

Children's Rights to Survival and Development:

Ensuring access to treatment for
children with hydrocephalus

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The most fundamental right of any child must be the right to life, survival and development. The United Nations Convention on the Rights of the Child (CRC) makes this clear in article 6, which provides that:

“States Parties recognize that every child has the inherent right to life [and] ... shall ensure to the maximum extent possible the survival and development of the child”.

Across the world, there are dramatic differences between children's enjoyment of that fundamental right, with the most economically prosperous democracies doing best in terms of reduced infant mortality rates and access to support services that optimise development.

Yet even within and across the European Union, children's chances of survival vary considerably. And when we look closely at certain groups of children, this variation is even more dramatic. In some European countries, children born with certain disabilities are denied access to basic life-saving treatment. Parents who are poor feel they have no alternative but to place their children with disabilities in a residential institution, where their chances of survival and development are further reduced. Once institutionalised, they are likely to remain so for life.

One such group of children are those born with hydrocephalus, a condition which causes a build-up of fluid on the brain that, if left untreated, can cause brain damage and even death. In some countries, parents are given no information or support when their child is diagnosed. Stigma attached to disability causes them to worry about how their children will cope when they grow up. They are advised by health professionals that a residential institution is the best option for their child, unaware of medical interventions that could enable the child to lead a meaningful life with their family. For children with hydrocephalus, the consequences of life in a large-scale institution can be fatal: without adequate treatment and support, many children die.

This report provides a summary of work undertaken by Lumos - together with governmental authorities, international partners, local medical professionals and families - to ensure that all children born with hydrocephalus receive the life-saving treatment they need, and which is their fundamental human right.

It identifies the challenges involved in changing systems, including financing mechanisms, to ensure treatment for children. It provides examples of good practice, as well as ideas for developing support systems for parents and children.

It is hoped that the successes recounted in this document will be of use to others facing similar challenges, as well as inspiration for all parents of children with hydrocephalus and the medical professionals who fight to save and improve their lives.

Lumos continues to work across the European Region to raise awareness of the condition and to improve services. It is our aim that, within five years all countries in Europe will ensure State provision of the medical treatment vital to save the lives of, and give the chance of a future to, all children born with hydrocephalus.

What is hydrocephalus?

Hydrocephalus is an abnormal build-up of cerebrospinal fluid in the cavities (ventricles) of the brain. If this fluid is prevented from draining at any point, the ventricles swell and compress the surrounding tissue. This causes increased pressure inside the skull, which in turn leads to progressive enlargement of the head, convulsions, blindness and learning disability.

Hydrocephalus can be congenital or acquired. Congenital hydrocephalus is present at birth and is caused either by problems in foetal development or by genetic abnormalities. Acquired hydrocephalus develops at birth or at some point afterwards. This type of hydrocephalus can affect individuals of all ages and is caused by injury or disease.

Hydrocephalus is not completely preventable; however, regular prenatal care can reduce the risk of congenital hydrocephalus through preventing and treating infections that can lead to it. Routine ultrasound scans can also detect the condition at an early stage, enabling steps to be taken that can stop the condition from deteriorating.¹ In addition, there is link between hydrocephalus and spina bifida; children born with the more severe type of spina bifida often also have hydrocephalus.²

The impact on children

The reality of hydrocephalus for many children across Europe and beyond is that the life-saving treatment they need is not provided, unless their parents can find a way to pay for it. Without support, families feel they have no alternative but to send their children to live in large-scale residential institutions, on the understanding that they will receive better care than families can provide. In reality, as for many other children with disabilities, institutional care is much more likely to have a negative impact on the children's health and development.

There is a significant over-representation of children with disabilities in residential care institutions and they are more likely to stay for longer periods of time than their peers. The level of care provided in institutions rarely meets the needs of children with disabilities. In some countries, the care is so poor that the results can be devastating. One study found that the most common reason for children with disabilities to be 'discharged' from an institution was because of death. For children under three 'discharged' from institutions, 28% of those children with disabilities had died in comparison to 0.29% of children without disabilities.³

Put another way, children with disabilities were 100 times more likely to die in the institutions than their non-disabled peers.

