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## ENABLING REFORM

Why supporting children with disabilities must be at the heart of successful child care reform

**EveryChild.**

**Better  
Care  
Network**

## ACKNOWLEDGEMENTS

This paper was developed jointly by the Better Care Network and EveryChild as part of the Better Care Network's series of working papers on alternative care. The paper was written by Emily Delap, EveryChild's Global Policy Advisor, and Chris Saunders, a consultant. Kathleen Riordan and Ghazal Keshavarzian of the Better Care Network conducted additional research for the paper and provided important comments on content. The reference group for the paper (listed in Annex 1) also provided many useful insights.

Emily Delap has worked on child rights for over 15 years, and for EveryChild—an international nongovernmental organisation (NGO) specialising in children without parental care—for the last two years. Before joining EveryChild, she worked as a researcher, trainer and policy advisor for a number of organisations, including Save the Children and Anti-Slavery International. She has a Master's degree in Social Policy and Planning in Developing Countries from the London School of Economics. This paper complements other policy papers produced by EveryChild which focus on various forms of alternative care. To receive these papers, please email: [policy@everychild.org.uk](mailto:policy@everychild.org.uk).

Chris Saunders has worked in international development for more than 30 years. His posts have included global policy adviser on childhood disability and head of the Southern Africa regional office for Save the Children. He has country and programme management experience in Africa and the Middle East, and most recently was CEO of Transaid, a development organisation specialising in transport and health delivery systems in Africa.

### **EveryChild**

EveryChild is an international charity working to keep families together, to support appropriate alternative care for children who cannot live with their parents, and to protect children who are alone and at risk.

4 Bath Place, Rivington Street London EC2A 3DR

Email: [policy@everychild.org.uk](mailto:policy@everychild.org.uk)

Tel: 00 44 (0) 20 7749 2490

[www.everychild.org.uk](http://www.everychild.org.uk)

Charity registration number: 1089879.

Company registration number: 4320643

### **Better Care Network**

Better Care Network is an interagency network dedicated to facilitating global information exchange and collaboration among the growing number of organizations, religious groups, governments and individuals working on the issue of children without adequate family care.

3 UN Plaza, Room 723-5

Email: [contact@bettercarenetwork.org](mailto:contact@bettercarenetwork.org)

Tel: 212.326.7104

[www.bettercarenetwork.org](http://www.bettercarenetwork.org)

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## EXECUTIVE SUMMARY

Around the world, many efforts are being made to reform child welfare systems to promote better care for children. As articulated by the Guidelines for the Alternative Care of Children, such reform should involve greater support to families to prevent a loss of parental care and efforts to provide quality alternative family-based care for children who cannot be with their parents. This paper aims to convince those who are developing and implementing such policies that they should place support for children with disabilities and their families at the heart of reform efforts, and to demonstrate, through examples, how this can be achieved.

The paper defines persons with disabilities as:

“... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (CRPD Art 1 UN 2006).

This paper builds on a social model of disability which recognises that disability is not just a consequence of impairments, but also reflects attitudes and responses to those with impairments. This model rejects a purely medical view of disability, which focuses exclusively on treatment and ‘cure,’ often in isolation from wider society. Instead, the model promotes efforts to change discriminatory attitudes and encourage the full integration of those with disabilities into families and communities.

The paper provides four key reasons for placing disability at the heart of child care reform agendas:

**Millions of children with disabilities remain in harmful institutional care:**

Depending on definitions and data collection methods used, between 14 and 35 per cent of children have disabilities. In some settings, substantial numbers of these children are placed in institutional care. In Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS), around one third of children in institutional care have disabilities. In countries such as Mexico and Viet Nam, governments continue to invest in institutional care for those with disabilities. Care in such large-scale facilities provides limited opportunities for rehabilitation and is often associated with abuse, neglect and an absence of individualised attention. Such poor care can cause or exacerbate disability.

*“I looked into the crib and saw a child who looked to be seven or eight years old. The nurse told me he was 21 and had been at the institution for 11 years. I asked her how often he was taken out of the crib and she said, ‘Never. He has never been out of the crib in 11 years.’” (MDRI investigator, Serbia, cited in MDRI 2007, p. v)*

**Families trying to care for children with disabilities at home receive no or minimal support:**

In resource constrained settings there is often only limited health and education service provision for children with disabilities. For example, there are no national rehabilitation services for those with disabilities in 62 countries of the world. In some settings, the only way to enable children with disabilities to receive health care or education is through residential care. Parents or extended family members frequently have to give up work to care for children with disabilities and get limited help with child care or social protection. Those with disabilities often face extreme stigma and social exclusion, meaning that even the important informal support of the extended family or community is not always forthcoming.

*"[Our son] has been staying [in an institution] for four years now, because we do not live close to the school and we cannot manage to go there every day and spend four hours commuting."* (Rita, mother in Latvia, cited in UNICEF 2005, p. 53)

**Domestic adoption and fostering are options rarely open to children with disabilities:**

Domestic adoption and fostering services are poorly developed in many parts of the world, especially for children with disabilities. A global overview of adoption services by the UN shows limited opportunities for adoption for children with disabilities in many parts of the world, and country level studies in China, Namibia, Ukraine, Nepal and Rwanda suggest that children with disabilities have not had the same access to already limited domestic adoption or foster care programmes as other children in these settings. General under-investment in these services, poor recruitment campaigns for carers, lack of knowledge and understanding of disability amongst social workers, limited care planning, lack of post-placement support and service provision, and wider stigma and discrimination associated with disability can all make it especially hard to find alternative family-based care for children with disabilities.

**There is a legal and economic imperative to provide proper care for children with disabilities:**

Together, the UN Convention on the Rights of the Child (CRC), the UN Convention on the Rights of Persons with Disabilities (CRPD) and the Guidelines for the Alternative Care of Children highlight the need to end unequal provision in children's care and the use of institutional care for children with disabilities, and instead support care in families and communities. Institutional care is expensive, much more so than support to parents or family-based care. In the long run, if poor care exacerbates disability or provides inadequate opportunities for helping those with disabilities to learn to live independently, children with disabilities will continue to need the support of the state long into adulthood.

This paper suggests that it is imperative for governments, UN agencies and civil

society groups working on both disability and alternative care to:

**1. Challenge discrimination and create the political will for change by:**

- Creating a strong alliance between Disabled Peoples Organisations and those working on alternative care;
- Highlighting the economic, developmental and legal imperatives for action; and
- Making children with disabilities more visible and empowered through better data collection and research, and promoting their active engagement in decision making and advocacy.

**2. Change national legislation and guidance on disability and alternative care to reflect the CRC, CRPD and Guidelines for the Alternative Care of Children.**

**3. Provide better support to families caring for children with disabilities, through integrated systems which link health care, education, child welfare and social protection services. These should build on Community Based Rehabilitation and integrated child protection models and involve children with disabilities in the design, delivery and monitoring of interventions.**

**4. As a matter of priority, end the institutional care of all children, including those with disabilities, and ensure that children with disabilities have a range of high quality family-based alternative care options open to them, through:**

- Investing in a range of different forms of domestic adoption and foster care, including respite care, and providing detailed guidance to foster care and adoption service providers on strategies to make such services more inclusive and aimed at meeting the needs of children with disabilities;
- Promoting proper care planning, gate-keeping and rehabilitation services to limit unnecessary time in alternative care for children with disabilities, and to ensure that the views of children with disabilities and their carers are fully taken into consideration;
- Exploring a limited role for small group homes and inter-country adoption for children with disabilities, in line with efforts to create a range of care options for all children;
- Carefully closing existing institutions, and ensuring that whilst children with disabilities remain in institutional care, they are properly protected and cared for and that adequate preparations are made for integration into families and communities; and

- Working to ensure the care and protection of children with disabilities in both normal and emergency settings.

Only through such efforts will it be possible to achieve much needed comprehensive reform of alternative care and child welfare systems which recognise the rights of all children, including those with disabilities.

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# 1. INTRODUCTION

Around the world, many efforts are being made to reform child welfare systems to promote better care for children. As articulated by the Guidelines for the Alternative Care of Children (UN 2010), such reform should involve greater support to families to prevent a loss of parental care, as well as efforts to provide quality alternative family-based care for children who cannot be with their parents. This paper aims to convince those who are developing and implementing such policies that they should place support for children with disabilities and their families at the heart of reform efforts, and to demonstrate, through examples, how this can be achieved. The paper clearly illustrates how a persistent failure to do this is hampering reform and threatening the rights of millions of children around the world. The paper uses evidence from Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS) to show how ignoring disability is preventing much needed reductions in harmful institutional care. It uses research and examples from Africa, Latin America and Asia to highlight the lack of support to families caring for those with disabilities, as well as the benefits of multi-sector, community-based approaches. It also draws on lessons learnt from North America, Australia and Western Europe to show how family-based care can be made more inclusive, acknowledging that even in these well resourced settings there is still a long way to go before children with disabilities have equal care choices.

The paper is based on a literature review and consultations with experts (see Annex 1). It is divided into two main parts. Following this introduction, the paper provides a clear case for ensuring that a consideration of childhood disability is at the heart of child care reform. It then explores key actions for meeting the needs of children with disabilities through these reforms. The paper concludes with a summary of the evidence and recommendations for policy makers.



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## 2.

### WHY CHILDHOOD DISABILITY SHOULD BE AT THE HEART OF CHILD CARE REFORM

In this section, the case for placing support for children with disabilities and their families at the heart of efforts to reform alternative care for children is explored. It is argued that:

*“No one who works in the field of child care or children’s services must continue to think that disabled children are someone else’s concern. We are all responsible.” (Cousins 2009)<sup>1</sup>*

#### Millions are affected by childhood disability

As shown in Box 1, below, far from being an issue facing a small number of individuals, estimates suggest that there are many millions of children with disabilities worldwide. These children have a wide range of impairments, with greatly varying degrees of severity, and face differing challenges with daily living and attitudes from society (WHO and World Bank 2011). As is discussed in more detail below, disability also has major ramifications for the livelihoods and lives of other family members, suggesting that many more millions of adults and children are touched by childhood disability.

