Deinstitutionalisation – A Human Rights Priority for Children with Disabilities

Georgette Mulheir[1]

The United Nations Convention on the Rights of the Child (CRC) clearly outlines a range of children's rights that, taken together, suggest that most children should live with and be cared for by their birth families (articles 9 and 7). It is the primary responsibility of parents to raise their children and it is the responsibility of the state to support parents in order that they can fulfil that responsibility (article 18). Children have the right to protection from harm and abuse (article 19), to an education (article 28) and to adequate healthcare (article 24). But they simultaneously have the right to be raised by their family. Where their family cannot provide the care they need, despite the provision of adequate support by the State, the child has the right to substitute family care (article 20).

Despite this, across the European region, it is likely that between 600,000 and 1,000,000 children are separated from their families and live in large residential institutions that cannot meet their needs.[2] There is a shortage of accurate statistics, but existing research suggests that children with disabilities are significantly over-represented in these institutions.[3] Research also demonstrates that the institutionalisation of children harms their health, development and future life chances.

It should be noted that the intentions behind this institutionalisation are usually good. Children with disabilities are often institutionalised as a way of providing "specialised" care. They are either considered to be ill,

therefore requiring constant medical care in long-stay hospitals, or are assessed with special education needs, which are provided for in centralised, residential special schools, often sited at a considerable distance from the family home. The logical intention of these institutions is to provide care and services to children. However, this results in the arbitrary separation of children with disabilities from their families and communities, and their isolation from society.

This article sets out some of the evidence of the impact of institutionalisation on children in Europe. It explores the human rights legislative and policy framework underpinning institutionalisation and outlines areas that require development. It assesses some of the most recent advances in policy and action to address the issue and makes recommendations for transforming systems of health, education and social protection services for children and families, in order to end the institutionalisation of children. In addition to published academic research, the article draws on the results of Lumos' research into placements of children in residential institutions in a number of countries.[4]

The Picture of Institutionalisation across the European Region

Over the past fifty years, most countries in the European region have begun to reform systems of care. In most cases the reform was triggered by a growing understanding

Photo credit: Lumos/Chris Leslie

of the harm caused by institutionalisation. In many Northern and Western European countries, reform efforts have resulted in a significant reduction in the numbers of children in institutions. However, in these countries, children with disabilities are still significantly over-represented in residential care. Furthermore, the picture across Northern and Western Europe is not uniform. Some countries continue to place even young babies in institutions of considerable size.[5]

The countries of Central and Eastern Europe (CEE) and the Commonwealth of Independent States (CIS) share a common history that includes decades of heavy reliance on the placement of children in large institutions. In these countries (with some exceptions), major efforts to reform systems of caring for children began in earnest over the past decade. This delay in reform is due to a number of factors, including:

- relative isolation, during the communist era, from international research evidence demonstrating the harm caused by institutionalisation;
- a lack of family- and community-based services, including sufficiently accessible health and education services;
- economic turmoil following the collapse of planned economies and the subsequent increase in poverty;
- a lack of professionals with specialised skills to address the needs of children with disabilities;
- The current global financial crisis, which, according to the World Bank, hit CEE/CIS countries harder than any other part of the world.[6]

Definition of an Institution

Most attempts to define institutions for children tend to focus on the number of children living together in one building. This does not

always provide a complete picture: a small group home with 15 children might have a staffing structure and ethos which means it functions in a family-like and inclusive way, whilst another with eight children might maintain an isolated, rigid and regimented system similar to that in a large institution.

Instead it is perhaps useful to focus on the definition of "institutional culture". The recent report by the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care,[7] known as the Spidla report, defines institutional culture through an examination of specific institutional characteristics. These include the precedence of the requirements of the organisation itself over the users' individualised needs, and the use of a medical model of care, which carries the risk of reducing individuals to their diagnoses.

Using the Spidla report's approach to the definition of institutional culture, institutions for children with disabilities are therefore defined as those residential facilities that:

▪ are isolated from the mainstream community, providing little opportunity for inclusion in normal everyday life and experiences;
▪ house relatively large groups of non-family members who are compelled to live together;
▪ result in prolonged periods of separation from the child's family, friends and community;
▪ are organised according to a regimented routine that cannot respond to the individual needs and wishes of the children; and
▪ segregate children from the community owing to a diagnosis of disability and/or chronic illness.

The Difference between Institutionalisation and Residential Care

Residential care does not automatically result in institutionalisation. Countries that have moved away from the use of large institutions have found that some children with very complex needs or challenging behaviours benefit from a placement in highly specialised, therapeutic residential care. This is ideally provided in small groups, living in normal houses, integrated into the community. A highly trained, professional workforce supports these children and, wherever possible, strong relationships with the birth and extended family are maintained. Where deinstitutionalisation has been successful, these residential placements account for a small percentage of the care provided to children with disabilities.

Most importantly, the difference between institutionalisation and good quality residential care can be demonstrated by the impact on health and developmental outcomes, as well as life chances and quality of life, for the children who live there.

The Impact of Institutionalisation on Children's Health, Development and Well-being

Over the past sixty years, research across Europe has demonstrated the harm caused by institutionalisation. In the 1950s and 1960s, studies in Britain and the former Czechoslovakia noted that children in institutions struggled to form healthy emotional attachments to their carers.[8] This was due to the number of carers working shifts in the institutions, and the regimented regime that could not respond to the individual needs and demands of children. The lack of emotional and physical contact, together with a lack of regular stimulation and interaction, resulted in specific developmental delays and challenging behaviours common to both the British and Czech children studied.