Lumos' own research resulted in similar findings. Of discharges from one institution for children with disabilities we found that **no** children went home to their families or into alternative care, 22% went to another residential institution and the remaining 78% died in the institution. In some countries, children with disabilities never leave institutions: at the age of 18, they are transferred to adult institutions where they remain until their death.⁴ In addition, children with disabilities are more likely to be victims of abuse than children without disabilities.⁵ Whether from bullying at the institution, violence, abuse or neglect, children with disabilities are particularly vulnerable to various forms of violence.

1 International Federation for Spina Bifida and Hydrocephalus, Can hydrocephalus be prevented? www.ifglobal.org/en/hydrocephalus/about-hydrocephalus/can-hydrocephalus-be-prevented

2 The Shine Charity www.shinecharity.org.uk/spinabifida/more-about-spina-bifida/types-of-spina-bifida

3 Browne, K, et al 'Mapping the number and characteristics of children under three in institutions across Europe at risk of harm'. Final Report of the Daphne Programme 2002

4 Georgette Mulheir et al (2012) Deinstitutionalisation – A Human Rights priority for Children with Disabilities, available at: www.equalrightstrust.org/ertdocumentbank/err9_mulheir.pdf

5 NSPCC (2003) 'It doesn't happen to disabled children', available at: www.nspcc.org.uk/Inform/publications/downloads/itdoesnthappentodisabledchildren_wdf48044.pdf

Placing a child with hydrocephalus in an institution is no guarantee they will receive the surgery they need. In many countries, it is common to find children with untreated hydrocephalus in institutions. Hydrocephalus affects the areas of the brain that control thought and learning. Children with the disorder may experience difficulties in concentration, reasoning, short-term memory and motor skills. If left untreated, hydrocephalus can lead to learning difficulties, brain damage, physical disability and death. It should also be noted that as the disease progresses, children are often in extreme pain.

Children with disabilities who do survive face significant barriers to full inclusion within society. Opportunities to receive an education, to access buildings, to participate in cultural and sporting activities and to receive health care can be limited or non-existent.⁶ Moreover, there is a powerful causal relationship between disability and poverty: if you are poor, you are more likely to have a child with disabilities. If your child has disabilities, their additional needs mean that you are more likely to live in poverty.⁷

Removing children from their families due to poverty or social issues is a violation of their human rights.⁸ This has a negative impact on their health and development and reduces overall life chances.

Lifesaving treatment

The standard treatment for hydrocephalus is the surgical insertion of a shunting device. A shunt is a system of tubes, which controls pressure in the brain by diverting the accumulated cerebrospinal fluid around the obstructed pathways, returning it to the bloodstream.

In most cases, the shunts are intended to stay in place for life, although alterations or revisions are sometimes necessary over time. For example, the tube or catheter may become too short as the child grows and an operation to lengthen it can become necessary.⁹ Shunt blockages that cause illness usually require an operation to replace or adjust the affected part of the shunt.

Research and experience show that children with hydrocephalus have the chance to reach their full potential through comprehensive medical care and plans for other forms of support. To achieve this, families and professionals must work together in an atmosphere of mutual trust and respect. The insertion of a shunt is a life-saving treatment vital for most children with hydrocephalus. These children should be given every opportunity to live as normal a life as possible, supported in their families, included in their communities.

⁶ UNICEF (2013) *The State of the World's Children – Children with disabilities*, available at: www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf

⁷ UNICEF (2007) *Promoting the Rights of Children with Disabilities, Innocenti Digest No.13*, available at: www.un.org/esa/socdev/unyin/documents/children_disability_rights.pdf

⁸ See articles 9 and 19 of the *Convention on the Rights of the Child*

⁹ Shine Charity, UK www.shinecharity.org.uk/hydrocephalus/more-about-hydrocephalus/what-is-a-shunt

Case Study

Lumos' work in Bulgaria

Lumos' work to support children with hydrocephalus and their families started after an assessment of children with disabilities in institutions carried out together with the State Agency for Child Protection. The assessment identified high numbers of untreated hydrocephalus in state institutions for children with disabilities. In some cases the children had been diagnosed but not treated due to lack of funds to buy the necessary shunts; in other cases their condition had not previously been diagnosed. Some children had received the operation, but due to insufficient medical care in the institutions, had not received proper post operational care and subsequently their condition was deteriorating.

