

2012 Annual Review

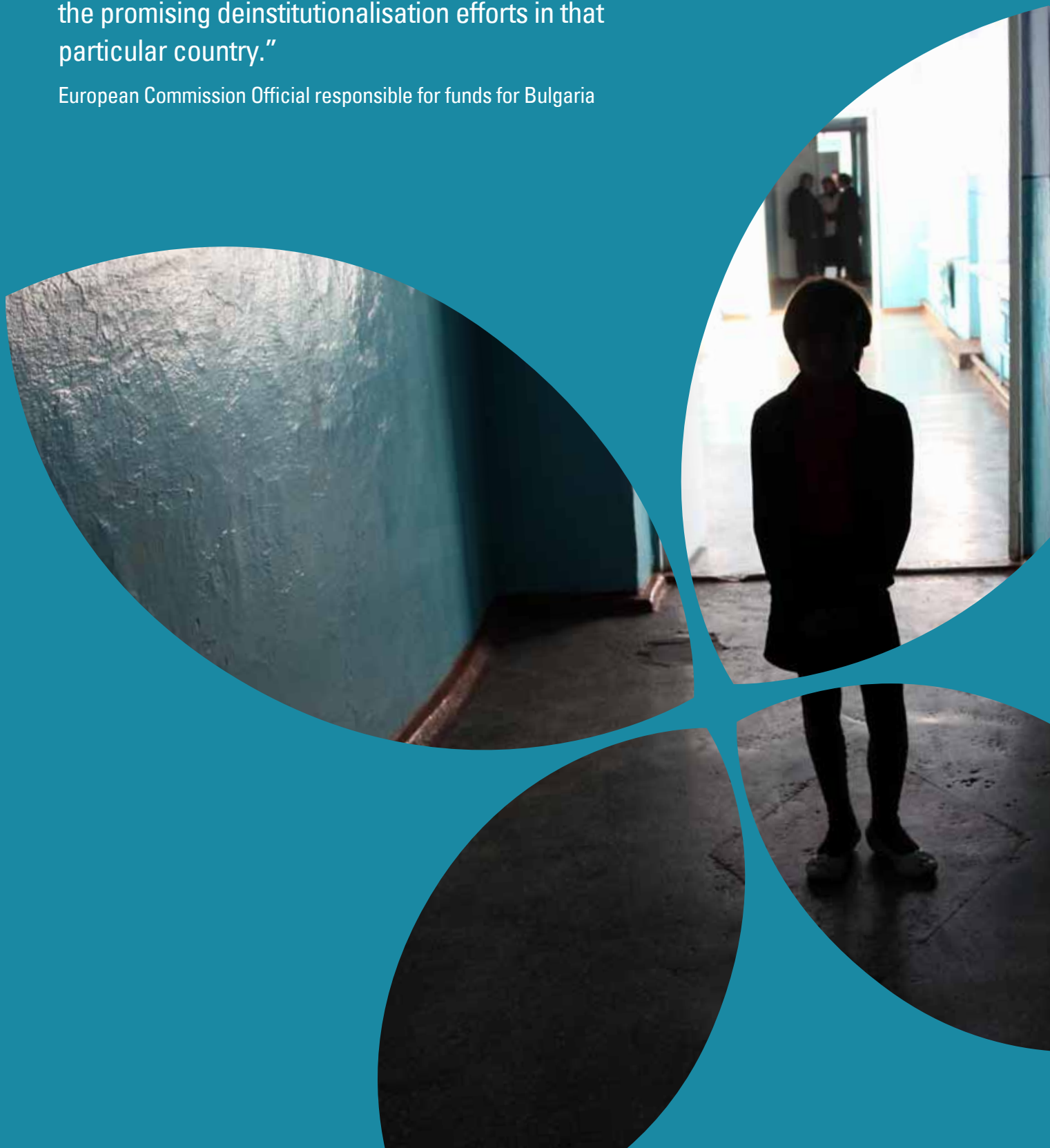


Protecting Children. Providing Solutions.



“Working with Lumos is a pleasure. Lumos provides reliable and timely information that efficiently feeds into the Commission's work and frequently allows us to identify needs for action, of which the Commission services were not previously aware. Lumos has shown amazing stamina, in particular in the case of Bulgaria and can claim large credits for the promising deinstitutionalisation efforts in that particular country.”

European Commission Official responsible for funds for Bulgaria



Annual Review 12

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"I was profoundly moved by the individual stories of children reunited with their families; of parents who felt they had no option but to place their children in institutions, but were provided with the support they needed so their children could come home."

J. K. Rowling

Foreword by JK Rowling

Founder and Chair of the Board of Trustees

2012 was a landmark year for Lumos. Our international team of dedicated professionals significantly scaled up its delivery of programmes that change the lives of Europe's most vulnerable children. This Review provides a snapshot of some of Lumos' extraordinary achievements.