More recent research has found significant impairment of brain development among

infants raised in institutions, with the first six months of life being the most crucial.[9] Most babies removed from institutions and placed in families before the age of six months recovered completely from this impairment. Those who remained longer than six months recovered only partially and demonstrated continued developmental and emotional difficulties throughout their childhood and adolescence.[10]

There is considerable evidence that children living in institutions are at a significantly higher risk of being abused or neglected than their peers raised in families. One Romanian study found a high prevalence of physical and sexual abuse of children in institutions.[11] Studies in the UK have found that children in residential care are at very high risk of sexual exploitation[12] and that disabled children are more likely to live away from home in residential care or in state-funded residential education.[13] Additionally, a report for the Council of Europe found that:

"[A]buse in institutional settings is regarded by many to be endemic and can take place against a pervasive culture of depersonalisation, lack of privacy, inactivity, inadequate food and heating, poorly trained and supervised staff and isolation from community activities."[14]

One of the most comprehensive studies to make comparisons across European countries in recent years found a disturbing pattern in the outcomes for young children with disabilities in institutions. It compared the movement of children from social care institutions to the movement of children from institutions for children with disabilities:

"Children under three from social care institutions were most likely to leave the institution and be returned to their biological family (32%) or be adopted nationally (24%). The most common reason for children to leave an institution for children with disabilities was because of death. For children under three leaving institutions, 28% of those children with disabilities had died in comparison to 0.29% of children in social care institutions."[15]

Experience of early institutionalisation continues to have a negative impact as children grow into adults. One Russian study found severely reduced life chances for adults who had spent their childhoods in institutions: 20% had a criminal record, 14% ended up in prostitution and 10% committed suicide.[16] A study in Moldova by the International Organisation for Migration found that young women raised in institutions were ten times more likely than their peers to be trafficked for the purposes of sexual exploitation.[17]

Children with a moderate to severe intellectual disability face an even bleaker future. Analysis of admissions to and discharges from children's institutions in a number of countries demonstrates that the majority of these children, once they reach adulthood, are transferred to an institution for adults. The majority remain institutionalised – with all that implies – until their death.[18]

In summary, the harmful effects of institutionalisation include:

▪ impaired early brain development, leading to delayed cognitive and physical development and, in some cases, resulting in the onset of an intellectual disability;

▪ attachment disorders, which may result in the development of autistic behaviours, self-stimulation, self-harming, aggression to others or cruelty to animals;
▪ poor cognitive processing, resulting in educational under-achievement;
▪ poor physical health, including chronic infections;
▪ non-organic failure to thrive;
▪ unusually raised anxieties, specifically the fear of being abandoned and the fear of being alone, resulting in nightmares and sleeping disorders;
▪ eating disorders;
▪ enuresis;
▪ difficulty understanding right from wrong, resulting in behaviour such as lying and stealing;
▪ difficulties in forming healthy emotional relationships as adults;
▪ increased risk of child abuse and neglect; and
▪ significantly reduced life chances and, in some cases, life expectancy.

Reasons for Institutionalisation

Orphaned and Abandoned Children – Dispelling Myths

Lumos carried out an analysis of admissions to, and discharges of, 1,600 children aged 0-18 years, from residential institutions in two European countries. This study confirms, and sheds further light on, the findings of previously published research. There are many myths associated with the reasons for institutionalisation of children in Europe. Firstly, it is commonly understood that many of these children are "orphaned" or "abandoned". Yet true "orphanhood" and "abandonment" accounts for a very small minority of children in institutions.

In relation to "orphanhood", Browne et al found that across Europe, less than 6% of children in institutions under the age of three were actually orphaned.[19] Lumos' study of 1,600 children in two countries found that only 9% were actually orphaned.

In relation to abandonment, Browne's study concludes that, in countries that were EU member states prior to 2003, only 4% of children under three in institutions were abandoned. Yet in new member states and other countries across Europe, 32% of the children were considered to have been abandoned. It is likely that this significant differential is in part due to a difference in the legal definitions of abandonment and in social work practice. In English law, for example, abandonment is defined very restrictively as a matter of criminal law. Under the Offences Against the Person Act (1861), it is a criminal offence to abandon a child under two, endangering its life or health; this is an extremely rare practice. In a number of countries in CEE, a child can be "declared abandoned" if a parent has expressed a lack of interest for a period of months. This means a parent has not contacted or visited the child in that period. Yet there is no obligation on the part of the state actively to encourage parents to maintain contact with their children. It is likely therefore that these figures on abandonment disguise motivations related to poverty and other social issues. A recent study on abandonment in several European countries confirms that the lack of a definition of "abandonment" results in groups of children with very different circumstances being grouped together, and in parents having been labelled as abandoning their children when they had no intention of doing so.[20]

Lumos' analysis of children in institutions confirms Browne's findings on the subject of abandonment. In the Lumos' study, 11% of the children reviewed were defined as abandoned. Significantly however, children with disabilities appear to be over-represented in this group: in one country children with disabilities accounted for 63% of children in institutions defined as abandoned and 52% of those who had been orphaned.

Abuse and Neglect – a Varied Picture

Another striking difference among states found in Browne's research related to abuse and neglect as a reason for placing children in residential care. In the EU countries that were member states prior to 2003, overall rates of institutionalisation were generally lower than in other countries in the region. Of those children who were removed from their families, 69% were removed due to abuse and neglect. In the new member states and other countries in Europe, abuse and neglect accounted for only 14% of admissions. In these countries, as we have seen, socially-related "abandonment" accounts for 32% of admissions. A further 23% of admissions are children with disabilities.

This is a significant finding, since it is clear that abuse and neglect are at times legitimate grounds for separating a child from the family. Under the CRC, while factors such as poverty and disability should never be the primary reason for separating a child from the family, abuse and neglect may be such reasons. It should be noted, however, that where children are separated for reasons of abuse and neglect, placement in an institution is likely to exacerbate the trauma suf-

fered. This is of even greater concern when child victims of abuse are placed together with children who have perpetrated abuse. In a number of countries, Lumos has found that children in such institutions face increasing vulnerability and a greater risk of further abuse. For this reason, Lumos concludes that child victims of abuse should, as a priority, be placed in substitute families.

There is a tendency on the part of society and professionals to fail to detect the abuse of children with disabilities. Communication difficulties can act as a barrier to children disclosing abuse. But studies have consistently shown that children with disabilities are more likely to be abused than their peers:

"Sullivan et al (1997) found that disabled children were 1.8 times more likely to be neglected; 1.6 times more likely to be physically abused and 2.2 times more likely to be sexually abused. Cross et al (1993) found that disabled children were 2.8 times more likely to be emotionally neglected; 2.1 times more likely to be physically abused; 1.8 times more likely to be sexually abused and 1.6 times more likely to be physically neglected. Overall they were 1.7 times more likely to be abused or neglected than non disabled children."[21]

Lumos' research found that in a number of countries children and adults with disabilities are placed together in so-called "social care" institutions. In some of these institutions, a great effort has been put into separating children and adults. In others, however, children and adults may even share bedrooms. When discussing such practices with professionals, in some cases there is little understanding of the risks to children. A number of profession-

als and policy makers appeared to view adults with disabilities as "eternal children", who would therefore not pose a risk to children. The research indicates a clear need for the implementation of appropriate child protection policies and training programmes in all services that care for children. In addition, training is required to change attitudes towards, and understanding of, the needs and rights of adults with disabilities.

