

Turning Words into Action

Children, parents, professionals and politicians as partners in building a more equal society



A guide to influencing national plans and policies through the active participation of children and young people with intellectual disabilities




LUMOS

Protecting Children. Providing Solutions.

About this publication

It is hoped that this document will be of use to parents, professionals and policy-makers; to all those who wish to improve the process of making and implementing policy for children and young people with intellectual disabilities. It is the authors' intention to provide an aid to the process of improving services and systems of support for children with intellectual disabilities and their families.

This document is a product of the Turning Words into Action project and is complemented by two other key publications:

- **Our Words. Our Actions.** This publication was written by the children and young people themselves. It presents their views on the BHBL Declaration and on the TWIA project itself.
- **Listening Together.** The document presents examples of child participation in action. It presents activities used by the three children and youth participation (CYP) co-ordinators that were successful in assisting the groups of children and young people to develop skills and to express themselves.

All three publications and other resources can be found at: www.wearelumos.org/stories/turning-words-action

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The “Turning Words into Action” project brought together self-advocates, family members, health and education professionals and legislators from Serbia, Bulgaria and the Czech Republic to find ways to implement the 2010 WHO Europe Bucharest Declaration *Better Health, Better Lives: children and young people with intellectual disabilities and their families*.

The project was funded by the European Commission and managed by Lumos with a steering group which included some of the experts originally involved in developing the Declaration. The project became a voyage of discovery. Innovative leaders in each country explored ways of making a reality of its bold objectives in different local and national situations. They sought to put children and young people with intellectual disabilities at the heart of shaping the policies and practices which have an impact on their lives.

The most exciting outcomes from the project were the ways in which Mihaela, a co-author of this foreword, and other self-advocates from the three participating countries grew in confidence and learnt to support each other, despite language barriers. Mihaela says, *“I have become braver, more confident; during the project meetings, I felt that people listened to what I told them. This has helped me to be a more thinking, independent and analyzing person.”*

Through the child participation activities of the project, inclusive steering group meetings and international meetings, the self-advocates made new friends and met politicians and other influential people. They realised that they could make demands about the implementation of the priorities identified in the Better Health Better Lives Declaration.

At the final project meeting, the self-advocates delegated everybody involved to think about them and their futures - as Mihaela said, *“to prevent us from becoming people without direction and future, because the project opened to me the door to society and gave me the first opportunity to realise my goals”*. We have learnt much more about what the empowerment of children and young people with intellectual disabilities really means and how we can work together in true partnership across many boundaries. This is the start of a journey in which we hope many others will join us.

Professor Sheila the Baroness Hollins *Steering Group Chair of the Better Health, Better Lives Declaration and Chair of the Turning Words into Action Project Steering Committee*

Mihaela Ivanova *Member of the Turning Words into Action Project Steering Committee and the Bulgarian National Working Group*

Introduction

Nearly twenty-five years ago, the Berlin Wall was breached. There followed a wave of revolutions and collapses of government across Central and Eastern Europe (CEE) and the former Soviet Union. The revolutions were mostly peaceful. The violence in Romania, although extreme, was mercifully short-lived. Across a region that had been dominated by dictatorship for decades many new ‘democracies’ were created, seemingly overnight. With remarkable speed, many of these countries fulfilled the criteria for admission to the European Union, healing the wounds of a continent divided since the end of the Second World War. The Union swelled to almost double its size, giving hope of future political stability and prosperity to millions of citizens who had lived their lives in fear for decades.

But democracy is not achieved overnight and the euphoria of 1989 was followed in many countries by cycles of economic collapse and political turmoil. Perhaps most disturbingly, the most hidden and disempowered victims of the dictatorships were revealed: the countless children living in horrific conditions in large residential institutions. Governments and societies, struggling to cope with the ‘transition’ to market economies and to democratic systems, initially had little time, energy and resources to deal with what seemed like a ‘minority’ issue.

In particular, inherited attitudes meant children with intellectual disabilities were not considered ‘useful’ to society. It was believed that these children would never work and therefore held no economic value. Thus institutionalisation was seen as a ‘humane’ way of ‘caring’ for these children. Doctors advised parents to give their children up to the State, convincing them that the ‘experts’ knew better how to care for their children. The institution provided food and shelter; the children were rarely provided access to formal education, as they were considered ‘uneducable’.

For many, the lack of stimulation, love and attention resulted in severe developmental delays, exacerbating their disability, which became compounded with challenging behaviours: self-harming, stereotypical behaviours or aggression towards others. Many were confined to their beds and rarely left the room, let alone the building. They rarely saw sunlight, or felt the wind on their faces. Most would remain in institutions for the rest of their lives.

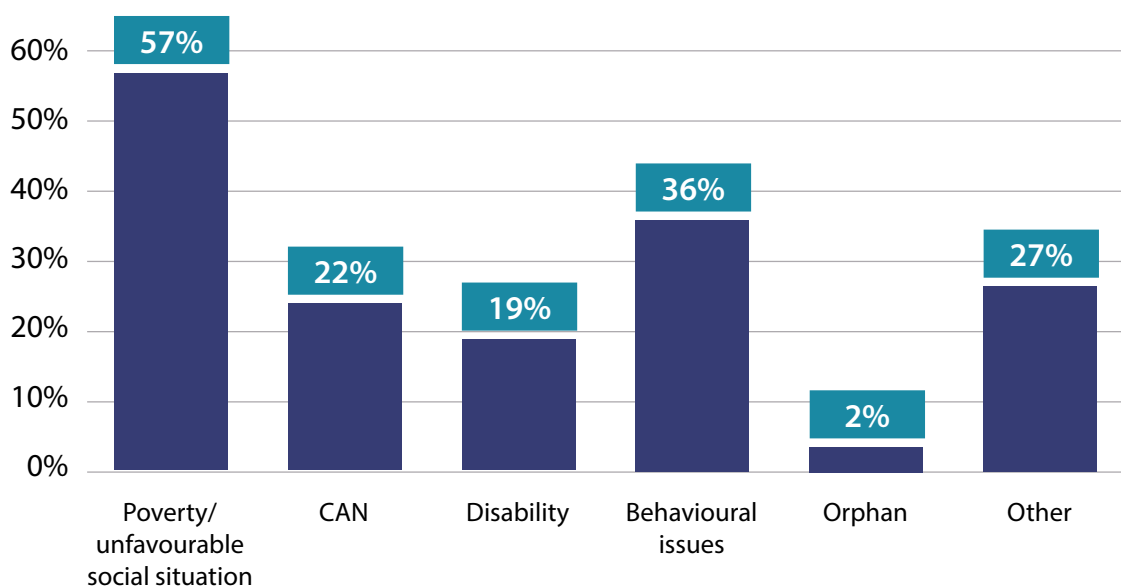
Their experience is the epitome of disempowerment and voicelessness. The idea of democracy for these children and their families was as remote as it could be.

What is ‘democracy’ and what does it mean to children with intellectual disabilities?

Fast-forward twenty-four years and there is no doubt that there have been significant changes. Across the region, many governments have taken seriously the process of reforming services and systems of care and support for children and families. Deinstitutionalisation programmes have been introduced in many countries. Romania, which arguably had one of the greatest problems of institutionalisation, is among the countries that have registered the greatest progress. In the early 1990s, an estimated 200,000 children were living in institutions in Romania. In 2013, that number was less than 10,000.

And yet, in the drive towards change, in many countries, children with disabilities are left behind. Lumos’ own research in four countries in Central and Eastern Europe has found that children with disabilities are significantly over-represented in institutions. Data collected for nearly 5,000 children in institutions found that for 19% of children resident, the primary reason for admission to an institution was disability. In 57% of cases, the primary reason was poverty (Table 1)¹.

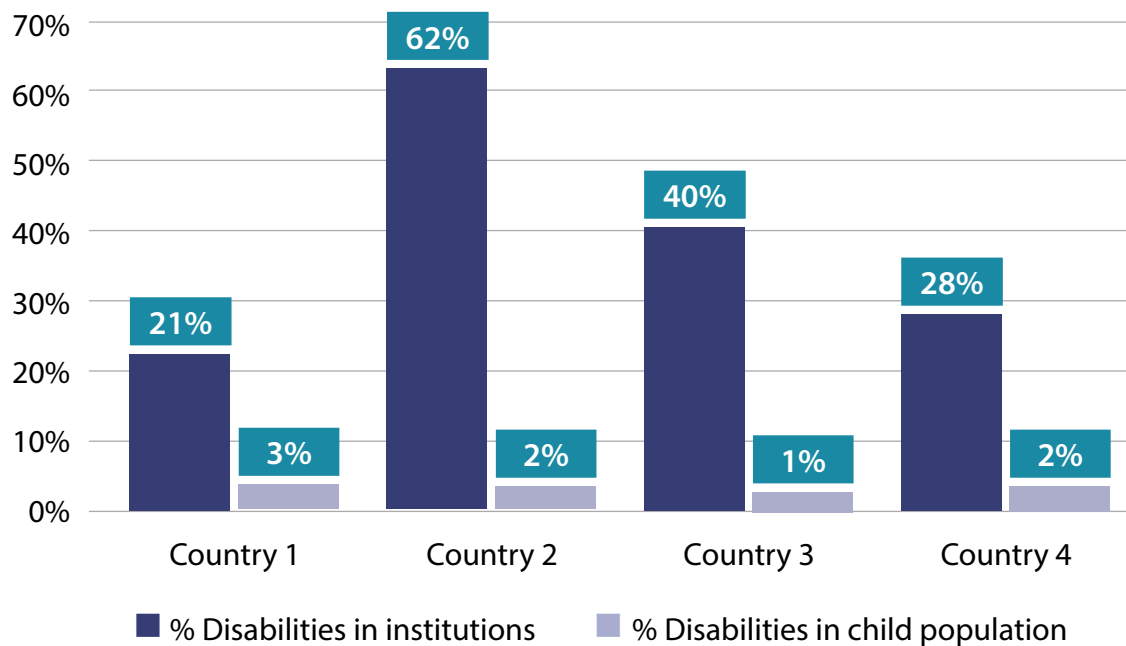
Table 1 Reasons for admissions to institutions in four countries



And compared to the percentage of children with disabilities in the general population, children with disabilities were dramatically over-represented in institutions (Table 2, next page).

1. CAN = Child Abuse and Neglect

Table 2 Percentage of children with disabilities in institutions compared with percentage of children with disabilities in the general population



For a wide range of reasons, children with disabilities continue to be admitted to institutions. Parents cite a lack of available support services in the community as one of the main reasons, as well as poverty and their limited access to employment, due to the need to provide additional care for their children. More worryingly, Lumos’ research suggests that in some countries, parents are still regularly advised by professionals to place their disabled children in institutions.² Therefore, children with disabilities remain among the most disadvantaged in the Central and Eastern European region.

What does democracy mean and how can societies work to achieve genuine access to democracy for children with intellectual disabilities? The Oxford English Dictionary defines democracy as “a system of government by the whole population”.³ True democracy is not about political parties – they are simply one of the mechanisms by which the people can be represented. Rather, is it a system and set of processes by which the individual citizen and communities can engage with the process of making decisions that affect them. Local and national elections should be a part of the process, but not the whole. Across the Central and Eastern European region, this idea of democracy as participation of its citizens in decision-making is still in its infancy.

2. Lumos carried out family assessments of more than 1,300 children with disabilities in institutions.

3. Oxford English Dictionary definition

According to Shkolnikov and Nadgrodkiewicz:

“Democratic institutions cannot be just minimalist frameworks that engage the citizenry only during periodic elections but between them provide little opportunity for policy input. This has been the Achilles’ heel of the young CEE democracies, as polls show that parliaments and political parties are among the institutions with the lowest levels of social confidence.”⁴

If it is the case that the majority of the population does not feel included in policy making, it follows that institutionalised children and children with intellectual disabilities are even further away from this democratic process. Children do not have the right to vote; but children in institutions rarely have the right to choose the clothes they will wear, the food they will eat, or with whom they will share a bedroom.