I was profoundly moved by the individual stories of children reunited with their families; of parents who felt they had no option but to place their children in institutions, but were provided with the support they needed so their children could come home.

And this year too, Lumos saved the lives of many more children in institutions who were dying as a result of neglect or a lack of access to proper medical care.

During 2012, Lumos' work to demonstrate best practices in changing systems of health, education and social services has become a model for others. Governments and organisations from many countries have asked Lumos to assist them in closing their institutions and setting up community services. Impressed by our success in Moldova, the Ukrainian national and regional level government, as well as NGOs, have begun to use Lumos' approach to develop national and regional action plans for change.

But the work of one NGO can never be enough to help all children in institutions. This is why we work to influence decision makers at the highest level. This year we have been successful in assisting the European Commission and European Parliament to make major changes in the way EU funding can be spent. Over the next few years, this will shift resources from institutions to the development of community-based services, marking the beginning of the end of institutions for children in Europe.

None of this could be achieved without the generous support of partners and donors. For this I thank you and I hope you will continue to work with us to bring an end to the institutionalisation of children.



J. K. Rowling

“Change on this scale requires advocacy across political and economic structures, collaboration with local and national government, partnerships with NGOs, the delivery of specialist advice, emergency intervention where necessary, the involvement of children and families in making decisions about the changes that affect them – and so much more.”

Georgette Mulheir
Chief Executive Officer, Lumos



Foreword by Georgette Mulheir

Chief Executive

This Review outlines how, at every level of engagement, Lumos' programmes are coming to fruition and beginning to achieve real, lasting change.

Sixty years of research demonstrates the harm caused to children by separating them from their families and raising them in large institutions. The negative effects of institutionalisation include developmental delays, chronic health problems, challenging behaviours and difficulties in forming relationships and integrating into the wider community.

Yet deinstitutionalisation is about so much more than just closing institutions.

It is about a single child discovering, for the first time, the joy of being part of a loving family; it's about hundreds of children with disabilities participating in mainstream education in Moldova; about our intensive feeding programme in Bulgaria, saving lives that would otherwise have been lost; it's about the vital amendment to child protection laws in the Czech Republic; and it's about training practitioners and delivering expert support, which helps to ensure sustainable reform as well as improved outcomes for individual children. These significant developments in 2012 are among those outlined in this Annual Review.

Change on this scale requires advocacy across political and economic structures, collaboration with local and national government, partnerships with NGOs, the delivery of specialist advice, emergency intervention where necessary, the involvement of children and families in making decisions about the changes that affect them – and so much more.

The progress and the achievements outlined in this report bring with them increased challenges and risks. As our work expands into more countries and involves more institutions, it is likely that new child protection cases will emerge and need to be addressed but what remains key is that we are able to help more children as we move forward. Indeed, to achieve this, financially, we need to continue to secure the long-term future of our organisation; and we need to ensure the health and safety of our personnel, who make such a valued and valuable contribution every single day.

We also need to build on the support of those people that share our achievable vision of a world. One in which all children have the opportunity to grow up in a safe and caring family setting or, where there is no alternative, in specialist placements that meet all their needs, respect their rights and ensure they can fulfill their potential. In 2012, more people than ever learnt about Lumos' work. Our YouTube films and TED talk have received over 300,000 views and we have stepped up our social media activity, reaching over 16,000 followers on Twitter. We hope that our new website offers a persuasive insight into what we do and into the lives of those children and families with whom we are privileged to work.

Thank you for your interest and support.



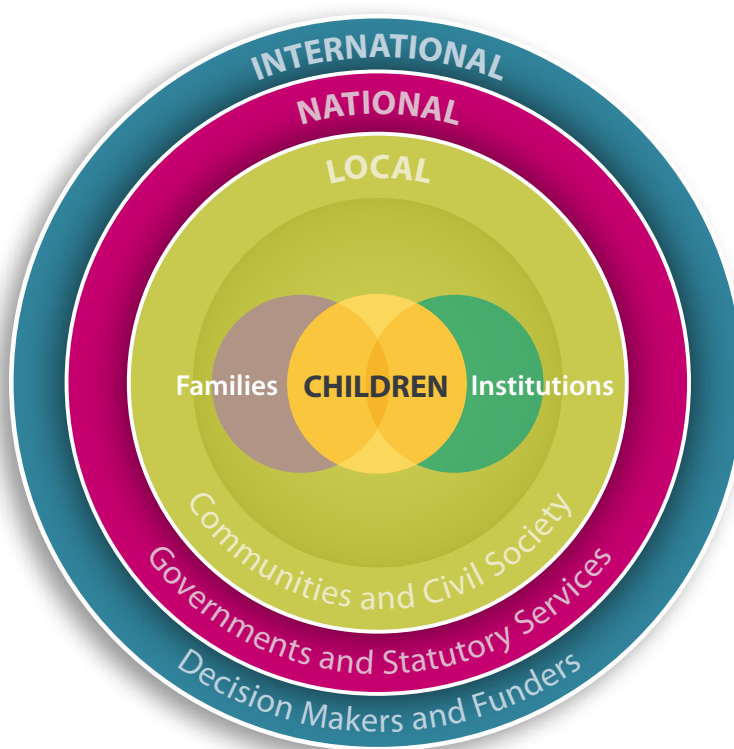
Georgette Mulheir

Our unique approach

Making vulnerable children safer and happier, and increasing their life chances, is at the heart of everything we do from lobbying international decision-makers to reuniting individual children with their families.