Poverty, Disability and Ethnicity

In addition to the considerable over-representation of children with disabilities in institutions, a number of studies also suggest that there is an over-representa-tion of children from ethnic minorities in institutions. However, it should be noted that data on ethnicity of children in care is often not available in the central databases of governments, or at times the individual files of children, and it is necessary to carry out in-depth research in the institutions themselves to provide an accurate picture. Where such research has been carried out, the results demonstrate a significant over-representation of ethnic minority children.

For example, Table 1, drawn from a recent European Roma Rights Centre study across six EU member-States, illustrates the dramatic over-representation of Romani children in institutions.[22]

Table 1: Romani Children in Institutions

	Bulgaria	Czech Republic	Hungary	Italy	Romania	Slovakia
Percentage of Romani children in children's homes visited	63.0%	40.6%	65.9%	10.4%	28%	82.5%
Share of Roma in the total population	10%	3%	7%	0.23%	9%	9%

The study demonstrates however that the picture is not uniform and there are significant differences between countries. Lumos' studies in a number of countries have produced similar findings to the above data in some countries, however in others, the over-representation was not so significant: for example 6% of children in institu-tions being Roma compared to 2% in the general population.

Grounds for Admission to Institutions

The reasons for admitting children to institutions identified by Lumos' study paint a complex picture of the inter-relationship between poverty, disability and ethnicity.

A Range of Reasons for Admission

Graph 1 represents a range of reasons given to Lumos for the admission of children within one country over one year.

These findings demonstrate that a relatively low percentage of children were admitted to institutions as they were orphans; there are three times as many children who are in institutions due to social

Graph 1: Reasons for Admission
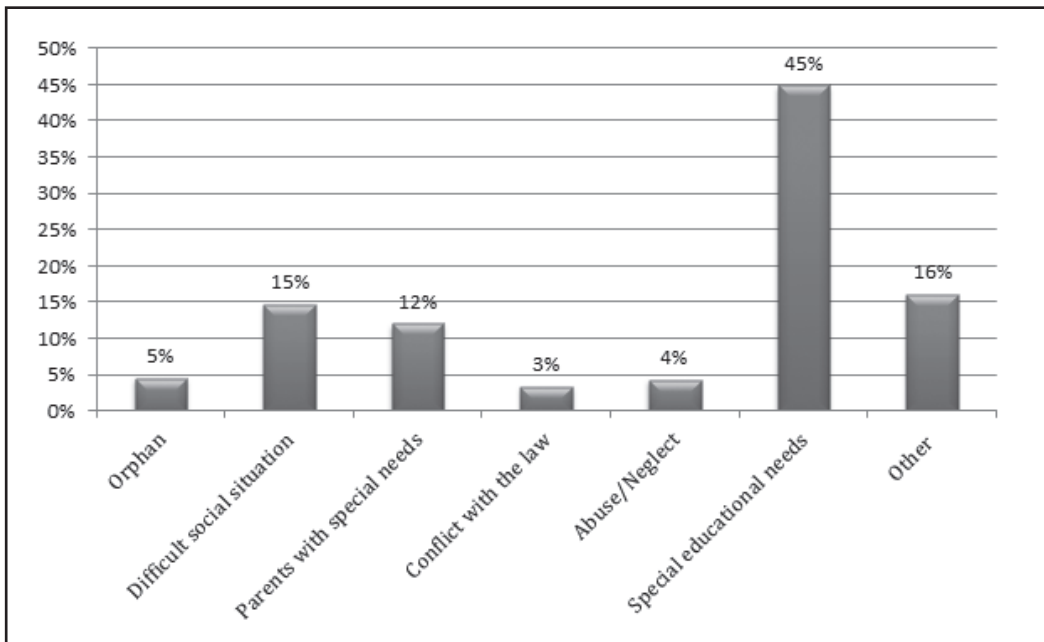
reasons as there are orphans. The "parents with special needs" include parents with special health needs, some of whom are likely to be able to look after their children if provided with some additional support. The prevalence of "special educational needs" highlights the need for a focus on inclusive educational services. Further, it demonstrates that in this country, nearly half of children in institutions are those with disabilities, placed for educational purposes.

Social Status of the Family - A Comparison between Three Different Children's Homes

Graph 2 provides a comparison of the family backgrounds of children within three institutions in **one country** as identified by Lumos' research.

A comparison of three institutions from another country demonstrates that a significant percentage of children come from situations of some kind of breakdown of

Graph 2: Family Backgrounds
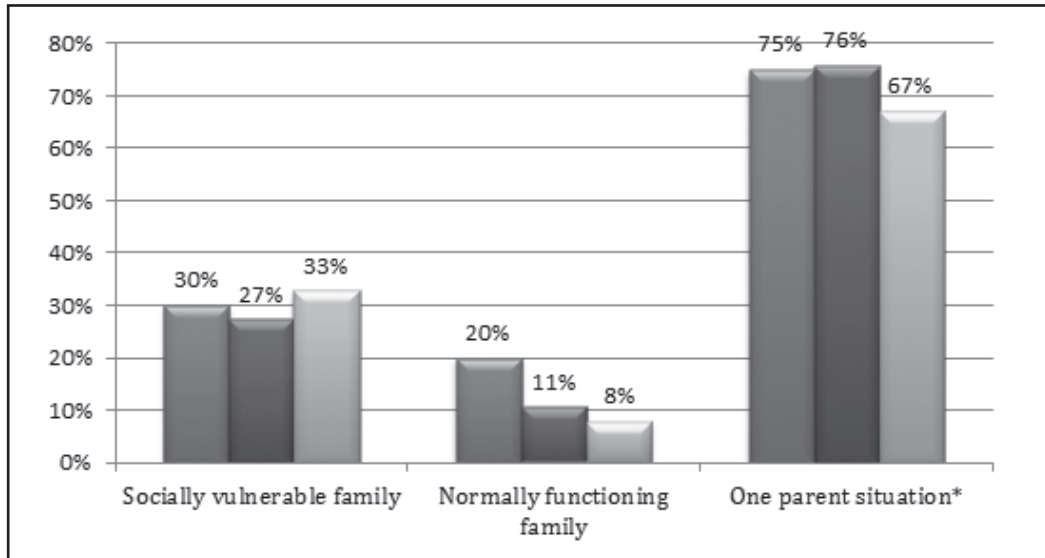
* One parent situation includes divorced parents, single parent, one parent in prison and one parent deceased.