In the developing world, childhood disability is closely associated with poverty and a failure of the state to provide basic health services for women during pregnancy and for children during their early years of life. In more affluent countries, childhood disability may conversely be linked to advances in medicine that sustain the lives of many newborn children who, a generation or two ago, would have died as a result of premature birth or the existence of congenital anomalies (WHO and World Bank 2011). It is therefore important to recognise that increased access to basic health care across the world will change the profile of childhood disability but may not necessarily reduce its overall prevalence. In any reform efforts, it is essential to accept and accommodate children with disabilities and to welcome them as children with as equal rights to any other child.

1. Page number not available because article was accessed online.

### Box 1: Definitions and prevalence of disability

#### Definitions of disability

The Convention of the Rights of Persons with Disabilities (CRPD) defines persons with disabilities as:

“... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN 2006).

This definition acknowledges the move away from a purely medical conception of disability, which focuses on impairments, towards a recognition of the importance of social context. Under this definition it is not only the impairment that is disabling, but also the attitudes and responses towards people with disabilities (see also below and WHO and World Bank 2011, WHO 2010a, UN 2006).

#### How many children have disabilities?

It is problematic to provide a universally agreed figure on the numbers of individuals with disabilities. Accurate diagnosis is often hard to achieve, especially in resource constrained settings, and where stigma is high, parents may be reluctant to admit they have children with disabilities (UN 2011). The cut-off points used in relation to the severity of impairments, reasons for data collection and method used to collect data also contribute to the difficulty of measurement and comparison (WHO and World Bank 2011, UN 2011). A recent World Health Organisation (WHO) and World Bank report (2011) indicates that 15 per cent of the population have disabilities and cites studies that suggest that between 13 and 150 million children have disabilities, depending on classification of severity. Other research places this figure at closer to 200 million children (UNESCO 2010). A recent UN report on children with disabilities suggests that in countries where data are available, 14 to 35 per cent of children have disabilities, but that the reliance on household surveys means that many children with disabilities living on the streets or in residential care go uncounted (UN 2011).

### Internationally agreed standards call for equality of treatment and family-based care for children with disabilities

Those working in support of disability rights have long understood that it is as much the barriers imposed by society that define disability, as it is the physical impairment of the person. The main thrust of the disability movement has been towards establishing a society that includes children and adults with disabilities on equal terms with those without disabilities, whether in rich or low-income

countries. These principles underpin all international conventions relating to human rights. They are clearly specified in the 1989 Convention on the Rights of the Child (CRC), which has been ratified by 194 nations, and the Convention on the Rights of Persons with Disabilities (CRPD), which has been signed by 149 nations and ratified by 103.<sup>2</sup>

The UN conventions are powerful instruments, to which ratifying states are bound by international law. Written into the CRC and the CRPD are specific articles that relate directly to acceptable and unacceptable practice in children's care. These standards have been enhanced by the detail outlined in the Guidelines for the Alternative Care of Children, an agreement that the UN General Assembly welcomed in 2009. Together the CRC, the CRPD and the Guidelines clearly call for:

- Freedom from discrimination and the rights of all children, including those with disabilities, to enjoy a full, decent life in conditions that ensure dignity and promote self-reliance and active participation.
- A right to life, and to be free from abuse and neglect.
- Support to families to prevent a loss of parental care, for all children, including those with disabilities, with specific reference to the importance of respite care where needed.
- A range of alternative care options for all children, with an end to large-scale institutional care, especially for children under the age of three, and the provision of foster care and adoption services that include children with disabilities.

Annex 2 provides more detail on these and other internationally agreed standards that relate to the care of children with disabilities.

## Millions of children with disabilities continue to be routinely placed in institutions

Residential care may be defined as:

*"Care provided in any non-family-based group setting, such as places of safety for emergency care, transit centres in emergency situations and all other short- and long-term residential care facilities, including group homes."* (UN 2010)

As implied by the Guidelines for the Alternative Care of Children (UN 2010), institutional care is a distinct form of residential care involving large-scale facilities

2. See: [www.un.org/disabilities](http://www.un.org/disabilities)

(see UN 2010, Art. 23). Other forms of residential care may include small group homes and children's villages. For the purposes of this paper, institutional care is defined as caring collectively in a purpose-built facility for groups of more than 12 children (see EveryChild 2011a for a fuller discussion of definitions).

Despite agreements in international conventions and standards that institutional care should no longer be used, evidence suggests that in many places, the numbers of children in such care is failing to fall or is actually increasing (EveryChild 2011a; Williamson and Greenberg 2010; UNICEF 2010). The strength of evidence on the rates of institutional care for children with disabilities is mixed. In CEE/CIS states, there are clear data to suggest that a disproportionate number of children with disabilities are in institutional care. Here, more than one third of children in residential care have disabilities, with most of these children placed in large-scale institutions. In some countries in CEE/CIS, as much as 60 per cent of all children in institutions have disabilities. The rate of institutionalization of children with disabilities has stayed the same over the past 15 years, even when the rate has fallen for other groups, suggesting that children with disabilities have largely been ignored in reform efforts (UNICEF 2010).

In Europe more broadly, WHO research suggests that 80 per cent of children in residential care have some degree of developmental delay or intellectual disability (WHO 2010b). In the United States (US), there is a strong tendency to place children with disabilities in residential care, despite acknowledgement of the known harm that this can cause (National Council on Disability 2008). There are around 200,000 children in residential care in the US, and depending on the definition used, between 10 and 31 per cent of these children have disabilities (Trout et al. 2010). In China, evidence also clearly suggests a high rate of institutionalization for children with disabilities (Xiang et al. 2003; Zhi 2011).

Elsewhere in the world, the evidence on the proportion of children with disabilities in residential care, as with the evidence on the numbers of all children in residential care (Williamson and Greenberg 2010), is more patchy. In Africa, Asia and Latin America, a review of the literature by the authors suggests that little is known about the proportion of children in residential care who have disabilities. As with all children, the vast majority of children with disabilities and without parental care in these regions are probably more likely to be found in extended family care. However, what evidence does exist suggests that there remain substantial numbers in residential care. For example, in Zimbabwe, research suggests a 70 per cent increase in the number of facilities between 1994 and 2004, largely due to the HIV epidemic, with around 4 per cent of children in residential care having disabilities (Powell et al. 2004). Many of these facilities are large scale-institutions.

In Mexico and Viet Nam, evidence suggests that far from closing down existing large-scale institutions for children and adults with disabilities, more money is being invested in building such facilities (Rosenthal et al. 2011; Rosenthal 2009). In some settings, the lack of services for children with disabilities in communities means that demand for residential care far exceeds supply. In Zimbabwe, it has been reported that families often want to place children with disabilities into residential care but cannot do so because there are not enough facilities (Powell et al. 2004).<sup>3</sup>

Children with disabilities may be especially vulnerable to losing parental care and being placed in institutions in emergency settings, with evidence suggesting that children with disabilities may sometimes be abandoned by families fleeing violence, especially if their agility makes them hard to care for in such contexts (Save the Children 2010).<sup>4</sup>

Overall, limits in the evidence on disability and institutionalisation make it hard to determine if children with specific types of disability are more likely to face institutionalisation. It is also hard to determine in all cases if boys or girls with disabilities, or older or younger children, are more likely to be placed in institutional care.

The reasons for high rates of institutionalisations of children with disabilities are discussed in more detail below. The evidence presented suggests this may be attributed to:<sup>5</sup>

- High degrees of stigma and social exclusion
- Limited support for families caring for children with disabilities and consequent high levels of poverty
- Lack of available health or education services, or an inability to access such services except in an institutional setting
- A belief in the 'medical model' of disability, and that children with disabilities can only be cared for by trained professionals
- The limited use of foster care and domestic adoption for children with disabilities

3. Similar anecdotal evidence from elsewhere in Africa has been provided by Deaf Child Worldwide.

4. This issue is important and beyond the scope of this study to explore in full.

5. See Cousins 2009; Beochat and Cantwell 2007; Cantwell et al. 2005; UNICEF 2005; UNICEF 2010.

## Institutional care is harmful to all children, especially those with disabilities

The continued widespread use of institutional care for children with disabilities is alarming because there is a substantial body of evidence to suggest that such care is extremely harmful. A failure to provide a child with a consistent attachment to a carer has been clearly and repeatedly demonstrated to have an impact on emotional, cognitive and intellectual development. Forming attachment is especially important for young children, but it can also impact the resilience and happiness of older children. Research has clearly shown that when children are cared for in large-scale institutions it is almost impossible for them to form these all-important attachments. Such care is also harmful in other ways; it is expensive and can detract resources away from support to families or the development of family-based care, such as foster care. It also leaves children vulnerable to abuse (see EveryChild 2011a, Williamson and Greenberg 2010, UNSG 2005 for a summary of this evidence).

A central premise of this paper is that good practise in children's care is good for all children, and that children with disabilities, like all children, need high-quality care that is appropriate to their needs and provides them with opportunities for attachment.

