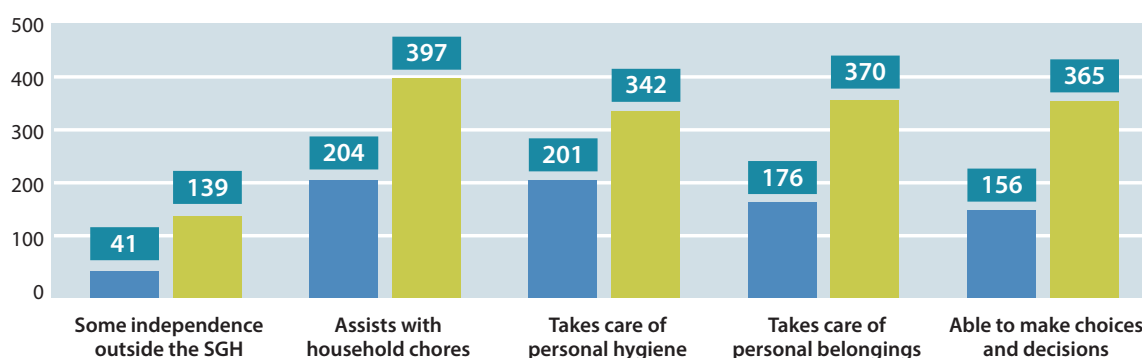
30 The diagnoses and therapies were analysed by Assoc. Prof. D. Terziev, MD, Chief of the Day Unit at the “St. Nikola” Child

“She chooses her clothes and shoes matching them by colour. When going to the hairdresser she chooses her hairstyle herself. She tidies her wardrobe and school bag. After school she puts her clothes into the laundry basket. She washes her hands, face, teeth independently and takes a shower with the guidance of a carer. She makes her bed without help, puts her toys in order, she takes part in preparing breakfast and peeling potatoes. She is friends with a girl from her school class and they go together to the tuck shop in the school.”

SGH, Chirpan

Despite of the different degrees of skill development, the data demonstrates a considerable increase in the number of children and young people who enjoy more independence now compared with when they were in the specialised institutions; this should continue to improve with the right support in place. Most significant was the increase in children and young people who can make choices and decisions, followed by those who help in the household and those who take care of their personal hygiene³¹ and belongings. Independence outside the SGH, for example by being able to go to the shop or knowing their way to school and back, is still low. However, even this demonstrates a significant increase compared with life in the institution. The staff in the SGH could benefit from further training to support this, for example in how to involve children and young people in everyday tasks.

Independence skills



“He has difficulty folding clothes but gladly puts them into the laundry basket and takes them to the washing machine.”

SGH, Berkovitsa

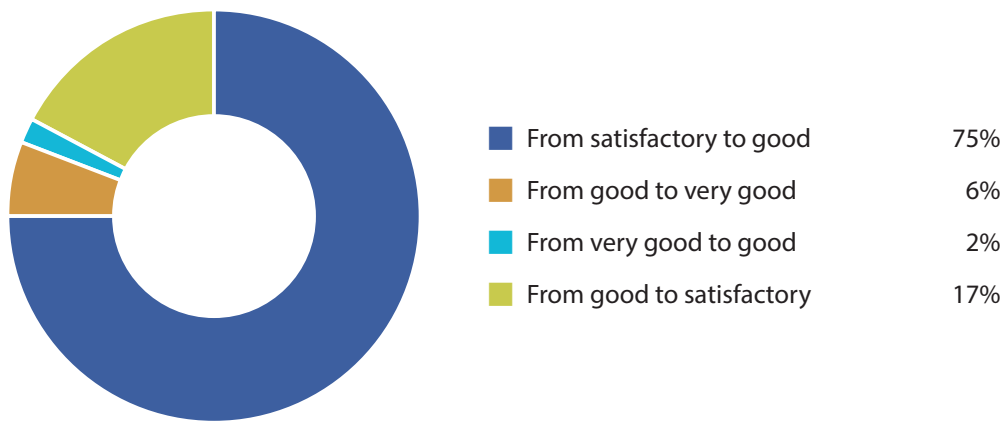
4.3. Health

Changes in health

Adequately meeting the health needs of children with disabilities during the DI process is often a source of concern; it is sometimes even cited as a reason for not moving such children out of harmful institutions. This is because the ‘medical model’ prevails, where professionals believe that disability is an illness that requires care in a hospital-like environment. However, the reassessment findings demonstrated no significant deterioration in health; where any change occurred (in 28% of individuals) it was overwhelmingly positive.

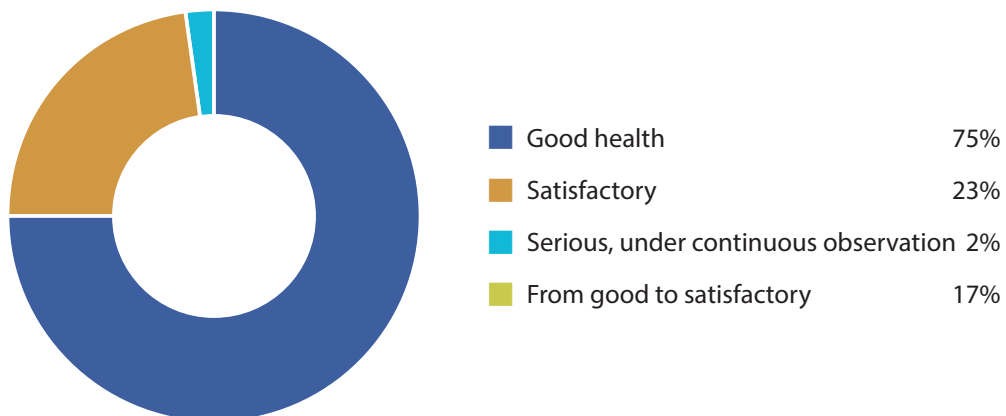
For the children and young people who experienced a change in their health, the majority experienced a positive change, 75% from ‘satisfactory’ to ‘good’ and 6% from ‘good’ to very good. Nineteen per cent experienced a negative change in their health, with 17% changing from ‘good’ to ‘satisfactory’ and 2% changing from ‘very good’ to ‘good’. These outcomes are very encouraging.

Change in health - 28%



Of the children who moved into the SGHs, 72% experienced no change in their health compared with when they were living in the institution. The majority of these children and young people (75%) are in good health; for 23% their status was defined as satisfactory, and 2% of children and young people still have a serious health condition under continuous observation – the same as when they were living in an institution.

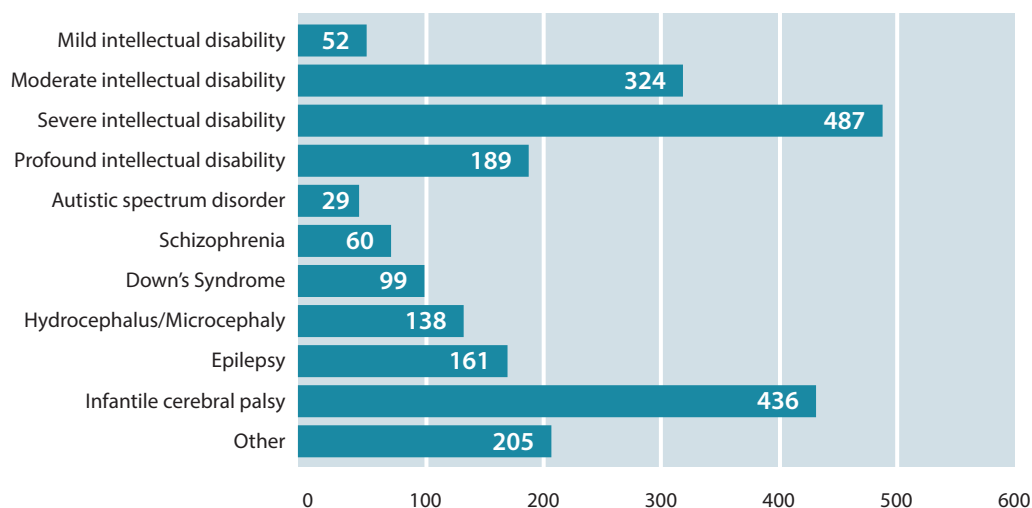
Children and young people with no change - 72%



Diagnoses and medication

Many of the children and young people had a diagnosis of combined physical and intellectual disabilities. The most frequently documented somatic/neurological diagnoses and disorders were epilepsy, Down’s Syndrome, infantile cerebral palsy and microcephaly.

Diagnosis



Analysis of the medications used in the residential services for children and young people with disabilities demonstrates the prevalence of several main types of psychotropic medications. In order to provide a proper analysis of the use of psychotropic medication, Lumos consulted an expert in the field. The diagnoses and therapies were analysed by Associate Professor D. Terziev, MD, Chief of the Day Unit at the “St. Nikola” Child Psychiatry Department of Aleksandrovska University Hospital in Sofia. The psychotropic medications used influence brain function, emotions and behaviour and/or suppress psychopathological manifestations. They are prescribed by specialists, used for a medicinal purpose and should involve follow up of the patients. Nevertheless, analysis comparing diagnosis and use of medication indicates that in some cases psychotropic medication is being prescribed to address challenging behaviour rather than a diagnosed psychiatric illness.