Our aim is that no child in Europe should be living in an institution by 2030. We believe that this goal is achievable but it requires fundamental changes in attitudes and a radical overhaul of how services for children and families are funded and delivered.

That is why we work systematically at seven levels to secure lasting change.



“Lumos' contribution to the development of Inclusive Education has been essential, particularly the support given to the national government in drawing up new legislation and regulation to reorganise and create new education services and make sure they are implemented; the activity of assessing children in residential institutions and integrating them into society, as well the training of stakeholders at all levels, has helped meet all the challenges in the field of Inclusive Education”

Moldovan government official responsible for education services

International decision makers and funders

We lobby and influence the European Commission and others to divert funding from large-scale, harmful institutions to more inclusive family and community-based services.

National governments and civil society

We help governments devise national action plans to replace all children's residential institutions with community based services. We work with UN agencies and other NGOs to avoid duplication of efforts, and support governments and communities to implement these plans. We have developed a model approach to moving children from institutions to community-based care that ensures the best of interests of each individual child is at the heart of all decision making. The model has been applied in many different countries.

Local government and statutory services

In the past it was often a shortage of easily accessible health, education and social services that led to children being institutionalised far from their family home. We work with local authorities to transfer resources from large institutions to strengthened local, community-based services.

Local communities and civil society

We provide on-the-ground support to community care-workers to bolster their services to children and families. We also work with the wider community to raise their awareness of children returning from institutions and to encourage them to help vulnerable families.

Institutions

We aim to improve the health, development and protection of children in institutions from the moment we start working with them.

Families

Many families felt compelled by circumstances beyond their control to institutionalise their child. We help individual parents find employment, better housing, develop parenting skills and establish local family support services for children with disabilities, all with the aim of making it easier for families to keep their children at home.

Children

We assess each child's individual needs before deciding whether their best future option is to be placed with their family, in foster care, local adoption or in a small group home. We prepare them for their move from the institution and continue to support them in their new setting.

Through training and support we empower children, parents and people with disabilities to act as self advocates.

Our Work in Focus

Key Achievements in 2012

1 Working with National Governments

Lumos' work in advising, guiding and supporting governments on all aspects of deinstitutionalisation led to landmark progress in 2012 – including the delivery of lifesaving intervention for many children.

