Ending the institutionalisation of children

A summary of progress in changing systems of care and protection for children in Moldova, the Czech Republic and Bulgaria
“My sister and I lived for a couple of years in that institution, where we saw sadness and suffering in each child’s eyes. We were not happy about living there either. We got lucky when some extraordinary people helped our grandmother to take us back home into the family. They had great confidence in my grandma and gave us hope. A year has passed since we came home to our grandmother and started going to the mainstream school, which we like a lot. It has been a really good year for my sister and me, with lots of positive moments. Every day we can feel the love of our grandmother who is taking good care of us. I have my grandmother, my sister and other relatives near me, whenever I need them. This is an amazing feeling”.

Raluca and her sister Angela were reunited with their family in Moldova
Introduction

Lumos’ mission

Lumos was founded in 2005 and our mission is to end the institutionalisation of children globally by 2050. There are an estimated 8 million children in institutions globally.¹ Research shows that more than 80% are not orphans and that children are primarily placed in institutions due to poverty or a lack of access to community-based services.² Children with disabilities and those from ethnic minority communities are considerably over-represented in institutions.³ More than 60 years of research evidence demonstrates that institutionalisation of children causes serious harm to their health and development, exposes them to a high risk of violence and dramatically reduces their future life chances.⁴

Barriers to change

There are significant barriers to change and major resistance to the process of deinstitutionalisation. A shift in resources from institutions to community-based services is needed. Investment funding is required to develop the community-based services to support children and families. Additional costs are incurred during the period where two systems are running in parallel – i.e. where community-based services are being established and institutions have not yet closed. There is often limited managerial capacity to plan and implement the change required. Many stakeholders – staff in institutions, politicians, the community, schools and even parents and children themselves – fear the changes and need considerable support. Changes in government mean that professionals, civil servants and NGOs must continuously raise awareness with all politicians to ensure continuity and sustained political will over a long period.

Lumos’ work

In order to enable complex system change that replaces residential institutions with community based health, education and social services, and to ensure sustainability of these services in the long term, Lumos works on seven levels, from the individual child, through to international decision-makers and donors.

We advocate for change, undertake demonstration programmes, build the capacity of politicians and professionals and empower children and families to take a lead role in transforming the services they need. We also leverage the finances, commitment and energy of other donors and stakeholders. We work in partnership with governments, international organisations, donors, NGOs, CBOs and communities.

About this report

In each country demonstration programme, together with government and local authority partners, Lumos regularly collects data to monitor progress.

This report presents a summary of progress in our first three country demonstration programmes – the Republic of Moldova, the Czech Republic and Bulgaria. The report focuses on the macro picture of systems change – presenting important indicators of success. However this only provides part of the picture. An accompanying report will be published in 2015, which provides a quantitative and qualitative analysis of the impact of the changes on the health, development, quality of life and future life chances of the children we have helped to leave institutions. A further report will provide a detailed analysis of financial issues related to deinstitutionalisation.
The Republic of Moldova

Lumos started a major programme in the Republic of Moldova in 2007. At that point Moldova had committed to a five-year plan to reduce the numbers of children in institutions by 50%. Supported by a number of NGOs, including Lumos, demonstration programmes were developed in a number of regions across the country.

The past seven years in Moldova have been marked by chronic political instability (four changes of government and a period of civil unrest). This, coupled with the fact that Moldova is the poorest country in Europe by some margin and was severely affected by the global financial crisis, would not appear to provide the most promising environment in which to achieve significant systemic development. Nevertheless, Moldova has implemented major positive change, which is transforming the lives of thousands of children and families.

Successive governments have continued in their commitment to reduce reliance on institutional care. Their sustained commitment, together with that from key NGOs including Lumos, as well as UNICEF and international donors such as USAID, the European Union and the World Bank, have resulted in radically altered systems of education, health and social services.

The following graphs provide a summary of that progress.

Helping children go home

The number of children in institutions nationally has reduced by nearly 70%.

This has been achieved because of a number of key developments at national level, including:

- Clear national strategies and policies for reform
- Consistent commitment and cooperation of all key stakeholders and cross-party political support for the reform programme
- Close cooperation of all government ministries, including Health, Education, Labour, Social Protection and Family and Finance
- Changes in legislation to ring-fence finances in residential care and transfer them to community based services, ensuring the sustainability of services needed to replace institutions
- Involvement of a number of NGOs working at county level to assist local authorities to implement change.
Lumos demonstration programmes

In addition to our national level work on policy, strategy, legislative change and capacity building, at the request of the government, Lumos worked in three demonstration sites – Ialoveni County, Floresti County and the largest institution in the Moldovan capital, Chisinau. Together with the authorities, Lumos’ Moldova team helped to plan, finance and implement major programmes of deinstitutionalisation. Lumos’ team of experts worked closely with local authority social workers, managers, teachers and health professionals to transform systems.