*"I need more [love and affection]. I am in a boarding school. I see my parents rarely."*  
(Eva, 12-year-old girl with disabilities living in an institution in Latvia, cited in UNICEF 2005, p. 19)

Indeed, evidence on the impact of institutional care on child development and disability could indicate that avoiding institutionalisation is particularly important for children with disabilities. Limited opportunities for attachment can impact child development, potentially exacerbating disabling conditions (Browne 2009; van Ijzendoorn et al. 2008). In some settings, children with disabilities are especially vulnerable to neglect, abuse and limited opportunities for rehabilitation (MDRI 2007; Rosenthal et al. 2011; WHO 2010b). In an overview of the global evidence, a report to the UN General Assembly concludes that ending the institutionalisation of children with disabilities is a matter of urgency because:

*"The conditions in large residential care institutions can often constitute cruel, inhuman or degrading treatment. Widespread evidence testifies to examples of children permanently tied into cribs and beds; suffering or even death from intentional lack of medical treatment, food or warmth; and lack of love or care."* (UN 2011)

Research by WHO in Europe suggests that low standards of care in some facilities can:

*"...aggravate intellectual disabilities or result in serious developmental delays amongst children who were not intellectually disabled at first."* (WHO 2010b, p. 10)

In Georgia, one study on institutional care shows staff-to-child ratios as low as 1:17, with more than one quarter of children with disabilities dying over a two-year period (Nachkebia and Rawls 2010). Research by Disability Rights International found similar examples of poor standards of care in many institutions in Serbia and Mexico:

*"I looked into the crib and saw a child who looked to be seven or eight years old. The nurse told me he was 21 and had been at the institution for 11 years. I asked her how often he was taken out of the crib and she said, 'Never. He has never been out of the crib in 11 years.'" (MDRI investigator, Serbia, cited in MDRI 2007, p. v)*

*"There were almost two dozen children with disabilities sitting on mats on the floor or on benches in total inactivity, practically motionless. Some were covered in blankets. Some sat staring at the walls. A few sat rocking back and forth or biting their fingers. Staff just looked on."* (DRI investigator in Mexico, cited in Rosenthal et al. 2011, p. 21)

*"We observed a young girl with arms left tied in her sleeves. Staff had no program to treat her self-destructive behaviour except to tie her down or hold her. As soon as the staff let go, we observed her hitting her head against the tile floor. The sound was so loud we could hear it out in the hallway."* (DRI investigator in Mexico, cited in Rosenthal et al. 2011, p. xii)

Research in the US highlights the particular emotional, behavioural and academic problems faced by children with disabilities, which are often not met by residential care systems even in this relatively well resourced setting (Trout et al. 2010).

A recent report from UNICEF on the CEE/CIS region suggests that children with disabilities in institutional care are more vulnerable to abuse than other children (UNICEF 2010). These findings are backed by wider global research (Ellery et al. 2011; Rosenthal 2011; WHO and World Bank 2011).<sup>6</sup> In Mexico, the vulnerability of children with disabilities is enhanced by the lack of inspection of these facilities and their location in isolated parts of the country, which makes it hard for families to visit children. Children entering such facilities are often not registered and some disappear from the system, with concerns that they may have been trafficked (Rosenthal et al. 2011).

6. See also The Guardian, "Patrol discovers horrific abuse of Iraqi orphans," 20 June 2007, available: <http://www.guardian.co.uk/world/2007/jun/20/iraq.simontisdall>, accessed 17 November 2009.

The disabling effects of institutional care, and the lack of attention paid to rehabilitation, can make it very hard for children to leave such care and return to their families or live independently as adults. The widespread use of institutional care for adults with disabilities in some settings may also make it harder for children and their carers to conceive of a life outside of residential care. As argued by Tolfree, isolation from the wider world can impact on children's belief in their ability to live independently:

*“Residential care tends to have a negative impact on the identity and self-worth of children with disabilities: rather than helping children to see themselves as full and participating members of their own communities, institutional care tends to encourage children to identify primarily with other disabled children in a sheltered situation, and to discourage them from seeing themselves as able to interact, on an equal basis, with others.” (Tolfree 1995, p.45)*

It should be noted that whilst evidence from research and international guidance on children's care suggest a need to end the institutionalisation of children, they do not suggest an end to all forms of residential care. Small group homes, providing individualised attention for groups of around 10 children, are seen to have a place in the alternative care system. The role of these homes in meeting the needs of children with disabilities is discussed in more detail below.

## The institutionalisation of children is based on an outdated medical model of disability

It is not only evidence in the field of alternative care provision that demonstrates the importance of challenging the institutionalisation of children with disabilities; evidence on appropriate responses to disability also suggests that change is urgently needed. For decades, the disability movement has been challenging a medical model of disability that promotes the isolation of children and adults with disabilities to enable specialised treatment. The medical model views disability as just a medical condition, leading to an approach that is entirely based on the 'cure' and rehabilitation of the impairment. This understanding of disability leads to attempts to change the child to fit society and to the exclusion of the child if this is not possible. As evidenced from Tajikistan – provided in Box 2, below – clearly demonstrates, the application of this model allows hospital treatment and institutionalisation to merge as a single concept.



The medical model has been challenged by the disability movement since the 1970s with arguments that the disabling condition suffered by many people is less to do with their impairment and more to do with social and physical barriers presented by those around them. This 'social model' of disability moves the focus away from impaired individuals and onto the disabling society (Finkelstein 2001; Oliver 2004). Over the last two decades, this approach has been adopted by the UN system (UN 1993; UN 2006) and increasingly by national governments (Pearson et al. 2011).

Shifting from a purely medical model of disability to a model that recognises the social aspects of the problems faced by those with disabilities is important because it shapes society's attitude towards disability, and in turn underpins policies and service provision put in place to support children and adults with disabilities and their families. Medical intervention to reduce or indeed cure impairment is of course vital, as is the use of rehabilitation and special education techniques to help improve a child's functional skills. However, it is also essential to recognise that it is what happens around this to the child and their family that shapes quality of life and equality of opportunity and determines whether those with disabilities are allowed to be included in the mainstream of society. Whilst a medical model encourages the isolation and institutionalisation of children with disabilities, a model that recognises these social aspects promotes changes in attitudes and access to services to ensure integration of those with disabilities in wider society. The social model of disability is therefore more closely aligned to wide-ranging support for children with disabilities and their parents or foster and extended family carers to enable children to remain within families and communities.

### Box 2: How medical models of disability shape children's care in Tajikistan

Research in Tajikistan (Tainsh and Badcock 2003) illustrates how an entrenched medical model of care shapes the attitude of staff, parents and children alike. This model has led to the belief that children with disabilities should be treated in a hospital type of setting by professionals with some form of medical training, utilising the disciplined systems necessary to ensure the smooth running of a hospital. Linked to this is the belief that children with disabilities are vulnerable and should not be exposed to ridicule and failure by the outside world, and that the correct approach of the state is to provide protection.

Institutional care staff working under this model who took part in the research presented themselves as experts in the care and training of children with disabilities and projected this attitude onto the parents. They compared their special training and knowledge to the absence of skills shown by parents. This elevated their position within the system and devalued the role of parents, particularly mothers. This devaluation was reinforced throughout the system. If the child's impairment was obvious from birth, there was a strong likelihood that the doctor would encourage the mother to hand over her baby to state care. This could even occur in cases of repairable impairments such as cleft palate.

Parents seeking help to understand the problems affecting their children and trying to find support instead found themselves channelled into a course of action that would lead to handing their children over to the care of the state. Those participating in the research saw themselves as unvalued and unskilled. Mothers, who take primary responsibility for children's upbringing in Tajikistan, would also often have to cope with blame from their husbands and the extended family for their children's disabilities. It was reported that husbands frequently divorced their wives as a direct result of giving birth to a child with a disability. Many children included in the research agreed with a need for medicalised and segregated care; for them, this protected world was all that they knew. But staff also reported that it often took children months to adjust to institutional life, and that many wanted to return home and some children did run away.

### Families caring for children with disabilities are not getting enough support

A key means of avoiding the institutionalisation of children is ensuring that children can be cared for in their families and communities (UN 2011; UN 2010). As shown below, many effective strategies for providing cost-effective support to children and their families have been developed. However, particularly in resource-constrained settings, this provision is piecemeal and families often receive minimal support in their efforts to care for children with disabilities (National Council on Disability 2008; UN 2011; UNICEF 2010; UNICEF 2005; WHO and World Bank 2011). Parents caring for children with disabilities often struggle to cope in the face of extreme stigma and discrimination and inadequate or non-existent service

provision. Many of those interviewed for this report argue that problems often start with poor and expensive diagnosis and limited information on disability or the availability of support.<sup>7</sup> Families caring for a child with disabilities often experience higher rates of poverty due to the costs of caring for those with disabilities, lost earning opportunities for carers and limited access to social protection. Caring for a child with severe disabilities can be extremely stressful, and there is often little or no formal psycho-social support to help deal with stress. Each of these issues is discussed in more detail below in relation to strategies to meet the support needs of families that include children with disabilities. Of course, such support is not only important to prevent institutionalisation; it is also essential for meeting the rights of children with disabilities. As such, it should be considered a priority even in settings where increased institutionalisation is not a threat.

## Children with disabilities do not have the same access to foster care or adoption as other children

An important strategy for stopping the institutionalisation of children is providing alternative family homes through adoption or foster care programmes for children who cannot be with their parents. Such provision is essential for ensuring that children with disabilities have a range of care choices so that the best form of care can be found for them (UN 2010; EveryChild 2011a,b). In some countries, particularly in Western Europe and North America, foster care and adoption are the most common forms of care for children outside of parental or extended family care. As with institutional care in these settings (see above), evidence suggests that children with disabilities are often over-represented in foster care and adoption programmes in these regions, highlighting the generally high proportion of children in care who have disabilities. In the United Kingdom (UK), some research suggests that as many as 40 per cent of children who have been adopted have some form of disability (Cousins 2009). In the US, 20 to 60 per cent of children entering foster care have developmental disabilities or delays compared with about 10 per cent of the general population (National Council on Disability 2008).

Even in these regions where foster care and adoption are widely used for children with disabilities, evidence suggests that children with disabilities may have more limited choices in family-based placements than other children. In the UK, for example, a disproportionately high percentage of children awaiting permanent placements have disabilities, and children with disabilities generally tend to wait much longer than other children before a long-term home can be found for them (Cousins 2009). While the majority of adopters will consider children who have

7. For example, staff of Partnership for EveryChild in Russia report the over-diagnosis of children with disabilities to ensure greater allocation of resources. Deaf Child Worldwide reports high costs of diagnosis and concern about stigma leading to poor diagnosis in Africa and other settings, and limited basic information about disability and its causes. Limited information about childhood disability and its causes has also been identified in other studies (World Bank 2009).

been sexually abused, only a minority will consider children with disabilities (Ivaldi cited in Cousins 2009).