Connecting policy makers with the most marginalised citizens

It could be argued that at a time when countries are dealing with the worst international financial crisis of a century, a project aimed at involving children with intellectual disabilities in policy-making is a luxury. In fact, the opposite is true. The engagement of all citizens in making decisions that affect them leads to greater democratic stability, which is a pre-requisite for long-term economic prosperity. Simultaneously, economic crisis must never be an excuse for postponing the fulfillment of rights for our societies’ most vulnerable citizens.

The *Turning Words Into Action* project attempts precisely to connect policy makers at the highest level with children with intellectual disabilities, particularly those living in institutions. It demonstrates how, in spite of the financial crisis, countries can take the first step towards involving the most disempowered and disenfranchised citizens in building policies for a fairer future. The project brings together a number of key strands:

- the power of international Conventions and agreements to engender change for the most vulnerable
- the obligation of national governments and local authorities to implement those Conventions
- the development of mechanisms to involve in a meaningful way children with intellectual disabilities, their families and carers in the development of policy
- the power of individuals and communities to drive local change and use this to influence national policy making.

4. Shkolnikov, A & Nadgrodkiewicz, A. THE FALL OF THE BERLIN WALL: TWENTY YEARS OF REFORM IN CENTRAL AND EASTERN EUROPE. *Caucasian Review of International Affairs*. Vol.4 (1) – Winter 2010.

Why are children with disabilities in institutions so vulnerable?

Institutions harm children's health, development and life chances

Over the past sixty years, research across Europe has demonstrated the harm caused by institutionalisation. In the 1950s and 1960s, in studies in the UK and then Czechoslovakia, it was noted that children in institutions struggled to form healthy emotional attachments to their carers. This was due to the number of carers working shifts in the institutions, and the regimented regime that could not respond to the individual needs and demands of children. The lack of emotional and physical contact, together with a lack of regular stimulation and interaction, resulted in specific developmental delays and challenging behaviours common to both the British and Czechoslovakian children studied.⁵

More recent research has found significant impairment of brain development among infants raised in institutions,⁶ with the first six months of life being the most crucial. Most babies removed from institutions and placed in families before the age of six months recovered completely from this impairment. Those who remained longer than six months recovered only partially and demonstrated continued developmental and emotional difficulties throughout their childhood and adolescence.⁷

There is considerable evidence that children living in institutions are at a significantly higher risk of being abused or neglected than their peers raised in families. One Romanian study found a high prevalence of physical and sexual abuse of children in institutions.⁸ Studies in the UK found that children in residential care are at very high risk of sexual exploitation⁹ and disabled children are more likely to live away from home in residential care or in state-funded residential education.¹⁰ A report for the Council of Europe found that: "Abuse in institutional settings is regarded by many to be endemic and can take place against a pervasive culture of depersonalisation, lack of privacy, inactivity, inadequate food and heating, poorly trained and supervised staff and isolation from community activities."¹¹

Experience of early institutionalisation continues to have a negative impact as children grow into adults. One Russian study found severely reduced life chances for adults who had spent their childhoods in institutions: 20% had a criminal record, 14% ended up in prostitution and 10% committed suicide.¹²

5. Bowlby J (1951). *Maternal care and mental health*. Geneva, World Health Organisation.; Matějček Z, Langmeier J (1964). *Psychická deprivace v dětství* [Mental deprivation in childhood]. Prague, Avicenum.
6. Nelson, C. and Koga, S. (2004) Effects of institutionalisation on brain and behavioural development in young children: Findings from the Bucharest early intervention project, paper presented at the International Conference on 'Mapping the number and characteristics of children under three in institutions across Europe at risk of harm', 19 March 2004, EU Daphne Programme 2002/3 and WHO Regional Office for Europe, Copenhagen, Denmark.
7. Rutter M et al. (1998). Developmental catch-up, and deficit, following adoption after severe global early privation. *Journal of Child Psychology & Psychiatry*, 39(4):465–476.
8. UNICEF, Survey on child abuse in residential care institutions in Romania, 2000. For a similar study in Serbia, see Mental Disability Rights International, *Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with disabilities*, 2007.
9. CEOP Thematic Assessment, *Out of Mind, Out of Sight – Breaking down the barriers to understanding child sexual exploitation*, 2011.
10. Stuart M., and Baines C., "Progress on safeguards for children living away from home – A review of actions since the People Like Us report", JRF, 2004.
11. Brown, H., *Safeguarding adults and children with disabilities against abuse*, Council of Europe Publishing, 2003, p. 31.
12. Pashkina (2001). *Sotsial'noe obespechenie*, 11:42–45. Cited in Holm-Hansen J, Kristofersen LB, Myrvold TM eds. *Orphans in Russia*. Oslo, Norwegian Institute for Urban and Regional Research (NIBR-rapport 2003:1).

In summary, the harmful effects of institutionalisation include:

- impaired early brain development, leading to delayed cognitive and physical development and, in some cases, resulting in the onset of an intellectual disability; attachment disorders, which may result in the development of autistic behaviours, self-stimulation, self-harming, aggression to others or cruelty to animals;
- poor cognitive processing, resulting in educational under-achievement; poor physical health, including chronic infections; non-organic failure to thrive;
- unusually raised anxieties, specifically the fear of being abandoned and the fear of being alone, resulting in nightmares and sleeping disorders, eating disorders and enuresis;
- difficulty understanding right from wrong, difficulties in forming healthy emotional relationships as adults and significantly reduced life chances.

Challenges faced by children with intellectual disabilities in institutions

For children with a moderate to severe intellectual disability, the future is even bleaker. Research shows that children with disabilities are at a greater risk of all forms of abuse than their peers.¹³ Since the risk of abuse in institutions is even greater than in families, children with disabilities are exceptionally vulnerable. Such abuse is not always intentional but rather results from the way the system is organised.

In a number of countries, the nature of institutionalisation (where the needs of the organisation take precedence of the needs of the individual) results in regimented programmes that cannot meet all the needs of any of the children who live there. For children with disabilities, these regimes can be fatal. In 2010, in one country, a number of institutions were the subject of an investigation into high levels of mortality due to malnutrition, which was highlighted in a report of the UN Committee Against Torture.¹⁴ This mortality was rarely due to a lack of available food. Poor staffing meant that insufficient time was afforded to help children with eating and drinking difficulties at mealtimes.

The long-term prognosis for children with intellectual disabilities in institutions is a cause for great concern in the region. Analysis of admissions to and discharges from children's institutions in a number of countries demonstrates that the majority of these children, if they reach adulthood, are transferred to an institution for adults. The majority of children will therefore remain institutionalised – with all that implies – until their death.

13. Department for Children, Schools and Families (2009), Safeguarding disabled children: a resource for local safeguarding children's boards. Download from <http://bit.ly/sYmsm1>

14. United Nations (2011) 47th session, Concluding observations of the Committee against Torture, Bulgaria, http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.BGR.CO.4-5_en.doc

One study found that:

“The most common reason for children to leave an institution for children with disabilities was because of death. For children under three leaving institutions, 28% of those children with disabilities had died in comparison to 0.29% of children in social care institutions.”¹⁵

Put another way, if you are a disabled child in an institution for babies and young children, you are 100 times more likely to die there than if you do not have a disability.

Lumos’ research has similar findings. Of children discharged from one institution for children with disabilities:

- no children went home to their families or into alternative care
- 22% went to another residential institution
- 78% died.

For the children who remained in the institution, the stays were very long, 32% stayed 12-15 years, 15% 15-20 years and 8% more than 20 years.

Challenges faced by children with intellectual disabilities during the deinstitutionalisation process

Significant progress has been made in the deinstitutionalisation process across the European region. Replacing institutions with services that support children to live with their families and be included in their communities has become a significant political priority for many EU member-States, for the European Commission and the European Parliament.

However, during this process of reform, children with intellectual disabilities face significantly greater challenges than their peers. These challenges include:

- When replacing institutions with community based services, children with the most profound disabilities are often left behind in institutions, or their institutions are left until the end of the closure process
- As a result, children with disabilities are frequently moved from one institution to another, as institutions with reduced numbers are amalgamated to save money

15. Browne, K, et al (2002) ‘Mapping the number and characteristics of children under three in institutions across Europe at risk of harm’. Final Report of the Daphne Programme.

- All children who are moving from institutions require preparation to help them cope with the major changes taking place in their lives. They need to understand what is happening to them and need to develop new relationships with their families or foster families. For children with more severe disabilities, this process is much more complex. Children with communication difficulties require skilled professionals who can help them understand; these skills are often difficult to find in countries that have relied heavily for decades on institutional care.
- In addition, many of the children are in very poor health; they may need specific interventions to ensure they are in a stable condition of health before they can move
- The support services required in the community for children with intellectual disabilities are more complex, take longer to develop and cost more. This can make governments reluctant to prioritise the development of these services. In times of financial crisis, it is easier for governments to suggest postponing the development of these services
- Many children with intellectual disabilities will require support services during the transition to adulthood and indeed some require support for the rest of their lives. Countries that have begun the deinstitutionalisation process for children rarely reform adult services at the same time. There is a danger that children with disabilities will be removed from institutions, placed in much higher quality forms of care, only to be moved back into an adult institution once they turn 18, because community services for adults have not been developed.

Challenges for ensuring the participation of children and young people with intellectual disabilities

Child participation is often misunderstood. In some cases, well-meaning adults write speeches for children to read, or coach children to express someone else's ideas. This is not participation, but is in fact manipulation. In other circumstances, children are consulted about changes taking place, but without proper preparation, children with intellectual disabilities are unlikely to understand well enough to be able to give an informed opinion. In many CEE countries, there is a common practice of 'involving' children in adult events by having them perform a song or dance, or read a poem. This is tokenistic.

True participation has to avoid these pitfalls and ensure that the child is expressing their own opinion, that their participation is an empowering and positive experience and that their opinions are taken into account, not ignored.

The role of the European Union in supporting change for children with intellectual disabilities

Across Europe, attitudes are changing towards both children in institutions and disability. The European Union (EU) has ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). As the first international body to ratify such a convention, this sends a strong message about the importance attached by the EU to disability rights. Similarly, countries across the continent are increasingly ratifying the CRPD Optional Protocol and putting deinstitutionalisation on their agendas.

The Report of the Ad Hoc Group of Experts on the Transition from Institutional to Community-based Care (known as the Špidla report) was welcomed by the European Commission as providing an excellent summary of the problem of institutionalisation in the European Union, as well as demonstrable solutions to the problem and a set of recommendations for EU member-States.

In his foreword to the report, then Commissioner for Employment and Social Affairs, Vladimír Špidla, wrote:

“For decades, the existence of such institutional care was seen as proof that society cares, that it does not leave vulnerable persons without assistance and that it provides the needy with food, shelter, clothing and treatment. But is this indeed the best possible model which advanced European societies can offer to these people in the 21st century? I am convinced that in an age when non-material aspects such as human dignity, autonomy and inclusion in the community are increasingly recognised as being of paramount importance, European societies should aim for more humane, person-centred, individualised models of care. The users themselves and, where applicable, also their families should become partners and take part in all decision-making. Everyone should be enabled to reach their full potential.”¹⁶

16. European Expert Group (2009). Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-Based Care. <http://tinyurl.com/phdcgey>

The European Union's Disability Strategy from 2010-2020 aims to break down the barriers which prevent Europeans with disabilities from participating fully in society. It has identified changing attitudes about disability and raising awareness of the human rights of people with disabilities as a key priority.

There is also increasing recognition from EU policy-makers of the link between child poverty, disadvantage and other key EU policy objectives related to economic development and societal cohesion under its Europe 2020 growth strategy. Recent initiatives such as the Social Investment Package and the *Investing in Children: Breaking the Cycle of Disadvantage Recommendation* stress the importance of addressing child poverty and disadvantage to achieving Europe's 2020 'smart, green and inclusive growth strategy' and recommend that EU funds are used to finance deinstitutionalisation programmes.