Medication	Use in the group of children and young people assessed
Anticonvulsants with anticonvulsant/antiepileptic effect, some which are commonly referred to as ‘mood stabilisers’, although their main use is in neurology for epilepsy. They are also used in psychiatry, mostly for purely psychiatric disorders such as affective disorders and schizophrenia (which only represent a small number of cases in the group assessed).	The data demonstrates that 425 children and young people are administered anticonvulsants, which surpasses the 221 diagnosed with epilepsy or schizophrenia. This indicates that these medications have been prescribed and used for another purpose, such as managing behaviour.
Neuroleptics are used for mental disorders such as schizophrenia, affective disorders, some cases of problematic and dangerous behaviour arising from an intellectual disability, autistic spectrum disorders and for severe chronic tics.	A considerable number (212) of the children and young people are administered neuroleptics. Bearing in mind that only 60 children and young people assessed are diagnosed with schizophrenia, in some of the cases where neuroleptics are prescribed it may be an attempt to control behaviour, including self-harm. Significantly, the use of neuroleptics has increased substantially in SGHs as compared with the institutions.
Tranquillisers and anxiolytics, such as diazepam and atarax are used in conditions connected with overwhelming and persistent anxiety. The prescription of these drugs has increased after the move to the new SGHs.	A total of 141 children and young people are prescribed tranquillisers and anxiolytics. The reason for use is not clear but it is most likely that they are prescribed to regulate the behaviour of hyperactive and/or anxious children/young people, in combination with other medications. The use of diazepam for behaviour regulation, however, remains inadvisable and problematic.

From the diagnoses listed above, only epilepsy is subject to mandatory medication to address seizures, and this is prescribed, managed and followed up by a neurologist. Intellectual disability is not subject to pharmacological or other treatment in Bulgaria. It is acceptable (and in some cases advisable) to use symptomatic medication in the presence of self-harming, harmful, destructive or otherwise aggressive behaviour which is persistent and cannot be treated in a socio-psychological way, in order to diffuse or partially control the risky behaviour. However, these

issues should be addressed through a range of measures that take the person's environment and routines into account. Medication should not be solely relied upon as this underpins a medical model of disability, rather than a social one. Therefore it is advisable that diagnoses and medications are reviewed.

Young Researchers' Findings and Recommendations

"We think that it is not good to always use pills and injections. In most of the cases this [challenging behaviour] is to show a wish which remains unnoticed and unexpressed because of sedatives. That is why, first, there should be a way to find the reason for the child's behaviour, and if it is discovered that the problem is big then they should take more serious measures."

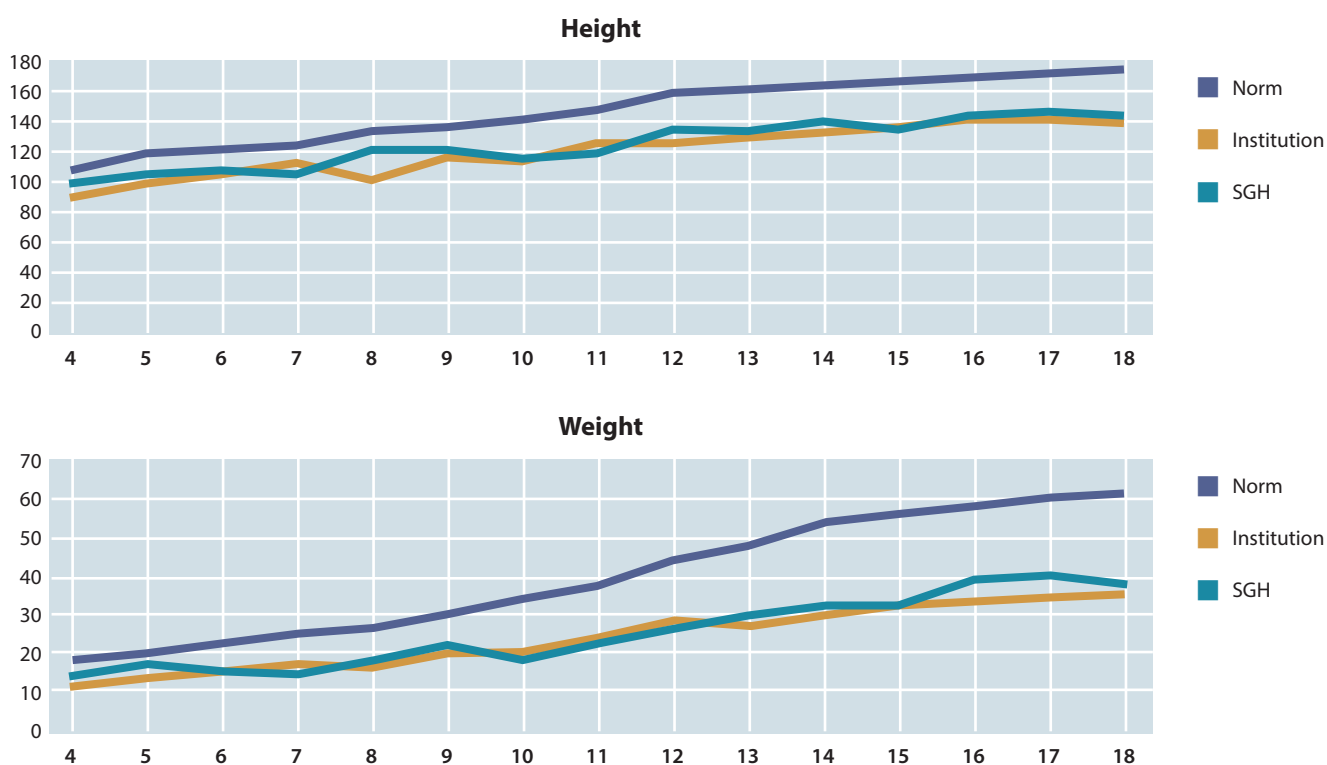
Current staffing levels mean that other strategies for controlling or managing behaviour are not being prioritised. This is an area which needs to be addressed, or the problem is likely to continue. This is an example of 're-institutionalisation' where, for some children and young people, the move to the SGHs has not resulted in a significant change in how they are treated, cared for and supported. Instead, the overuse of medication to control behaviour is contrary to the UN Convention on the Rights of Persons with Disabilities (CRPD), in that it does not encourage independence and inclusion.

4.4. Physical development

Some developmental progress can be attributed to the children and young people getting older. However, many of them were underweight and short for their age, probably as a result of institutionalisation. The reassessment data therefore focuses on comparing the 'catch up' in height and weight against the norm.³²

Height and weight

The height and weight of children and young people demonstrated some positive increases since their departure from the institutions. As mentioned above, these increases are partly due to natural increases in height and weight; however, there is also some catch up towards the norm.

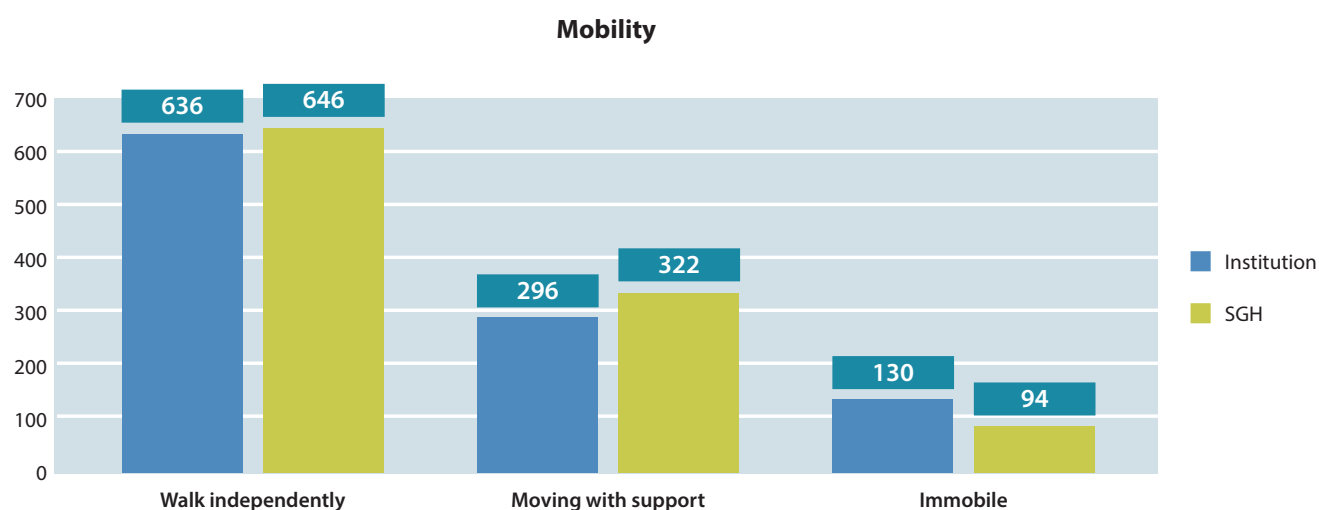


³² Norms available at Ministry of Health, Ordinance № 23 from 19 July 2005 to physiological norms for diet; http://www.mh.government.bg/bg/normativni-aktove/naredbi/?from_date=06.06.2005&to_date=06.08.2005 [accessed 06/06/2016]

Despite this positive progress towards the norm, the length of stay in the institution means that some individuals may never catch up completely. For the adults in the group assessed only 4% were within the height norm for an 18-year-old or above while they were in the institution. This has only slightly increased to 5% in the SGHs. With regard to weight, the results are more positive, with 11% meeting the 18-year-old norm or above in the institutions compared to 20% now in the SGHs.