Foster care and domestic adoption programmes are often poorly developed in resource-constrained settings (EveryChild 2011b; UN 2009). Where such programmes are used, evidence suggests that children with disabilities have more limited access to these forms of alternative care. In its global overview of adoption, the UN's population division found that children with disabilities are less likely to be adopted and more likely to be found in residential care (UN 2009). This appears to be especially the case in relation to domestic adoption as opposed to inter-country adoption. In China (Dowling and Brown 2008), Namibia (Government of Namibia 2009), Ukraine (Cantwell et al. 2005), Nepal (Terre des Hommes 2008) and Rwanda (Save the Children 2001), children with disabilities have not had the same access to already limited domestic adoption or foster care programmes as other children. Reasons cited in these studies suggest that stigma and discrimination, the high direct and indirect costs of caring for a child with disabilities and the lack of services and support all reduce the likelihood of children with disabilities being adopted domestically or fostered. Evidence suggests that inter-country adoption is an option open to a wider range of children with disabilities than domestic adoption in many settings (Boechat and Cantwell 2007; Cantwell et al. 2005; Dowling and Brown 2008; Gamer 2011). The role of inter-country adoption in the care of children with disabilities is discussed in more detail below.

The current limited access to some domestic adoption and foster care programmes for children with disabilities should not be taken as an indication that it is somehow impossible to find alternative families for children with disabilities. Evidence suggests that with the right investments in recruitment, service provision and support, families can often be found for children with disabilities who cannot be cared for by parents (Cousins 2009). Strategies to develop alternative family-based care for children with disabilities, including the provision of such care in resource-constrained settings, are discussed in more detail below.

### 3. ACTIONS NEEDED TO PLACE DISABILITY AT THE HEART OF CHILD CARE REFORM

The evidence presented above clearly demonstrates that urgent action is needed to meet the needs of children with disabilities in child care reform efforts. It shows how children with disabilities are commonly left to languish in harmful forms of residential care. Families striving to care for children with disabilities in their own homes receive scant support, and children with disabilities who cannot live with their own families are often unable to access appropriate foster care and adoption programmes. In this section, the key actions needed to reverse this position and ensure that children with disabilities have the same range of high-quality care options as other children are outlined. Cutting across each of these actions is the need to recognise diversity, both in terms of recognising the range of impairments experienced by children with disabilities and acknowledging that attitudes and responses to disability may vary according to the type of impairment and context. It is also important to remember that children with disabilities may experience other forms of exclusion and disadvantage, such as those associated with age, gender and poverty (WHO and World Bank 2011).

#### Challenge discriminatory attitudes and move away from a medical model of disability

Stigma around disability is common in many settings and may be linked to a lack of information about the causes of disability (WHO and World Bank 2011; UN 2011). For example, recent research in India suggests that disability is closely linked to the concept of karma and is often seen as a punishment for misdeeds in the past or the wrong doings of parents. Surveys suggest that a significant proportion of households, including some households with members with disabilities, believe that disability is a curse from god. These beliefs are strongest in relation to mental or visual impairments and are least likely to be held in relation to physical impairments caused by injuries or accidents (World Bank 2009). Research in Zimbabwe has shown that some communities saw disability as a consequence of witchcraft, promiscuity of the mother during pregnancy or punishment by ancestral spirits (UNICEF 2001).

Challenging negative attitudes towards disability at the societal level is important for child care reform for several reasons. Such attitudes can prevent the political will for change, which, as discussed below, is essential for successful child care reform. Negative beliefs about disability can lead to marital breakdown,<sup>8</sup> especially if mothers are blamed for children's disability. As shown in the example in Box

8. See Box 2 in relation to Tajikistan. Deaf Child Worldwide reports a similar situation in Kenya.

2, above, this can lead to child abandonment if mothers feel unable to cope alone. Discriminatory attitudes can also lead to social exclusion and prevent the wider community support on which many vulnerable families rely. For example, the beliefs about disability in India described above have led to those with disabilities being seen as inauspicious and unable to take part in community events such as weddings. These beliefs have also contributed to the reluctance of extended families to support those caring for children with disabilities (World Bank 2009). The stigma associated with disability may be closely linked to the institutionalisation of children in some parts of the world because it leads to responses that encourage isolation and separation rather than inclusion (Tainsh and Badcock 2003; UNICEF 2005).

In many settings it is not only important to challenge the stigma associated with disability, but also to move away from the medical model of disability described above. For example, many CEE/CIS states have inherited the USSR policy of state provision of care that was focused entirely on curative – not preventative – procedures in which clinically trained ‘defectologists’ assessed children for institutionalisation. Under communist ideologies, the care of such children was deemed to be the responsibility of the state. This system was retained for many years after the end of the USSR (UNICEF 2005), and it is estimated that this region still has the highest rate of children in institutions in the world (UNICEF 2010).

Several strategies have been identified for changing attitudes towards disability, including providing accurate information about its causes and highlighting the achievements of those with disabilities (Miles 2000; World Bank 2009). The important role of Disabled People’s Organisations (DPOs) in challenging discriminatory attitudes and moving towards a social model of disability has also been widely demonstrated (Dube 2007; WHO and World Bank 2011).

## Create the political will for change

Existing evidence on the successful reform of childcare systems clearly demonstrates that reform requires a genuine and substantial commitment to drive this change forward at the most senior level (BCN et al. 2009a,b; EveryChild 2011a). Governments need to be reminded of several imperatives for action, including:

- **The legal imperative:** States who have ratified relevant international conventions, including the CRC and CRPD, have an obligation to ensure that children with disabilities are properly cared for. This includes an obligation to

support families caring for children with disabilities to prevent a loss of parental care, as well as wider efforts to prevent disabilities.

- **The economic imperative:** Institutional care for children with disabilities is expensive, much more so than family-based care (EveryChild 2011a). A lack of proper care is making children's impairments worse and hindering their ability to live independently and make productive contributions to society as adults.
- **The development imperative:** Disability is not specifically mentioned in the Millennium Development Goals (MDGs), yet it is widely acknowledged as having a major impact on the achievement of the MDGs as it impacts on health, education and poverty alleviation (WHO 2010a; UN 2011). Children's care and protection have also been shown to affect the achievement of the MDGs (Delap 2010). Making links between childhood disability, protection and care and the MDGs may persuade some donors and governments committed to the MDGs of the value of addressing child care reform and disability.

As with challenging discriminatory attitudes, DPOs can play a central role in creating the will for change, and children with disabilities can be powerful advocates for change. It is also necessary to enhance the evidence base on disability and to challenge the current invisibility of children with disabilities. As noted above, there are major gaps in understanding on the care of children with disabilities in some parts of the world. Routinely collecting data on the use of institutional and other forms of care and disaggregating data by age, gender and disability would be a major step forward (UN 2011).

## Create appropriate national legislative frameworks and guidance

Legislation is needed both to challenge discrimination against those with disabilities and to ensure appropriate reform of the child care system. Legislation around child care reform also needs to be extrapolated through more detailed guidance, and disability issues need to be mainstreamed throughout. The CRC, CRPD and Guidelines for the Alternative Care of Children provide clear guidance on appropriate legislative and policy changes (see Annex 2, and see also UN 2011). Of course, the existence of legislation is very different from its implementation, and even in settings with good legislation on care and disability, there is no guarantee that the rights of children with disabilities outside of parental care will be met (Dube 2007).

## Build on the community-based rehabilitation model and integrated systems of child protection

Efforts to reform child welfare systems can build on the community-based rehabilitation (CBR) model, which is used to support children with disabilities and their carers in a number of settings. Although CBR models were initially developed with a focus on primary health care and low-cost aids, over time they have “...evolved to become a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services.” (WHO 2010a p.1)

The CBR model has been recently articulated in new WHO CBR guidelines (WHO 2010a). These guidelines state that rather than create a parallel system for children with disabilities, CBR approaches should aim to ensure that the needs of children with disabilities are met through existing service providers such as local schools and clinics (WHO 2010a). CBR often involves the use of outreach workers to identify children with disabilities and offer appropriate support and linkages to other service providers. CBR does not in itself usually provide many of the specialist technical requirements of children suffering severe impairments, though it can provide effective referral to other forms of support, if such support exists. The WHO CBR guidelines place a strong emphasis on empowerment and encourage a role for self-help groups and DPOs. This CBR model also calls for strong engagement of those with disabilities in the design and implementation of interventions and in advocacy for change (WHO 2010a). More details on the components of CBR are included in Box 3, below.

The emphasis on inclusion in the CBR approach is not without its challenges. There are varying perceptions of exactly what inclusion should involve, with some calling for all children with disabilities to be placed in mainstream schools and others arguing for a more nuanced approach that reflects the differing needs of individuals or groups. Some argue that whilst a fully inclusive education system may be the ultimate goal, in the current context of stigma and discrimination and extreme paucity of support in mainstream schools for children with disability, there continues to be a need for specialist schools in many settings. Others believe that children with disabilities will always benefit from being with other children with disabilities, especially if, as with children with hearing impairments, there are particular issues with communication. It is also argued that children with disabilities need not only to engage with those without disabilities, but also to experience positive role models of adults and other children with disabilities to demonstrate what is possible in their lives (see Miles 2000; WHO and World Bank 2011 and UNESCO 2010 for a summary of these debates).



CBR models are based on community-centred support; thus, they have the potential to help prevent a loss of parental care by providing support to families caring for children with disabilities. CBR approaches could also be used to support other family or community-based care, such as small group homes embedded in communities, or foster or extended family carers. To ensure that the care and protection needs of children with disabilities are met, CBR models may need to be adapted to provide linkages with child welfare systems. These systems rely heavily on professionally trained social workers in Western settings and many CEE/CIS states, but they also use community-based child protection mechanisms, run by local volunteers, in many low-income countries.<sup>9</sup> CBR models may also need to place a stronger emphasis on consultation and empowerment of children with disabilities, including those outside of parental care.

The CBR approach takes disability as its starting point, and other approaches that focus on child protection may also be valuable in ensuring that children with disabilities are properly cared for. Integrated models of child protection are widely promoted by agencies such as UNICEF (2008) and Save the Children (2009b). These models call for co-ordinated, multi-sector efforts to meet the various needs of vulnerable groups in need of care and protection, and place a strong emphasis on child participation and family-based care. These models aim to provide comprehensive support for vulnerable children and families, whilst recognising that some groups, including those with disabilities, may need specialist intervention.

9. See Wessells 2009 for a general description of such community-based mechanisms in relation to the protection of all children.