As we researched the matter further, it became clear that families were placing their children with hydrocephalus in institutions for a number of reasons, but that the primary motivation was a lack of funds to pay for the shunts.

Under Bulgarian law, medical treatment for children is provided free of charge. However, the health insurance does not cover medical devices. Thus the State health system would cover the cost of surgery, but the parents must pay for the shunt. Lumos intervened with a combination of emergency response and longer-term advocacy, including:

- Funded the shunts for seven children who critically needed this emergency intervention as they were at imminent risk of sustaining brain damage which would be too severe for a full recovery. Some of the children were about to be placed in institutions by their families, but are now living at home as a result of Lumos' intervention.
- Engaged in high-level advocacy, working together with other lobbying and pressure groups. We entered into dialogue with the Ministry of Health and State Agency of Child Protection to identify a mechanism by which the State could begin to pay for the shunts.
- Conducted awareness raising activities, including a national conference in November 2011, which aimed to make sure that the shunts are funded by the authorities, that doctors are aware of the availability of shunts for poor families and that parents are aware of their children's rights and needs.
- Supported the development of the Bulgarian Spina Bifida and Hydrocephalus Association (ARSBH), to become a resource for support to the families affected and a voice to continue the advocacy and lobbying activities started by Lumos.

The Result

As a result of the advocacy work, in November 2011, the Ministry of Health announced temporary provisions for the shunts to be covered by the State Fund for the Medical Treatment of Children. Since this decision 251 children have received the necessary treatment through this fund.

This is a huge achievement, of which the Bulgarian government should be rightly proud. It is now essential that the appropriate legal policies and procedures be put in place in order to eradicate the placement of children with hydrocephalus in institutions. Lumos is working with Bulgarian authorities to achieve the following:

- **Redirection of funding for medical treatment:** instead of being funded by a special fund, the cost of shunts and treatment needs to be fully integrated into the mainstream Health Insurance Fund, in order that a temporary measure becomes a permanent resource.
- **Awareness-raising events** to share best practice in community-based services, preventing hydrocephalus and spina bifida and the importance of early intervention for children with these conditions and support to their families.
- **Commitment of the Government to full implementation of the CRC and CRPD.** Together with the Office of the Ombudsman, Lumos is working to ensure that all children with disabilities are provided with the medical and social services they require to be able to live with their families, included in their communities and to develop to their full potential. In particular, replacing institutions with adequately funded community based services is essential.

The situation in Europe

The rights of children with hydrocephalus and other disabilities need specifically to be protected by national governments, as well as at a pan-European level. Access to treatment for hydrocephalus is not uniformly available throughout European region; the knowledge may exist in most countries, but the facilities, supplies and willingness to provide operations may be lacking. For example in Belarus and Ukraine doctors are trained to operate on children with hydrocephalus, however the cost of shunts and the operation is not covered.¹⁰

Romania

Every year, more than 600 children in Romania are born with hydrocephalus or spina bifida. At the time of writing this report, it was still the case in Romania that, whilst the medical system is generally free of charge, parents have to pay for the shunt, the CT scan and medication related to their child's condition. This is similar to the situation that pertained in Bulgaria until 2011. Most parents cannot afford the shunts: a good quality shunt costs €300 while the average monthly salary in Romania is €380. Moreover, parents report that they are often told their child has no future, and are advised to leave their children in institutions where many are not referred to surgeons for the operation they need.

The Romanian Association for Spina Bifida and Hydrocephalus (ARSBH) was founded in 2005 to fill the gap by funding the shunts for approximately 150 – 170 children per year. The work of ARSBH in Romania has eliminated waiting lists for operations and has decreased the time from diagnosis to operation from months, or even years, to a matter of days. In 2012, the ARSBH ran out of funding and turned to Lumos for support. To date, Lumos has provided funding for 85 shunts and we are committed to funding 35 more in 2013.

Adriana Tontsch - President of ARSBH

“Do all children in Romania have the chance to live? Prior to 2004, for children diagnosed with spina bifida/hydrocephalus this was not the case. Parents had to pay for expensive shunts. Due to poverty many of them could not afford the shunt. This is the main reason children did not receive the necessary surgery in Romania.