the parents' relationship (single-parents, one parent deceased, divorced parents). It would appear that a breakdown in the relationship between the parents is a predictor of social vulnerability that may require additional services for single parents in order to prevent separation of children from their families. It is common knowledge that single parents are more likely to be living in poverty than those in couples. Furthermore, a number of studies demonstrate that disability can be a cause of breakdown of the relationship of the parents.[23]

Length of Stay Correlated with Disability and Ethnicity

Lumos' analysis has confirmed that not only were Romani children over-represented in institutions, but they also tended to stay for longer periods of time than children from the majority ethnic group. In the most extreme example of one institution, 69% of Roma children stayed for a year or more but only 18% of the majority population stayed longer than a year.

Similarly, children with disabilities or special health needs are generally more likely to stay longer in institutions. In one institution for babies where 50% of children had a disability, 90% of children who stayed for only up to three months did not have a disability. In another institution 57% of children with no special needs stayed for six months or less, whereas those with a sensory disability always stayed at least a year and 46% of those with an intellectual disability stayed for two years or more.

In the disability institutions most stays are long term, frequently 3.5 years and more.

This is a very long time to be separated from the family and the community. Lumos' research also highlights that once children are admitted to residential homes for disabled children, for the most part they stay there and later go on to another institution. Once admitted, children are not likely to be placed elsewhere, be it with the birth family, a foster family or in a better care facility.

Taking account of the negative impact of institutionalisation on a child's health, development and well being, it is evident that children with disabilities and those from ethnic minorities are likely to experience a greater impact of institutionalisation. This is likely to result in more severe developmental delays or disturbed behaviours than their peers.

Article 2(1) of CRC states that:

"States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status."[24]

It is clear therefore that the over-representation of children with disabilities and those of ethnic minorities in institutions, coupled with their extended stays, represents a contravention of Article 2 of the Convention.

The Link between Poverty and Disability

The relationship between poverty and disability has been well researched. It is a complex two-way relationship, in that disability causes poverty and poverty causes disability. A recent study in the UK found that:

"[W]ealthy families are a third less likely to have a disabled child. Families with a disabled child were on average £50/week worse off than others; despite the fact that **extra costs for raising a disabled child** means families need an extra 18% of income". (Emphasis added)[25]

Although the available research data in the CEE/CIS countries has been insufficient, a UNICEF study in 2005 found that:

"In Moldova, one third of households that have a child with disabilities fall into the lowest-income quintile, while only 8 per cent were in the highest quintile. In Romania, households that have children with disabilities have 65 per cent of the per capita income of those without."[26]

These figures are not surprising, since the additional care needs of a child with a disability often limit its parents' ability to undertake paid employment. Research also demonstrates that, particularly in lower and middle-income countries, poverty is a direct cause of disability, where:

"[T]he proportion of disability caused by communicable, maternal and perinatal diseases and injuries and the proportion of childhood disability are higher than in developed countries. Much of the disability in developing countries stems from preventable impairment, and a large part of the disability could be eliminated through treatment or alleviated through rehabilitation. Nutrition is particularly important."[27]

The impact on individual children of this poverty-disability axis is much greater in lower income countries, where the consequences can include high infant mortality rates and widespread lack of access to ad-

equate nutrition. Therefore, where children in lower income countries with a disability are more likely to live in poverty, the results of that poverty are more likely to harm the health and development of a child.

As children with disabilities grow into adults, they are more likely to live in poverty than their peers:

> "Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below poverty level, and less likely to have savings and other assets than the non-disabled population. These findings hold for both developing and developed countries."[28]

Thus it is evident that poverty is significantly more likely to affect the entire lives of children with disabilities than the lives of their peers. When planning support structures and services, this should be taken into account.

The Link between Poverty and Ethnicity

Recent research also demonstrates a strong link between poverty and ethnicity in Europe. For example, a survey conducted by the World Bank in Serbia found that 60.5% of the Roma population were considered "very poor," as compared to 6.1% in the general population.[29] A study by UNICEF also presented a very high poverty level for Romani children: 66.6% of children from Serbian Roma settlements and 83% of those living in slums were considered to be under the poverty line.[30]

In 2010, the World Bank found that approximately one third of the wage gap between Roma and majority populations was a result of discrimination and other factors beyond differences in education, experience,

and place of residence.[31] Other studies have shown a link between unemployment and the number of children in care.[32]

Lumos' study of 1,600 children admitted to institutions showed significant over-representation of Roma children and those from socially vulnerable families, reinforcing the World Bank findings which link poverty and unemployment with the separation of children from their families and their placement in institutions.

The Challenges for Children with Disabilities in Some Ethnic Minority Communities

Research indicates that there have been specific challenges for children with disabilities in specific ethnic minority communities. For example, amongst Roma populations in some European countries, discrimination appears to have led to the systematic misdiagnosis of Roma children as having special educational needs. Research in Hungary showed that the percentage of children in care categorised as having an intellectual disability was significantly higher among Romani children; one estimate was as high as 90% of the children with disability. The study indicated that the information provided by some of the children's home directors showed a higher percentage of Roma children with intellectual disabilities and it was suggested that at times the testing of these children was a matter of "social deprivation, diagnosed as disability".[33] There is evidence to suggest that such diagnoses were influenced by "scholastic aptitude tests", which were designed to reflect the dominant culture and language.