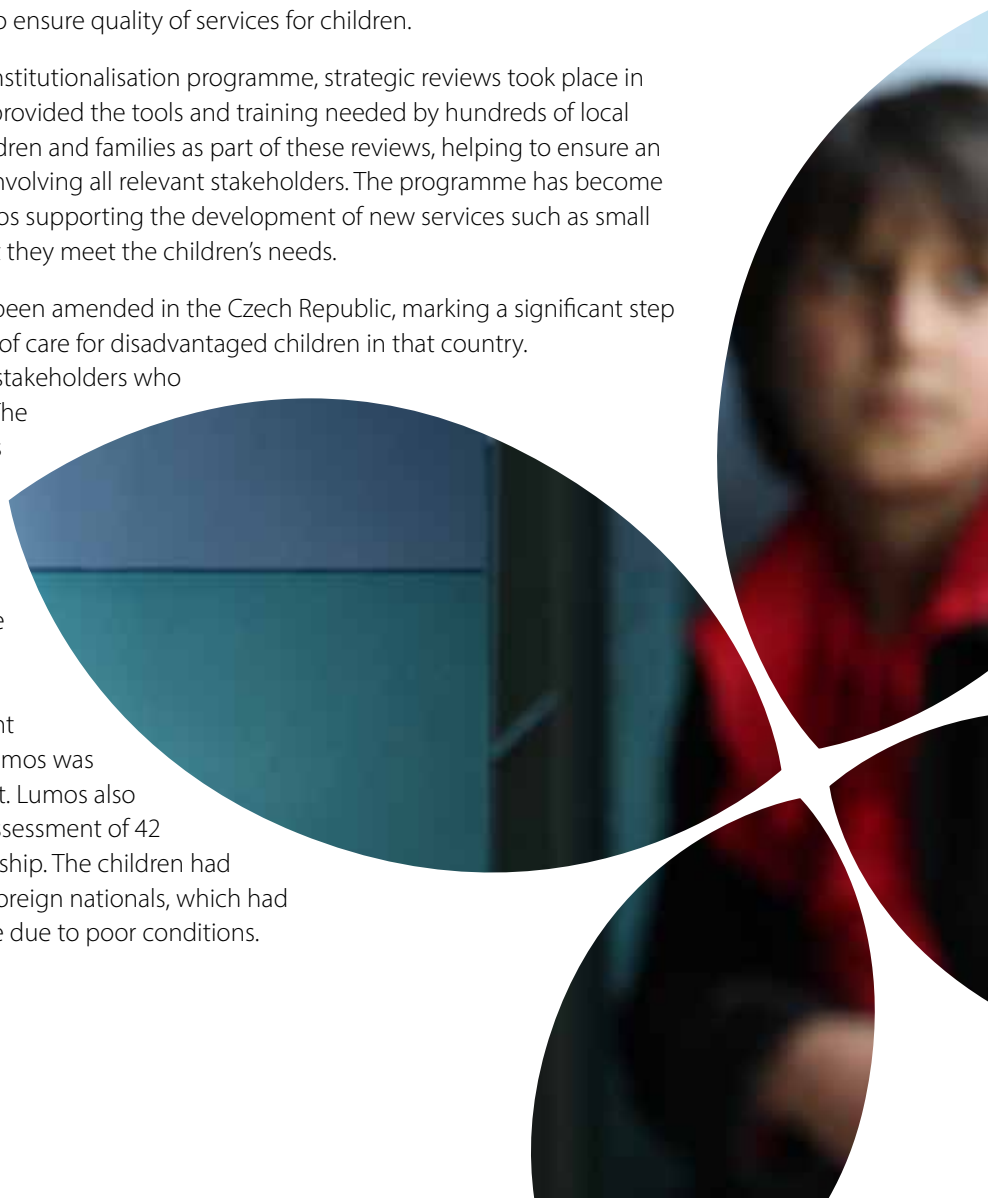
Deinstitutionalisation

In Moldova, in Lumos' demonstration regions, there has been a 90% reduction of children in institutions following the closure of two establishments which were replaced with new services. The provision of foster care and family welfare facilities were enhanced and regulatory frameworks developed accordingly. As a result of Lumos' close cooperation with the Moldovan government, a law on the accreditation of service providers was also approved and published in 2012. This law is fundamental to an effective inspection system for social services, in order to ensure quality of services for children.

As part of the Bulgarian deinstitutionalisation programme, strategic reviews took place in Varna and Dobrich. Lumos provided the tools and training needed by hundreds of local social workers to assess children and families as part of these reviews, helping to ensure an evidence-based approach involving all relevant stakeholders. The programme has become more sustainable, with Lumos supporting the development of new services such as small group homes to ensure that they meet the children's needs.

Child protection laws have been amended in the Czech Republic, marking a significant step towards the transformation of care for disadvantaged children in that country.

Lumos was among the key stakeholders who advocated for this change. The programme team continues to work closely with the Ministry of Labour and Social Affairs (MOLSA), the Ministry of Education and others, providing advice and support on all aspects of deinstitutionalisation; for example, a family assessment framework developed by Lumos was adopted by the government. Lumos also undertook an emergency assessment of 42 children with foreign citizenship. The children had been placed in a home for foreign nationals, which had been fast-tracked for closure due to poor conditions.





The Ukrainian government asked Lumos to assist in drafting a national action plan for deinstitutionalisation. Relationships were established with key NGOs and state partners in three regions of Eastern Ukraine and two study visits took place: one focused on babies and children with HIV and the other on social care services for children and families. These visits

led to the implementation of two strategic reviews which will form the basis for planning complete deinstitutionalisation. Training programmes for social workers, local decision makers and practitioners are also underway.

Moldova's Infant Mortality Reduction Programme

Specialists were provided in pilot regions to work closely with social workers and medical personnel in the community. The programme's cross-sector working model was acclaimed as 'best practice' at a workshop organised by the Ministry of Health and the World Health Organisation (WHO) office in Moldova. There has been a 4% reduction in infant mortality since Lumos started the project and further data will be compiled to determine its long-term impact.

Intensive Interaction and Feeding (IIF) in Bulgaria

Life-saving work has also taken place in Bulgaria where, through a programme of IIF, the mortality rate in two institutions fell by more than 90%. The Bulgarian State Agency for Child Protection approached Lumos for support after an initial assessment of 1,800 children with disabilities. This process identified a particularly vulnerable group of children and young people in institutions at risk of serious harm or death as a result of malnutrition. Lumos specialists worked closely with practitioners to develop and implement feeding recommendations through applying Intensive Interaction. Intensive Interaction is an approach to teaching the pre-speech fundamentals of communication to children and adults who have severe learning difficulties and/or autism and who are still at an early stage of communication development. The work has led to significant improvements in health and development.