“Our organisation began to provide shunts in 2005. Since then we have provided more than 1,000 children with shunts. But our activity depends on donations. Because of financial problems we cannot always buy the shunts consistently. Thanks to Lumos, we can continue our work, provide the shunts and children in Romania can have the operation. Lumos has helped us to go on with our aims to give children the possibility to have a normal life.”

¹⁰ Chernobyl's generation of suffering The Guardian 23 April 2006 www.theguardian.com/world/2006/apr/23/ukraine.theobserver

¹¹ The average income per person was RON 856 (less than EUR 190), according to the Romanian Statistics Institute's (INS) family budget survey of household income and expenditure in Q3 2012. www.romania-insider.com/average-romanian-household-income-was-eur-540-a-month-in-q3-2012/72668

Lumos is proud to support the provision of shunts in Romania that save children's lives and give them the chance of a future. However, such medical treatment should not rely upon charitable donations; rather should it be provided free of charge by the State medical system. It appears that Romania faces similar challenges to those identified in Bulgaria in 2011, including:

- **Inefficient use of government funding**

The surgery is provided free of charge, but the shunts must be paid for by the parents. As a result, many children with hydrocephalus are raised in State institutions. Years of institutional care is much more costly to the State than the shunt.

- **Discrimination against children with disabilities**

It is still the case that some professionals view children with disabilities as 'less important' or less deserving than children without. As a result, the care of children with disabilities is not prioritised. There are still cases where medical professionals advise parents to send their children with disabilities to institutions.

- **Wider discrimination against people with disabilities**

Due to wider societal discrimination against people with disabilities, families are often ashamed of having a child with a disability. Parents choose to send children to institutions because of poverty and because they lack information about the disorder. In some cases, families keep children at home, untreated, in order to receive disability benefits.

We are therefore delighted to report that on the 24th of October, at a conference organised by Lumos in Sofia on treatment of hydrocephalus, as a result of partnership working between Lumos, the Office of the High Commissioner on Human Rights (OHCHR), the ARSBH, advocating for change, it was announced that the Romanian government has committed to fund the shunts for children with hydrocephalus from the 1st of January 2014. From now on, no child in the European Union should ever go without this treatment.

United Kingdom

It is estimated that spina bifida affects one baby in every 1,000 born in Britain. Most of them will have hydrocephalus. Both congenital and acquired hydrocephalus are treated with either shunt surgery or neuroendoscopy covered by the National Health Service.¹² Other support for children and adults with hydrocephalus includes: disability living allowance, carer's allowance, personal independence payments, and employment allowance. There are also a number of NGOs in the UK that provide support to children and their families including home visits, education support, health and professional advice for children with hydrocephalus and their parents or carers.¹³

Finland

In Finland 50 children are diagnosed with hydrocephalus each year. In addition to basic healthcare there are numerous services available, including disability benefits, personal assistance, rehabilitation and medical equipment. A social worker can assist with finding the most appropriate services for the individual. There is also 'social rehabilitation' available, to support the individual's personal relationships and social interaction. This can be individual or group support, such as adaptation courses and training programmes for the individual and their family, organised by the hospitals or NGOs. The Finnish CP Association have organised a network of peer group support for families and persons with hydrocephalus or spina bifida.¹⁴

¹² NHS Choices, available at: www.nhs.uk/conditions/hydrocephalus/Pages/Introduction.aspx

¹³ SHINE, UK, available at: www.shinecharity.org.uk/how-we-help/welfare-benefits

¹⁴ The Finnish CP Association www.cp-liitto.fi

The experience of parents, children and doctors

“Believe in your child and be with your child”

Dimitar, from Bulgaria, whose daughter has hydrocephalus

“When it becomes clear that it is hydrocephalus, the parents fall into a world of horror. Most likely they have never heard the word hydrocephalus before - but their child needs them more than ever.

“What you need is information for the parents: what to do, how to behave, what to expect, what types of treatment are available. The lack of information sometimes make it difficult to make the right decisions. I can only imagine what the situation would be for people that have no access to internet, are illiterate or don't speak foreign languages.