Resistance to change was significant and local capacity to manage change was limited. Thus Lumos provided a wide range of opportunities to build professional capacity and to visit community services in other countries. Communications strategies were implemented to influence the attitudes of key stakeholders.

Because of the additional resources and support provided by Lumos in the demonstration sites, the reductions of numbers of children in institutions were considerably more dramatic, as the following graphs demonstrate

In Ialoveni, the numbers of children in institutions reduced by 100% in six years.

Although there were a relatively small number of children in the institution in Ialoveni, the programme was hugely challenging. This was a residential special school for children with physical disabilities. The children came from all over Moldova, so reuniting these children with their families required the team to work across the whole country and to help more than 20 counties to set up support for the children, so that they could return home to their families and be educated in the mainstream school environment.

In Floresti County, the numbers of children in institutions reduced by 100% in seven years.

Floresti had its own particular challenges. As far as possible, Lumos works to support institution personnel to be retrained and redeployed in the new community based services set up to replace the institutions. Napadova institution was in a remote and isolated rural area. As a result, none of the personnel could be redeployed, since the services had to be established in the towns and villages where children needed them. Lumos provided additional redundancy payments to personnel to help ease this process.
Marculesti institution was a residential special school for children with intellectual disabilities. In order to make it possible for these children to move home to families, it was essential to develop inclusive education with an adapted curriculum and additional support teachers. That required a major shift in national policy, strategy and professional capacity and the redeployment of financial resources, as well as major attitudinal change in schools and communities, many of which were initially resistant to the inclusion of children with disabilities.

The government also asked Lumos to work in Chisinau, where the situation is extremely complex, with large numbers of children in institutions, who come from all over the country. Lumos agreed to work with Institution no. 2, because it was one of the largest in the country and the conditions were extremely poor. In addition, many of the children had been assessed as having challenging behaviour and many were already older teenagers. Experience teaches that family reunification would be an unlikely outcome for many of these children. When Lumos agreed to undertake this programme, it was in the knowledge that a long-term commitment was needed.

In Chisinau, the number of children in Institution no. 2 has reduced by 95% in seven years.

Experience in many countries shows that young people leaving care are especially vulnerable. The Lumos Moldova team developed a care-leavers’ support programme as part of the project, to ensure that young people getting ready to leave the institution were supported into housing, continued education, or employment, as well as provided with assistance to develop a support network in the community. This has been a key ingredient of success in Chisinau, where the number of children in the institution has reduced by 95% in seven years.

Lumos is working to ensure appropriate placements for the remaining 31 children in 2015. This highlights a key aspect of Lumos’ approach to ending institutionalisation.

No child is left behind.

No matter how complex their needs or how challenging their behaviour, Lumos is committed to ensuring that every child we work with moves from the institution to the placement that best suits their needs, making it possible for them to develop to their full potential.
The number of children in the institution in Orhei decreased by 63% in one year.

In addition to our demonstration sites, Lumos was asked last year by the government to intervene in an institution in Orhei where there were serious concerns about the levels of care for children. Where possible, Lumos attempts to be responsive and to support governments to address situations that are causing the greatest difficulty. There has been significant progress and the number of children has reduced by 63% in one year. Lumos is planning for the remaining 32 children to move to appropriate placements in 2015.

**Substitute family care**

The majority of children Lumos has helped to move from institutions were able to go home to their own birth or extended family, or were older teenagers supported into independent living. However, not all children can go home: a small number are orphaned and, in a very small number of cases, no matter what support was offered, the families were unable to provide a sufficiently safe and nurturing environment for their children.

Thus the development of substitute family care was essential.

As deinstitutionalisation programmes have been implemented across Moldova and numbers in institutions have reduced significantly, the numbers of children in foster care have increased by 260%.

Again, in Lumos demonstration sites, the rate of increase in foster care was even more dramatic.
Inclusive Education

When Lumos started work to end institutionalisation in Moldova, there was no national system for inclusive education. Therefore a significant percentage of children in institutions were separated from their families and living in residential special schools, often far away from home. Because of this, most deinstitutionalisation work taking place in Moldova was at that time focusing on children without disabilities, because not only did these children need to be placed in a family, but also they needed a place at school.

Therefore, the development of a strategy to end institutionalisation in Moldova required a comprehensive and coordinated strategy for the development of inclusive education. Lumos has led on the development of this strategy at national level and in demonstration regions. This has included, inter alia:

- Supporting changes in legislation and regulation
- Development of an adapted curriculum
- Training more than 10,000 teachers, policy makers and other stakeholders
- Designing and developing demonstration inclusive schools
- Establishing a system for the multi-disciplinary assessment of Special Educational Needs (SEN)
- Supporting the reform of the University curriculum for all trainee teachers.