At the same time, Lumos' research found a lack of available evidence regarding Romani children with disabilities. A number of international organisations have written about the misdiagnosis of Romani children as having in-
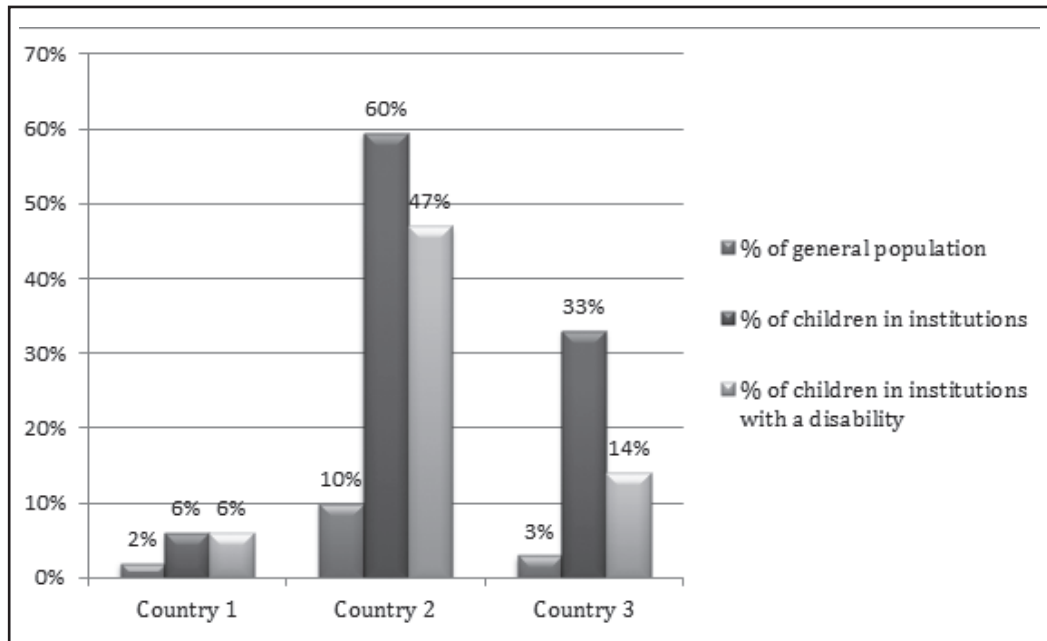
tellectual disabilities.[34] However, the specific topic of disability among Romani children and in the Roma community in general seems to be under-researched. Lumos' research suggests that some non-governmental organisations (NGOs), governments and communities may be reluctant to address the issue of disability among Romani children for fear of reinforcing the attitudes that have led to the misdiagnosis of many Romani children and their arbitrary separation from their families. However, this may result in Romani families of children with disabilities not accessing the services they require and is likely to delay interventions that might ameliorate the impact of disabilities on children's life chances.

Lumos' findings reflect those of a Council of Europe report, which demonstrates the links between disability and ethnicity and the sub-sequent social disadvantage and lack of access to support.

"People with disabilities from ethnic minorities are doubly disadvantaged in their dealings with social and welfare institutions and in their vulnerability to racially motivated abuse and discrimination. These "extra" disadvantages are not separate entities, running in parallel, but act as multipliers of difficulty and create a unique identity for disabled individuals who may be resisting hostile attitudes to disability within their own communities at the same time as they are struggling with the effects of social and economic discrimination due to racism from the dominant community."[35]

Graph 3: Romani Children with Disabilities in Institutions

Legend:
- % of general population
- % of children in institutions
- % of children in institutions with a disability

Country 1: 2%, 6%, 6%
Country 2: 10%, 60%, 47%
Country 3: 3%, 33%, 14%

However, despite a significant over-representation of Roma children in institutions, in some countries this was less of an issue among children with disabilities. This is shown in Graph 3, presenting the proportion of Roma in the general population, compared with the proportion of Romani children in institutions and disabled Romani children in institutions.

In addition, Lumos' research suggests that Roma families were more likely than the majority ethnic population to maintain relationships with their disabled children placed in institutions.

Poverty-Disability-Ethnicity Nexus

Many ethnic minority communities have higher levels of poverty and are therefore likely to have higher levels of disability among children. Yet discrimination suffered by some communities may result in under-reporting of disability. As a result, children with disabilities from some communities are likely to access services later than their peers in the majority community. Early intervention is crucial to ameliorating the impact of disability and maximising children's potential. It is, therefore, evident that planning services for children with disabilities should take these complex relationships into account.

Thus it would appear that in some European countries poverty and discrimination based on disability and ethnicity intersect to reinforce and exacerbate each other. Unpacking the reasons for admission to institutions and the practices that result in the over-representation of certain groups of children is essential to correcting these practices and implementing reforms that ensure all children, irrespective of background, can enjoy all the rights provided for by the CRC.

In this regard, Lumos' research found a number of factors common across many countries that still rely heavily on large residential institutions to look after vulnerable children. The findings summarised below are drawn from:

▪ the analysis of 1,600 admissions to institutions;
▪ the analysis of 102 cases of children referred to social services (through a process of considering each case, from the point of referral to case closure);
▪ the assessment of 1,388 families of children with disabilities in institutions.

Lack of Sufficient Support Services for Families in Poverty

In our study, social workers cited unemployment, housing and lack of access to basic material necessities as a primary cause of many cases of children referred to social services. Most social workers felt they had little or no options to offer these families other than an institutional placement.

Stigma and Discrimination Attached to Disability

Families cited frequent occasions when health, education or social work professionals had advised them to place their children in an institution. Professionals expressed a belief that most families of children with disabilities did not want their children and cited a lack of contact with children as evidence. However, many parents involved in the family assessment stated that when they tried to find out more about their children, they were informed that the child had severe disabilities and there was no point in coming to disturb and upset them (or, for that matter, upset themselves). Some parents were also informed that it was best for their child if they did not visit and did not enquire after them, as the child would get upset after each visit.

The family assessment found that 53% of families who had lost contact with their children with disabilities expressed a desire to re-establish contact and for their children to be placed close to them to facilitate this contact.

Discriminatory Assumptions about Romani Families

The misdiagnosis of Romani children as having special educational needs appears to be based on rigid and discriminatory approaches to assessment and has resulted in high levels of Romani children without disabilities admitted to residential special schools. In addition, Romani families frequently faced discrimination when attempting to access services for their children (such as health care).