Treatment for Children with Hydrocephalus

In 2011, Lumos raised awareness of Bulgarian children with untreated hydrocephalus and the government committed to meet the medical costs of treating this condition. Throughout 2012, Lumos continued to work on this issue to ensure that this commitment was fulfilled. The government's Children's Treatment Fund has been used to provide medical shunts for life saving treatment for more than 80 children.

2 Strengthening Universal Services

Inclusive education in Moldova

Inclusive education is an essential component of community-based care. However, no government funding had previously been made available in Moldova to enable children with Special Educational Needs (SEN) to access meaningful education. In 2012, Lumos worked with the Ministry of Education to redirect money from institutions towards funding inclusive education services. As a result, 449 children with SEN are now being educated alongside their peers in mainstream schools. In addition, 40% of schools in the country have received funding for support teachers and for the development of inclusive education resource centres. Six such centres have already been opened in partnership with Lumos.

Inclusive education has also become a mandatory module for teacher training after Lumos proposed and developed the content. From now on, teachers from all disciplines will undertake a module of SEN as part of becoming a qualified teacher.

Preparing children for change in the Czech Republic and Moldova

Even when children are removed from institutions to a more loving, child-centred environment, failure to prepare them effectively for change can cause the new arrangement to break down. In 2012, Lumos ran two training programmes for institution directors and other key stakeholders who were planning to move children out of institutions in the Czech Republic. One programme focused on the transition to small group homes and included information about preparing children with severe communication difficulties. The second programme looked at supporting children of all ages to enter foster care or to return to their birth families, including managing challenging behaviour.

In Moldova, twenty-nine children were integrated into their birth families during 2012, totalling 191 since the start of the deinstitutionalisation project. Twenty-one children went into foster care, totalling 32 since the start of the project. Significantly, 114 children were prevented from entering institutions. Careful preparation and follow-up has ensured that, despite the precarious economic situation in Moldova, fewer than 1% of placements have broken down.

Work continued on two deinstitutionalisation books for children, one for younger children and one for older children. Content has been developed in consultation with children's focus groups to ensure that the books respond to real concerns and worries about changes to their care. The books address the institution closure process and how it might affect them, together with the roles of the people involved. They are being developed into Easy Read by CHANGE (see next page) to ensure that they are accessible for children with learning disabilities.



CHANGE

CHANGE is a human rights organisation, led by disabled people, which employs people with learning disabilities to work alongside people without disabilities. Lumos provided a grant to CHANGE to enhance the inclusion of people with disabilities in its work. In addition to training Lumos on developing Easy Read and other accessible materials, joint activities in 2012 included CHANGE training key stakeholders on social models of disability and person-centred planning during study visits. For most people, this was the first time that they had been trained by someone with a learning disability and the feedback has been positive.

Working with children with challenging behaviour in Bulgaria

A Lumos training programme for professionals about how to manage challenging behaviour has had a direct impact on children's outcomes: experts are now supervising and advising practitioners in Bulgaria on nine specific cases and report positive changes in the condition and behaviour of the children and young people involved.



3 Providing Expert Support

Remote Expert Support Service

Improving children's lives through deinstitutionalisation requires experience and specialist knowledge. Underpinning all of Lumos' activity is its Remote Expert Support Service (RESS) team: a group of professionals who ensure quality and safety across all operations. From supporting personnel on the ground to helping children adapt to a new care system, RESS provides assessment tools, advice, placement planning and service development.