The European Commission fully endorsed the World Health Organization's Better Health Better Lives (BHBL) Declaration and its priorities. It provides a basis for member countries to approach the health of children and young people with intellectual disabilities. In calling for proposals, the Commission singled out deinstitutionalisation and the rights of children and young people with intellectual disabilities as areas of concern. As the next section shows, *Turning Words into Action* was funded as a pilot project to explore what would need to happen to make some of the agreed priorities within the Better Health Better Lives Declaration into a reality for children and young people in three countries.

The European Commission on the need for action

"People with disabilities are one of the largest groups of disadvantaged individuals in the EU. One in six people in the European Union has a disability that ranges from mild to severe. This makes a total of around 80 million, and this number is set to rise as the EU population is ageing.

"Most of those people are prevented all too often from participating fully in society and the economy because of all the physical barriers that we have created, and the attitudinal barriers that we, as a society, have accepted. The ten-year strategy that we have just launched sets clear objectives to remove those barriers, in many areas of everyday life. We have identified in our strategy eight main priority areas: Accessibility, Participation, Equality, Education, Employment, Health, Social Protection, and External Action. Also, we have set up a plan of concrete actions to reach those objectives.

"For the action areas that are most relevant for the life of children and young people with intellectual disabilities, such as education and training, healthcare, and participation in society, the main responsibility is with the individual Member States of the European Union; however, we are convinced that EU action is needed to support those national efforts."

Silvio Grieco, European Commission Directorate-General for Employment, Social Affairs & Equal Opportunities, launch of the WHO BHBL Declaration, Bucharest 27 November 2010

The BHBL Declaration

Recognising the serious disadvantage suffered by children with intellectual disabilities, in 2009, the World Health Organization (WHO) Europe initiated a process of drafting and consultation that led to the Declaration “Better Health, Better Lives”.¹⁷ The Declaration was drafted with the broadest possible participation: academics and experts joined forces with people with disabilities, parents and policy-makers across the European region, to develop a document that would help advance the rights of children with intellectual disabilities and their families.

The Declaration lists ten key priorities that countries should address:

- 1. Protect children and young people with intellectual disabilities from harm and abuse**
- 2. Enable children and young people to grow up in a family environment**
- 3. Transfer care from institutions to the community**
- 4. Identify the needs of each child and young person**
- 5. Ensure that good quality medical and physical health care is coordinated and sustained**
- 6. Safeguard the health and well-being of family carers**
- 7. Empower children and young people with intellectual disabilities to contribute to decision-making about their lives**
- 8. Build workforce capacity and commitment**
- 9. Collect essential information about needs and services and assure service quality**
- 10. Invest to provide equal opportunities and achieve the best outcomes.**

Why BHBL matters

The WHO Declaration Better Health Better Lives is the first international agreement to implement parts of the CRPD for a specific group of disabled people. Moreover, it bridges the gap between the CRC and CRPD. Children with disabilities are not represented as robustly as they might be in the CRC, while the CRPD refers predominantly to the rights of adults with disabilities. The ten priorities in the BHBL Declaration make explicit the rights for children with intellectual disabilities that are perhaps not so clearly defined as they might be in both Conventions.

17. WHO, Europe (2010) Better Health Better Lives, <http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/activities/intellectual-disabilities>

BHBL is a practical Declaration. Ten clear priorities, of equal importance, are accompanied by a series of support documents written by academics and practitioners. Each of the priorities has an Expert Paper, including the research evidence behind the priority as well as examples of good practice, case studies and references to further resources. The Declaration is also accompanied by an Action Plan, which explains how governments might ensure each priority is implemented.

BHBL has been signed by 53 governments and was endorsed at the WHO's Regional Committee meeting, giving it the power of a Resolution; instead of a declaration of intent or aspiration, the Resolution is now a binding obligation.

As we shall see later in this document, BHBL can be used as a practical tool for improving policy. It was the aim of Lumos and all partners in this project to ensure that BHBL would do just that, hence the title: *Turning Words Into Action*.

Why were the specific countries chosen?

The TWIA project aimed to demonstrate the power of BHBL and therefore chose to do so in three countries to start with: Bulgaria, the Czech Republic and Serbia. The reasons for selecting these countries were as follows:

- All three face serious challenges regarding numbers of children in institutions. In all three countries, institutions house both children and adults with disabilities together.
- However, all three have also made significant commitments to transform their systems of services for children, including those with disabilities.
- The countries represent significant differences in terms of culture and economic development. The Czech Republic is considerably more economically developed than Bulgaria. This demonstrates two important issues. Firstly, economic development does not automatically result in access to rights and democracy for all citizens. Secondly, even in very poor countries, and during financial crisis, positive changes can be made - ie poverty is not the only reason for continued institutionalisation.
- Serbia was also included because it is a pre-accession country. Through this project, countries that were admitted relatively recently to the EU can share their experience with pre-accession countries and support them in their journey towards EU membership.
- Prior to the project, none of the three countries had a structure in place for the meaningful inclusion of the voices of children with intellectual disabilities in the process of making policy.

Purpose of this document

This document does not provide a chronological history of the TWIA project. Instead it attempts to provide the reader with:

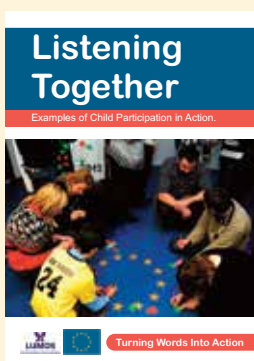
- documentation of the processes followed during the project
- a presentation of the challenges faced by participants
- a summary and celebration of key achievement and outcomes
- an outline of the key lessons learned, in terms of using the BHBL Declaration as a tool for change.

It is hoped this document will be of use to parents, professionals and policy-makers; to all those who wish to improve the process of making and implementing policy for children and young people with intellectual disabilities. It is the authors' intention to provide an aid to the process of improving services and systems of support for children with intellectual disabilities and their families.



This document is complemented by two other key publications:

- **Our Words. Our Actions.** This publication was written by the children and young people themselves. It presents their views on the BHBL Declaration and on the TWIA project itself.
- **Listening Together.** The document presents examples of child and youth participation in action. It presents activities used by the three children and youth participation (CYP) co-ordinators that were successful in assisting the groups of children and young people to develop skills and to express themselves.



From international policy to local action: an example of empowerment in practice

This document will demonstrate that the Turning Words Into Action (TWIA) project registered significant success in a challenging field. In order to understand how that success was achieved, this chapter outlines the key activities implemented and summarises the most important lessons learned. Further detail of all activities and achievements is provided in the subsequent chapters.

2.1 Objectives of TWIA

The TWIA project had four key objectives, summarised as follows:

To provide opportunities for the **genuine inclusion of the voices of children and young people with intellectual disabilities**, their families and carers. To provide a model of good practice in inclusive participation.

This primary objective was to ensure that politicians, practitioners, parents and carers were all involved in developing the environment that would make it possible for true and meaningful participation of children and young people with intellectual disabilities.

Using the BHBL Declaration as a framework to **assist countries to develop national action plans for deinstitutionalisation**, specifically including in the process the opinions of children with intellectual disability.

The deinstitutionalisation process is vast. Whilst this project envisaged the eventual development and implementation of national action plans, the primary aim was to assist countries to make a start.

To increase mutually beneficial partnerships, both in-country and internationally

Each country has its own strengths and challenges. By providing opportunities for the groups from each country to meet, it was possible to learn from each other's strengths and to realise that we all face a common challenge.

To strengthen the understanding and implementation of international law and human rights instruments in meeting the needs of children with intellectual disabilities and their families. In particular, the harm caused by institutionalisation and children's rights to live with their families.

Although prior to the project, all three countries had embarked upon deinstitutionalisation programmes, it was still the case that many national and local authorities saw residential care in small group homes as the primary alternative to institutions for children with disabilities. There was a reluctance to believe that families wanted their children and, with support, could look after them well.

2.2 Key components of successful implementation

The following is a summary of the key components of project implementation that contributed to TWIA's success.

2.2.1 Partners with a range of strengths

The project was implemented by four partner organisations, each of which brought different strengths and perspectives to the table:

- Lumos, the lead organisation, is a leading NGO in the field of deinstitutionalisation internationally. Lumos was involved with the development of the BHBL Declaration from the early stages, facilitating and coordinating the input of NGOs to the draft and supporting child and youth participation activities at the Bucharest conference, where the Declaration was adopted.
- Karin Dom, the Bulgarian partner organisation, is a service provider NGO for children with disabilities and their families. Karin Dom is an example of excellence for the CEE region; its cutting edge services have prevented many children with disabilities from being separated from their families and placed in institutions
- Pardubice County Authority, the Czech Republic. Pardubice County is one of the first counties in the Czech Republic to begin to implement the National Action Plan for The Transformation of Children's Services. As such it has been selected by the national government as a pilot county for reform. Therefore, the authority plays a key role not only in improving services for its own citizens, but also in sharing its learning with other regions of the country.
- The Centre for Child Rights, Serbia, is a leading national organisation on the implementation of children's rights. It has campaigned for changes in legislation and for the implementation of the deinstitutionalisation process.

2.2.2 Guidance and support structures

The project was complex and ambitious and required specific skills to ensure that all people involved would feel empowered and supported. To this end, five support structures were put in place from the outset:

- **Steering Committee.** The Steering Committee was chaired by Baroness Sheila Hollins, a member of the United Kingdom House of Lords. It included a number of professionals who were involved in drafting the BHBL Declaration. Adult self-advocates were also included, as well as children with intellectual disabilities and parents. The Steering Committee assisted with the design of the project and, where necessary, assisted the project team to refocus its activities.
- **Expert Mentors.** Each country was provided with a senior academic or practitioner who acted as an Expert Mentor. They provided guidance to the National Working Groups in-country, assisting them in developing their plans for policy change.
- **Project Implementation Team.** A team of professionals from Lumos ensured the day-to-day implementation of the project and responded to the needs in each country.
- **Child and Youth Participation coordinators.** Coordinators were appointed in each country. Each was an experienced practitioner who had worked for many years with children with disabilities. However, none had previously used the child participation approach piloted by the project.
- **External Evaluator.** The External Evaluator, Dr. Roger Banks, was involved with the project from the outset and gave advice on project design and implementation. An internationally renowned expert in the field, he assisted the project implementation team to reflect upon progress, learn lessons and modify the process as appropriate.

2.2.3 Developing expertise for child and youth participation

- **Learning from experts elsewhere.** The CYP coordinators were provided training by Triangle, a UK-based organisation with many years' experience in child participation activities with disabled children.
- **Modelling.** An adult self-advocate from the UK, who has intellectual disabilities, acted as a trainer and mentor for the children and young people, who saw him as a role model for what was possible in their lives. The trainer, from the organisation CHANGE,¹⁸ helped the young people develop their skills in speaking out for themselves and others in creative and imaginative ways.

18. <http://www.changepeople.org>

2.2.4 Ensuring the CYP groups were representative

In order to demonstrate that the child participation activities could be successful for all children, as well as ensuring full representation of children from different backgrounds, groups were selected taking into account the following criteria:

- A gender balance of boys and girls/young men and young women
- A range of ages – from 10 to 30.
- The inclusion of Roma children. In many CEE countries, Roma children are significantly over-represented in institutions. Roma children with disabilities are therefore subject to even greater discrimination than disabled children in the ethnic majority population.
- Children from institutions as well as those from families. This was essential for both groups of children and young people to understand the impact of institutionalisation, as well as to understand what living in families and the community would mean. This was a huge opportunity to learn from each other.
- Children with a range of intellectual disabilities. It would have been less challenging to include children with only mild intellectual disabilities, but that would have been contrary to the ethos of the project. The aim was to be as inclusive as possible.