Lack of Sufficiently Accessible and Supportive Universal Health and Education Services

The lack of inclusive education services for children with disabilities in many countries results in continued arbitrary separation of children from their families and placement in residential special schools, often sited a considerable distance from the child's home.

Lack of Sufficient Investment in Frontline Social Work

Common findings in most of the social work cases studied include:

▪ All social workers had high case loads and were over-stretched, making it difficult to allocate sufficient time to each case.
▪ In many cases, this resulted in an inability to intervene early; as a result, many cases were referred several times to social services before action was taken. This usually resulted in deterioration in the case and action being taken once the situation had reached crisis point. In these cases, the most common result was removal of the child from the family and their placement in an institution.

▪ Once children were placed in institutions, social workers felt these children were "safe" and therefore focused on other pressing or crisis cases; as a result there was little follow up or review of children's placements. Children then spent long periods of time in institutional placements.
▪ Social workers cited insufficient training and a lack of regular supervision and professional support. Many social workers were taking significant levels of responsibility for decision-making in challenging cases without appropriate guidance.
▪ A lack of tools for systematic assessment, decision-making, monitoring and follow up of children was identified by the researches among social workers from a number of countries. Where assessments existed, these often focused on material welfare and rarely involved direct discussion with, or observation of, the children involved.
▪ A lack of alternatives to institutional placements meant that, faced with cases of severe risk to children, social workers felt they had no alternative but to place children in institutions. In a number of countries, foster care was under-developed. Where it existed, it tended to operate as quasi-adoption, where placements were considered permanent and foster parents were reluctant to facilitate contact with birth families. Foster care is still not available for children with disabilities in many countries. In addition, some countries are reluctant to place young babies in foster care, despite the fact that the greatest harm caused by institutionalisation occurs in the first six months of life.

Legal and Human Rights Framework

Previously published academic research and Lumos' analysis presented in this article

demonstrate that the rights of children separated from their families and placed in institutions are infringed on a number of levels. This raises questions regarding the human rights legislative framework, including:

▪ Are the human rights instruments sufficiently understood by governments and communities involved in reforming and providing services?
▪ Are there sufficient resources for governments to make the changes necessary to implement the human rights framework for children with disabilities?
▪ Is the human rights legislative framework sufficiently robust to ensure all children, including those with disabilities and the most complex needs, receive the support and services they need to develop to their full potential?

A number of international human rights instruments are relevant to the care and protection of children with disabilities. The strengths and limitations of three key instruments are considered here.

The UN Convention on the Rights of the Child (CRC)

As outlined at the beginning of this article, the CRC provides a clear framework regarding the care and protection of children, including the following principles:

▪ Parents have the primary responsibility for raising their children;
▪ The state should support parents to fulfil their responsibilities;
▪ Where, despite support, parents are unable to care properly for their children, children have a right to protection from harm and abuse;
▪ If that protection involves removal from the family, placement in a substitute family is the preferred option; and

▪ All these rights apply to all children, including children with disabilities.

However, references to disability in the CRC could be interpreted in ways that are contrary to the rights framework outlined above. Disability is only mentioned in two articles throughout the whole Convention: articles 2 and 23. The specific article on disability (article 23) does not mention the child's right to family life. Instead, it focuses on children's development of independence and their access to health, education and other services. This, coupled with article 20, which allows placement in "suitable institutions", appears to have been interpreted in some countries as a justification for institutionalisation. Since there are inadequate community based specialised health and education services, institutionalisation in residential special schools or special hospitals is seen as a way of ensuring children's rights to access those services. But this is at the expense of the right to family life.

The UN Convention on the Rights of Persons with Disabilities (CRPD)

The welcome advent of the CRPD begins to address the lack of detail on disability in the CRC. The Convention sets up a framework to ensure the fullest possible independence and integration in the community of persons with disabilities. Article 19 is widely cited by Disabled Persons Organisations (DPOs) and other NGOs to argue for an end to institutionalisation of disabled adults. The focus of article 19 is the right to "live independently and be included in the community". However, in many respects this article is predominantly focused on adults. In fact, children need to be cared for in families, in order to grow into independent adults.

Article 7 of CRPD, which is the article specific to children, states:

"1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right".

This article is important, but it is quite general, reflecting the essence of articles 2, 3 and 12 of CRC. Specifically, it does not emphasise disabled children's right (and need) to be raised in a family environment. As with the CRC, the concept of "best interests of the child" is open to interpretation.

Article 23 of CRPD guarantees respect for home and the family. Article 23 (3) states that:

"States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families."

However, article 23 does not explicitly prohibit the use of arbitrary separation under the guise of providing children with health and education services, which research has shown is the primary reason for institutionalisation of children with disabilities in Central and Eastern Europe. Article 24 of CRPD is of some value in this regard as it emphasises the right to inclusive education.

The European Convention on Human Rights (ECHR)

This Convention is of great importance, since it is legally binding for all member states and sanctions can be applied if it is contravened.

Article 8 of ECHR guarantees the right to respect for private and family life and requires that any interference with this right by a public authority be justified as being in accordance with the law and necessary in a democratic society. But this Convention has no specific references to children, for whom interference in private and family life has a different meaning compared to that of adults.

In summary, the Convention on the Rights of the Child has little focus on disability and the Convention on the Rights of Persons with Disabilities appears to be drafted primarily with adults in mind. The European Convention on Human Rights contains no reference to children at all. This lack of reference does not automatically mean lack of protection, since children are rights holders under ECHR. However, there is a risk that the potential of the ECHR, and its case law, to act as a living instrument that protects children with disabilities, will not be fully realised. Unless all the Conventions are interpreted holistically and purposefully by governments and judicial authorities, there is a risk that children with disabilities may fall between the gaps of the human rights legal framework.

Cost Effectiveness and Cost Benefit of Deinstitutionalisation

Removing children from their families due to poverty or social reasons represents a violation of their rights. As argued above, it has a negative impact on their health and development and reduces their life chances. However, it is also a relatively expensive way of looking after children. Often one of the greatest challenges faced by governments in trying to fulfil their obligations under international Conventions is the financial cost involved. The deinstitutionalisation process does require investment, but in the long run proves to be cost effective for governments.

In most cases, the cost of supporting a child to remain in their family is significantly lower than the cost of placing a child in residential care, whilst outcomes are considerably better.