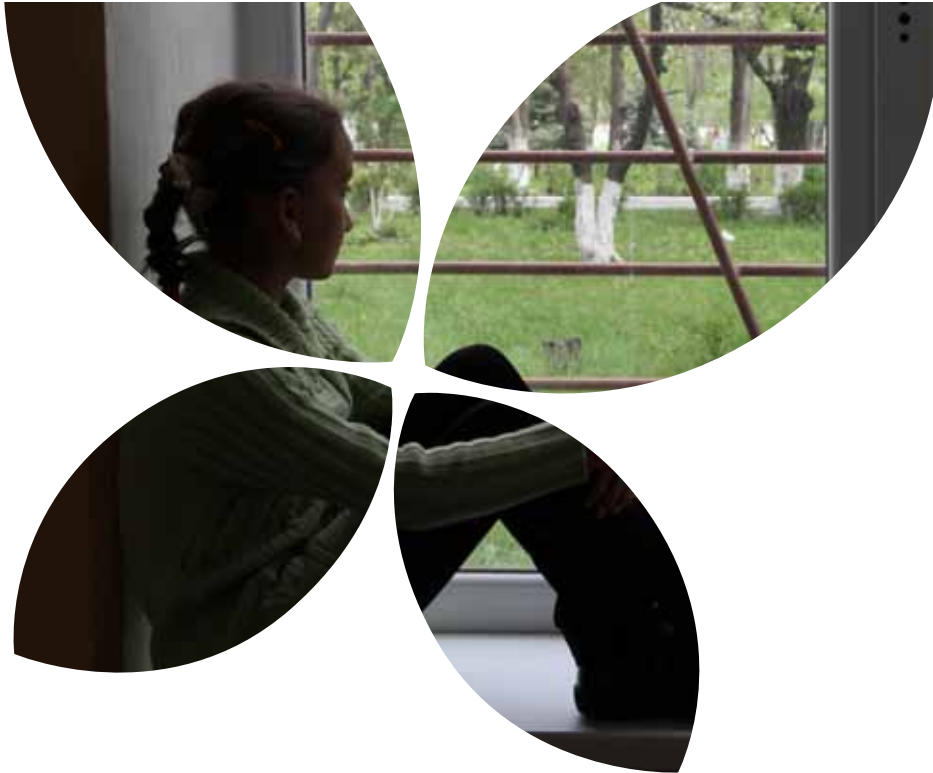
Training to achieve sustainable change

Training professionals in programme countries is an essential component of long-term, sustainable change. In the short term, effective training can also mean the difference between life and death. Feeding severely disabled children can be difficult: consequently, they are frequently undernourished and at risk of malnutrition. At one institution in Bulgaria, seven children were severely malnourished and on the brink of death. Lumos delivered emergency Intensive Interaction training, as a result of which the health and physical condition of the children improved noticeably.

The projects in Moldova also have a strong focus on strengthening human resources capacity. During 2012, Lumos organised 262 training programmes, seminars, workshops and conferences in Moldova. A total of 6,078 participants attended, ranging from officers and employees of government departments, NGOs, teachers, mayors, health and social service professionals and parents.

Other training delivered by Lumos in 2012 included the training of judges in the Czech Republic to help facilitate new child protection legislation and training for deinstitutionalisation managers in Hungary, the Czech Republic and Moldova.





4 International Advocacy

Common European Guidelines on Deinstitutionalisation

In 2011, European Commission (EC) officials asked the European Expert Group on Deinstitutionalisation, for which Lumos provides the Secretariat, to produce guidelines for deinstitutionalisation which could be used by European Commission officials, member state Governments and local civil society.

In 2012, the Common European Guidelines on Deinstitutionalisation and the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community Based Care were launched in Brussels, with high-level engagement from the EC. The year-long drafting consultation process was managed and funded by Lumos, which has also set up a website to host the publications in eleven languages. The Guidelines provide detailed advice on developing deinstitutionalisation programmes for children, people with disabilities, people with mental health problems and elderly people in Europe. The Toolkit explains how deinstitutionalisation programmes can best be developed within EC regulations.

Influencing EC funding

It is vital that EC funding supports reform programmes, rather than being used to renovate or build new institutions. This means that Lumos must make the case for deinstitutionalisation to managers across the European Union (EU). In 2012, more than 4,000 people signed a Lumos petition to influence EC funding and to ensure the long-term sustainability of reform programmes in countries where Lumos operates. When the EC published its draft Regulations for the next EU funding period (2014 – 2020), Lumos' advocacy work focused on ensuring that specific articles relevant to deinstitutionalisation were included. Deinstitutionalisation also formed part of the European Union's Disability Strategy and Anti-Poverty strategy.

5 Empowering children and families

Many children in institutions have never been asked to share their views or to make their own choices. Enabling them to become active participants in changes to their circumstances is the first level of child participation. At the second level, children act as advocates for themselves and others, directly influencing policy-making over relevant issues.

In many cases, Lumos' work in preparing children effectively for major changes in their lives has had a direct impact on their health and development. Anxieties and subsequent behavioural difficulties are reduced, improving the life chances of all children involved.

“When specialists came to the institution and started to talk to me and to other children about the possibility to return into a family, I felt that this was my hope for the future. The specialists came often to talk to us, to explain what was going to happen to us. Those discussions were very helpful for me and for other children from the institution, because they prepared us for the move to a new environment. When I came to live with my foster family, I felt that this was the best thing that could happen to me after the years spent in an institution. I received a lot of help, and so did my foster family. Now I understand how much the specialists worked with me and with other children who moved from that institution. I decided for myself that I will study as much as I can in order to become a social worker and help other children too.”

13 year old girl from Bulgaria

Turning Words Into Action project

2012 saw the launch of an innovative and empowering child participation project. Turning Words Into Action (TWIA) is a Lumos-led, EC-funded project implemented in Bulgaria, the Czech Republic and Serbia. It brings together children and young people with intellectual disabilities, policy makers and experts to develop ways of making society more inclusive.