Mobility

The reassessment showed a decrease in the number of children and young people who spend all their time lying immobile in bed and a corresponding increase in the number of children and young people who walk or move independently or with some support. However, further development in this area is necessary. The range of available support equipment - such as wheelchairs and walkers - is poor; it is concerning that the use of this equipment is restricted, since these are basic requirements to help children and young people leave their beds and reach a level of mobility that will further support their development and independence.



Young Researchers' Findings and Recommendations

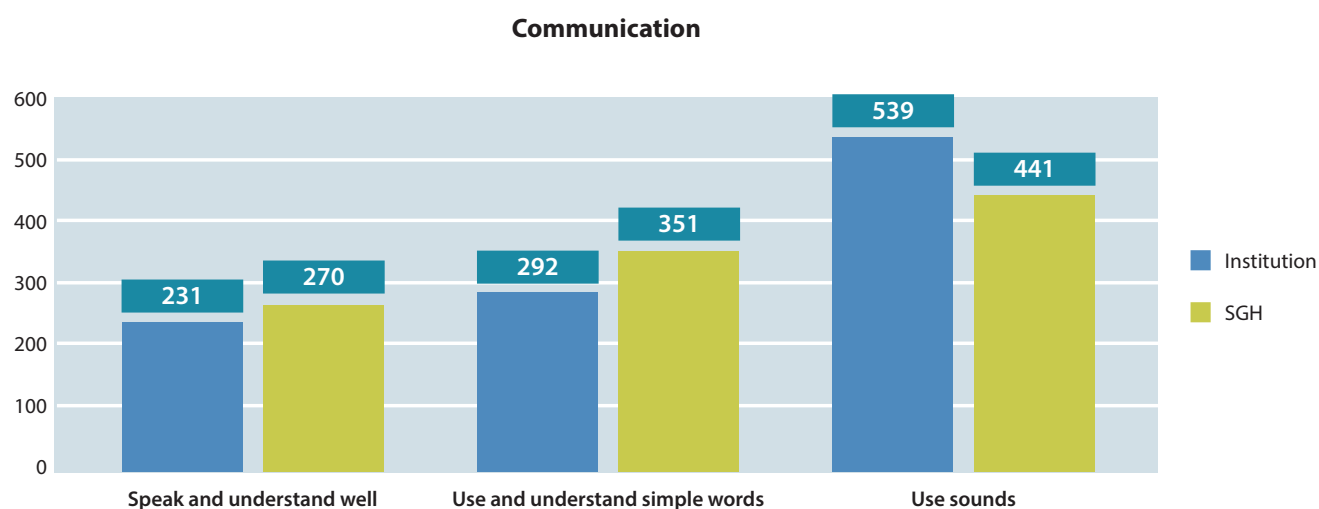
"Children do not move around enough. Yes, they move but only very little. There are children who are only staying in bed. So we have a suggestion – let's have morning exercises in these houses, no matter how simple the exercises are; to have available or adjusted assistive devices to enable children to be upright at least for some time."

When children are supported to become more mobile it can make a significant difference to their quality of life, as demonstrated by the following example:

When one young man, aged 17, was initially assessed in the institution it was noted that he spent most of the time lying in bed, with minimal mobility. As part of Lumos' work to prepare children and young people for transition out of the institutions, the staff started to work with him, taking him out of his bed, providing physiotherapy and supporting him to use a wheelchair. This work is continuing in the new SGH and the young man has significantly increased his autonomy. In a supportive environment he moves quickly and skilfully with the wheelchair. Being able to move around is a pleasure for him and allows him to join in activities, or move to places or people that interest him. He often holds out hands to catch people who are passing by him, asking them to help him stand up and walk with support.

4.5. Communication

The reassessment showed some improvement in communication skills for children and young people in their new setting. The following graph demonstrates a marked increase in the number of children and young people who speak and understand well, as well as a significant increase in the number who now use and understand simple words. However, it is still the case that the majority have little verbal communication. No full evaluation has been undertaken of what and how much the children and young people. No alternative communication systems or techniques are in use, with the exception of 12 children who use pictograms or pictures. Continuous support from personnel is essential for developing their communication skills. Insufficient provision of alternative communication methods, such as pictures or pictograms, places many children and young people in a non-stimulating environment where communication is entirely absent or reduced to a minimum. There is a need for investment in communication methods and training of personnel to work actively in improving communications abilities of the children and young people.



4.6. Challenging behaviour

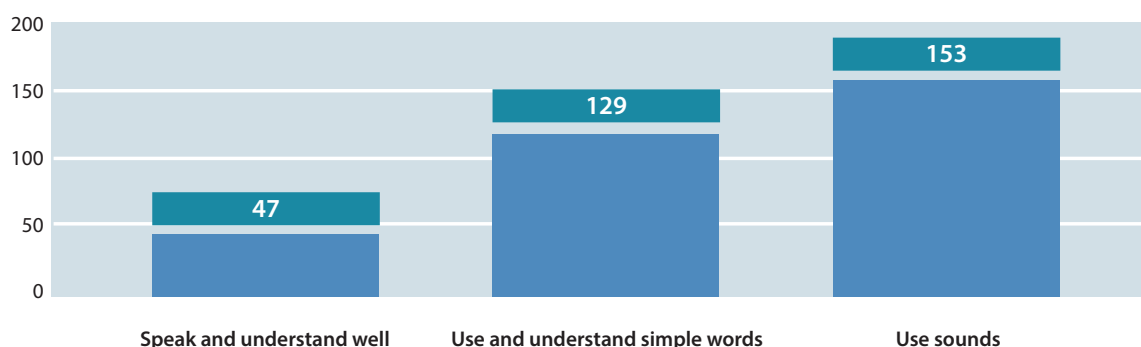
Although there are some instances of positive changes in the behaviour of children and young people, overall the percentage of children and young people with challenging behaviour remains steady at around 30%.³³ The number displaying challenging behaviour has reduced slightly from 345 (32%) in institutions to 329 (31%) in SGHs. These are cases which, especially in their most severe forms and manifestations, are beyond the control of staff. It is important to emphasise that in many cases, personnel have not been provided with the necessary regular training and supervision to enable them to handle these situations. Personnel do not have specialist knowledge of how to work with this group of children and young people who need long-term, regular and targeted support and interventions.

Very often, children and people with challenging behaviour are not well understood and there are too few personnel to respond appropriately to the behaviour. This leads to enormous pressure, both on employees and on the service users. Some children and young people have frequent outbursts which cause serious material damage and which, more importantly, risk seriously harming themselves and others. Children and young people with challenging behaviour are one of the main reasons why employees choose to leave the SGHs.

Since a lack of communication skills can underpin challenging behaviour, it is important to point out that only 47 children and young people with challenging behaviour have verbal skills and are able to communicate in a conventional manner. One hundred and twenty-nine can use and understand simple words, whereas the remaining 153 are non-verbal and only vocalise.

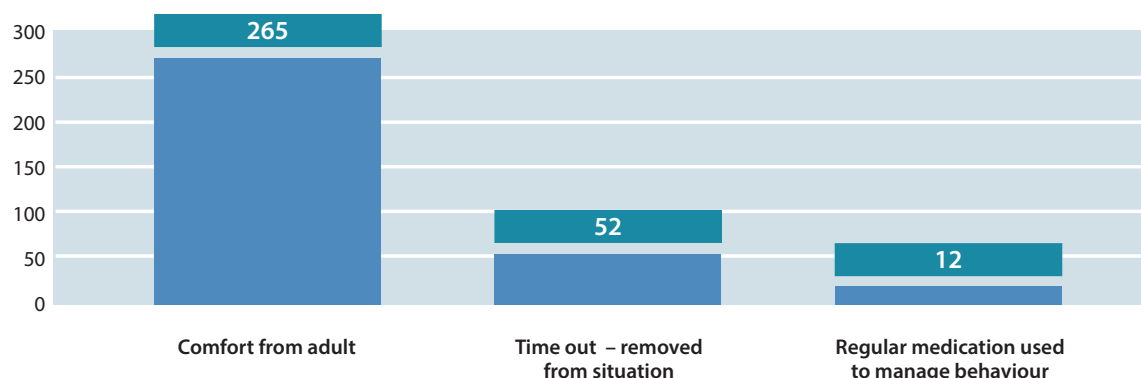
³³ Challenging behaviour is considered every socially abnormal behaviour (behaviours) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or interfere with regular communication.