Graph 4 presents examples from two European countries, Sweden and England, outlining the costs per child per year to place them in residential care, in foster care or to support them in their family.

Although the residential care provided is extremely expensive, very few children with disabilities require this service and most are cared for at home. For example, in one county in England, only 0.7% of children with disabilities lived in residential care. In one county in an Eastern European country, that rate was 7%: the government of a much poorer country was paying for ten times as many children with disabilities to live in residential institutions.

The process of moving from heavy reliance on large institutions to a system of family and community based care should be an exercise in the reinvestment of resources. By reducing

Graph 4: The Cost of Supporting a Child
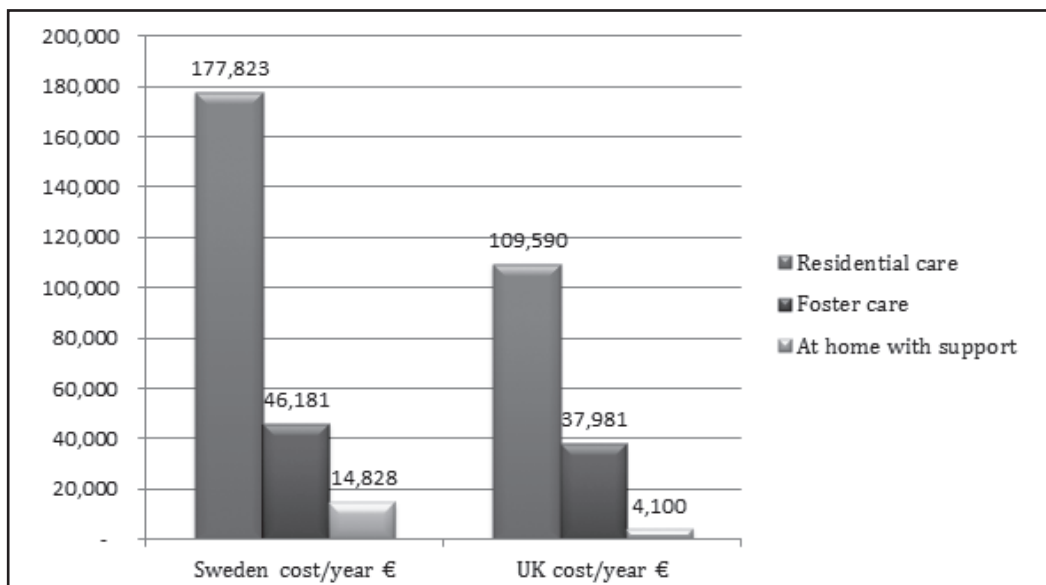
the numbers of children in residential care, money can be freed up to support much larger groups of children to live in families. This can also make increased funding available for the small minority of children with highly complex needs, for whom the provision of high quality care requires significant investment.

A number of studies have demonstrated the cost benefit of investment in good community support services for children with disabilities.[36] Early intervention in particular ameliorates the impact of disability and improves children's chances of completing education, gaining employment as adults and contributing to the economy. This approach also reduces the amount the state needs to spend on provision of support services throughout the life of a person with disabilities.

Key Developments in Policy and Advocacy

In recent years, a number of advocacy and policy developments have taken place at the international level that are paving the way for deinstitutionalisation of children with disabilities. A number of key examples follow.

Better Health, Better Lives

The World Health Organisation's Better Health, Better Lives Initiative was launched in 2008. The initiative aims to:

> "[E]nsure that all children and young people with intellectual disabilities are fully participating members of society, living with their families, integrated in the community and receiving health care and support proportional to their needs."[37]

The Initiative takes a holistic approach to the health, development and well-being of children with intellectual disabilities and the role of different agencies to achieve 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 goes some way to bridging the potential gap on the rights of children with disabilities and in particular, by making explicit the implied inter-connected rights of children to live with their families *and* access appropriate health and education services *and* participate fully in the community, live with dignity and achieve independence. Moreover, it provides a framework for ensuring these rights are realised.

The Spidla Report

In 2009, EC Commissioner for Employment and Social Affairs, Vladimir Spidla, asked a group of experts to produce a report on deinstitutionalisation in Europe. The report covered the situation of four groups of people – children, adults with disabilities, people with mental health problems and older people. The Expert Group represented a range of NGOs, DPOs and service providers across Europe.

The report made a range of specific recommendations to EU member states and to the EC itself. Key recommendations included: all countries to develop national action plans for deinstitutionalisation; the EC to ensure deinstitutionalisation is factored into its work with countries outside the EU; the development of a set of Common European Guidelines on deinstitutionalisation that could be used by EU member state governments to plan reform, but could also be used by EC desk officers in assessing reform projects and allocating funding.[38]

Common European Guidelines and Toolkit

On the basis of the recommendations of the Spidla report, the European Expert Group on the Transition from Institutional to Community Based Care is currently developing a set of Common European Guidelines on deinstitutionalisation and an easy-to-use Toolkit for assessing financing programmes and initiatives in the context of the use of EC Structural Funds.

Recommended Priorities for Future Action

It is evident that children with disabilities face multiple disadvantages throughout their lives. There are strong links between disability and poverty, abuse, social exclusion, and lack of access to adequate health care and education. Investing to ensure equal rights in most cases requires the direction of additional funds towards these children and their families, in order to:

▪ Lift them out of poverty;
▪ Protect them from harm and abuse;
▪ Ensure they can live with and be cared by their families, included in their community;
▪ Ensure they receive the healthcare and therapy they need to develop properly; and
▪ Ensure they receive education that gives them the opportunities to learn and develop to their full potential.

The institutional system should be seen as a resource to be reallocated to community based services and to strengthen and make more accessible universal healthcare and education services, in order to ensure full access to rights for all children with disabilities.

With this in mind, the following recommendations are made:

▪ Countries that still have significant numbers of children living in large residential institutions should develop national action plans for complete reform and deinstitutionalisation.
▪ These plans should prioritise young babies and children with disabilities, since they tend to be the most vulnerable children in institutions. In addition, it is often the case that children with disabilities are left until last in reform programmes, as authorities tend to focus first on children who are considered to be "easier to place".
▪ Plans for reform should ring-fence resources from the institutional system and reallocate them to family and community services.
▪ The next programming period for EC funding should prioritise deinstitutionalisation, in order to fulfil the EU's responsibilities under the CRPD. Regulations should be developed to avoid the investment of EC funds in renovating large institutions or the development of other services that would continue to isolate or segregate children with disabilities.
▪ Other donors should coordinate their efforts to support the deinstitutionalisation process. Donors should be discouraged from investing in the "improvement" of institutions, as this often results in a reluctance to reform them.