“Support is non-existent generally speaking. The only communication you have is with the doctors about the condition of your child but no one tells you how to deal with it. After the operation you are on your own. No one gives you a programme on what to do in the next six months or beyond...you have to learn by yourself. The only doctor available is the General Practitioner but he is not a specialist and so very often they don't know what to do. No one follows-up. It's all up to the parent. And when the parent does not know himself what to do...we have heard stories about children that did not end up well.

“Parents of children diagnosed with hydrocephalus should believe in their child and be there for their child regardless of what may come. We parents are the only ones who can help our child become a person and it is up to us. It is very important not to listen to well-meaning friends, family and neighbours who tell you, “leave the child in an institution, you will have another one”. Focus only on your child, on helping your child get better and finding the treatment you need. Because in that moment you are desperate and when someone tells you – leave them in an institution, have another one – it can seem like a good solution, but it is not. The only chance for the child is if the parent is right there next to them - although it is emotionally and financially very hard on us.”

“It is possible to overcome this disease.”

My experience of hydrocephalus by Maria

“17 years ago at the age of 13 I was hit by a ball at school and developed hydrocephalus. The operation was quite hard on me and my family. My parents had to ask for money from their friends, colleagues, everyone they knew in order to pay for the shunt. They even sold their car. Later at school some of the kids made fun of me but it did not stop me to continue with more faith and fight for what I want in life.

“I now have a Masters in Public Administration and I work at the municipality. I have a child and I consider my life to be a success. I want to say to the people that with the shunt you can live a normal life like everyone else.

It is possible to overcome this disease.”

“This is their chance for life”

Neurosurgeon, Dr Alioski talks about hydrocephalus and working with Lumos in Bulgaria

“Two years ago when a parent with a child with hydrocephalus came to me, I had to tell them that they needed to find the money for the treatment. Now I don't have to worry how to explain to the parents that, aside from the tragedy of the diagnosis, they need to buy a costly shunt.

“The difference to a child receiving this intervention is significant. In some cases it is a chance for life. This is the difference. The quality of life improves. Some of them develop normally and go to regular schools. But for many of them it is simply the chance to live.

“I hope there will be more organisations like Lumos that will help change the health insurance system here in Bulgaria. From this year I can see the difference this is making to children. I don't have to feel uncomfortable in front of parents anymore.”

The cost of caring for children with hydrocephalus: institutional versus family-based care

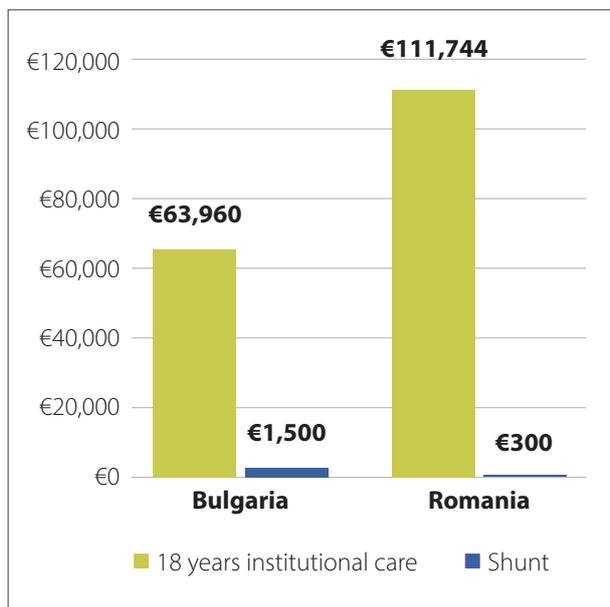
Replacing institutions with family-based care not only leads to better developmental outcomes, it also allows greater numbers of children to benefit from financial and other resources.

Institutional care is expensive because it requires round-the-clock staffing - even institutions with the poorest conditions are costly to national governments. Actual costs vary between countries and programmes, but comparisons¹⁵ consistently demonstrate that institutional care costs significantly more per child than family support services or foster care. This is also the case for children with disabilities.

Resources used to sustain institutional care could be redirected to provide improved care for a much larger number of children through family- and community-based services.