Children and young people with challenging behaviour - communication



The most common strategy for managing challenging behaviour used by staff members in milder cases is that of 'calming' – such as providing comfort, using soothing words. Physical restraint, exiting the situation, removing the trigger and use of medications are applied in more challenging cases. In the most serious outbursts of challenging behaviour, the alternatives often are to call emergency medical teams, doctors and sometimes the police, as well as resorting to medication as described above. There needs to be a sufficient number of personnel working on shift and they require relevant training in order to deal with these cases appropriately.

Challenging behaviour management strategy



Integrating children and young people with challenging behaviour in schools as well as in other support services is also problematic, since teachers and other professionals are not always appropriately trained to work with those who have these difficulties.

It should be noted that some challenging behaviours have ceased with time after a period of adapting to the new environment. There is a clear need for additional personnel, specialised training in the management of challenging behaviour and a focus on supporting children and young people in finding different ways to communicate.

4.7. Eating and drinking

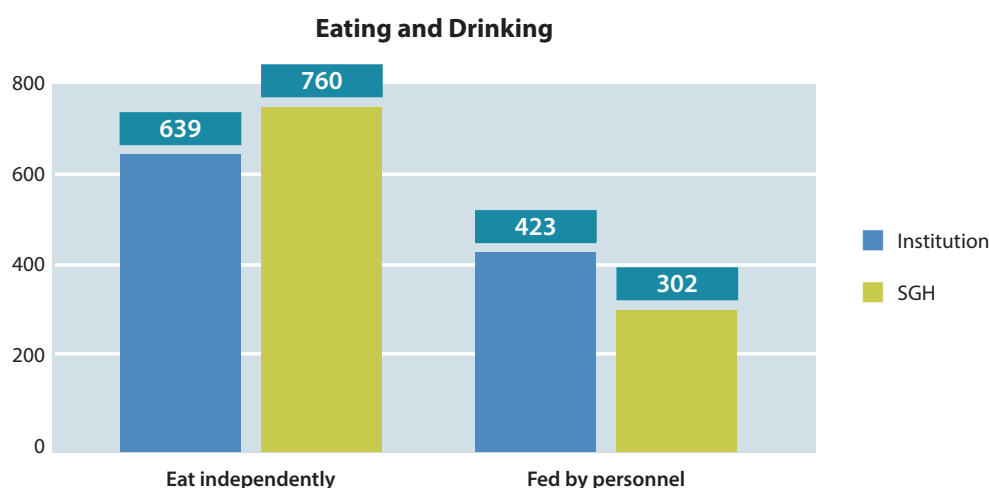
Eating and drinking can be a serious problem for institutionalised children and people with disabilities, especially for those who are unable to eat without assistance and who are entirely dependent on personnel. In some institutions there were malpractices in feeding, such as children being fed whilst lying in their beds and force-feeding. In many cases, personnel levels were low, which reduced meal time to a few minutes - or as little as 1 min 20 seconds per child, from the research carried out by a Lumos consultant.³⁴ When the reform programme began, a number of children were on the verge of starvation as a consequence of inappropriate feeding methods. It should be noted that many instances of mortality referred to the Bulgarian Helsinki Committee report in 2010 were related to malnutrition.³⁵

³⁴ Lumos. (2011) Unpublished data: on file with Lumos.

³⁵ Kukova, S. (2011). Op. cit.

The reassessment does show some positive results for the children and young people who moved into the SGHs. The implementation of the Childhood for All project introduced a number of initiatives and training programmes aimed at addressing poor feeding practices for children and young people with disabilities. Prior to moving out of institutions, feeding was a key topic in the training programmes for the new personnel. In some institutions, 'feeding instructions' were prepared for individual children and young people. These were passed on to personnel at the new services to ensure that the positive practices would continue. This led to positive changes in many SGHs: children were taken out of bed to eat sitting up, or positioned in a more vertical position during feeding. The number of children who now eat in a sitting position with other children has increased, as has the number who eat independently. For some children, a transitional process from bottle feeding to spoon feeding has started. Others are, for the first time, working on the development of skills for independent eating.

However, due to inadequate numbers of personnel in the SGHs (there are usually two employees on duty during meal time, who have to assist up to 12 children and young people to eat), an institutional culture with regimented meal times is unfortunately being reintroduced in many of the SGHs. There is a tendency for meals to be reduced simply to the intake of a set amount of food in a set period of time. This means insufficient attention is paid to the importance of the environment in which the child eats, the individual speed of each child, the individual approach of the adult, and the quality of the interaction between them. 302 children and young people in SGHs still depend on personnel to be fed in a healthy and caring way, with due attention, respect and time necessary for a healthy diet and life.

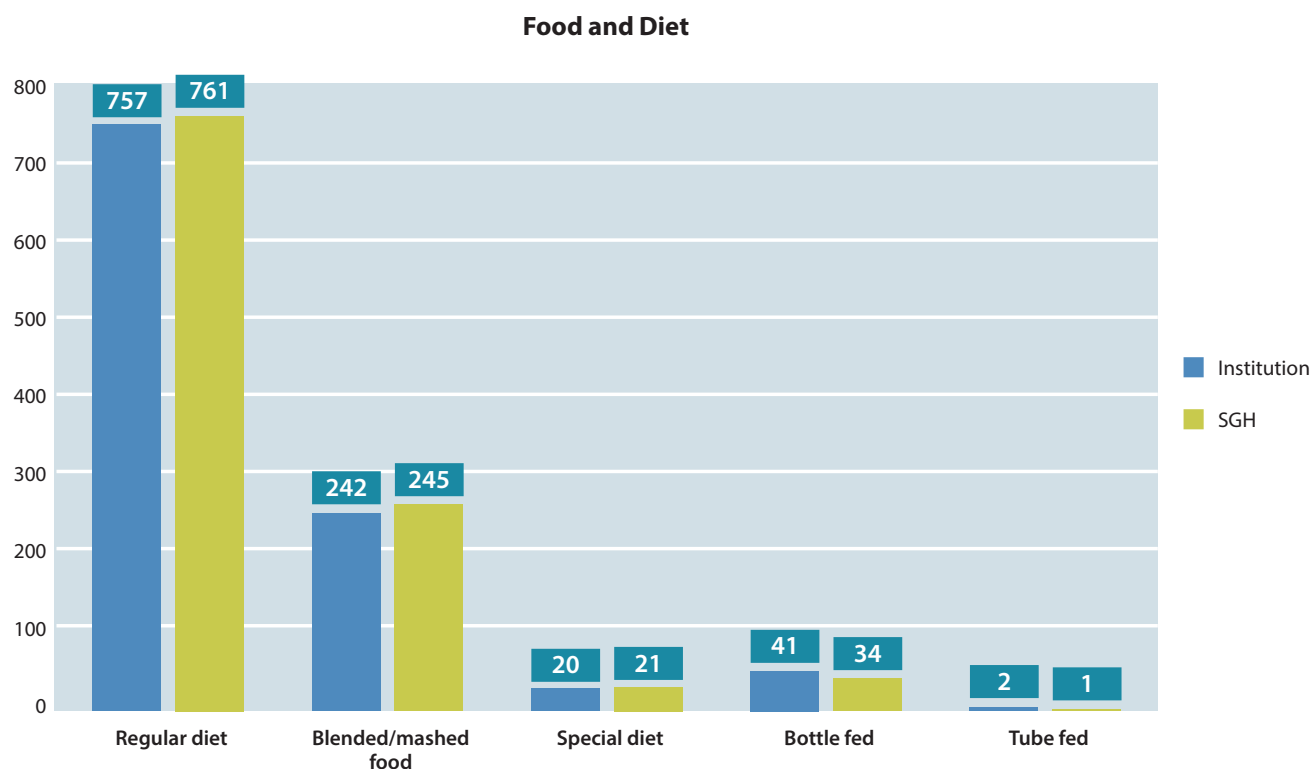


For children with severe and multiple disabilities, in some SGHs the extremely harmful institutional practice of feeding children and young people while they are lying in their cots has continued (75 in the institutions, 70 in the SGHs).