### Box 3: Components of CBR and an example from Nepal

| Components of CBR in WHO CBR Guidelines: <sup>10</sup> |   | Application of CBR approach in a national programme in Nepal: <sup>11</sup>   |
|--|---|---|
| Health:  | Preventing impairment, ensuring access to medical care and providing assistive devices  | <ul style="list-style-type: none"> <li>• Providing preventative health care and corrective surgery to reduce the overall numbers of children with disabilities</li> <li>• Providing assistive devices and physiotherapy, and training mothers to assist in the rehabilitation of their children</li> <li>• Advocating to ensure the needs of those with disabilities</li> </ul> |
| Education:   | Ensuring access to schooling at all levels, including early childhood   | <ul style="list-style-type: none"> <li>• Working to integrate 10,000 children with disabilities into mainstream schools or provide them with access to special schools, including over 500 children with hearing impairments who are learning in mainstream schools</li> <li>• Advocating for legislative change to provide disability scholarships</li> </ul>                  |
| Livelihood:  | Promoting skill development, access to employment, financial services and social protection   | <ul style="list-style-type: none"> <li>• Creating a disability identity card system to ease access to allowances</li> <li>• Providing vocational training for young people with disabilities</li> <li>• Providing training, micro-finance and help with employment for parents, including day care centres for children with disabilities with working parents</li> </ul>       |
| Social:  | Supporting family relationships and ensuring leisure and cultural opportunities and access to justice   | <ul style="list-style-type: none"> <li>• Raising awareness and advocacy to reduce stigma against those with disabilities</li> <li>• Increasing the understanding of disabilities in families and providing support to promote positive relationships</li> <li>• Helping parents to communicate with children with hearing impairments by teaching them sign language</li> </ul> |
| Empowerment:   | Supporting self-help groups and DPOs, empowering those with disabilities to communicate and advocate for policy change and enabling political participation | <ul style="list-style-type: none"> <li>• Creating a strong role for DPOs and self-help groups in the implementation of all elements of the programme</li> <li>• Ensuring that children with disabilities have access to children's clubs in schools</li> <li>• Involving DPOs and children with disabilities in advocacy</li> </ul>   |

## Focus on preventing a loss of parental care and support to families

Support to prevent a loss of parental care and support of kinship carers have been identified as priority areas for action in child welfare reform in the Guidelines for the Alternative Care of Children (UN 2010). In delivering support to families, it is important to recognise that disability does not just affect the child who has a disability, but may also have an impact on others in the household, including other children. The exact nature of family support required is likely to vary with context and according to the specific needs of the child and his/her family, and local-level research and analysis is a necessary first step. Here, it is important to remember that women commonly take on the bulk of care for children with disabilities and may need particular support (WHO and World Bank 2011). Some commonly needed forms of support are discussed in more detail below.

### Provide adequate social protection

Poverty is often a factor contributing to the loss of parental care and the institutionalisation of children (EveryChild 2011a). There is clear evidence to suggest that families containing a member with disabilities are more likely to live in poverty. Disability can be caused by poverty, due to factors such as limited access to adequate health care, malnutrition or poor housing (WHO and World Bank 2011). Disability can also lead to poverty as a result of the high direct costs of medical care or assistive devices such as wheel chairs, and the lost opportunities to work due to the need to care for someone with disabilities. This can impact on families whilst caring for children with disabilities and long into the future, as lost earnings can mean no savings or access to pensions (Marriott and Gooding 2007; UN 2011; WHO and World Bank 2011;). In Bangladesh, for example, research suggests that 57 per cent of families with a child with disabilities reported extra costs that on average amounted to two months of normal income. Children with severe disabilities were reported to be three times more expensive to care for than children without disabilities (Chowdhury cited in Marriott and Gooding 2007).

These strong links between poverty and disability have led to much recognition that families affected by disability need help with employment and access to social protection provision. The CRPD (UN 2006), for example, recognises that people with disabilities should have equal access to social protection, and much literature on child sensitive social protection acknowledges the particular vulnerabilities created by childhood disability (DFID et al. 2009; Roelen and Sabates-Wheeler

10. From WHO 2010a.

11. From Save the Children (2010) Final Evaluation of Community Based Rehabilitation Program, Save the Children, Nepal.

2011). Some countries, such as Namibia (Government of Namibia 2009), do recognise the needs of families caring for those with disabilities in their social protection provision. However, global analysis suggests that such provision is often inadequate, or poorly designed, often due to a failure to consult with those who are directly affected (Marriott and Gooding 2007; WHO and World Bank 2011).

Marriott and Gooding (2007) argue that far more research is needed regarding social protection provision for families affected by disability, but that the following factors must be taken into consideration to ensure such provision is effective:

- **Make provision empowering:** If poorly designed or based on a medical model of disability, social protection provision can lead to welfare dependency and a failure to recognise the capacities of families to help themselves. Linking social protection to support with child care and appropriate employment for carers, and to efforts to prepare children with disabilities to live independently as adults, are ways to ensure that this provision is empowering.
- **Link social protection to other services:** By ensuring that children with disabilities also have access to schooling, health services, child protection and rehabilitation support, social protection will allow the children and their families to flourish rather than just survive.
- **Conduct proper assessments to ensure that the amounts provided are adequate:** Here it is important to consider both the direct and indirect costs of caring for a child with disabilities, and to ensure that children with disabilities have been identified and properly diagnosed.
- **Carefully consider targeting:** Explore whether it is best to determine eligibility by disability (with challenges of appropriate diagnosis) or by the poverty that families caring for those with disabilities often face. Explore who should be targeted: the child with the disability, the carer or the household.
- **Recognise discrimination within as well as outside the home:** Recognise that children affected by disability may be discriminated against by family members and, for example, be denied access to school by their carers or school authorities. Conditional grants may help here, but may also carry with them numerous problems, such as imposing requirements on carers that they may have difficulty fulfilling in often very challenging and discriminatory contexts.
- **Monitor inclusiveness:** Regularly assess social protection programmes to ensure that the needs of families and individuals affected by disability are being met.

Analysis specifically of the links between social protection and children's care

and protection further suggests that programmes must be designed to reach children with disabilities who are not being cared for by parents, and to avoid perverse incentives that can lead to family separation. For example, some reports suggest that providing higher grants to kinship or foster carers than to parents can encourage parents to give children up to the care of relatives (see Delap 2010).

### **Reduce violence and abuse in the home**

Violence, abuse and neglect are major violations of children's rights and are common causes of a loss of parental care around the world (EveryChild 2010). Data cited in the UN Secretary General's Study on Violence against Children suggest that children with disabilities are nearly twice as likely to suffer violence or abuse than their peers without disabilities, whether at home or in alternative care (UNSG 2005). The study goes on to illustrate how a child's vulnerability can be a trigger for violence or abuse, particularly if the child is born into a setting where violent or predatory behaviour already exists (UNSG 2005). Additionally, adults can act violently out of extreme frustration, or as this example from Palestine suggests, may lack the knowledge and resources needed to provide adequate care and protection for children with disabilities (see also UN 2011):

*".... In one of the Palestinian camps in Lebanon, I saw a family tying their disabled girl child aged 10 to a metal chain for fear of her running in the neighborhood and being raped by adults. The girl weighs 60 kg at the age of 10 because the mum told me that only food keeps her quiet so she is overfed ... The family was never visited by a social worker or a doctor for guidance and support. Only sedative medicines are prescribed for her." (A Save the Children disability specialist interviewed for this paper)*

In some instances, the violence, abuse and neglect of children with disabilities could be reduced through proper support such as that offered under a CBR or integrated child protection model. In some cases, the best interests of the child may be best served by removal and the provision of appropriate alternative care, on either a temporary or permanent basis.

### Ensure access to basic and particular services to those with disabilities

Inappropriate, inadequate or poor quality service provision for those with disabilities and their carers can have a major impact on choices about children's care and on child well being. Negative attitudes and a medical model of disability in maternal health services can support the institutionalisation of children with disabilities because women are often encouraged by staff on maternity wards to abandon babies with disabilities (see Box 2 and MDRI 2007). Children with disabilities may be placed in residential care because free and accessible medical or rehabilitation support is not available close to their homes (Rosenthal et al. 2011; UNICEF 2005; UNICEF 2010):

*"I love my son, but I cannot afford medications. So I must send him to [the institution.]"*  
(Letter from a parent with a child with disabilities in Mexico cited in Rosenthal et al. 2011, p. x)

In some countries, children with disabilities are commonly sent to institutions or residential schools to receive an education because there are limited opportunities in home communities. The dividing line between a boarding school and an institution is often extremely thin, with children in facilities referred to as boarding schools often having no or minimal contact with home (EveryChild 2011a; UNICEF 2005).

*"[Our son] has been staying [in an institution] for four years now, because we do not live close to the school and we cannot manage to go there every day and spend four hours commuting."* (Rita, mother in Latvia, cited in UNICEF 2005, p. 53)

Global research shows that despite widespread recognition that those affected by disability should have access to health and education services in home communities, these services are often not available, especially in resource constrained settings. Barriers include physical accessibility, attitudes of service providers and costs (WHO and World Bank 2011). Girls with disabilities may be particularly vulnerable to limited access to service provision. Evidence shows that in common with all girls, girls with disabilities are less likely to attend school than their male counterparts (WHO and World Bank 2011). Women and girls with disabilities may also face restrictions in accessing health care or other services due to cultural restrictions and the low prioritisation of their needs by families in some contexts (WHO and World Bank 2011).

Access to service provision is likely to vary significantly depending on the nature and severity of impairments and variations in attitudes towards different impairments. For example, in India, research suggests that there are more positive

attitudes towards the integration of children with impairments that inhibit movement than those with vision, speech or hearing impairments, with extremely negative attitudes towards the integration into mainstream schooling of children with mental illness or impairments (World Bank 2009).