With concerted efforts, it is possible to ensure that all children with disabilities can enjoy their rights to be raised in their families, included in their communities, provided with education and healthcare, have their voice heard and develop to their full potential.

---

1   Georgette Mulheir is the Executive Director of Lumos. This article was written in association with Lina Gyllensten, Iliana Tsankova, Jan Klusacek and Bisser Spirov. The authors work for the international children's char-

ity Lumos, which works to put an end to the systematic institutionalisation of children within the next 20 years, ensuring that all children have the opportunity to grow up in a safe and caring family environment or, where there is no alternative, in specialist services that meet all their needs, respect their rights and ensure they can fulfil their potential.

2   The broad range of 600,000 to 1,000,000 is the result of a shortage of reliable data to cover the whole European region (as defined by the UN). The figures in this report are drawn from a combination of sources, including: *Transmonee* (http://www.transmonee.org); Browne, K., Hamilton-Giachritsis, C., *Mapping the number and characteristics of children under three in institutions across Europe at risk of harm*, University Centre for Forensic and Family Psychology (European Union Daphne Programme, Final Project Report No. 2002/017/C), 2005; European Commission, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care.* Brussels: European Communities, 2009.

3   Browne, K., Hamilton-Giachritsis, C., above note 2.

4   Where no source reference is provided, the statements in the report are made with reference to own studies conducted by Lumos in the period 2007–2012. Due to the nature of our work and to maintain confidentiality in our research we have refrained from naming the particular countries involved.

5   Browne, K., Hamilton-Giachritsis, C., above note 2

6   The World Bank, *The Crisis Hits Home: Stress-Testing Households in Europe and Central* Asia, 2010.

7   European Commission, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, Brussels, 2009, p. 8.

8   Bowlby, J,. *Maternal care and mental health,* Geneva, World Health Organisation, 1951; Matějček Z., Langmeier, J., *Psychická deprivace v dětství* [Mental deprivation in childhood], Prague, Avicenum, 1964.

9   Nelson, C., Zeanah, C., et al, *Cognitive Recovery in Socially Deprived Young Children: The Bucharest Early Intervention Project,* Science, Vol. 318, No. 5858, 2007.

10   Rutter, M., The English and Romanian Adoptees Study Team, "Developmental catch-up and deficit, following adoption after severe global early privation", *Journal of Child Psychology & Psychiatry,* Vol. 39, 1998, pp. 465-476.

11   UNICEF, *Survey on child abuse in residential care institutions in Romania,* 2000. For a similar study in Serbia, see Mental Disability Rights International, *Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with disabilities*, 2007.

12   CEOP Thematic Assessment, *Out of Mind, Out of Sight – Breaking down the barriers to understanding child sexual exploitation,* 2011.

13   Stuart M., and Baines C., "Progress on safeguards for children living away from home – A review of actions since the People Like Us report", *JRF*, 2004.

14   Brown, H., *Safeguarding adults and children with disabilities against abuse*, Council of Europe Publishing, 2003, p. 31.

15   See Browne, above note 2, p. 22.

16   Pashkina quoted in Holm-Hansen, J., Kristofersen, L. B. and Myrvold, T. M. (eds.): *Orphans in Russia*, NBR-rapport 2003, Vol. 1, p. 83**.**

17   International Organisation for Migration, *Protecting Vulnerable Children in Moldova*, 2007.

18   Lumos' analysis of residential institutions 2009-2012.

19   See Browne, above note 2, p. 1.

20   Browne, K., Chou, S., Whitfield, K., *Child Abandonment and its Prevention in Europe*, 2012.

21   Sullivan, P. M., Knutson, J. F., "Maltreatment and disabilities: a population-based epidemiological study", *Child Abuse and Neglect,* Vol. 24, 2000, pp. 1257-1273; Cross, S. B., Kaye, E., Ratnofsky, A. C., *A report on the maltreatment of children with disabilities,* National Center on Child Abuse and Neglect, 1993. For further information, see www.nspcc.org.

22   European Roma Rights Centre, *Life Sentence: Romani Children in Institutional Care,* 2011, p. 7.

23   See, for example, UNICEF, *Children and Disability in Transition in CEE/CIS and Baltic States*, 2005.

24   Convention on the Rights of the Child, 1989, Article 2(1).

25   Blackburn, C., Spencer, N., Read, J., "Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey", *BMC Pediatrics,* Vol. 10, 2010, as quoted in Ramesh, R. "Study shows links between poverty and disability are more pronounced", *The Guardian*, 19 April 2010.

26   UNICEF, *Children and Disability in Transition in CEE/CIS and Baltic States*, 2005, p. 25.

27   Elwan, A., *Poverty and Disability,* World Bank, 1999, p. iv.

28   Ibid.

29   World Bank, *Serbia and Montenegro Social Exclusion and Poverty Report*, 2003, p. 3.

30   UNICEF, *The State of Children in Serbia*, 2006, p. 26.

31   World Bank, *Roma Inclusion – an Economic Opportunity for Bulgaria, Czech Republic, Romania and Serbia*, 2010, p. 11.

32   Carruth, A., Oswald, A., *An Empirical Study of Unemployment and the Number of Children in Care*, CEP Discussion Papers, Centre for Economic Performance, LSE, 1991.

33   See above, note 21, p. 4.

34   See, for example, European Roma Rights Centre, *Stigmata: Segregated Schooling of Roma in Central and Eastern Europe*, 2004; Open Society Institute, *Roma Children in Special Education in Serbia*, 2010.

35   See above, note 13, p. 4.

36   See, for example, Walsh, K., Kastner, T., Green, G., "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research", *Mental Retardation*, Vol. 41, 2003, pp. 103-122.

37   World Health Organisation, *Conference on children and young people with disabilities*, Bucharest, 2010, available at: http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/activities/intellectual-disabilities.

38   European Commission, above note 2, p. 2.