Young Researchers' Findings and Recommendations

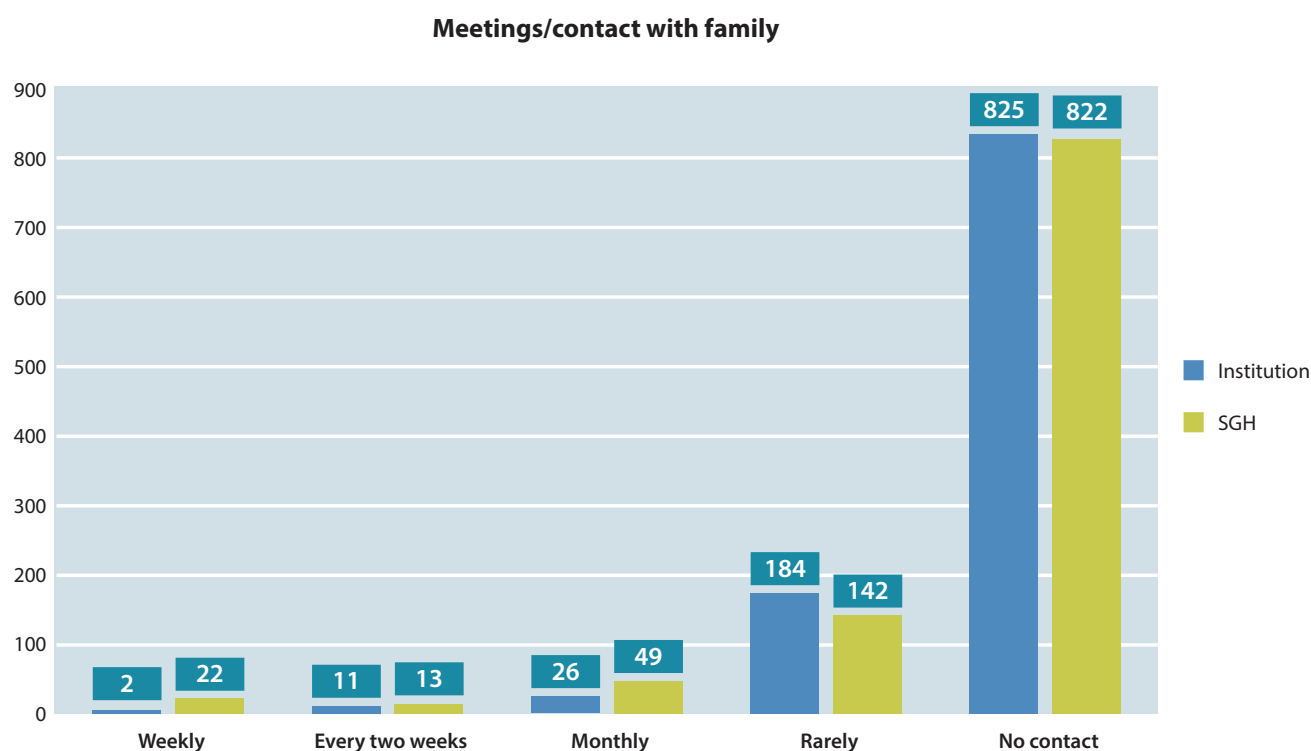
"I have seen how they feed people there. Something that struck me was that everything was happening so fast. The staff were feeding them so quickly that I had the feeling food was not chewed but directly swallowed. I think this is harmful for the stomach because this is not proper eating, just filling up the stomach and this is stressful to the body. In my opinion, the reason for this is the insufficient number of staff."

With regards to food and diet, the picture in the new SGHs is very similar to that in institutions, with a minimal increase in children and young people who have regular diet from 757 in the institution to 761 in the SGHs, and a decrease in the number of children who are fed with a bottle (41 to 34). Improvement in the area of eating and drinking should therefore be a top priority for resource allocation.



4.8. Contact with parents and family

The reassessment looked at the number of children and young people who kept in contact with their family in the SGHs compared to in the institutions.



Although the number of children and young people who have contact with their families is somewhat similar to that of the institutions, the move to SGHs has led to increased frequency in contact. In 45 cases the contact became more frequent after the children and young people moved into the SGHs. The following case study demonstrates the difference that can make in a person's life.

K. is 23 years old. He was placed in an institution when he was 13 years old. His father tried to visit him once a month even though the institution was located 75 km away from the family home. In 2014, K was moved out of the institution and into a small group home, just a few blocks away from where his parents and younger brother live. K. spends every weekend in his parents' house together with his family and he helps his father with the housework. The parents also have weekly meetings with the personnel of the service.

SGH, Pomorie

A Lumos study carried out in 2011, in conjunction with the State Agency for Child Protection and the Agency for Social Assistance, looked at the attitudes, willingness and opportunities of families for maintaining contact with their child. It showed that more than 50% of parents wanted to keep in touch with their child when they moved into the new SGH.³⁶ Some of these had had no contact with their child before, or even knew that their child was still alive. It is essential that this desire for contact is supported and that work with the families continues, so that it can become an integral part of the overall process of DI of these children. The local authority social workers should work actively to re-establish contact between children and their families.

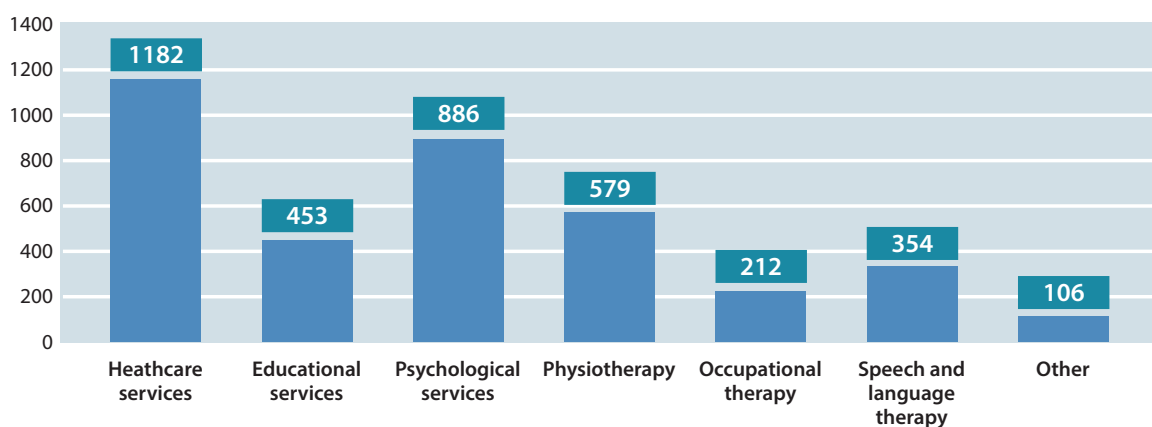
4.9. Support services

The DI process involves the creation of a range of new services, both for those moving out of institutions as well as preventative services for vulnerable children and families. In order for this process to be sustainable and successful in the long term, it is essential to ensure that these new services are working well, are accessible and meet the children and young peoples' needs.

The newly-built SGHs were designed to be places where the children and young people would spend only part of their time 'at home'. During the day, they would use other support services in the community, including schools, day care centres and community social services such as centres for social rehabilitation and integration. This is partly to reduce the practice of isolating children and people with disabilities, as well as ensuring that they are accessing essential services and specialists. Therefore, access to other services is an indicator of quality of life and of how far the DI process is improving the children's access to their right under the CRPD to be included in the community.

As the graph below demonstrates, universal healthcare services cover all children and young people, but the situation is different for educational services. Although almost half of the residents in the SGHs are school-age children, not all of them are accessing the education system. The other services in the graph are provided both by SGHs and social services in the community.

Number of children and young people using services whilst living in the SGHs



Access to healthcare

All children and young people who live in the SGHs have access to a doctor and in all the services there is a system for regular, or needs-based, monitoring of the residents' health. In addition to health checks by the doctor, depending on their health state and needs, the residents are able to access other specialists such as psychiatrists, neurologists, ophthalmologists and urologists.

In relation to dental care, in theory all children and young people have a personal dentist. However, in some places the dentists are not willing to work on children and people with disabilities under anaesthesia. This raises a training need.

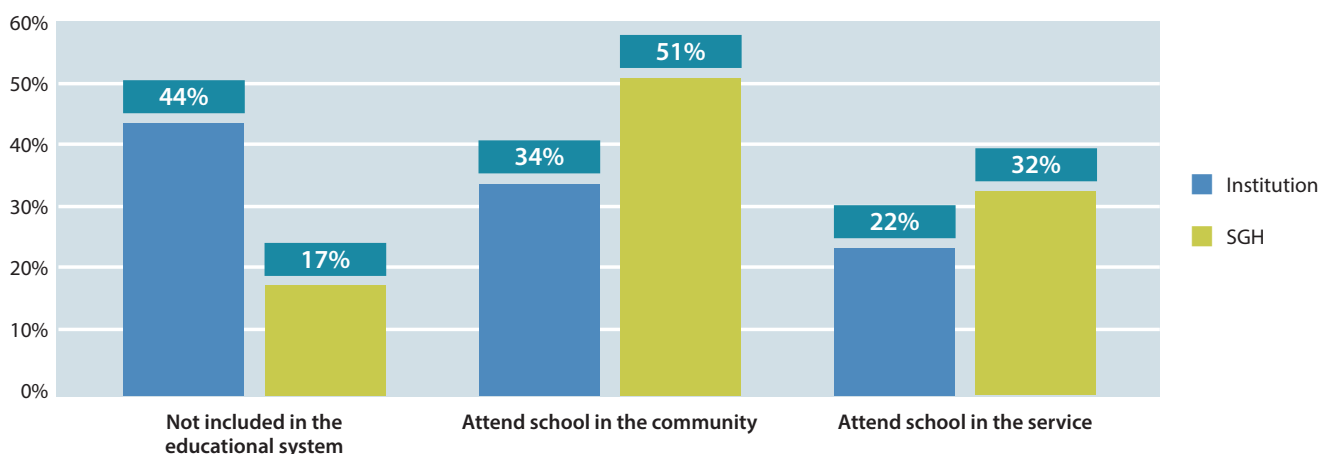
Young Researcher's Findings and Recommendations

"One of the biggest problems of these children is their health. Yes, each one of them has a doctor, but almost no one wants to take care of their teeth. In order for this to be an easier process, specialists should be taught how to approach them. Dentists' offices must be improved because not every child can be treated in the environment of a typical dentist's office."