In addition to access to health and education services, children with disabilities may also need specialised support and assistance to enable participation in daily life. This may include, for example, aids for mobility or help communicating, a particular problem in families with children with hearing impairments. Access to service provision may be especially important for very young children and their parents. In addition to avoiding the abandonment of newborn babies, early diagnosis and treatment is essential for reducing the effects of impairments (WHO and World Bank 2011). As with education and health care provision, such support is often unavailable, especially in low-income countries. WHO reports that there are no national rehabilitation services for children with disabilities in 62 countries of the world (WHO 2010a), although evidence from Afghanistan demonstrates that it is possible to provide such support at a relatively low cost through a CBR model (Coleridge 2002). Limited access to services often begins with poor diagnosis; thus, it is essential to make a greater investment into proper assessments (WHO and World Bank 2011).

Box 4, below, uses examples from Russia to illustrate the kinds of inclusive service provision needed to keep children with disabilities within families to avoid harmful institutional care.

#### Box 4: Inclusive services to keep children in families in Russia

16-year-old Yura from St. Petersburg, Russia has cerebral palsy and was encouraged to go into residential care at an early age. His mother fought to have him accepted at his local primary school and accompanied him as his classroom assistant for his first three years in school. Yura has progressed through the system and now has plans to study languages at university. Yura says, *“Mostly my parents helped me to overcome these hardships. In some schools my mother was told that their curriculum was too hard for me and I wouldn’t succeed.”*

His mother adds, *“...I needed to do everything by myself. Specialists mainly suggested special boarding schools. When Yura started to go to regular school and it was clear that he was succeeding and nothing special was being demanded from the school and teachers, everyone was at rest.”*

Yura and his mother would have liked more assistance from the school and more help with equipment to enable Yura to get to and around the school. Yura and his mother also report benefitting from respite care provided by the Russian NGO Partnership for EveryChild. This flexible form of foster care offers short breaks from a few hours up to 15 days a year to parents or other carers of children with disabilities. Foster carers are carefully selected and trained before they start fostering and are carefully matched with the children to ensure that they are able to meet the children’s needs. Of the 60 children with disabilities involved with the programme so far, all have remained in the care of their families, with evidence to show significant quality-of-life benefits for the child, their parents and other children in the families involved in the programme.<sup>12</sup>

#### Provide parenting support

Challenges dealing with stigma and discrimination, as well as the stress of caring for a child with disabilities, have been identified as factors leading to the institutionalisation of children (UNICEF 2005). Support to parents is often unavailable, especially in resource-constrained settings (WHO and World Bank 2011). Parents and carers of children with disabilities need support as soon as the child’s difficulties have been identified, because it is difficult for a parent to accept that their child has disabilities, particularly if the impairments are severe. As the quotes below from the parents of an autistic boy demonstrate, parents can struggle to accept a diagnosis of disability:

*“I went through a stage when he was younger of going through a bereavement of what he was not going to be ... you actually come through that and come out the other side. I think I have accepted him as he is.”* (Father of James, an autistic boy in the UK, Production for BBC Radio 4, first broadcast on 3 July, 2011).

At such times, support from professionals is important, but help from other parents

12. Yura and his mother were interviewed by Partnership for EveryChild in Russia. For the evaluation of this project, see Donlan 2010.



is equally valuable. As noted above in the discussion of the CBR model, self-help groups and DPOs can play an important role. Training workshops that focus on parenting skills and use the experience of peer educators, or groups that target the fathers of children with disabilities, have proved to be useful tools.<sup>13</sup> This type of information and support is not a “one-off” process. Like all children, the needs of children with disabilities change as they grow through childhood to adolescence and into adulthood. Each stage in growth and each realisation of the child’s changing character and potential requires time for adjustment.

In some cases, having a child with a disability in the home can be exhausting for parents, carers and other family members, especially if wider community support or service provision is not available. For example, parents caring for a child who requires considerable supervision because of a severe behavioural disorder can find the constant requirement for attention tiring and limiting of their own activities. Such emotional and physical strain can become the deciding factor for the parents’ ability and willingness to continue caring for their child at home. In such cases, respite care can be extremely valuable. Respite care is specifically recognised in much guidance on the care of children with disabilities and is included in the Guidelines for the Alternative Care of Children (UN 2010). Box 4, above, provides an example of respite care that has been shown to reduce the placement of children with disabilities in institutional care.

It should be noted that any provision of support to parents must be non-judgemental and recognise the extreme challenges faced by parents caring for children with disabilities. As noted below, it should not automatically be assumed that placing a child in the care of others is a result of ‘bad parenting,’ as this may sometimes be in the best interest of the child with disabilities and other children in the family.

## Ensure proper gate-keeping, care planning and reintegration efforts

As stated in the Guidelines for the Alternative Care of Children (UN 2010), proper systems must be developed to manage the entry of individual children into care, to determine which forms of care are most appropriate, to regularly review care plans and to manage the eventual exit from the care system. These systems must involve consultations with children and families. Such mechanisms are essential for ensuring that children receive the best care for them and that they are not placed or kept in institutional care when it is not in their best interest (Evans 2009).

13. From documentation and information provided by Dr. Greg Powell, Paediatrician, Director Kapnek Trust, Harare.

Although evidence is limited, there is some information to suggest that proper gate-keeping, care planning and reintegration is not happening for children with disabilities. Research in the UK suggests that children with disabilities are rarely included in decisions that affect their care (Cousins 2009). Research in Mexico shows that children with disabilities who enter institutional care are not properly registered and are often placed in care indefinitely, with no review of their suitability for alternative options (Rosenthal et al. 2011). In Viet Nam and Serbia, the placement of children with disabilities in institutions is not subject to periodic review, and children can remain in such care for a lifetime (Rosenthal 2009; MDRI 2007). The example provided in Box 5, below, highlights the value of effective gate-keeping for keeping children with disabilities out of institutional care.

A global review of the literature on reintegration suggests that the needs of children with disabilities are not routinely considered (Wedge 2011), and an analysis of institutional care for children with disabilities in Mexico shows that staff exclude children with disabilities from reintegration programmes. Here, children with disabilities are subject to regimented routines and limited choice over their daily lives, making it hard for children to learn the skills needed to live in families or communities (Rosenthal et al. 2011).

Wider evidence on child participation clearly demonstrates that children with disabilities can and should take part in decisions that affect their lives, but they are often excluded. Some guidance has been provided in ensuring the participation of children with disabilities (MENCAP 2003; MENCAP 2008; Save the Children 2001). Comments from experts interviewed for this report also highlight the importance of fully engaging parents in decisions about children's care, and of adopting a sympathetic attitude that recognises the difficult choices parents have to make in the context of stigma, discrimination, poor service provision, poverty and the differing needs of family members.

### Box 5: Implementing gate-keeping programmes in Azerbaijan

United Aid for Azerbaijan has recently implemented a gate-keeping programme in three areas of Azerbaijan as part of wider efforts to improve care for children with disabilities. In this programme, volunteer social workers evaluate the needs of children with disabilities and their families and then link them to support structures to prevent institutionalisation or ensure reintegration for children already living in institutions. These gate-keepers are unfortunately not yet formally linked to official decision-making structures that often make the final decision about children's care. However, when referrals are made by such structures, project evaluations suggest that gate-keepers can often successfully support families to care for children with disabilities at home. Overall, gate-keepers have had a success rate of over 80 per cent in their efforts to keep children within families. Some key lessons learnt from this project include:

- The need to ensure that gate-keepers are properly resourced
- The importance of a multi-disciplinary team and proper coordination between relevant departments
- The value of proactive efforts to identify children with disabilities as opposed to relying on referrals.<sup>14</sup>

## Ensure that foster care and adoption are options open to children with disabilities

There are many different possible forms of foster care and adoption, ranging from care in which children are fully integrated into their adoptive family and lose all contact with their parents, to the temporary respite care of a few days or even hours described in Box 4, above. Ideally, children with disabilities, like all children, will have access to numerous types of foster care and adoption so that the form most appropriate to their needs can be selected (EveryChild 2011b). Despite perceptions that children with disabilities are unadoptable and cannot be fostered, evidence demonstrates successful outcomes for children with disabilities who are included in good quality foster care or adoption programmes (Boechat and Cantwell 2007; Cousins 2009). The development of foster care programmes may be a good starting point for ensuring that more permanent placements are available. Evidence in the UK suggests that many foster carers who were uncertain about their capacity to take on the long-term care of a child with disabilities go on to adopt children with disabilities in their care (Cousins 2009).

14. Melikadze, K., Keeping Vulnerable and Disabled Children with their Families, Azerbaijan. Final Evaluation Report, UAFA and EveryChild (unpublished), 2010; UAFA and EveryChild, End of Grant Report. Big Lottery Fund, UAFA and EveryChild (unpublished), 2010.

As noted above, many domestic adoption and foster care services do not fully include children with disabilities. In some settings, inter-country adoption is more widely used for children with disabilities as a means of placing children who cannot find adoptive parents in their own countries. In some countries, including China and some CEE/CIS states, half or more of the children sent to the US for adoption have disabilities (Gamer 2011). Currently, inter-country adoption may be a more widely used option than domestic adoption for some children with disabilities, because levels of stigma tend to be lower in receiving countries and service provision and support tend to be greater (Boechat and Cantwell 2007; Terre des Hommes 2008; Dowling and Brown 2008). The use of inter-country adoption for children with disabilities may enable some children to quickly leave harmful institutional care, and, at least in the short term, may be the only means by which children with disabilities in some settings can rapidly leave this damaging care. As with national adoptions, some evidence also suggests positive outcomes for children with disabilities who are adopted internationally (Dowling and Brown 2008).

In any placement of children with disabilities for inter-country adoption, it is of course important to recognise the general principle, as articulated in the Hague convention,<sup>15</sup> of ensuring that children are only placed for inter-country adoption when all realistic possibility of domestic adoption has been exhausted. It is also essential to ensure that this particularly vulnerable group are protected from corrupt or inappropriate practices sometimes associated with inter-country adoption (Chou and Browne 2008; Dowling and Brown 2008, Terre des Homme 2008).