The case of children with hydrocephalus provides a stark example of the inefficient use of funds. If children do not receive the surgery they need, they are unable to develop properly, the disease progresses and they are usually in severe pain. Parents do not feel able to cope and they are encouraged to place their children in institutions, where they will stay usually for the rest of their lives. Instead, if they are provided with the surgery and follow up support, most children can live in their families, be included in their communities, develop to their full potential and become economically contributing members of society. As the following table demonstrates the cost of 18 years of institutional care is by far more expensive than the cost of a shunt.

Table 1: Comparison of the costs of institutional care versus the provision of shunts



Reducing the number of children in residential care frees up the resources needed to establish family and community-based services for children with disabilities. This enables greater numbers of children to live within families rather than in a depersonalised environment in which they receive no love and limited care. Reinvesting resources in this way also increases the funding available for the minority of children who have such highly complex needs that they need specialist, quality care, which can be more expensive. In addition, early intervention will also have an impact on an individual person's net cost or contribution to society as adults. A cost benefit analysis would show even greater returns for the government, as a person in employment will be a net economic contributor through tax revenue, as opposed to requiring the cost of lifetime care.

Children with hydrocephalus have the potential to lead much more fulfilled and meaningful lives if they receive comprehensive, integrated medical care along with developmental support. The need to institutionalise these children can be averted through the transition to community-based care.

Conventions and initiatives for children with hydrocephalus

Children with disabilities encounter various forms of exclusion and are affected in different ways. Under the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD), all children have the right to the highest attainable standard of health. It follows that children with disabilities are equally entitled to the full spectrum of available care.¹⁶ Article 23 of the CRC stipulates that a mentally or physically disabled child should enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community. Ensuring that children with hydrocephalus have the right treatment, family life and enjoy these rights on a par with other children should be the objective of health, education and other service provision.

All European Union Member States recognise that families with children with disabilities have the right to assistance and support; this recognition, however, is often not reflected in the national policies and regulations that enable families to access the support they need. Research shows that there can be a discrepancy between the authorities' legal commitments and the implementation of policy, which often results in inconsistent or non-existent support for children with disabilities and their families.¹⁷

Consequently, a number of advocacy and policy developments have taken place at an international level in recent years.¹⁸ The examples that follow are paving the way for deinstitutionalisation of children with disabilities.

Better Health, Better Lives

The World Health Organization Europe's Better Health, Better Lives Initiative was launched in 2008. The Initiative takes a holistic approach to the health, development and well-being of children with intellectual disabilities and the role played by different agencies in achieving this. As a next step, in 2010 the European Declaration and Action Plan on the Health of Children and Young People with Intellectual Disabilities and their Families was signed on behalf of 53 Ministers of Health of the European region and endorsed by a group of international NGOs at a conference in Bucharest. The Declaration was formally endorsed as a Resolution in 2011. The Declaration bridges the potential gap on the rights of children with disabilities. It also explicitly highlights the implied, interconnected rights of children to live with their families and to access appropriate health and education services in order to develop to their full potential.¹⁹

The 'Špidla' Report

In 2009, the then European Commissioner for Employment and Social Affairs, Vladimír Špidla, asked Lumos and a number of other NGOs and international agencies to form a group of experts to report on institutionalisation in Europe. The Report of the Ad Hoc Expert Group on the Transition from Institutional to Community Based Care ('Špidla' Report) was published in September 2009. It made a range of specific recommendations to EU member states and to the EC itself. These included: a requirement for all countries to develop national action plans for deinstitutionalisation; ensuring that deinstitutionalisation is factored into its work with countries outside the EU; and the development of a set of Common European Guidelines on deinstitutionalisation.²⁰ The Report was welcomed by the European Commission as an important contribution to the development of EU policy and action on social inclusion. In 2012 Lumos produced an Easy Read version of the report, to ensure that it was accessible to all stakeholders.²¹

The Common European Guidelines and Toolkit on the use of Structural Funds for the transition from institutional to community based care.²²

The Guidelines and Toolkit provide advice for governments and NGOs on the use of European Union Structural Funds to facilitate the provision of community based services and reduce reliance on institutions. In this regard, EU Structural Funding could be used to fund the development of community based medical and social support services for children with hydrocephalus.