Access to education

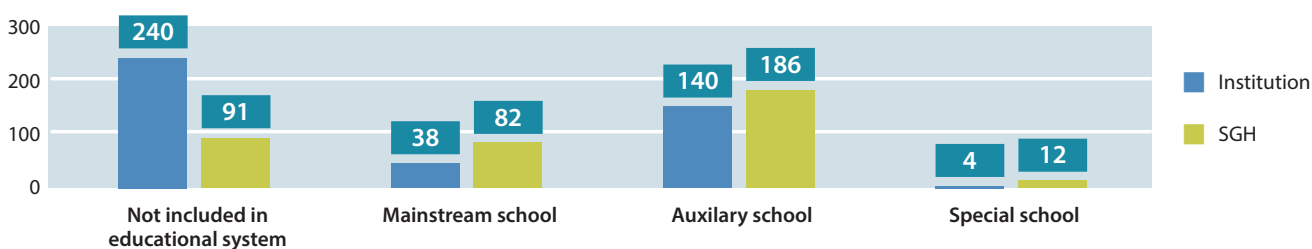
All children have a right to education. While the move to SGHs resulted in a significant decrease in the percentage of children outside of the educational system, 17% of those living in SGHs under the age of 18 are still not included in any form of education. The majority of the children and young people are included in the educational system, although 32% still receive their education in the residential service in the so-called outreach classes.

School attendance



When children attend school in the community they have the opportunity to develop friendships and build networks outside of the SGH. The majority of the children who attend school attend an auxiliary school, which is a form of special school.

Independence skills

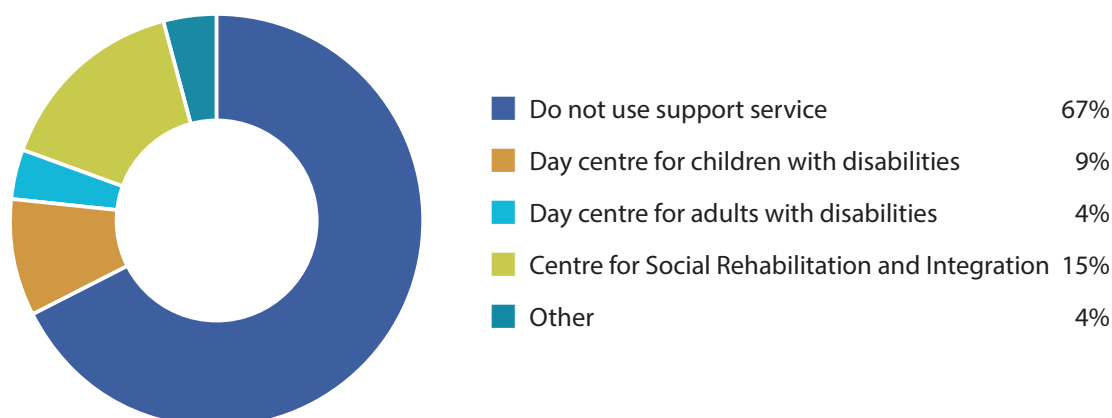


There is a need for further development of inclusive education in Bulgaria. In the initial *Vision* document for DI, the inter-ministerial group did not include the Ministry of Education. This resulted in residential special schools not being included in the DI process. There are some inclusive education programmes running, although their implementation is sporadic. However, had joint planning been undertaken, it would have been possible to develop inclusive education in schools near to the newly developed SGHs. This should have made it possible for many more children to access their rights under the CRPD to inclusive education. It is of considerable concern that 91 children of school age are still not included in any form of education. Joint planning is required between the State Agency for Child Protection and the Ministry of Education to rectify this situation and to ensure closer harmonisation between the deinstitutionalisation process and the development of inclusive education.

Access to community-based services

In the institutions, only 6% of the children and young people accessed some form of support service in the community and in the SGHs this has increased significantly to 33%. However, this means that 67% are still not accessing other services. The most common reasons for this are insufficient capacity of the existing services or a lack of services in the area. Another common issue is the lack of transport provided by the SGHs. This leads to a situation similar to the institutional approach where the residents are forced to spend all their time in one place.

Support services - SGHs



Further services should be developed and capacity in the existing ones increased, as well as training for the carers in the SGHs to support the residents' access to other services. This should be a key priority for the new National Action Plan.

4.10. Placing children and adults together

One of the concerns identified during the research was that there are some SGHs where children and adults have been placed together. This was largely undertaken to ensure that extremely vulnerable children and adults, such as those with severe, multiple disabilities, would not be placed in SGHs together with physically stronger children who may have challenging behaviours. Although this motivation is understandable, unrelated children and adults should not be living together and there are particular child protection risks in arrangements of this kind.

Children and adults have different needs and services should be designed accordingly. If they continue to be placed together, there is a risk of infantilising adults with disabilities and viewing them as 'eternal children'. The SGHs where adults and children are living together should be reassessed to ascertain whether more appropriate arrangements can be made. At a minimum, ways should be found to separate out adults and children and provide different approaches to both groups. Where possible and appropriate to the individual needs of the child, social workers should be attempting to move children in SGHs towards family placements (reunification, fostering or adoption).

With adults, the planning should be more about moving towards independent or semi-independent living in the community.

Of course, some of the children and adults will always require 24-hour residential care and support. In this regard, there is a longer-term piece of planning needed in relation to services for adults with disabilities. As children turn 18 years of age, will they move to another SGH or will this be their 'home for life'? If the former, these moves must be managed carefully and under no circumstances should they be moved to institutions for adults. If the latter, how will the authorities manage the changing nature of the home and the fact that they will end up with a home for children and adults?

It is recommended that the proposed expert Working Group should also consider this issue as a priority, to ensure that plans can be made ahead of time and make sure that no child or adult is arbitrarily moved from one service to another and that no-one in an SGH can be moved back into the institutional system.

4.11. Findings of the young researchers

As outlined in Methodology and Limitations, a group of five self-advocates from Lumos' children and youth participation group in Bulgaria carried out their own research and set up a focus group to find out - from a peer-to-peer perspective - about life in the new SGHs. The findings and analysis of the research of the focus group will be presented at the main reassessment meeting in Sofia in June 2016 and a more comprehensive analysis will be delivered in the autumn of 2016.

The findings of the young researchers to date focus on four key areas. Details of these findings and related recommendations have been included throughout the document, but are summarised here.

- Eating and drinking. The young researchers were concerned by the speed of feeding and felt this was likely to be harmful. They concluded this was due to insufficient staffing levels.
- Overuse of medication. The young researchers were concerned to see frequent use of medication to control behaviour. They felt the behaviours came predominantly from frustration or the inability to communicate.
- Health, in particular dental care. The young researchers felt little attention was paid to dental care and that dentists should adapt their surgeries to be more accessible.
- Movement. The young researchers were concerned to see some children who only stay in bed. They recommended daily exercise and movement programmes in all the SGHs.

Following this research the young researchers have reflected on how important this type of work is and how it can ensure that the children and young people's voices are heard. They also reflected on how much the research has helped them develop their own skills; for example, they have learned how to count and analyse results of this type of research for the first time.

4.12. Children returned to families: reintegration, foster care and adoption

As indicated in the earlier section about the Bulgarian Reform Programme, more than 450 children with disabilities were moved out of the specialised institutions to live in families through adoption, reintegration into their birth families or placement in foster families.

Children who live with a family when they leave an institution usually recover better than those who move into an alternative residential service. Nevertheless, they will also need to access services in the community and must be taken into account when planning service capacity. In order to draw objective conclusions, further research and assessment of all cases, whether reintegrated or in foster care, should be made. This data is essential to provide evidence as to whether or not raising children with disabilities in a family environment is safe and results in improved health, development and inclusion. It is important also to be able to compare costs and outcomes of different forms of care, as this information is essential to planning future services and reform programmes.

The fact that children with disabilities can live in families, rather than in 'specialised' placements under 24-hour observation and the care of medical specialists, is of great importance. In most cases, parents and families - if adequately supported by the system – provide an environment much more conducive to the child's development than even the best institution.³⁷ The two case studies below provide examples where children with disabilities can live in families with no risk to their development and condition. They also demonstrate the importance of never giving up on a child.

Case study: **Foster Care**

The Dimitrovs have been foster parents since 2008. The family has one grown-up son who lives independently. Previously Mrs Dimitrov used to work in an institution for children with disabilities. When the time came for her to retire she decided to become a foster parent for N. – a girl from the institution who had been living for years in isolation, lying in her cot and displaying symptoms of depression.

N was abandoned at birth and placed in a specialised institution. At the time when she was brought to foster care in 2008 she was 14 but her physical development corresponded to that of a two- or three-year old: her weight was 12.3 kg and height was 108 cm. She was not able to move on her own and could not sit independently. She had difficulty turning from front to back and vice versa. She used to eat blended food from a bottle. She had no speech. She had no gross or fine motor skills. She had no social contacts, she had never been visited by her family and she did not attend school or social services in the community. She had no attachment relationships with any of the personnel. In the foster mother's words, N. was in a grave physical condition at the time she was brought to her care and the prognosis was not optimistic.