2.2.5 Preparing the groups

For all children and young people involved, making their opinions heard depended upon their abilities first of all to form an opinion. None of the children were used to being asked their opinion on complex matters. And for those who had lived in institutions, their ability to form an opinion was further restricted by the fact that they were rarely allowed to make simple choices about their lives, such as what they would like to eat, what they wanted to wear, what games they would like to play. Preparation activities therefore involved at least the following:

Assisting children to learn to make choices.

This might be simple choices to start with, such as what snack they would like to eat, what game they would like to play. As confidence grew, children became more able to form and express an opinion on increasingly complex matters.

Empowering and building self esteem.

In order to be able to share your opinion, you must first believe your opinion has value. This depends on self-esteem, which was often extremely low among the participants when they first engaged with the projects.

Developing the ability to speak up for oneself.

As self-esteem built, children and young people were encouraged to speak up for themselves – what they wanted, liked and disliked, and what they would like to see change in the future.

Developing the ability to speak up for others.

Once the children and young people were confident in speaking up for themselves, they were encouraged to think about the needs of others who do not get the opportunity to speak and to think about how they might represent them.

Unlocking creativity and leadership skills.

Play, theatre and imagination were all used to encourage children and young people to have their own ideas: not only to form their own opinions, but also to choose the methods they wished to use to share them. During this process, many of the children and young people began to display leadership skills - encouraging, guiding and supporting their colleagues to ensure they were fully included.

Making communication aids available.

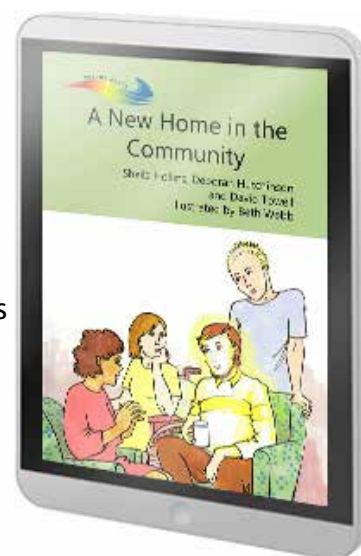
The BHBL Declaration was made into an *Easy Read* book and poster.¹⁹ *Easy Read* is a technique using pictures and simple jargon-free language to explain often complex issues. This was helpful for children and young people who had a basic level of literacy. For children and young people with more profound intellectual disabilities, *Books Beyond Words* were used.²⁰ *Books Beyond Words* use pictures alone to tell stories that engage and empower people and professionals use them to aid communication.

Having fun.

This was a pre-requisite for developing self-esteem and finding creative ways to communicate their opinions.

Books Beyond Words

Books Beyond Words can be a great tool to help people with intellectual disabilities and communication difficulties to explore and understand new concepts and challenges in life. These books tell stories in pictures and make learning and communication easier, more enjoyable and effective.



Find out more by visiting:

www.booksbeyondwords.co.uk

19. Lumos, (2011), <http://wearelumos.org/stories/better-health-better-lives>

20. Books Beyond Words: Books Beyond Words tell stories in pictures to help people with learning and communication difficulties explore and understand their own experiences. <http://www.booksbeyondwords.co.uk>

2.2.6 National working groups

National working groups (NWGs) were formed in each country. In both Bulgaria and Serbia, this included politicians at the highest level, as well as practitioners, parents, carers and children and young people from the child participation groups. In the Czech Republic, initially it was more challenging to involve senior politicians. However, towards the end of the project, they became more engaged. The groups worked together in the following way:

- They reflected on BHBL in relation to the national situation.
- They identified specific priorities for their countries
- They developed initial plans to address these priorities.

The activities of the NWGs are covered in greater detail in chapters 6 and 7.

2.2.7 Raising awareness

The project included activities that were led by the child and youth participation groups, aimed at raising awareness and changing attitudes among the general public as well as politicians. This included:

- Local action – where children and young people with and without disabilities came together in creative activities to influence their communities
- National action – where children and young people with and without disabilities worked together to challenge their politicians
- International action – where the groups from Bulgaria, Serbia and the Czech Republic joined together to share their opinions with politicians, practitioners and parents from all three countries – and elsewhere.

These activities are outlined in detail in Chapter 7.

2.2.8 Transnational cooperation

All participants found the transnational meetings beneficial. The key benefits included:

- Sharing challenges
- Sharing successes
- Learning from each other
- Forming lasting relationships.

Detail of the transnational work is found in Chapter 8.

2.2.9 Evidencing the changes that took place

The project was complex and involved change on so many levels that measuring such change is challenging. Nevertheless, the following methods were found to measure and evidence the change that took place:

- KAP analysis. This analysis of Knowledge, Attitudes and Practices was carried out at the beginning of the project to provide baseline data. Follow up data was collected at the end of the project and compared with the baseline.
- Action plans. The focus and quality of the action plans produced demonstrate the impact of the project.
- Changes in practice. Significant positive changes were seen in the practice of carers working with children and young people with intellectual disabilities following the implementation of the project.

A summary of the key outcomes is found in Chapter 9.

2.3 Lessons learned

The following is a summary of the key lessons learned, according to the participants in the project:

2.3.1 BHBL is a practical tool. All participants found that the Declaration provided a focus for discussion about the needs and rights of children with intellectual disabilities.

2.3.2 Care, time and skill is needed to empower children with intellectual disabilities to participate in a meaningful way.

2.3.3 Politicians, parents, carers and practitioners were all surprised by the ability of the children and young people involved. On reflection, many admitted they had underestimated the children's abilities to understand, communicate and express an opinion.

2.3.4 With care, thought and a little extra resource, the most vulnerable citizens can be empowered to sit with politicians and influence policy for the better.

2.3.5 We can all learn from each other and we have much to learn from children themselves.

2.3.6 The children and young people involved all benefited from the experience. Significant improvements were registered in their abilities to communicate and express themselves and there was a considerable increase in self-esteem.

Perhaps the best summary of the lessons learned is provided by one of the Expert Mentors:

*“When I was invited to take the role of expert mentor for Bulgaria, I was intrigued yet hesitant since I did not have much experience with children with intellectual disabilities prior to this project. I was aware that my background in social policy, human rights and inclusive education had hardly prepared me for the challenges of my role and fortunately I had the support of experienced practitioners in the project team. I interpreted my role as facilitator of the national working group, trying to provide safe and friendly space for exploration, deliberation and informed action. **With hindsight I can say that for me this project was a unique journey of learning and discovery.***

First of all, I discovered the world of children with intellectual disabilities and their families, a world of despair and hope, of parental sacrifice and commitment, of daily struggle for dignity and recognition in an insensitive and often unfriendly environment.

I also learnt how unprepared the public authorities in Bulgaria are to adequately address the needs of these children and young people. In the course of our work we discovered that the welfare and educational system in Bulgaria suffers from a specific blend of selective blindness towards the problems of these children, which was made possible by decades of centralised policy of institutionalisation and marginalisation. Keeping people with intellectual disabilities away from mainstream social life under the guise of “proper care” allowed the authorities and the society at large to remain conveniently and “innocently” ignorant of the dire circumstances – and sometimes of the very existence – of these people. The national working group had to face this unsettling reality and cope with the ensuing feelings of shame and guilt. Yet the group provided a way out – the best, and only possible, way to undo the wrongs of the past for each and every member was to find his or her very personal way to contribute to the project and consider a lasting commitment to its cause.

But most important, I discovered, along with the other participants in the project the amazing energy and creativity dormant in the children and young people with intellectual disabilities, which was released by the excellent opportunities for participation, provided by the project. The empowerment of the self-advocates to speak and act on their own behalf was an enormous challenge not only for the public authorities, but for the whole culture of dependency and exclusion, permeating Bulgarian society – a culture that nourishes biased attitudes and obsolete practices towards different people.

I believe that the lasting achievement of the project in the Bulgarian context is the fact that it dismantled the established culture of facade engagement and enabled an altogether different mode of relating to emerge between the participants in different roles – children and parents, politicians and public authorities, professionals and policy experts – benevolent relations based on genuine understanding and care. Thus the project triggered an inclusive, yet fragile process of empowerment, participation and reflection, which enabled the actors to identify and explore key issues concerning the circumstances for children with intellectual disabilities and come up with brave ideas and relevant methods for policy action. It is to be seen how this transformative process will continue after the end of the project, whether it will prove sustainable and self-reinforcing and to what an extent it will affect the broader system of service delivery and the awareness in the community.”

Dr. Haralan Alexandrov, Expert Mentor, Bulgaria

Empowering children and young people

3.1 Activities and achievements

After forming, training and supporting the development of the child and youth participation groups, they became involved in a whole series of activities. Examples include the following:

3.1.1 Local child participation groups.

The children and young people learned about themselves and others. They shared their likes and dislikes, as well as their dreams and wishes for the future, for example:

I like drawing

I like having snacks and talks

I would like to have a friend

I like talking to people and I do not like it when they avoid me

I like games

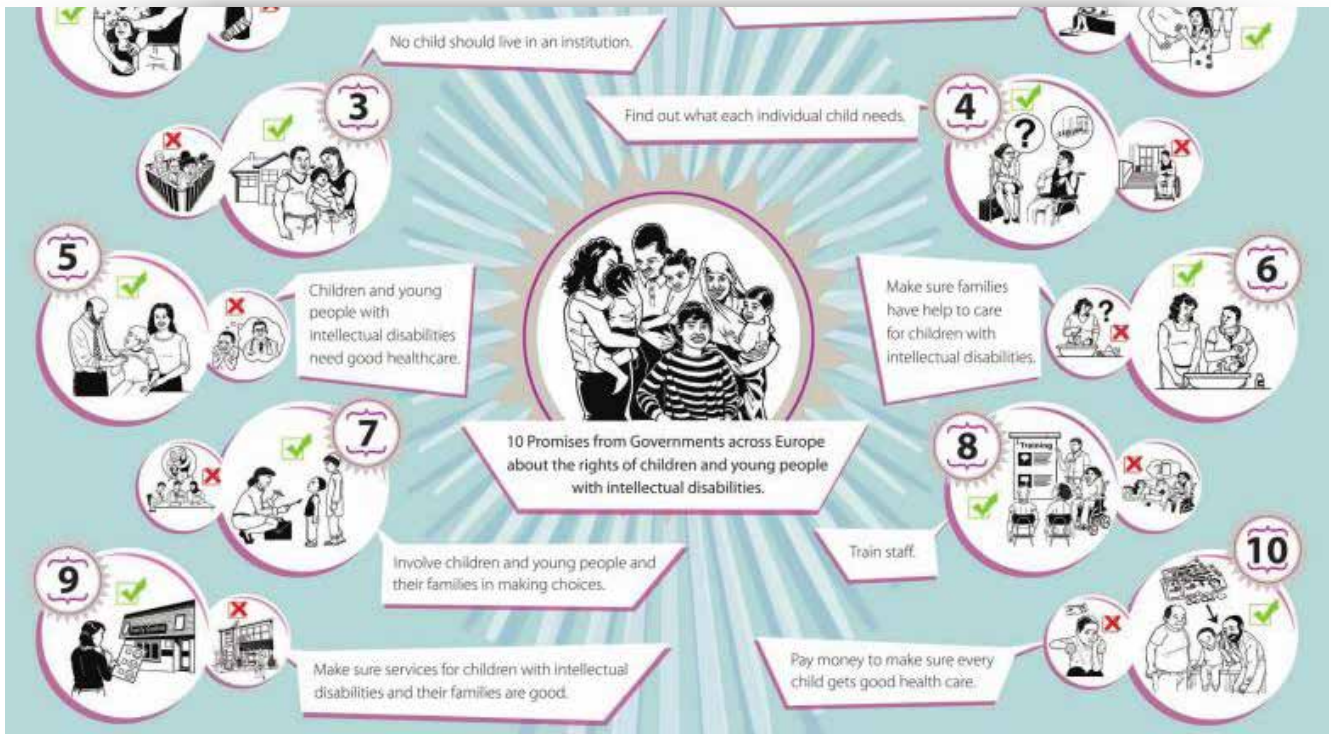
It was hard for me to be a part of the school process; I couldn't concentrate. I was lucky enough to have a good teacher

I like making necklaces

If I had a chance to change something, I would change people's attitude to me. I wish they could see me as an equal person

My dream is to work at a library but that can't happen because I don't have an education

I would like to fly a plane



Easy Read Declaration poster, courtesy of CHANGE

3.1.2 Focus on the BHBL Declaration.

In order to support the children and young people to think about what the BHBL Declaration means in their lives, an Easy Read version of the Declaration and a poster were produced. The production of Easy Read materials was illuminating in itself for the project team, as finding ways to communicate the meaning of more complex concepts required their clarification. For example, what does *Declaration* mean? Or *Community*? How do you describe a *Politician*? Or a *Government*? What is the *European Union*? The most telling point was the definition of a Declaration. This translates into Easy Read as ‘a list of promises’. As a result, the children and young people involved are clear that the politicians have promised to implement the priorities – and they made that message clear to the politicians involved.