Viewing inter-country adoption as an option for some children with disabilities outside of parental care does not mean it should be seen as an unproblematic or universal long-term solution for this group. As noted by Boechat and Cantwell (2007) it is important not to see inter-country adoption as a cure for the stigma and poor service provision that lead to so many children with disabilities being placed in the care of the state:

*“... It is important to remember that adopters who are both willing and fit to care for children with special needs are a small minority. As a result, no country of origin should look to inter-country adoption as a solution for the predicament of such children.”*  
(Boechat and Cantwell 2007, p. 27)

Recognising the limits of inter-country adoption is further supported by research by Chou and Browne (2008), which suggests that the availability of children without disabilities for inter-country adoption may make it harder to place children with disabilities seeking domestic adoption in receiving countries. In

15. Convention on protection of children and cooperation in respect of inter-country adoption (May 1993).

line with the critique of the medical model of disability outlined above, it is also essential to check eligibility criteria and ensure that social aspects of disability are being considered along with a medical diagnosis of disability in making decisions about whether it is in the best interest of the child to be adopted internationally. Such considerations include analysis of access to services and degrees of social exclusion, along with work to ensure that maximum efforts have been made to solve the challenges faced by children with disabilities and their families. More widely, it is important to combine the use of inter-country adoption services for children with disabilities with investments in support to families and domestic foster care and adoption services so that inter-country adoption is no longer the only family-based option for some children with disabilities who are outside of parental care.

Once a decision has been made that adoption or foster care is in the children's best interest, evidence suggests the following principles for good practice to ensure that services are ethical and meet the best interests of children with disabilities:

- **Ensure proper diagnosis, and work to reduce wider stigma around disability:** Make sure that children's disabilities do not go unrecognised by service providers and are not exaggerated to, for example, enable speedier inter-country adoption. Reduce wider stigma and discrimination against those with disabilities that act as a major barrier to prospective adoptive parents or foster carers (Cantwell et al. 2005).
- **Develop recruitment campaigns specifically aimed at finding more carers for children with disabilities:** Raise awareness about the specific need for foster carers and adopters for children with disabilities, and actively search for suitable candidates (Cantwell et al. 2005). Provide general information about disabilities and the needs of children with disabilities to enable prospective parents an opportunity to connect with children with disabilities (Cousins 2009). Recognise the value of long-term support in recruitment efforts, because foster carers and adoptive parents often have concerns about caring for a child with disabilities if no such support is offered (Cousins 2009).
- **Provide proper information and work to properly match children with appropriate carers:** Work to match children with the right carers for them, and not the other way around. Make sure that both carers and the children have proper information about the process. Ensure prospective carers have accurate information about the nature and level of disability (Cousins 2009; Gamer 2011; Peake 2009; Schweiger and O'Brien 2005). Be wary of parents who resign themselves to caring for a child with disabilities after being unable to adopt a

child without disabilities (Boechat and Cantwell 2007). Do not reject parents on the grounds of socio-economic status (Spark et al. 2008).

- **Train carers and offer them ongoing support, including post-adoption support:** Provide generic training on the disability for prospective foster carers and adopters, as well as specific training for meeting the needs of children with particular disabilities (Peake 2009). Provide ongoing support, for both adoptive parents and foster carers, considering the issues outlined in the support to families above. Consider support groups and mentoring programmes for adoptive parents and foster carers, and recognise the particular challenges that children who have been in institutional care may face due to poor quality care or limited opportunities for attachment (Spark et al. 2008).
- **Change attitudes and develop the capacities of social workers:** Reduce discrimination amongst social workers by providing training on disability and ensuring that they recognise children with disabilities as potential candidates for foster care and adoption (Cousins 2009; Peake 2009; Schweiger and O'Brien 2005).
- **Consider relationships in the wider family:** Recognise the impacts of caring for a child with disabilities on the wider household, and include this in assessments and support. In particular, consider impacts on siblings (Schweiger and O'Brien 2005).
- **Work towards permanency:** As with all children, ensure that the goal of providing a child with disabilities a permanent home is given prominence in care planning. However, if such a home cannot be found, consider other options, such as long-term fostering, rather than leaving a child to languish in a large-scale institution (Cantwell et al 2005).
- **Support care leavers for independent living:** Work towards ensuring that children can live independently as adults by building necessary skills and supporting access to education, employment, social protection and assistance (National Council on Disability 2008).
- **Monitor inclusivity:** Check that efforts are successful. See how many children with disabilities are being adopted or fostered, and talk to them and to their carers about their experiences (Peake 2008). Seek the opinions of children who have been fostered and adopted, and ensure that those monitoring services are trained and able to communicate with these children (Spark et al. 2008).

In Western Europe, North America and CEE/CIS, much of the work to improve the

quality of foster and adoption services for children with disabilities could be done by social workers. Elsewhere, alternative strategies are needed because the social workforce is extremely lacking in capacity (Lim Ah Ken 2007; Davis, 2009; IACR 2005). The CBR model, the engagement of local leaders and the use of community-based child protection mechanisms can all be helpful in this situation. It is also essential to carefully define the role of social workers to ensure that they work in areas, such as child abuse cases, where their skills are most needed (EveryChild 2011b).

### Support a limited role for small group homes

As noted above, whilst there is unequivocal evidence about the harm caused by large-scale, institutional care for children, many of those working in child care reform accept a role for small group homes, which provide individualized care for groups of up to 12 children (EveryChild 2011a; Save the Children 2009a; Williamson and Greenberg 2010). Such care can serve a number of functions, many of which may be especially beneficial for children with disabilities. For example, such facilities can provide short-term and respite care and specialist medical and therapeutic services, along with a place for long-term care if family-based care is not possible (EveryChild 2011a; Save the Children 2009a). Small group homes may be particularly relevant for the small proportion of children with disabling conditions that are very severe and manifest themselves in complex, high-dependency requirements. Family-based care or adoption would be highly unlikely for high-dependency children, leaving residential care as the only likely alternative.

Whilst small group homes can offer a valuable care option, they should be used and developed with caution. Affluent countries may have the resources available to provide quality assured and appropriate care in such facilities, but provision of this type of care in low-income countries will absorb a substantial amount of the total expenditure for care of children with disabilities and support to their families. Small group homes may also be presented as a solution for children with disabilities, reducing motivation for developing family-based alternatives. If not properly embedded in communities, small group homes may lead to the isolation of children with disabilities from wider communities. Small group homes should only ever be offered as part of a wider range of care options to ensure that real choices can be made about appropriate forms of care, and that children with disabilities are only placed in residential care when such care is determined to be in their best interests.

As with all forms of care, the care of children with disabilities in small group homes must be regularly reviewed to ensure that it continues to be appropriate (see EveryChild 2011a for a wider discussion of small group homes).

## Carefully plan the closure of large-scale institutions for children with disabilities

The need to end the use of harmful forms of residential care for children with disabilities does not mean that change can or should happen overnight. Efforts are needed to develop alternative forms of care and strategies for supporting children and families through reintegration processes, all of which takes time, especially if social services are weak (Browne 2009; European Commission 2009). The need for careful and well-planned closure of large-scale institutions means that children with disabilities may remain in institutional care even after decisions have been made to close facilities. Therefore, improving conditions in existing institutions has to take place in parallel with prevention, re-integration and placement into family-based care. Key elements of quality in residential care are outlined elsewhere (see BCN and UNICEF 2009; EveryChild 2011a; UN 2010). These principles relate equally to children with disabilities. However, special measures may also need to be taken. For example:

- **Reduce discrimination and train staff:** As outlined above, there is often considerable discrimination and reliance on the medical model amongst care staff in institutions, which needs to be challenged. Staff need proper training to meet the needs of children with a range of impairments (Ellery et al. 2011).
- **Ensure proper child protection measures are in place :** As noted above, children with disabilities in institutional care are more vulnerable to abuse. They may need particular child protection measures, and they must be given more opportunities to report abuse or raise concerns. Children with some impairments may need help communicating, and facilities should be inspected regularly by specially trained personal who can communicate with children with disabilities.
- **Provide care planning and support efforts to help children with disabilities to live independently:** As noted above, children with disabilities in institutions often receive limited support in learning to live independently, and the use of residential care for adults can lead to the assumption that they will remain in care for life. Particular efforts need to be directed at supporting independent living, and regular reviews of their care are essential.



- **Do not isolate children with disabilities in institutional care:** Lessons learnt around the importance of inclusion suggest that children with disabilities in institutional care should, where possible, be given opportunities to access mainstream education and interact with families and wider communities.

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## 4. CONCLUSION AND POLICY RECOMMENDATIONS

The paper provides four key reasons for placing disability at the heart of child care reform agendas:

**Millions of children with disabilities remain in harmful institutional care:**

Depending on definitions and data collection methods used, between 14 and 35 per cent of children have disabilities. In some settings, substantial numbers of these children are placed in institutional care, and some governments continue to invest resources in institutional care for children with disabilities that could be better spent in support to families. Care in such large-scale facilities provides limited opportunities for rehabilitation and is often associated with abuse, neglect and an absence of individualised attention. Such poor care can cause or exacerbate disability.

**Families trying to care for children with disabilities at home receive no or minimal support:**

In resource-constrained settings, there is often only limited health and education service provision for children with disabilities. In some settings, the only way to enable children with disabilities to receive health care or education is through residential care. Parents or extended family members frequently have to give up work to care for children with disabilities and get limited help with child care or social protection. Children with disabilities often face extreme stigma and social exclusion, meaning that even the important informal support of the extended family or community is not always forthcoming.

**Domestic adoption and fostering are options rarely open to children with disabilities:**

Domestic adoption and fostering services are poorly developed in many parts of the world, especially for children with disabilities. General under-investment in these services, poor recruitment campaigns for carers, lack of knowledge and understanding amongst social workers, limited care planning, lack of post-placement support and service provision, and wider stigma and discrimination can make it especially hard to find alternative family-based care for children with disabilities.

**There is a legal and economic imperative to provide proper care for children with disabilities:**

The CRC, CRPD and the Guidelines for the Alternative Care of Children highlight the need to end unequal provision in children's care and the use of institutional care for children with disabilities, and instead support care in families and communities. Institutional care is expensive, much more so than support to parents or family-based care. In the long run, if poor care exacerbates disability or provides inadequate opportunities for helping those with disabilities to learn to live independently, children with disabilities will continue to need the support of the state long into adulthood.