However, after just one year in foster care N. had changed completely. She developed physically: her height increased to 120 cm and weight to 20 kg and she started taking her first unsupported steps. She started to eat regular food instead of being bottle fed and began responding to music by drumming with her fingers and making dance-like movements. She started to smile and make eye contact. According to the foster mother the hardest thing for N. was to trust and to create an attachment relationship. Now, seven years later, N. is able to walk on her own and has some independence in her daily self-care. She is 140 cm tall and weighs 40 kg – normal height and weight for a 12-year-old. She vocalises and says "ma-ma, ma-ma". She feels comfortable in the company of strangers, waves her hand to say "Hello!" and "Bye!" She smiles and follows the movements of people with her eyes. She is able to communicate what she wants and what she likes.

Case study:

A successful case of reintegration of a baby from baby institution

This boy was born in 2015 with Spina bifida. He had surgery and the parents were consulted by medical professionals and social workers from Child Protection Department (CPD). According to the doctor, the child had to be under medical supervision because it would be too risky for the parents to take care of the child at home. The CPD suggested the mother and child to be placed together in a local baby institution, to keep the emotional mother-baby bond. The child was duly placed in the home and the mother was admitted 5 days later, since according to the rules and procedures of the institution she had to run some tests to verify that she is in good health. The mother was accommodated in a special room and under medical supervision started learning how to take care of her baby. She took part in feeding, bathing and bandage change. In that way the child was able to hear her voice, to feel the rhythm of her heartbeat, recognise her smell and to be comforted by her when feeling pain or other discomfort. She noticed that her son calmed down and smiled when hearing her voice. When they were together she hugged him, talked to him, held him in her arms and sang him lullabies. Their close contact and relationship lasted only 5 days because the mother became ill and had to leave the institution.

The mother told the researchers that during her five-day stay in the baby institution the staff explained to her that the child would have to stay there at least 6 months and perhaps even longer and that it was not certain if the child would ever recover. Due to the indefinite period of the stay and probably because of other hints on behalf of the staff, the mother refused to go back to the institution but was always present at the consultations with specialists – neurosurgeon, neurologist and others. She also received very strong support from the social worker from CPD both regarding the child and the possibilities for him to be raised in a family environment. The social worker also counselled her regarding difficulties she was having with her partner, with whom she broke up soon afterwards.

Now six months old, the boy is living with his mother and feels calm and happy. He regularly visits the GP and his physical development is normal for his age. He sits with support, his head and back are steady and upright and he turns his head to look around. While lying face down he lifts his head and chest up. When he is on his back he lifts his head to see his feet. The child is active and shows interest in everything around him. He vocalises a lot both to himself and others and laughs out loud during play. He demonstrates a strong attachment to his mother.

These cases demonstrate the crucial impact of attachment, individual attention and a stimulating family environment on a child's development. All children have potential and all children deserve to grow up in a loving and caring environment. With support, the vast majority of children do not need any form of residential care, although some may need specialist foster care. It is recommended that the government build on the current positive practices in this area. It is also strongly recommended that the state authorities undertake a reassessment of all children who moved from institutions to families.

5. Funding

This reassessment and the review of services provides an opportunity to reflect on the progress and challenges in the Bulgarian reform programme so far and to focus on plans moving forward. It is clear that a number of these challenges relate to the resources available.

Institutions are expensive to run and the outcomes for children are poor. Lumos' financial analysis³⁸ show that institutional care is by far the most expensive, and least efficient, model. Supporting families to look after children in the community – shown by research to produce the best outcomes for children – is the least expensive.

One of the key principles of successful DI is that of ring-fencing: protecting and reserving the resources currently in the system before transferring them across to support the community-based services that are developed to replace institutions.

The SGHs are still less expensive than the institutions. As demonstrated in the Lumos report *Ending Institutionalisation: An analysis of the financing of the deinstitutionalisation process in Bulgaria*,³⁹ the Bulgarian Government is already making a saving of 13,313,905 BGN (6,807,024 EURO) annually with the reforms so far. The aim of a reform programme is not to cut costs, but rather to reinvest funds saved from institutions in better services that can support more children and result in better outcomes.

Therefore, it is recommended that the savings made in reforming children's care services away from an institution-based system should be reinvested in two areas:

- Family support services, health, education and social work at community level. This will result in better outcomes for children and should also further reduce admissions to institutions, releasing further funds to reinvest in community-based services.
- Improving the financing standards (see below) for children and young people in the SGHs, with a particular focus on increasing staffing levels and providing access to assistive devices and other communication methods to make sure children receive adequate care.

Financial standards (fixed payments)

It should be noted that children and people with disabilities range from those who are quite independent to those who require much greater support and attention. Therefore, a single, fixed financial standard that covers all residents in SGHs is unlikely to meet the needs of all children and young people. A review of the way in which services are financed is needed in order to ensure greater flexibility and to apply more funds where necessary (and less where the money is not needed). Another challenge with this approach to funding is that where homes are funded 'per child', there is an incentive for managers to try to fill the homes to full capacity. This can act as a 'pull factor', where children are placed in residential care when a better – and more cost-effective - family-based alternative could have been provided in the community. And the larger the number of children in an SGH, the more difficult it is to avoid an institutional culture and to provide a family-like environment.

- The current financial standard is inadequate to meet the service needs of the children and young people and to ensure their full enjoyment of their rights under the CRPD. There is a need for additional financial resources for training, supervision for personnel, for sharing good practice and for hiring experts when needed.
- Optimising the financial standards or developing new financing mechanisms should be based on an assessment of the services: the level of need, improvements required and new services needed. The financial parameters should be determined according to the individual needs of the children, which also means a differentiated approach to financing services for children and families.
- An exploration is needed of the possibility of financial decentralisation of the services at local level, where the needs are much better identified by the local stakeholders. This must, however, be accompanied by the decentralisation of adequate budgetary resources to meet local needs.

6. Conclusions and Recommendations

General conclusions

1. The Bulgarian Government should be commended for the progress of reform achieved over such a short period of time, and for the monitoring and evaluation of this process. The reassessment shows that, in only two years, this first phase of reform has led to notable improvements in the health, development and quality of life of children and young people with disabilities.
2. Bulgaria has taken steps towards ensuring that all children have their basic rights met. It is to the credit of the Bulgarian Government that they chose to prioritise children with the most severe disabilities when planning and implementing deinstitutionalisation.
3. The DI process often involves major changes in practice and attitude. It requires continual monitoring to ensure that things are going according to plan and that the plans are effective. Outcomes for children and young people are an essential part of this: at each stage, the children's best interests need to be at the heart of every decision. Those decisions reflect the questions that most parents would ask on behalf of their children; for example, are they being educated and if not, why not? Are they eating sufficient food and receiving enough nutrition? Are they getting exercise or physical therapy? Are they going outside, or into the community? Are they making decisions about their daily life?
4. Current services are underfunded. In some cases, there are insufficient staffing levels, staff do not have the training and support needed, and children and young people would benefit from further assistance and alternative models of care. There is a perception that better-resourced SGHs would be too expensive for the government to finance for the long-term. However, a financial analysis of the DI process demonstrates that, compared with budgets for institutional care in 2009, an annual saving is being made of approximately 13,313,905 BGN (6,807,024 EURO). These funds could be reinvested in making significant improvements to the SGHs.
5. The service provided by the SGHs varies across the country, with different regions and individual SGHs developing their own approaches. For example:
 - in some, food is prepared in the home; in other places it is catered externally
 - some SGHs have a greater focus on daily routines and participating in activities than others
 - in many SGHs, there is a high staff turnover
 - some municipalities provide additional resources, such as experts from NGOs to support the work with the children with more complex needs or challenging behaviour.

There are models which have been developed at a local level which are working well, but a regional or national approach is needed to ensure that they can be replicated elsewhere.

Assessment conclusions

Independence

- The transition from institutions into SGHs led to a clear improvement in the level of independence enjoyed by children and young people. The SGHs provide a safe environment for the gradual development of these skills. In almost all cases of increased independence, regardless of the area and the degree of independence, the following were observed: increased self-confidence, willingness to interact (verbally or non-verbally), increased physical and/or psychological activity and improved emotional state.
- However, an insufficient number of children and young people have any form of independence outside the SGHs, which inhibits their inclusion in the community. Improvements are also needed in relation to involving the children and young people in everyday tasks.

Health

- A majority of children experienced no change in their health, and where there were changes they were mostly positive.
- However, there is a need to review diagnosis and prescriptions of medication. The use of medication is considerably higher than expected in view of the diagnoses of the children and young people assessed. It is likely that medication is being used in some cases to control challenging behaviour. Furthermore, there was still a tendency among professionals working with children and young people with disabilities to focus on the medical model of disability rather than the social.

Physical development

- The height and weight of children and young people have improved. Whilst it is natural to expect some natural increase in height and weight with growing children, there is also some catch up towards the norm.
- Although more children and young people use assistive devices such as wheelchairs and walkers compared with when they were in the institutions, their use and availability is insufficient, leaving some children and young people entirely dependent on personnel to move around.