Turning Words Into Action

This project came about as a result of the ‘Better Health, Better Lives’ resolution of the WHO. Signed by 53 European Countries in 2010, this resolution sets out ten priorities which, if put into practice, would result in the full inclusion in society of all children with intellectual disabilities. TWIA ensures that young people with intellectual disabilities are able to influence how the resolution is put into practice.

Around 50 children and young people with learning disabilities were regularly involved in the TWIA discussion groups. Activities in each country varied according to the wishes of the young people, but all aimed to change the attitudes of politicians, parents, professionals and the public to children with learning disabilities and to influence policy decisions.

The work received positive feedback from families and parents of the children. One of the parents of a child involved in the child participation activities noted:

“These child participation activities are changing our mindset, too. At first I was shocked when I was asked what my child can do. It had never occurred to me that I did not consider what he could do; I only thought about the things he couldn’t do.”

Family assessments in Bulgaria

There are many reasons why children end up being separated from their parents; some families were forced to give up their children due to difficult circumstances. Many may be able to look after their children again with appropriate support, others may not. Whatever the background, involving families is an essential part in reforming the system of care for vulnerable children - and Lumos' holistic approach to deinstitutionalisation empowers families to play a bigger role in the process.

In 2012, Lumos organised the assessment of 1,386 families of children with disabilities in institutions. This assessment ensures that the needs of families will be fully met once the institutions have closed. The results clearly demonstrated the importance of including the families in the deinstitutionalisation process: 53% of families wanted to rebuild their relationship with the children - only 33% did not wish to maintain contact. This came as a surprise to the authorities, as prior to the assessment they had believed that most families would not be found or would not be interested in their children's situation.

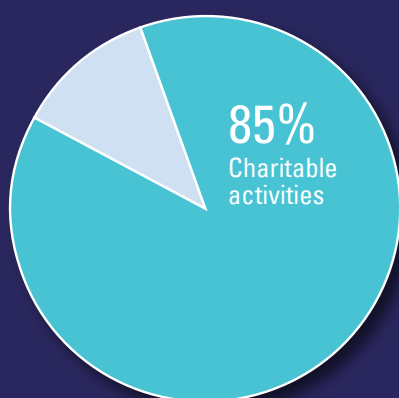


Financial review information

For the year ending 2012

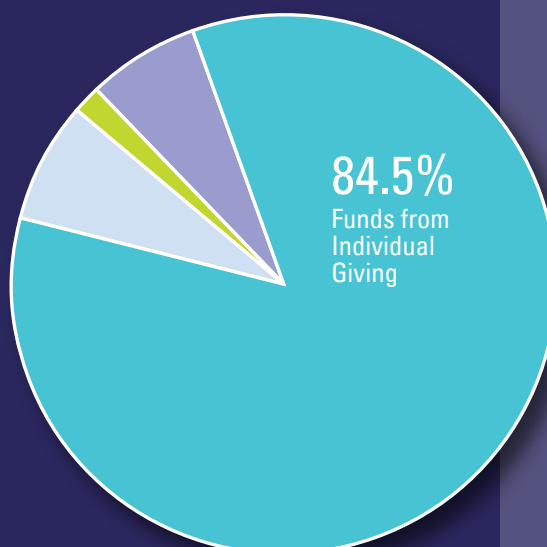
Income	2012	2011
Lumos' incoming resources total	£3,759,294	£794,922
Funds from individual giving, including Gift Aid	£3,166,196	£20,806
Royalties income	£269,349	£491,575
In addition:		
Lumos received grants totalling	£63,142	£58,826
Investment income	£253,853	£223,715
Foreign exchange gains	£6,754	(£11,586)
Expenditure	2012	2011
Total outgoing resources	£3,097,829	£2,427,383
Resources expended on charitable activities	£2,741,151	£2,189,334
Total resources expended	88.5%	90.2%
Costs of generating voluntary income, communication and donor communication costs	£341,413	£195,070

85% of Lumos resources are expended on charitable activities vs 15% on costs



Income source breakdown

- 84.5% Funds from Individual Giving
- 7.3% Royalties
- 1.6% Grants
- 6.6% Investments and Foreign Exchange Gains



Trustees

J.K. Rowling (Chair)
 Dr Kazem Behbehani
 Neil Blair
 District Judge Nicholas Crichton CBE
 Rita Dattani
 Bryan Ellis (Hon Treasurer)
 Sandy Loder
 Sir Roger Singleton CBE
 Lucy Smith
 Rachel Wilson

Chief Executive:
 Georgette Mulheir

Thank you

Thank you to the following organisations for their generous grants in support of our work in 2012

European Commission
European Commission Social Innovation Fund (they funded TWIA)
Leonardo da Vinci

Thank you to all those who have fundraised and donated to Lumos over the course of the year, we are truly grateful for your commitment to helping us in our work to end the institutionalisation of children