3.1.3 Learning about leaving institutions.

In the Czech Republic, the group included young adults living in an institution who were preparing to leave. The group worked with a ‘Book Beyond Words’ about a young person moving out of an institution. It helped the young people to understand that when they left the institution they might be living on their own. They were then able to express their preferences – to live alone or with friends.²¹

21. For more detail on the use of the Books Beyond Words in the project, see the publication *Listening Together*, at <http://wearelumos.org/stories/turning-words-action>

3.1.4 Writing the book and making films.

All children and young people contributed to the development of a publication in easy read format, *"Our Words. Our Actions"*. It was produced to share the children and young people's views of the BHBL Declaration, their experience of the project and their messages and key recommendations to policy-makers. It has been translated into various languages and is intended to inform future national policy processes in the project countries and elsewhere in the Region. Notably, related to this specific project objective, the children made strong statements stressing the importance of deinstitutionalisation, for example:

Promise 1: Keep all children safe



“Children should be protected at all costs!”

“Children should be able to play, go for walks and feel safe everywhere!”

“Ensure that all parents treat their children well.”

Promise 2: Support children to grow up with families



“I think helping families should be a priority - when a child is born with a problem, parents have to be helped by specialists.”

“Everybody should have a family and live with their family.”

“When you're with your family you feel safe and there are people you can rely on.”

Promise 3: No child should live in an institution



“Every child needs a kiss goodnight.”

“We want to be supported to live independently in our communities - not segregated in large residential institutions.”

“Close all institutions, the children's place is in the family!”²²

22. The English language version of *Our words. Our Actions* Can be found at: <http://wearelumos.org/stories/turning-words-action>

3.1.5 Three 'child choice' events

The Child Participation activities in all three countries culminated in three unique Child Choice Events. In line with the project description, children and young people were provided with support and resources to design, plan and carry out a fun event of their choosing. In each case this was highly visible to the general public and sought to demonstrate their inclusion in the community and to highlight the BHBL Declaration's priorities. In all three countries, a key focus of the child choice event was to reach out to the wider community, demystify disability and build bridges.

In Bulgaria, the Child Choice Event that the children organised was a three-day trip from Varna around the country and on to Sofia, which the children called their "Tour of Dreams." At stops along the way they met and debated with groups of young people - members of youth councils and voluntary organisations, civil society groups and political representatives - advocating for recognition of their rights and for the changes they thought were needed to make the BHBL Declaration a reality in Bulgarian law and practice. The children prepared their own materials for their tour, including posters and a carpet into which they wove their interpretations of the Declaration's priorities.

In the Czech Republic, the work of the Child Participation Group culminated in a Child Choice event which the group decided on, designed and organised themselves. The young people did not feel ready to lobby policy makers and decided instead to hold a concert to which they could invite their friends and the community. The coordinator and school staff assisted in planning activities and producing a poster about the BHBL and similar materials about their rights and wishes, the children and young people being responsible for the activities themselves. The highlight was a performance by their favourite music band, Bedňáci, which included young musicians with disabilities. This event attracted the interest of the local media and a film of it was shown to participants at the second transnational workshop.

In Serbia, the Child Participation Group decided to hold its Child Choice event at a major shopping centre in Belgrade just before New Year 2013. The children and young people designed and painted two large cubes with pictures and mottos from their discussions on the BHBL Declaration, representing their understanding of the priorities. They installed the cubes at the heart of the shopping centre and handed out bags printed with their drawings, together with New Year greetings cards they had designed themselves and 'easy read' versions of the Declaration.

For both children and the professionals involved, this truly represented the culmination of their work in all the workshops over the course of the project. A busy shopping centre was chosen as the most visible way to reach out to the community and demystify disability.

The events resulted in improved relationships between people with and without disabilities in the community and all three received positive national media coverage. It is hoped that such changes in attitudes will contribute to increased visibility and improved social inclusion of children with intellectual disabilities.

KAP Survey Result:

There is some evidence of a shift in the perception of the public attitude towards disability during the project period. At the beginning of the project only 50% of Czech National Working Group respondents agreed that people in their society were “welcoming to individuals with intellectual disabilities”. This figure had increased to 64% at the end of the project. However, such a change was not noted in the other project countries.

KAP Survey Result:

In the Czech Republic, 50% of the children and young people with intellectual disabilities questioned at the beginning of the project agreed that “people often ignore or avoid me”, this figure had dropped to 20% by the end of the project. In Serbia meanwhile, the figure dropped from 100% to 57%. This indicates a major shift in the children’s perceptions of the attitudes of the wider community which could be a reflection of their positive experiences of engaging with the community through the child choice events and other activities. However, it is worth noting that similar results were not recorded in Bulgaria.

3.2 Lessons learned

When the children and young people were asked the question, ‘Why is Child Participation Important?’ they responded:



Enabling parents and enlightening professionals

4.1 Activities and achievements

The Knowledge, Attitude and Practice (KAP) survey at the beginning of the project demonstrated that the attitudes of some parents and carers towards children and young people with intellectual disabilities were not as positive as they might have been. As a response, the three Local Coordinators between them organised 15 meetings and training sessions for family members, personnel working in residential institutions, members of the National Working Groups and NGOs, to raise their awareness on the rights of children with intellectual disabilities and the basic principles of Child Participation.

At these meetings parents and carers discussed children's abilities and their capacity to contribute to decisions about their own lives, as well as the need to overcome the many negative stereotypes of disability with which they are often confronted. The following are some examples of the comments made by parents and professionals.

"These child participation activities are changing our mind-set, too. At first I was shocked when I was asked what my son can do. It had never occurred to me that I did not think about what he could do; I only thought about the things he could not do."

A mother speaking about child participation activities in Varna, Bulgaria.

"For many years we have been learning all these different methods and ways of working with children, now I understand that we were missing the main piece: the children's opinions and participation."

Director of a special school in Pardubice, Czech Republic.

"It was a very new experience for us to give a space to young people with intellectual disabilities to speak. I was impressed by the strength of their voice".

National Working Group Member.

"My daughter has had positive expectations from each group activity, waiting for another meeting and asking me when the next one will be. For many years, my husband and I have been facing huge barriers in supporting our daughter's communication with others. Thanks to this project, our daughter's communication has got a lot better".

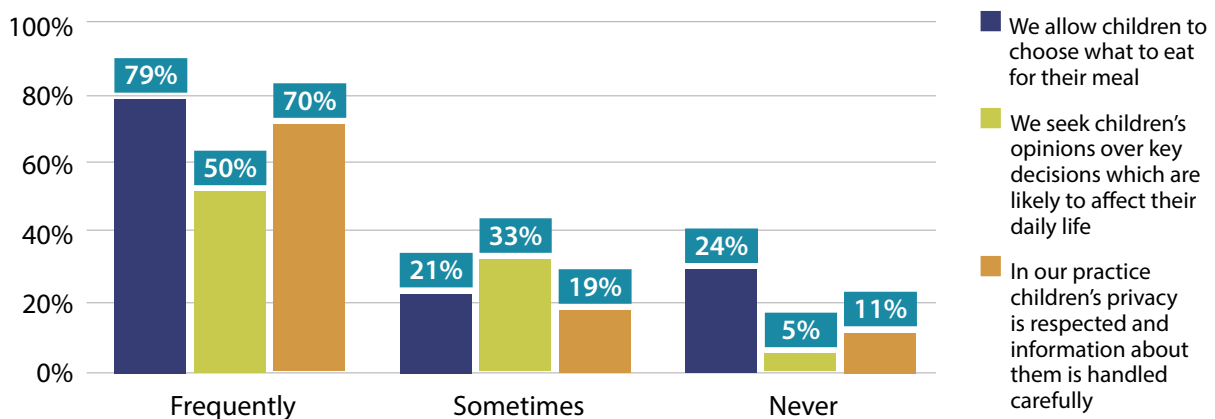
Parent of a child who participated, Bulgaria.

KAP Survey Result:

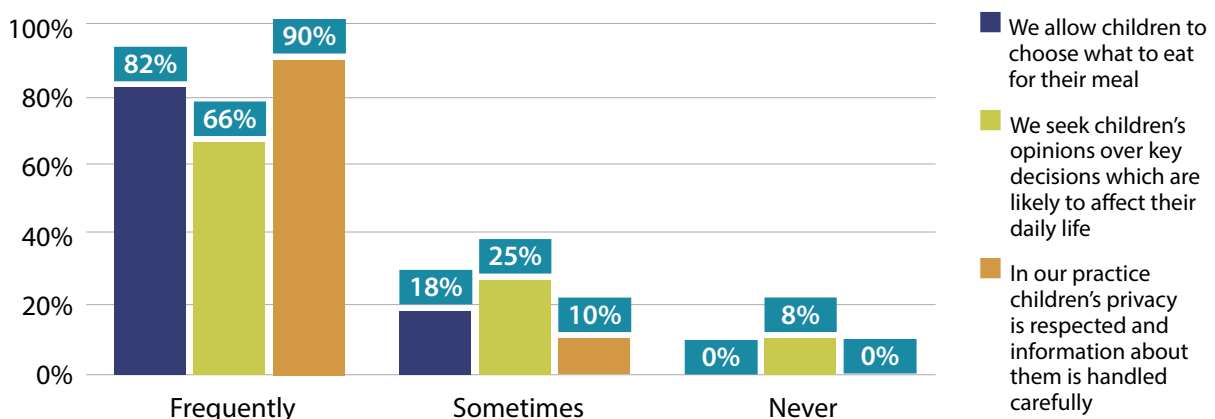
A change in practice of professionals, service providers and carers in Bulgaria was noted during the project. For example, at the beginning of the project, 70% said that in their practice, “children’s privacy was respected”. This had risen to 90% by the end of the project. Similarly, at the beginning of the project 24% said that they never “allow children to choose what to eat for their meal”, a figure which had dropped to 0% by the end of the project. It can therefore be said that the involvement of service providers and carers in both the child participation groups and the National Working Group in Bulgaria had a direct impact on the way they and their colleagues worked with children.

KAP Question on Practice: for practitioners, service providers and carers

Bulgaria (1st survey round)



Bulgaria, (2nd Survey Round)



4.2 Lessons learned

The approach taken to the project in each country was different, since it represented a response to the particular national situation. Whilst in Bulgaria and Serbia it was possible to develop a fully-fledged National Working Group that worked together on national plans for change, the situation in the Czech Republic was different. Initially it was difficult to get the engagement of national politicians, although by the end of the project many had come on board.