Since 2010, the changes have been dramatic. This has made it possible for many children with disabilities to go home to their families and has prevented many others from being separated in the first place, as the following graph demonstrates.

The number of children with disabilities separated from their families and living in residential special schools has reduced by 47% in four years.

The number of children with disabilities educated in inclusive mainstream schools has increased by 350% in four years.

Moldova is committed to ending institutionalisation within the next five years. This report demonstrates this is eminently possible.
The Czech Republic

When Lumos began its work in the Czech Republic in 2008, the situation was considerably different to that in Moldova. The Czech Republic is an advanced country economically and its institutions for children were of a much higher quality than those in Moldova (better physical conditions, smaller numbers per institution, better trained personnel). Nevertheless outcomes of institutionalisation were poor. However, there was little political will to change the system and there were no national strategies in place to transform systems of care.

The Czech Republic, too, has seen its fair share of political instability. From 2008 to 2014, Lumos has worked with five different governments. During the first two years of Lumos’ work, the focus was on changing attitudes and supporting a small number of champions of reform in government to influence the attitudes of their colleagues and build a critical mass of support for reform. Lumos supported the development of a national strategy to transform the system of care for children and trained national policy makers, local politicians and managers of health, education and social services, as well as institution directors across the country.

In 2011 and 2012, Lumos, together with other NGOs campaigned for a major change in the legislation, aimed at preventing admissions to institutions and supporting children to stay in their families. The new law came into force in 2013. The results of this advocacy, capacity-building, training and campaigning work can be seen in the reduction of numbers of children in institutions.

Whilst numbers reduced only slightly from 2008 – 2010, more significant reductions have been seen over the past 3 years. In total, the number of children in institutions has reduced by nearly 20% in six years.

Even more significant is the reduction of the number of children admitted to institutions in 2013, which would appear to coincide with the change in legislation.

Whilst admissions had remained fairly static each year from 2008 – 2012, in 2013 the number of children admitted to institutions reduced by 16%. If this trend continues, as is likely, the next few years should see major reductions of the numbers of children in institutions.
Demonstration County

Lumos has worked closely with Pardubice County to build capacity of the local authorities, train professionals and encourage the development of community-based support services. As a result, the changes in Pardubice have been considerably more dramatic.

The numbers of children in institutions in Pardubice have reduced by 17%, but the rate of admissions has recently changed significantly, as the graphs below show.

Between 2008 and 2013 numbers of admissions to children’s homes in Pardubice reduced by 75%.

A similar trend is found in the numbers of babies and young children in institutions in the county. This is particularly gratifying, since babies are at significant risk of harm in institutions, particularly to their early brain development.
Comparing Pardubice County with the rest of the country, it can be seen that provision of additional support and capacity building has considerably accelerated the process of reform.
Substitute family care

Reform efforts have also seen numbers of children in foster care in the Czech Republic almost double since 2008.

Perhaps even more significant is the increase in emergency foster care. One of the key services needed to prevent babies and young children from being admitted to institutions is the provision of emergency foster care. Lumos supported the development of legislation, policies and training for emergency foster care and worked with another NGO to pilot the service even before the change in legislation.

Lumos supported emergency foster care to develop from a standing start in 2010. But since the change in legislation, the numbers have increased eleven-fold.

Lumos’ work with the authorities to promote foster care has also resulted in a significant increase in applications to become foster parents.
**Family support**

Last but by no means least, Lumos has trained social workers and helped the development of a national assessment framework, in order to support families and prevent separation.

The number of families supported by the county has increased ten-fold in the last eight years.

Thus it is clear that the key ingredients for ending institutionalisation in the Czech Republic are now in place. If the political and professional will continues, and if sufficient resources are allocated, it is eminently possible that, by 2020, there will be no more children in institutions in the Czech Republic.
Bulgaria

In 2009, the Bulgarian government developed its “Vision for Deinstitutionalisation of children in Bulgaria”. The European Commission Bulgaria desks of DG Regio and DG Empl, as well as the Bulgarian Ministry for Labour and Social Welfare, asked Lumos to assist them in transforming the Vision into a National Action Plan. Lumos assisted the government to:

- Facilitate an inter-ministerial and inter-agency planning process that put in place a plan to end institutionalisation of children by 2025
- Negotiate with the European Commission to allocate more than 100 million euros to the deinstitutionalisation programme
- Develop and implement assessment processes for children in institutions
- Provide urgent and live-saving interventions for hundreds of children at risk in institutions
- Develop management mechanisms at national and regional level to oversee the implementation of the plan.