Thank you to our partners

Agency for Social Assistance, Bulgaria
Alexei Mateevici Theoretical High School of Sanatauca, Moldova
Amanda Ely
Ambler Children's Centre
Archway Children's Centre
Ashbourne Children's Centre, Derbyshire
Ashcombe Children's Centre, Western Super Mare
Barking Children's Home
Barnet Adult Social Care services
Barnet Council children and Family Services
Bemerton Children's Centre
Bluebell Hill Primary School, Nottingham
Bluecoat School, Nottingham
Brian Smith
British Association for Adoption and Fostering
CAMHS, Weston Super Mare
CCF Moldova
CHANGE
Child Rights Information Center, Moldova
Children's Involvement Team, Sheffield
Confederation of Family Organisations in the EU (COFACE)
European Association of Service Providers for People with Disabilities (EASPD)
European Disability Forum (EDF)
Coin Street Children's Centre
Crabtree Primary School, Nottingham
Dennitsa Georgieva
Department for Education, UK
Derby Integrated Disabled Children's Services
Dr. Apostol Apostolov
Dr. David Towell
Dr. Haralan Alexandrov
Dr. Matt Muijen
Dr. Roger Banks
Dr. Veronika Išpanović

Ealing Children's Services
Early Support Services / Early Support Consortium of National Children's Bureau
Open University
Embassy of the United Kingdom in Bulgaria
Embassy of the United Kingdom in Czech Republic
Embassy of the United Kingdom in Moldova
Enable
European Network on Independent Living/
European Coalition for Community Living (ENIL/ECC)
European Social Network (ESN)
Eurochild
European Federation of National Organisations Working with the Homeless (FEANTSA)
Evans Vettori Architects
Family Care Adoption Services, Nottingham
Femeia si Copilul – Protectie si Sprijin Association, Moldova
Floresti County Council
Gloria Nimenko
Government of Montenegro
Government of the Republic of Moldova
Government of Bulgaria
Government of the Czech Republic
Gymnasium of Ciutulesti, Moldova
Gymnasium of Malcoci, Moldova
Healthy Living Centre, Weston Super Mare
Hilton Primary School, Derbyshire
House of Lords
Ialoveni County Council
Inclusion Europe
Ines Bulić
Institute of Educational Sciences
Ion Pelivan Theoretical High School of Razeni, Moldova
Jae Watson
Kate Greenway
Kent Local Authority Fostering Social Work Team
Keystone Human Services International Moldova Association
Know How Centre
Lough Road Respite Service
Lynda Baxter
Margaret Clapson
Mayorality of Chisinau Municipality
Melita Murko
Mental Health Europe
Mental Health Initiative Open Society Foundations
Michaela Ivanova
Mihai Eminescu Theoretical High School of Ghindesti, Moldova
Miron Costin Theoretical High School of Floresti, Moldova
Motivatie Association, Moldova
National Council of Child Rights Protection

National Council of Evaluation and Accreditation in Healthcare
Nottingham Children and Family Services
Nottingham City Council Children's Services
Oakfield School, Nottingham
Ofsted
Parent Partnership programme, Kensington and Chelsea
Partnership for Every Child, Moldova
Petra Šramková
Petre Ștefănuță Theoretical High School of Ialoveni, Moldova
Professor Sheila Baroness Hollins
Ruby Lalor
European Commission in the Czech Republic
Robert Owen Early Years Centre
Samir Bičak*
Sheffield City Council
Sheffield City Council Adult Social Care Services
Sheffield City Council Children and Family Services
Sneinton Children's Centre, Nottingham
Speranta Center, Moldova
St Quintins Children's Centre
Supported Fostering Services, Kent
Susan King
Talbot Special School, Sheffield
Terre des homes Moldova
Bulgarian Association for Hydrocephalus and Spina Bifida,
The Inner London Family Proceedings Court
The Municipality Of Balchik, Bulgaria
Centre for Child Rights in Serbia
Pardubice County, Czech Republic
Karin Dom Foundation in Bulgaria
Municipality Of Dobrich, Bulgaria
Municipality Of Dolni Chiflic, Bulgaria
Municipality Of Krushari, Bulgaria
Municipality Of Provadia , Bulgaria
Municipality Of Varna, Bulgaria
Regional Administrations in the Varna and Dobrich regions, Bulgaria
The Bulgarian State Agency for Child Protection
Theoretical High School of Costesti, Moldova
Theoretical High School of Frumusica, Moldova
Theoretical High School of Puhoi, Moldova
Theoretical High School of Tipala, Moldova
Triangle
Umbrella Charity, Derby
United Nations OHCHR Regional Office for Europe
UNICEF
Vasile Alecsandri Theoretical High School of Marculesti, Moldova
Weston Central Children's Centre
Weston General Hospital, Weston Super Mare
Whitefield School, Waltham Forest
Yvonne Spencer

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

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