As the Expert Mentor for the Czech Republic explains, the change of emphasis had some surprisingly positive outcomes:

“The main focus of the Czech version of TWIA began from the experiences of disabled children and young people both inside and outside (i.e. living with their families) [an] institution. This focus became the main stimulus for engaging family members, staff in social care, education and health, and in due course, the County authorities, in exploring how local policies and practices could become more ‘child-centred’, especially in strengthening the voice of the children in shaping their own lives. In my judgment, this year of creative and sensitive work has achieved encouraging progress, not only in building the self-confidence and ‘community connections’ of the young people but also in raising expectations among both family members and direct care staff – although it is only as this project comes to an end that we are beginning to see real interest at County level in both sustaining this work and spreading it more widely. Innovation can be a fragile flower!

One story from this work illuminates the subtle and sometimes unexpected ways in which genuine ‘child participation’ can promote wider change. The first transnational workshop in Sofia included several children and young people who demonstrated spontaneous enthusiasm and self-confidence in presenting their demands for better lives. These young people had been born after 1989. Many of the adult leaders, by contrast, had grown up under conditions of totalitarianism and the young people’s behaviour was a revelation of the extent to which as adults they still felt constrained by conformity and lack of self-confidence in relating to ‘authority’. For the Czech participants, this experience was a powerful reminder of their former President Vaclav Havel’s argument for the importance of ‘Living In Truth’.

Meanwhile, lacking an official mandate, but with excellent support from another Lumos staff member skilled in policy analysis, the volunteers who came together under the title of ‘National Working Group’ redefined their task as being to create an agenda for policy change. Some undertook to continue as an advocacy network, which would ‘self-organise’ around opportunities to advance this agenda as these arise.

Compared with the project aspiration for ‘national action plans’ this outcome may seem disappointing but there is an alternative hypothesis. Of course, large-scale change in children’s lives requires national action expressed in legislation, better policies and the allocation of resources to

implement these. But the transformation towards equal citizenship for disabled children and young people – more simply ‘ordinary lives’ like their non-disabled peers – cannot be delivered only or mainly from the top down in Czech society. ‘Policy push’ must be complemented, and indeed driven by ‘community pull’.

This initiative was a modest start in strengthening the voice of children and young people, both individually and collectively; likewise their families. It was also about raising public awareness of their rights and potential contributions. These are essential building blocks of ‘community pull’.

The third element in a strategy for transformation is development of the professional attitudes and skills to deliver child-centred practice based on this vision of equal citizenship. Our hypothesis is that real change in Czech society requires the judicious connection of ‘community pull’, enhanced professional leadership and ‘policy push’.

This was of course a modest initiative. I would argue that its success to date (at least in the Czech Republic) lies not in producing ‘national plans’ or paper ‘commitments’ but rather in the more intangible but nevertheless important ‘products’ of raised awareness, new leadership – including among young people – enhanced connections and better engagement with public authorities to advance the transformation agenda.”

Dr David Towell, Expert Mentor, Czech Republic.

Engaging politicians

5.1 Activities and achievements

In each country, the National Working Group analysed the BHBL Declaration to identify where national implementation was lacking. An analysis of the political environment and opportunities for influence in each country enabled the National Working Groups to effectively target their proposed action.

This call for action took the form of:

- a new National Action Plan in Serbia focusing on the Declaration as a whole
- suggested improvements to existing plans and policies in Bulgaria, notably related to education policy
- specific improvements to local policies and practices in institutions and a list of recommendations for national action in the Czech Republic.

Children's and young people's views on the Declaration and how its priorities are implemented in their lives have been reflected in these documents.

Each country's experience and key outcomes are detailed in turn.

5.1.1 Serbia: Key Recommendations for National Action from the Serbian National Working Group

- Full implementation of the National Action Plan developed by the National Working Group
- To incorporate text from the National Action Plan across a range of legislation and instruments
- Properly accessible community-based services for all
- To extend the application of child participation for all children with intellectual disabilities, both in policymaking and other areas of their lives

A formal National Working Group was set up under the auspices of the Ministry of Health and was responsible for the development of an official National Action Plan. The group included members of the relevant ministries (Health, Social Policy, Education, and Local Government), the Centre for Child Rights, a number of other non-governmental organisations, institutions working with children with intellectual disabilities, family organisations and young self-advocates. The Group met four times.

The group determined priorities and, given the limited time available, decided to focus on reforms within the healthcare system and on the coordination of services.

The draft National Action Plan produced by the group is currently being revised by the Ministry of Health. This National Action Plan details how to address all ten priorities of the Declaration which the Ministry of Health will adopt and oversee its implementation after revision.

Some of its recommendations have already been taken forward. For example, the Ministry of Health has committed to building an education programme for medical practitioners on developmental issues relating to intellectual disability, such as early identification of disability and child/family friendly communication methods.

A reference to the new National Action Plan has been made in the new draft **National Strategy for Protection from Discrimination**.

All involved in the process have made clear their determination to ensure it does not stop now. The National Working Group will continue to meet formally after the end of the TWIA project to ensure the recommendations in the Action Plan are incorporated into policy and followed through in practice at an institutional and community level.

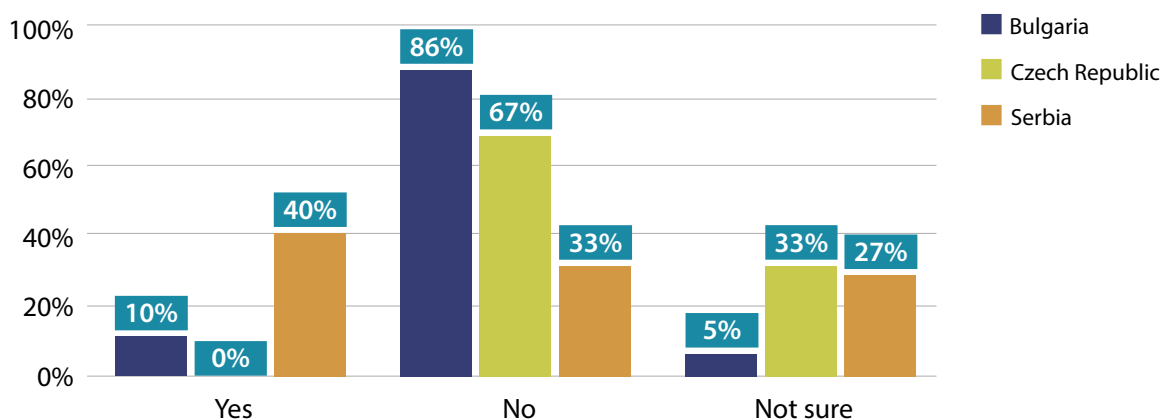
The Action Plan was developed under the Ministry of Health but its recommendations for other ministries are not binding. The group, however, which includes representatives of those ministries, will continue to meet and advocate for their implementation.

KAP Survey Result:

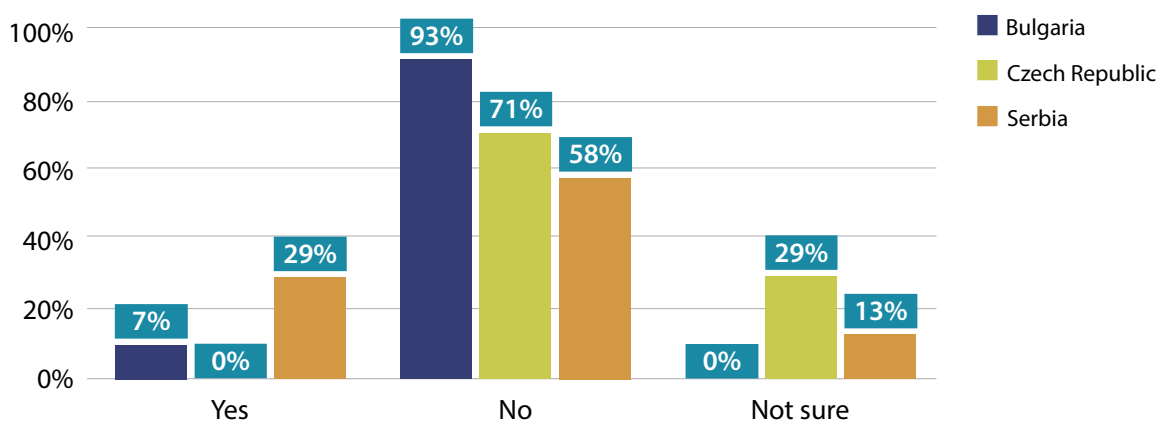
A significant change in attitude towards institutions among members of the National Working Group in Serbia was noted during the project. At the beginning of the project only 33% disagreed with the statement, “Children with intellectual disabilities are better protected from verbal abuse and humiliation in institutions rather than in the community.” This had risen to 58% by the end of the project.

KAP Survey Statement: Children with intellectual disabilities are better protected from verbal abuse and humiliation in institutions rather than in the community

1st Round



2nd Round

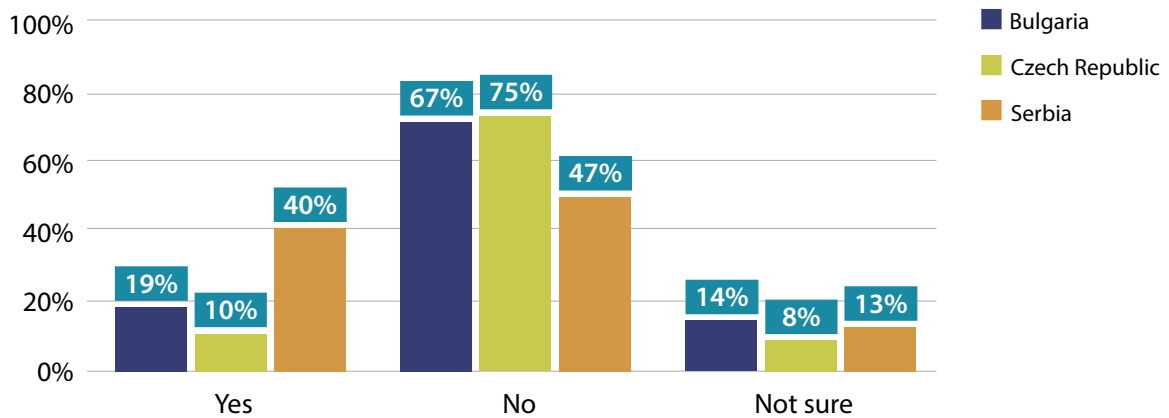


KAP Survey Result:

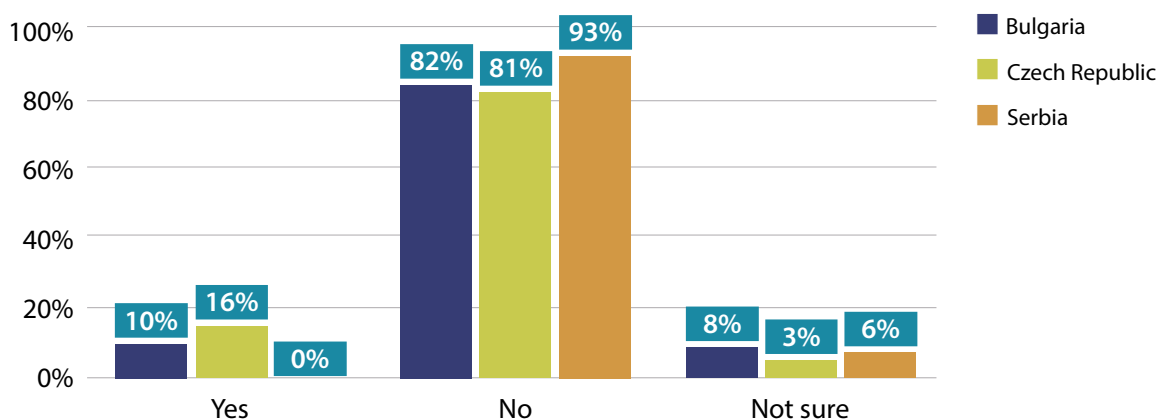
At the beginning of the project, 40% of Serbian National Working Group respondents agreed with the statement, “Some children with intellectual disabilities are uneducable.” This had dropped to 0% by the end of the project. More analysis of the reason for this major shift in attitude is required, but it likely the shift was influenced by the inclusive child participation methodology of the project having demonstrated the capacities of young people with intellectual disabilities.