This paper suggests that it is imperative for governments, UN agencies and civil society groups working on both disability and alternative care to:

1. Challenge discrimination and create the political will for change by:
  - Creating a strong alliance between DPOs and those working on alternative care;
  - Highlighting the economic, developmental and legal imperatives for action;
  - Making children with disabilities more visible and empowered through better data collection and research; and
  - Promoting the children's active engagement in decision making and advocacy.
2. Change national legislation and guidance on disability and alternative care to reflect the CRC, CRPD and Guidelines for the Alternative Care of Children.
3. Provide better support to families caring for children with disabilities to prevent a loss of parental care, through integrated systems that link health care, education, child welfare and social protection services. These systems should build on CBR and integrated child protection models and involve children with disabilities in the design, delivery and monitoring of interventions.
4. As a matter of priority, end the institutional care of all children, including those with disabilities, and ensure that children with disabilities have a range of high-quality family-based alternative care options open to them by:
  - Investing in a range of different forms of domestic adoption and foster care, including respite care, and providing detailed guidance to foster care and adoption service providers on strategies to make such services more inclusive and aimed at meeting the needs of children with disabilities;
  - Promoting proper care planning, gate-keeping and rehabilitation services to limit unnecessary time in alternative care for children with disabilities and to ensure that the views of children with disabilities and their carers are fully taken into consideration;
  - Exploring a limited role for small group homes and inter-country adoption for children with disabilities, in line with efforts to create a range of care options for all children;
  - Carefully closing existing institutions and ensuring that whilst children with disabilities remain in institutional care, they are properly protected and cared for and that adequate preparations are made for integration into families and

communities; and

- Working to ensure the care and protection of children with disabilities in both normal and emergency settings.

Only through such efforts will it be possible to achieve much needed comprehensive reform of child care and welfare systems that recognise the rights of all children, including those with disabilities.

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## ANNEX 1: THOSE CONSULTED FOR THIS REPORT

The following people made important contributions to the paper through discussion, interviews, copies of papers and comments on the various drafts:

Amanda Griffith, Anna Feuchtwang, Lucy Morris, Tracey Martin and Richard Ponsford from EveryChild in London

Andrew Dunn, international consultant and specialist in child protection

Andro Dadiani, Country Director, EveryChild, Georgia

Armine Gmyur, educational psychologist, Armenia

Balakrishna Venkatesh, disability expert, India

Dr. Greg Powell, paediatrician, Director Kapnek Trust, Harare, and former director of the Children's Rehabilitation Unit, Harare

Dr. Margaret Lynch, paediatrician, international consultant and specialist in child protection

Dr. Pamela Zinkin, paediatrician, international consultant and specialist in CBR

Dr. Susan Miles, Senior Lecturer in Education, Manchester University, international consultant and specialist in inclusive education

Elayn Sammon, UNICEF Zimbabwe

Felicity Rickett, child care worker, House of Hope, Transnistria, Moldova

Gary Gamer, consultant and specialist in disability and inter-country adoption

Gautam Chaudhury, disability expert, India

Gwen Burchell, Director of UAFA Azerbaijan

Jennifer Cousins, disability consultant, UK

Jo Rogers and other members of the Partnership for EveryChild team in Russia

John Parry Williams, international consultant and specialist in child protection

John Williamson, USAID

Jumanah Zabaneh, Regional Representative, Child Protection and Child Rights and Governance Initiatives in Middle East and Eastern Europe, Save the Children

Kate Wedgewood, Head of Programmes at UK Department for International Development, Uganda, formerly Country Director for Save the Children, China

Kendra Gregson, Senior Advisor, Social Welfare and Justice Systems UNICEF Child Protection, New York

Laurie Ahern, Director of Disability Rights International

N. Beth Bradford, International Services Coordinator, Bethany Christian Services International

Nicola Pigott and Ruth Ayarza, Deaf Child Worldwide

Nino Gogichadze, psychologist, The Public Health and Medicine Development Fund of Georgia

Nurten Yilmaz, Programme Officer, Social Welfare and Justice Systems, UNICEF Child Protection, New York

Peter Coleridge, international consultant and specialist in disability rights

Peter Gross, child protection specialist (alternative care), UNICEF Child Protection, New York

Professor Dana E. Johnson, Division of Global Pediatrics, International Adoption Clinic, University of Minnesota

Rachel Tainsh, Early Years Support Centre, Tajikistan Project Manager, HealthProm

Yura Glukharyevyi, student, St. Petersburg, Russia

## ANNEX 2: INTERNATIONAL CONVENTIONS AND GUIDANCE RELATING TO DISABILITY AND CHILDREN'S CARE

### Convention on the Rights of the Child (1989)

- Preamble: all children should grow up in a family environment in an atmosphere of happiness, love and understanding, the family should receive necessary assistance to fulfil its responsibilities;
- Article 2: the right to protection against all forms of discrimination;
- Article 3 & 9: children should not be separated from their parents unless it is in their best interest;
- Article 18: parents have the prime responsibility to care for children and states should offer support in helping parents fulfil child-rearing responsibilities;
- Article 20: the right of any child deprived of a family environment is entitled to special protection;
- Article 23: specifically relates to children with disabilities and recognises their right to "...enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community"; and "..... the right of the disabled child to special care ....subject to available resources."

See also relevant rights in relation to freedom from exploitation and abuse, education and development, and health and survival.

### The Standard Rules on the Equalization of Opportunities for People with Disabilities (adopted by the UN General Assembly 1993)

- Rule 9: Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counseling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-care services should be made available to families which include a person with disabilities. States should remove all unnecessary obstacles to persons who want to foster or adopt a child or adult with disabilities.

### Convention on the Rights of Persons with Disabilities (2006)

This convention emphasizes the need to focus on the child's abilities not disabilities, and on the right to social inclusion, and in particular recognises the obligations of the state to:

- Article 19: "States Parties to this Convention recognise the equal right of all persons with disabilities to live in the community with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right."
- Article 23: make provision of support to families in order to ensure against the abandonment or concealment of child with disabilities;
- "... where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting."

See also relevant articles on non-discrimination, social protection, education, health and the importance of disaggregated data collection.

### Guidelines for the Alternative Care of Children (UN 2010)

The Guidelines recognise the family as the 'natural environment' for children and call for a range of high-quality, protective care environments for all children who cannot live with their parents. The Guidelines make repeated references to children with disabilities, including:

- Article 9: "As part of efforts to prevent the separation of children from their parents, States should seek to ensure appropriate and culturally sensitive measures... [t]o support family caregiving environments whose capacities are limited by factors such as disability..."
- Article 10: "Special efforts should be made to tackle discrimination on the basis of any status of the



- child or parents, including ... mental and physical disability.”
- Article 34 (b): “Supportive social services ... and services for parents and children with disabilities. Such services, preferably of an integrated and non-intrusive nature, should be directly accessible at the community level and should actively involve the participation of families as partners, combining their resources with those of the community and the carer.”
- Article 38: “States should ensure opportunities for day care, including all-day schooling, and respite care which would enable parents better to cope with their overall responsibilities towards the family, including additional responsibilities inherent in caring for children with special needs.”
- Article 58: “Assessment should be carried out expeditiously, thoroughly and carefully. It should take into account the child’s immediate safety and well-being, as well as his/her longer-term care and development, and should cover the child’s personal and developmental characteristics, ethnic, cultural, linguistic and religious background, family and social environment, medical history and any special need.”
- Article 86: “Carers should ensure that the right of every child, including children with disabilities, living with or affected by HIV/AIDS or having any other special needs, to develop through play and leisure activities is respected and that opportunities for such activities are created within and outside the care setting. Contact with the children and others in the local community should be encouraged and facilitated.”
- Article 87: “The specific safety, health, nutritional, developmental and other needs of babies and young children, including those with special needs, should be catered for in all care settings, including ensuring their ongoing attachment to a specific carer.” Article 117: “Agencies and facilities [responsible for formal care] should ensure that, wherever appropriate, carers are prepared to respond to children with special needs, notably those living with HIV/AIDS or other chronic physical or mental illnesses, and children with physical or mental disabilities.”
- Article 132: “Children with special needs, such as disabilities, should benefit from an appropriate support system [in relation to process of transition from care], ensuring, inter alia, avoidance of unnecessary institutionalization.”

### Other global guidance

Other international guidelines recognise, support and build on these conventions and reinforce their strength as instruments that can be used to ensure compliance and challenge transgression. For example:

The recommendations of the Committee of Ministers to the Council of Europe on the de-institutionalization and community living of children with disabilities.<sup>16</sup>

The European declaration on the health of young people with intellectual disabilities calls for transferring care from institutions to the community.

Voluntary international agreements also play a part. For example:

The International Committee of the Red Cross and Red Crescent (2004) Inter-agency Guiding Principles on Unaccompanied and Separated Children in emergencies, while not specifying needs of children with disabilities in particular, recommends “ ... that all actions and decisions taken concerning separated children ... respect the principles of family unity and the best interests of the child. All stages of an emergency are addressed: from preventing separations, to family tracing and reunification, through to interim care and long-term solutions ...”

16. Council of Europe CM/Rec 2, adopted on 1076th meeting of the Council of Ministers’ Deputies, 3 February 2010.

## EveryChild.

EveryChild is an international charity working to keep families together, to support appropriate alternative care for children who cannot live with their parents, and to protect children who are alone and at risk.

4 Bath Place, Rivington Street London EC2A 3DR

Email: [policy@everychild.org.uk](mailto:policy@everychild.org.uk)

Tel: 00 44 (0) 20 7749 2490

[www.everychild.org.uk](http://www.everychild.org.uk)

Charity registration number: 1089879.

Company registration number: 4320643

## Better Care Network

Better Care Network is an interagency network dedicated to facilitating global information exchange and collaboration among the growing number of organizations, religious groups, governments and individuals working on the issue of children without adequate family care.

3 UN Plaza, Room 723-5

Email: [contact@bettercarenetwork.org](mailto:contact@bettercarenetwork.org)

Tel: 212.326.7104

[www.bettercarenetwork.org](http://www.bettercarenetwork.org)