Recommendations for change

- **Ensure that shunts are provided and paid for by the State, along with other medical supplies, across the European region**

Shunts are a life-saving treatment for children with hydrocephalus and full medical assistance should be given to offer children with disabilities the best chance in life. It is their basic human right. States that do not yet provide the shunts should compare the cost of the shunt with the cost of institutional care and develop mechanisms to shift financing from institutional care to medical treatment and community based support services.

- **Prevent institutionalisation**

Preventing institutionalisation in the first place is essential when it comes to protecting the rights of children with disabilities. Despite the good intentions of institutional care, large-scale institutions cannot provide children with the loving, attentive environment they need to develop and thrive. Children with disabilities are even less likely to have their medical or emotional needs met and can be put at greater risk by a complete absence of medical care.

- **Improve rehabilitation services and the provision of equipment for children with hydrocephalus:**

- Children should be able to access rehabilitation services up to the age of 18.
- Services should be available regardless of where the child is located, not just in big cities.
- Support should be multidisciplinary, involving a range of professionals working together: rehabilitator, child psychologist, speech therapist.
- Funding for wheelchairs and other equipment should be prioritised. In Bulgaria for example, a wheelchair costs between €1,000 and €2,000, whilst families are only entitled to €200 of support from the State. Parents are left with no option but to buy a poor quality wheelchair for €250.

- **Provide families and institution managers with information about hydrocephalus and its treatment**

As outlined, the lack of adequate information and support for families is a root cause of institutionalisation of children with hydrocephalus.

Faced with a diagnosis of hydrocephalus, families need to receive information and guidance so that they can understand the needs of their child, both now and in the future. Information about shunts and advice about how to obtain funding for them should be readily available to all parents so that they are able to make an informed decision in the best interests of their child. All medical staff in maternity wards, paediatric services and general practice should be trained to help parents understand their child's disability and to outline the treatments available, to have a positive attitude to children with disabilities and not to encourage placement in institutions. In those countries that have not yet completed the transition to community-based care, institutions which still house children with hydrocephalus should be fully informed and engaged in managing their treatment programmes effectively.

- **Empower parents, children and self-advocates** to follow-up on achievements so far and to further improve the situation of children with hydrocephalus and their families.

- **European Union funding to be used to develop medical and social services for children with hydrocephalus.**

The European Union has signed and ratified the UN Convention on the Rights of Persons with Disabilities. Thus any EU funds expended should ensure programmes comply with the CRPD; programmes that forward a country's compliance with the CRPD should be prioritised for EU funding. Therefore EU desk officers should work with country governments to prioritise funding medical and social services for children with hydrocephalus.

16 UNICEF (2013) The State of the World's Children – Children with disabilities, available at: www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf

17 UNICEF (2007) Promoting the Rights of Children with Disabilities, Innocenti Digest No.13, available at: www.un.org/esa/socdev/unyin/documents/children_disability_rights.pdf

18 Georgette Mulheir et al (2012) Deinstitutionalisation – A Human Rights priority for Children with Disabilities, available at: www.equalrightstrust.org/ertdocumentbank/err9_mulheir.pdf

19 Ibid

20 Ibid

21 Easy Read version of the Špidla report can be found on Lumos' website: www.wearelumos.org/sites/default/files/research/120926%20Spidla%20easy%20read.pdf

22 Download documents at: www.deinstitutionalisationguide.eu

References and further information

Useful links

Lumos

www.wearelumos.org

International Federation for Spina Bifida and Hydrocephalus

www.ifglobal.org/en

Spina Bifida and Hydrocephalus in Bulgaria' Association

www.sbhb.org

WHO Better Health Better Lives Declaration

www.euro.who.int/__data/assets/pdf_file/0003/126408/e94421.pdf

European Guidelines and Toolkit on the Transition from Institutional to Community Based Care [www.](http://www.deinstitutionalisationguide.eu)

www.deinstitutionalisationguide.eu

Information on the Turning Words Into Action project on Lumos's website

www.wearelumos.org/stories/changing-attitudes-through-child-participation

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

Lumos Foundation, founded by J.K. Rowling, is a company limited by guarantee registered in England and Wales no. 5611912. Registered charity no. 1112575.

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