KAP Survey Statement: Some children with intellectual disabilities are uneducable

1st Round



2nd Round



5.1.2 Bulgaria: Key Recommendations for National Action from the Bulgarian National Working Group

- Raise public awareness about disability and support inclusive education for all
- Integrate child participation at all levels of society and provide training to parents, carers, practitioners and all other relevant stakeholders
- Encourage partnerships between stakeholders
- Create competition between NGOs in service provision to improve the quality of the services
- Improve conditions for health and social work practitioners
- Improve support to parents and carers
- Create a common register for all children and young people with intellectual disabilities
- Establish 'cradle to grave' structures of care focused on the needs of the individual
- Make transport and facilities accessible
- Open emergency temporary crisis centres
- Provide social services for those over the age of 18
- Create part-time work opportunities for parents and for young people with disabilities.

The National Working Group in Bulgaria looked at existing policies and national action plans and ways to influence their implementation in line with the rights contained in the BHBL Declaration. As a National Action Plan for Vulnerable Children already existed, it was not appropriate to develop a new plan. However the group identified opportunities to ensure that the needs of children with intellectual disabilities could be better represented in the existing plan and in policies and practice. For example, the group developed a series of key recommendations for improving the existing National Action Plan to address the lack of practical measures they had identified related to children with intellectual disabilities.

Following discussions with National Working Group members, the Ministry of Education agreed to include measures addressing the support needs of children with disabilities within the inclusive education section of the new Draft Education Act. This had been identified by the National Working Group as a key area of concern. Another outcome of the National Action activity of the Bulgarian National Working Group was a commitment from the government to develop vocational and independent living opportunities for young people with intellectual disabilities. A working group has been set up to develop these plans.

“Following our involvement in the TWIA project- where the State Agency for Child Protection and the Agency for Social Assistance were also involved, we have together set up a working group to develop a new Programme to help children and young people with disabilities build skills for an independent life.”

Mrs Reneta Manolova - Head of the Department of Child Protection - Ministry of Labour and Social policy/Agency for social Assistance and a member of the TWIA National Working Group (speaking in May 2013)

Note: At the time of writing, (July 2013), political instability in Bulgaria is causing some uncertainty regarding the legislative timetable for these policy developments. It is hoped that the multi-sector and consensual nature of the National Working Group will ensure that these commitments are upheld. Lumos helped establish and is actively participating in a new coalition of organisations “Children 2025” which is seeking to ensure that children’s rights and deinstitutionalisation remain on the political agenda, irrespective of which government is in power.

5.1.3 Czech Republic: Key Recommendations for National Action from the Czech National Working Group

- **Increase autonomy and self-determination of children with intellectual disabilities both in residential institutions and in family environments**
- **Change the attitudes of service providers**
- **Increase cooperation between education and social protection providers**
- **Facilitate the sharing of good practice between peers, especially through site visits to social care homes and services**
- **Support self-help and self-advocacy groups for children and parents**
- **Establish a Children’s Ombudsman**
- **Update the Framework Education Programme for special schools**

In the Czech Republic, Lumos worked with project partner Pardubice County to implement the TWIA project. Approximately 100 kilometres from Prague, Pardubice County is a pilot county in a National Project working on the transformation of systems of care for vulnerable children. It is home to a large-scale residential institution which has been identified as a particular priority for deinstitutionalisation given that children with disabilities live there together with adults, putting them at risk of serious harm. Children living there are currently being prepared for a new life in family-based settings and small group homes in the community.

National Working Group members agreed on the need for action and for a working group to coordinate it, but also felt strongly that the process should be a Czech one in order to meet the

specific needs of the country. Attitudes towards deinstitutionalisation in the Czech Republic are sometimes negative and the group felt that a clear basis for it in local practice and local advocacy needed to be developed which could then influence and inform national processes. After the project had already begun, the central government in the Czech Republic made a commitment to deinstitutionalisation under the 2012-2015 National Strategy to Protect Children's Rights. This opened up the way for more fruitful action at national level, building upon the work done in Pardubice County.

This optimism was confirmed by the commitment shown by high-level government representation at the second transnational workshop in Prague. Keynote presentations highlighting the importance of the rights of children with intellectual disabilities included: Head of the European Commission Representation in the Czech Republic, Deputy Minister of Education, the Parliamentary Ombudsperson for Human Rights; Deputy Minister of Labour and Social Affairs and the Vice-President of the Senate.

As a result of the project, Pardubice County have made commitments to share their experience, tools and methods learnt on Child Participation with other counties and children's institutions. In so doing, it has laid the foundations for policy and practice improvements across the country. The National Working Group has developed draft recommendations, which it is hoped can be used to improve existing national plans and policies regarding children with intellectual disabilities in the future. The project experience of the Czech Republic is notable for the direct impact that was noted on staff behaviour and procedures within institutions, as evidenced by the following quotes.

"We would like to keep up these activities, maybe with a bigger group, and even extend them into other residential care services. We are already thinking about the sustainability of these activities for children and young people more generally. [Given appropriate support] we would like to create a kind of network of workers with pedagogical training or experience in working with children. We could then easily spread this initiative to other institutions in Pardubice County, for example. Our manual could be very useful for them in providing some idea of where to start, what to focus on and what to achieve."

Head of Direct Care, Pardubice County.

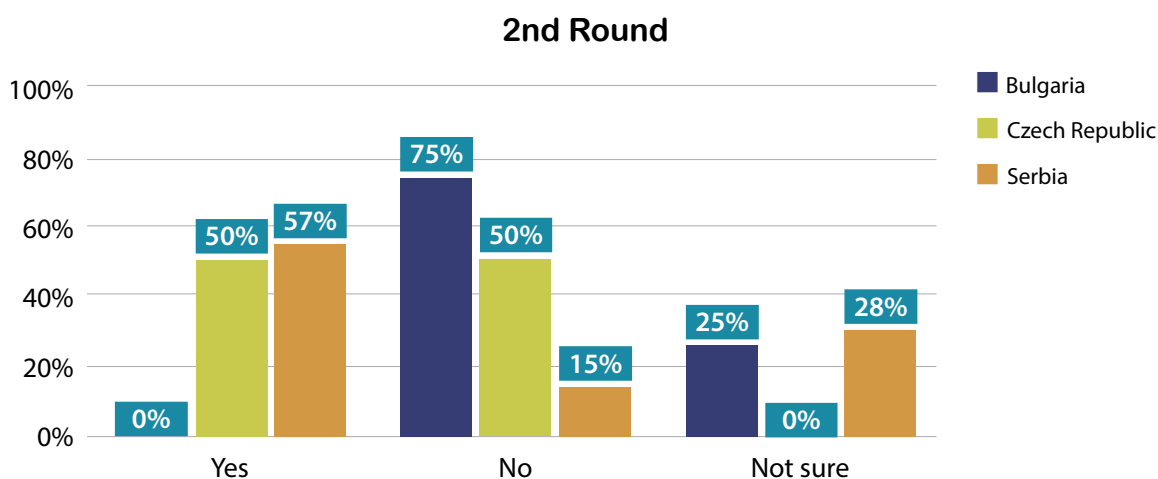
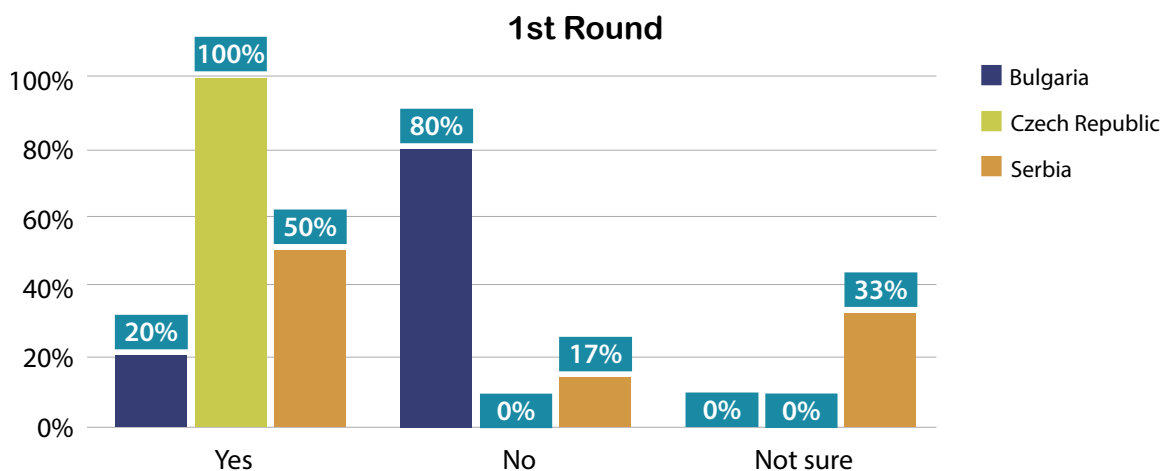
"Our experience of communicating with children with difficulties and identifying their views is growing. We are doing our best to make it a common part of our county experience. We see it as a priority to prepare young people for reintegration. We would like to use [the child participation approach] in other institutions and share it with relevant stakeholders in neighbouring counties."

Director of the Social Affairs Department in Pardubice County

KAP Survey Result:

An interesting change in attitude of children and young people to institutions was noted in the Czech Republic during the project. At the beginning 100% of the children and young people surveyed agreed that, “Children are treated well in institutions.” This figure had fallen to 50% by the end of the project. Given that some of the Czech children and young people surveyed lived in institutions, this could be a reflection of an institutionalised culture where there were previously few opportunities to express opinions. Following the project activities and the change in approach of the institution staff to encourage meaningful participation as outlined above, their confidence to share their own opinions would appear to have increased. In addition this change in attitude could be explained by the project having increased their awareness of their own rights and alternatives to institutions (for example by having met children and adults with intellectual disabilities from other countries who grew up in family environments). It is also possibly the case that those children surveyed who do not live in institutions, changed their positive attitudes towards institutions after interacting with their peers from institutions.

KAP Survey Statement: Children are treated well in institutions



5.2 Lessons learned

As demonstrated in the above activities, all politicians involved felt they learned a great deal from their involvement in the NWGs and, in particular, from the participation of children and young people at those meetings. The lessons learned are perhaps best articulated by two senior politicians as follows:

“People - and especially children - with intellectual disabilities are treated in Serbian society as a group that needs care and the State has done a lot to improve the help they receive. But the majority of these measures are planned for them not with them. We welcome the Turning Words into Action initiative precisely because it requires the full participation of the beneficiary group and we hope that this practice will become a model for the future.”

Mirjana Makismovic Social Inclusion and Poverty Reduction Unit of the Ministry of Health, Serbia (SIPRU) Representative speaking at the first NWG meeting

I was wondering how to begin my speech, but listening to your words reminded me how much better it would be if we, politicians, spoke less and you, children and young people, spoke more. That would help us understand and fulfil the meaning and purpose of child participation better - and it is still not a well-understood concept in many countries, not only in Europe, but also around the world. Listening to you, I have to admit I was very moved, because the issue of children and young people with intellectual disabilities is not well understood. I was reminded how much more meaningful and powerful it is when you, the people directly affected, speak about this issue to convince those who are not yet sufficiently prepared to understand your problems and accept you as part of society, as the worthy and diverse citizens that you are. We want to hear your opinions; for you, who have concrete ideas, to talk instead of us, so that we can execute your suggestions, your solutions and your wishes, because we have been elected to work for you.”