Communication

- While there was some improvement in the communication skills of the children and young people, many are non-verbal and are not able to communicate in a conventional way. The lack of alternative communication methods places some children and young people in a non-stimulating environment where communication is entirely absent or is reduced to a minimum.
- Lack of communication is defined as a very serious problem both in terms of a person's development and with regards to behaviour: one of the most common reasons for challenging and aggressive or self-harming behaviour in the SGHs would appear to be lack of communication or poor communication.

Challenging behaviour

- The number of children and young people with challenging behaviour has only slightly reduced in the SGHs, and there is a need for training and new models to address this.
- Children and young people with challenging behaviour continue living in a precarious situation in which their basic needs and rights are not always guaranteed and they often present a risk to themselves as well as other children and young people and adults.
- Staff members in SGHs and semi-independent living services need structured and regular support from trained professionals in their work with these children and young people.

Eating and drinking

- As a result of the implementation of the *Childhood for All* project, a number of initiatives and training sessions were provided which led to improved eating and drinking for young people with disabilities. In many SGHs, this good practice has continued and was observed by the assessors.
- However, incorrect and harmful practices were also observed in some cases: feeding children lying in their cots, force-feeding and the use of inappropriate cutlery. This may be due to low staffing levels or it may indicate the need for specialised support to staff. This needs to be addressed as a priority.

Contact with parents and family

- Despite some improvements, the overall level of contact between the child or young adult in SGHs and their families remains quite low.
- There is a lack of clear procedures in relation to making and keeping contact with the family of children and young people living in SGHs. It may also be the case that professionals and experts still believe it is too risky or even impossible for children with disabilities to be successfully raised in a family environment. This is an entrenched approach which will require considerable effort in order to be changed.
- Regular and purposeful work with parents is at the core of DI, and it is necessary to reconsider how the childcare system can adopt this.

Support services

- Many more children are accessing education in the SGHs than in the institutions and there is good access, in theory at least, to services from doctors and dentists. However, since the majority of the children and young people do not attend other support services in the community, access to professionals such as psychologists, physiotherapists and speech and language therapists has become more limited.
- The reassessment shows that an efficient network of supportive services for these children and young people has not yet been developed. It would be useful to analyse the current situation at a municipal and regional level, to identify deficiencies and problems and to plan relevant measures to ensure that that children and young people's needs can be met. This should form part of the next National Action Plan for reform.

Recommendations

Recommendations about extending and improving access to community-based services

- For the new care system to meet the needs of children and young people, community-based services need to be developed – such as inclusive schools, accessible transport, support to gain employment and to access entertainment - need to be developed. This will ensure that children and young people are not only living in homes in the community, but are included in the everyday life of the community.
- Current services should be more accessible. This should include further development of Bulgaria's inclusive education strategy, harmonised with the reform of children's care services, the adequate provision of transport, inter alia. Training of SGH personnel is also necessary to support the children's and young people's access to other services. This should be a key priority for the next National Action Plan and the next programming period of European Union funding.
- Ensure the provision of inclusive education, or vocational training, for all children and young people who moved from institutions to SGHs, foster families, or birth or adoptive families. This should be planned and developed in tandem with the DI strategy. Savings from the closure of institutions can be used to fund inclusive education services and other community support services.

Recommendations about the provision of care

- Increase staffing levels, based on the individual needs of children and young people in the SGHs. Provide more carers on each shift to ensure the continuing presence of key figures for every child and young person.
- Apply differentiated models of care, services and support for children and young people with specific needs and problems such as challenging behaviour, multiple impairments and eating and drinking difficulties. Provide specialist training, support and supervision for personnel relating to supporting eating and drinking, improving communication and addressing challenging behaviours.
- Establish an expert working group to address the main challenges in the running of the SGHs, based on the analysis and conclusions from the reassessment. In this way, existing good practice can be shared and solutions found for more complex issues. Members of the working group should be practitioners from the services who are most aware of the problems and concerns through their own work. Different experiences and approaches would improve residential services for children and young people both methodologically and practically. The expertise and capacity of civil society organisations can also be used to implement proven models and approaches for improvement. A universal view held by the consultants-assessors was that achieving the desired synergy between government, local authorities and the non-governmental sector is a key factor in promoting quality of life for children and young people with disabilities in residential services.
- Reduce the over-reliance on medication to deal with challenging behaviours. This can be achieved through a) increasing staffing levels; and b) providing regular training, supervision and psychological support for the care team without frequent changes in supervising psychologists. It is not only theoretical knowledge that is needed from supervisors, but practical, hands-on activities with the service users, which would raise the competency levels of caregivers.
- Provide assistive devices or alternative communication methods to all who require them. The lack of opportunity for free movement for people with disabilities is a barrier to achieving the goals of DI. Individual assessments of children and young people with disabilities should be undertaken to identify individual need. A range of assistive technical devices should be available, together with specialised training on their proper use. This should be based on good practice in physiotherapy and occupational therapy.
- Training for dentists and doctors is needed in some areas to improve practices when working with children and young people with disabilities.
- The SGHs where adults and children are living together should be reassessed to ascertain whether more appropriate arrangements can be made. At a minimum, ways should be found to separate out adults and children and provide different approaches to both groups. It is recommended that the proposed expert Working Group should consider this issue as a priority, to ensure that plans can be made ahead of time and make sure that no child or adult is arbitrarily moved from one service to another and that no-one in an SGH can be moved back into the institutional system.

Recommendations about working with parents and families

- The financial analysis by Lumos of the DI process shows that supporting parents to look after their children is the most economically efficient option,⁴⁰ in most cases, it also provides the best outcomes for children.⁴¹ The Government must ensure that sufficient prevention services and mechanisms are in place to provide consistent and purposeful support to families, so they can care adequately for their children in a strong and encouraging environment. This involves an attitudinal change among professionals, particularly in relation to overcoming parents' fears.
- A fundamental right of children is to live with and be cared for by their parents and, if for any reason this is not possible, the authorities should in most cases ensure that contact with parents and relatives will be maintained, unless this is not in their best interest.

40 Lumos (2015) Op. cit.

41 Berens, A. & Nelson, C. (2015) Op. cit.

- Regular reviews of placements should be mandatory and efforts should continue to be made to reunite children with their family, including the provision of support services to birth and extended families. It is likely that at least some of the 5,556 children – in care of different kinds in 2014 could live with families in the community, with some support (or for adults, independently). Children who are moved to families are likely to demonstrate even better results in terms of improved health, development and quality of life.

Recommendations about further assessment and monitoring

- The *Childhood for All* reassessment only documents children who moved to SGHs, not those who returned to their families, were adopted or placed in foster families. The authorities should reassess the development of all children who moved from institutions so that future reform is based on the best available evidence. Reassessments are also essential to ensuring that each individual placement is working for each child.
- While the height and weight of the children and young people improved overall since the closure of the institutions, average height and weight are still below the norms. The reasons for this should be further assessed and measures put in to place to address it, where possible. It should be noted that experience elsewhere has demonstrated that children who are institutionalised for long periods may never fully recover their developmental delays.
- A unified information system should be created which will allow input and summary of information about individual children, in order to be better able to monitor progress.
- To better understand and reduce mortality, it is important consistently to collect detailed information about each case so that this can be addressed urgently. A formal system of reviewing deaths in care should be introduced in order to reduce risk and improve the response to child mortality.

Recommendations about finance

- In 2010, the Government made a public commitment⁴² to ring-fence funds in the institution and reinvest savings from reform into the new care system. It is important that this pledge is executed so that services receive sufficient funding to meet the needs of children. As a priority, savings already made should be invested in increasing the number of high quality personnel for SGHs, and preventing mortality in baby institutions.
- Mechanisms for funding services should be developed based on the identified needs of individual children and provide tailored financial support, rather than using a general categorisation of 'need'. Bulgaria should consider models used by other countries to ensure that financing can be used flexibly and efficiently.

⁴² "It is necessary to develop a clear financial mechanism to ensure that the resources of currently existing specialized institutions will be transferred to the new services that will be developed under the Action Plan and will start operating as delegated by the state after completing the EU projects." National Action Plan for implementation of Vision for DI 2010 - 2015, page 33, <http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=601>

About Lumos

Lumos, an international non-profit organisation founded by J.K. Rowling, is dedicated to ending the institutionalisation of children – a practice that decades of research have shown is harmful to child development. We are working with many others and at all levels to ensure the right of every child to family life and transform the lives of eight million children currently living in institutions and orphanages. We help countries transform education, health and social care systems for children and their families, and help move children from institutions to family-based care.

By advocating at all levels, collaborating widely and running evidence-based demonstration projects that prove reform can work, we are able to achieve maximum impact from our funding to benefit some of the most vulnerable children in the world.

Lumos is founder member of the European Expert Group on the Transition from Institutional to Community Based Care (EEG) and has been instrumental in the development of guidelines and toolkit in 13 European languages in order to guide national governments through the process of deinstitutionalisation and transitioning to community-based care services. For more information see: <http://deinstitutionalisationguide.eu>.

We are also a founding member of the Global Partnership for Children with Disabilities in Development, and member of the Leaders Council for the US-based Global Alliance for Children.

For more information visit our website wearelumos.org
find us @Lumos on Twitter or email us on info@wearelumos.org

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