Bulgaria is one of the poorest members of the European Union and in recent years has also proved a politically unstable environment. Since 2010, Lumos has worked with five successive governments. Sustaining political will has been a challenge. Nevertheless, progress has been significant.

Helping children go home

Since Lumos started its work in Bulgaria, the number of children in institutions has reduced by 54%.

This is all the more impressive since the Bulgarian plans decided to start with the most vulnerable children – young babies and children with multiple complex disabilities.

Even more significant is the recent reduction of admissions to institutions.

The numbers of admissions to institutions nationally have reduced by 34% since the ‘Vision’ was articulated. The reduction has accelerated considerably since 2012, coinciding with the development of community support services and foster care.
**Substitute family care**

Prior to the National Action Plan, authorities had found it difficult in Bulgaria to develop the foster care system.

But since the implementation of the EU funded programme, the numbers of foster families have increased by 440%.

**Demonstration regions**

Lumos has been working with two demonstration regions – Dobrich and Varna, where the results of work with the authorities are beginning to bear fruit.

In Dobrich the numbers of children in institutions have reduced by 58%.

In Varna, the numbers of children in institutions have reduced by 53%.

It is particularly encouraging to see the significant reduction of numbers of babies in institutions, as the example from Varna shows.

Although Bulgaria is a more recent programme for Lumos, the progress has been dramatic and rapid. This is testament to a joined up approach of government, NGOs and the European Commission as a funder. Bulgaria has set itself the target of 2025 to end institutionalisation. If the political will can be sustained, and EU funding continues to be channelled towards changing systems of care, it is likely that the target will be achieved much earlier.
The Last Word

This report has focused on providing documented numerical evidence of the dramatic changes in systems of care and support for children and families in three countries. However, numbers only tell part of the story. In 2015, Lumos will publish an accompanying report, which provides a quantitative and qualitative analysis of the impact of the changes on the health, development, quality of life and future life chances of the children we have helped to leave institutions.

Until then, we leave the last word to those most affected by the change – politicians, professionals, parents and, most importantly, children.

“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 regulations 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 as 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

“I attended different training programmes offered by Lumos on how to develop an individualised approach for the child with special educational needs. This is very important knowledge that helps us teachers to support every child. For example, one year ago a girl who had moved from an institution was integrated in my class, in the mainstream school. It was hard for her at the beginning to learn all the new lessons and do all the homework as well as her peers, but she has a strong personality, she is very industrious. I supported her after school. Now she is more confident and has made a lot of progress; she sometimes helps other children with their work. I am happy for this girl. She is a true example that inclusive education works when we provide the right support.”

Teacher in a mainstream school that has developed inclusive education with Lumos’ support
“I am so happy that you have helped us and I thank you – it’s because of people like you that I have my child beside me.”

*Maria and her son were reunited by Lumos*

“My name is Razvan and I lived in the residential institution for more than two years, feeling like I was nobody’s child. But now I want to tell you that I feel happy. I am happy because I live in a family, happy that I go to a school where you really can learn different things, and happy that my mother decided to offer me the possibility of the warmth of a family.

What could be more beautiful than family?”

*Razvan, aged 13, placed in family with Lumos’ support*
References

1 UNICEF estimates that more than 2 million children are in institutional care around the world, but this is an outdated figure based on a limited country scan, and UNICEF frequently acknowledges it as an underestimate. See UNICEF (2009), Progress for children: A report card on child protection. A 1985 report, which has been cited in other reports, puts the figure at 8 million. See Defence for Children International (1985), Children in Institutions, DCI, Geneva.


6 Lumos and ME unpublished data, 2014.

7 Lumos and ME unpublished data, 2014.

8 Lumos and ME unpublished data, 2014.


10 Lumos and ME unpublished data, 2014.


12 This is a combined figure of children in foster care and children in Family Type Children's Homes, a type of foster care where families take 3 – 5 children.


15 Official unpublished data of the National Bureau of Statistics, Moldova.

16 Lumos calculations based on data from Ministries of Labour and Social Affairs and Education and the Institute for Health Information and Statistics.

17 Lumos calculations based on data from Ministries of Labour and Social Affairs and Education and the Institute for Health Information and Statistics.

18 Lumos calculations based on data from Ministries of Labour and Social Affairs and Education and the Institute for Health Information and Statistics.

19 Lumos calculations based on data from Ministries of Labour and Social Affairs and Education and the Institute for Health Information and Statistics.

20 Institute for Health Information and Statistics, unpublished data.


29 Lumos internal communication, 2014.

30 Data from the Social Assistance Directorate, internal document, 2014.

31 Child Protection Department, Varna, internal communication with Lumos, 2014.

32 Child Protection Department Varna, internal communication with Lumos, 2014.