Kalin Kamenov, Chairman of the Bulgarian State Agency for Child Protection speaking at the TWIA Transnational Meeting in Sofia, September 2012

The power of transnational cooperation

6.1 Activities and achievements

When implementing international standards, much can be gained from sharing experiences across borders. Taking its inspiration from the BHBL Declaration which was itself agreed by 53 countries, the TWIA project set out to ensure that learning was shared between the three countries.

It did this by organising two Transnational Workshops where self-advocates and other members of the three 'National Working Groups' could come together and discuss progress.

The first such workshop, held in Sofia, focused on four key areas:

- **sharing and learning from each other**
- **key elements of policy and practice**
- **promoting child participation**
- **how to make change happen.**

The second workshop, in Prague, included presentations about the Child Choice events and their impact on the children, on policy makers and on the public. This meeting was attended by eight senior government officials and representatives of the European Commission, as well as by Baroness Sheila Hollins, Chair of both the Steering Committee for the BHBL initiative and of the TWIA Steering Committee.

The Prague workshop was opened by Jan Michal, the European Commission's Representative in the Czech Republic, who had adapted his presentation into 'Easy Read'. He introduced the European Union, what it means and how it is growing. Self-advocates who attended said they found his presentation very helpful and that for the first time they understood what the EU meant.

Progress between the two events was very marked. At the Sofia workshop, there were both parallel and joint sessions, with self-advocates working separately at times from the politicians, practitioners and parents. In Prague there was no need for separate sessions because a common agenda with a common approach to working together had been agreed. In advance of each workshop, CHANGE worked intensively with the self-advocates to prepare them for the joint sessions and supported them to prepare and deliver their presentations. Pictures, mimes and simple slogans were used to overcome language barriers and demonstrate the common concerns of children with intellectual disabilities across the three countries.

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At the Prague workshop, the children and young people made it clear that they did not want the end of the project to mean the end of their work together. The politicians, practitioners and parents in the room all made a commitment to find a way to help them continue their activities.

6.2 Lessons learned

Again, the transnational workshops provided opportunities for the professionals to raise their expectations of the children and young people with whom they work.

One professional from the Czech Republic said:

"We have children and young people with intellectual disabilities in this room. The more participation opportunities they get, the more adult their behaviour is. I would never have thought that they would get through the day without being tired. There were no outbursts of anger. Of course they are tired, but they are rather adult in their behaviour. I saw one boy working with the earphones [of the translation device]; he learned well and could react when Czech was spoken. Children should be able to access these kind of opportunities."

As countries across the European region prepare to report to WHO Europe on their implementation of the BHBL Declaration in 2015, it is clear that further transnational forums of this kind should be organised where countries can share their experiences so far and renew their commitment to implementing it. These forums in themselves can demonstrate child participation in action and push the boundaries of what is possible.

Post-project successes²²

A lesson of this project is that true participatory approaches need to involve everybody. At the trans-national meeting in Prague, the children and young people asked the adults involved in the project to come up with a simple message to all of the children who had been involved in TWIA. The steering group members, expert mentors and Lumos staff agreed that the work this project had started must continue. The simple words, “We promise to support the groups after the end of the project” were presented to the young people in the three project languages with drawings.



The partners involved in the project intend to live up to their commitment to the children and young people and ensure there are continued and increased opportunities for the children and young people to build on their extraordinary work.

22. This chapter was amended in the second edit of this publication October 2014

The project was only a beginning; already a number of additional successes have been achieved in the year since the project officially ended

- **Ongoing support to the groups**

Lumos continues to support the groups formed under the TWIA project in Bulgaria and Czech Republic. They meet regularly and continue to advocate for their rights locally and nationally. In Serbia, a new EU funded project started in 2014. Building on the innovative, child-participation approach started by TWIA, Lumos and the Child Rights Centre are working with children's groups to assess the General Protocol for the Protection of Children from Abuse and Neglect. This ground-breaking approach to child protection will see children with intellectual disabilities co-training alongside experienced child-protection professionals and trainers to ensure children's messages around the key themes of recognition, referral, communication, inclusion and justice are fully included.

- **New groups formed in Moldova**

Using the methodology established under TWIA, Lumos now supports groups of young people with and without disabilities in Moldova. Based around newly inclusive schools, these groups are breaking down barriers and changing attitude to disability in their schools and communities. Lumos has supported these groups to share their views at key events including an international conference on inclusive education and the visit of the Global Alliance for Children to Moldova. Two young people from this group will speak at an international conference on deinstitutionalisation being organised by Lumos in London in November 2014

- **Spreading the Learning through 'Hear our Voices'**

This project is another EC-funded programme, being implemented in partnership with Inclusion Europe and Eurochild who, having heard about TWIA, asked Lumos to join forces with them and to ensure that the activities of 'Hear our Voices' learn from and build on the achievements of TWIA. As part of the Hear our Voices project, a delegation of young people from the Czech Republic and Bulgaria shared their TWIA experiences in an interactive workshop at the Inclusion Europe Annual Conference in Belfast, Northern Ireland. At this workshop, in May 2014, they were joined by Spanish children with intellectual disabilities from the Hear our Voices project. Through Hear our Voices, Lumos staff and self-advocates have also met with and shared their experiences and advice with other groups of self-advocates and professionals.

- **Mainstreaming the participation of children with intellectual disabilities into child participation initiatives**

In July 2013, after the end of the project, Lumos arranged for representatives from the Serbian and Bulgarian groups to participate at a major international conference in Switzerland, "Children as Actors for Transforming Society" (CATS) organised by Initiatives of Change, in partnership with the Child to Child Trust. This event brought groups of children from around the world to explore new ways of working together to influence change. The TWIA representatives were the only group made up of children with disabilities and were able to share the experiences

of this project and raise awareness of the rights of children with intellectual disabilities at this mainstream international event. Following the success of the participation of children and young people from the TWIA project at the CATS conference in 2013, a larger delegation of young people from Bulgaria and Czech Republic took part in 2014. These groups led a workshop on participation for children with disabilities, spoke at the plenary session and widely featured in international media coverage of this event.

- **Spreading the model in Pardubice**

The local authorities in Pardubice have asked Lumos to work with them to disseminate further this model of child participation, so that it becomes normal practice for all children living in institutions and other forms of state care.

- **International Advocacy Opportunities**

Representatives of the TWIA project from Bulgaria and the Czech Republic spoke at a Lumos conference on deinstitutionalisation in the European Parliament in Brussels in November 2013. They also presented a film that the young people had made following their work on the TWIA project. In August 2014, two young self-advocates from the Czech group spoke at the UNESCO International Youth Symposium in Dublin. In February 2015, the Turning Words into Action project will be showcased at the international Zero Project conference in Vienna. A delegation of young people from the self-advocacy groups will present their experiences as part of a panel on child participation and deinstitutionalisation.

“As a result of TWIA, a legacy has been left in Serbia. Firstly, the National Working Group continues advocating for the implementation of rights of children with intellectual disabilities and, secondly, the voices of children and young with intellectual disabilities became more present and influential in the community. They continue to gather regularly, they are more proactive in networking with other young people, and some have gone on to, for the first time in Serbia for young people with intellectual disabilities, co-train the trainers of professionals from the health, police, education and social services on child protection issues. One can say that an important step toward genuine participation of young with intellectual disabilities has been made.”

Dr. Veronika Išpanović, Expert Mentor, TWIA -Serbia

Next steps

1. Continuing the work of National Working Groups (dependent upon the political situation in Bulgaria and the Czech Republic). In particular, Lumos aims to support those involved with the National Working Groups to work towards full national action plans, as part of their countries' obligations under the BHBL Declaration.
2. Sharing the Self Evaluation Toolkit with other countries, including the development of a training programme on its use. The final draft of the tool has been tested; modifications will be introduced and the tool will be translated into at least five languages, to make it as widely available as possible.

Image 1: The Self-Evaluation Toolkit in action



Image 2: The Self-Evaluation Toolkit

Care in the Community

Residential institutions that have a negative impact on the health and development of children and young people should be replaced by high quality community support. New admissions to such institutions should be stopped through the development of community services. Adequate replacement services include kinship care, foster care and adoptions, regulated in ways that encourage the recruitment of persons who are motivated to care for such children, sensitive to the specific needs of children with intellectual disabilities and likely to benefit them.

Providing and securing access to inclusive, comprehensive and effective health, social and educational services in local communities and combining them with clear targets related to deinstitutionalisation will enable the phasing out of long-stay residential institutions for children with disabilities.

Continuing Care

Service providers take measures to improve the competence of caregivers in existing institutional care. Continuing education, specialist support and supervision are provided as children and young people are prepared for transfer to family care in the community.

Image 3: The Self-Evaluation Toolkit

LUMOS European Union European Social Fund

TWIA Self Evaluation Results

This text describes the results and how you can save and export them into a pdf to share. Lorem ipsum dolor sit a wala cleo wen dee amet, urb an rot ornare ligula vitae nisi tristique lobortis. Lorem ipsum will provide gob bell lee gook odio hendrent odio cris tea aniverra tempus lobortis metus pretium. Ut mollis pulvinar port. Sus an null fokaugue viverra prawn av lobortis metus pretium. Ut mollis pulvinar port. Sus an null fok.

Name of Country or Individual
Date Created

Category	Score
Care in the Community	95
Equal Inclusion	85
Information Exchange	80
Child Protection	75
Family Care	70
Good Quality Care	65
Non-Profit Capacity	55
Inclusive Decision Making	50
Special Needs	45
Social Inclusion	40

Final words – children and parents

Statistics and the comments of professionals provide evidence of change. But the best evidence is found in the words of the children and parents themselves. Throughout this project, the children and young people have said so much that is of value. Many of their words are included in the publications *Our Words*, *Our Actions* and *Listening Together*. A small selection is presented here.

One member of the TWIA group defined child participation as follows:

“It helped me to become useful for myself and also for others. I became brave, more confident, and I started to feel that people are listening to what I have to say. I became a thoughtful and more independent person who is able to analyse things. The project opened a door for us to achieve more in our lives.”

Another participant spoke of the importance of the project:

“Through the project my new friends and I met politicians and influential people to whom we gave the task to think about us and to prevent us from becoming people without direction and without a future when we leave school.”

One boy from Bulgaria rarely spoke when he first joined the child participation group. But after being encouraged and supported to participate, he found his voice. In the summer of this year, he took part in CATS, an international child participation conference in Switzerland in 2013. The TWIA group of children and young people were the only ones present with an intellectual disability. But they were not daunted by the process; proper preparation helped them feel confident, happy and included. On returning from the conference, one young self-advocate's mother wrote the following letter to the Child Participation coordinator, Aneta.

"Our children were important, they communicated with everybody as equal persons, as friends. Nobody, for no reason, showed that our children are different. Here we were united in our differences. We all witnessed what a success and interest the Bulgarian presentation provoked in others. After that we received lots of greetings and new invitations. The facilitator said, 'you belong here in this place with us'.

Bisser, he was shining, he was happy. He met so many people. During his stay at the conference he became like other children, free, without barriers. He felt he was important. He decided to share his opinion and to stand behind it. I came back to Bulgaria with a new person, who wants to speak up. I hope here, in Bulgaria, nobody will break my son's wings. Finally, I would like to express my special gratitude to Lumos, and particularly to you, Annie. Without you I think he could never, I repeat, never have had a chance to show his potential. My son is flying now thanks to you because you discovered another world for him – a world where there is a place for him."

Acknowledgements

About Turning Words into Action

The Turning Words into Action Project took place over 21 months during 2011-2013. Its activities and outcomes are detailed in full in various publications and films, which can be downloaded from www.wearelumos.org

- **Turning Words into Action:**
A Guide to Influencing National Policies through the Active Participation of Children and Young People with Intellectual Disabilities
- **Our Words. Our Actions:**
An easy read publication sharing the views and opinions of the young people involved in the project.
- **Listening Together:**
A summary of tools used by the project team to develop effective child and youth participation.
- **Various films made with and by the children and young people who participated in the project.**

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**For more information:
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