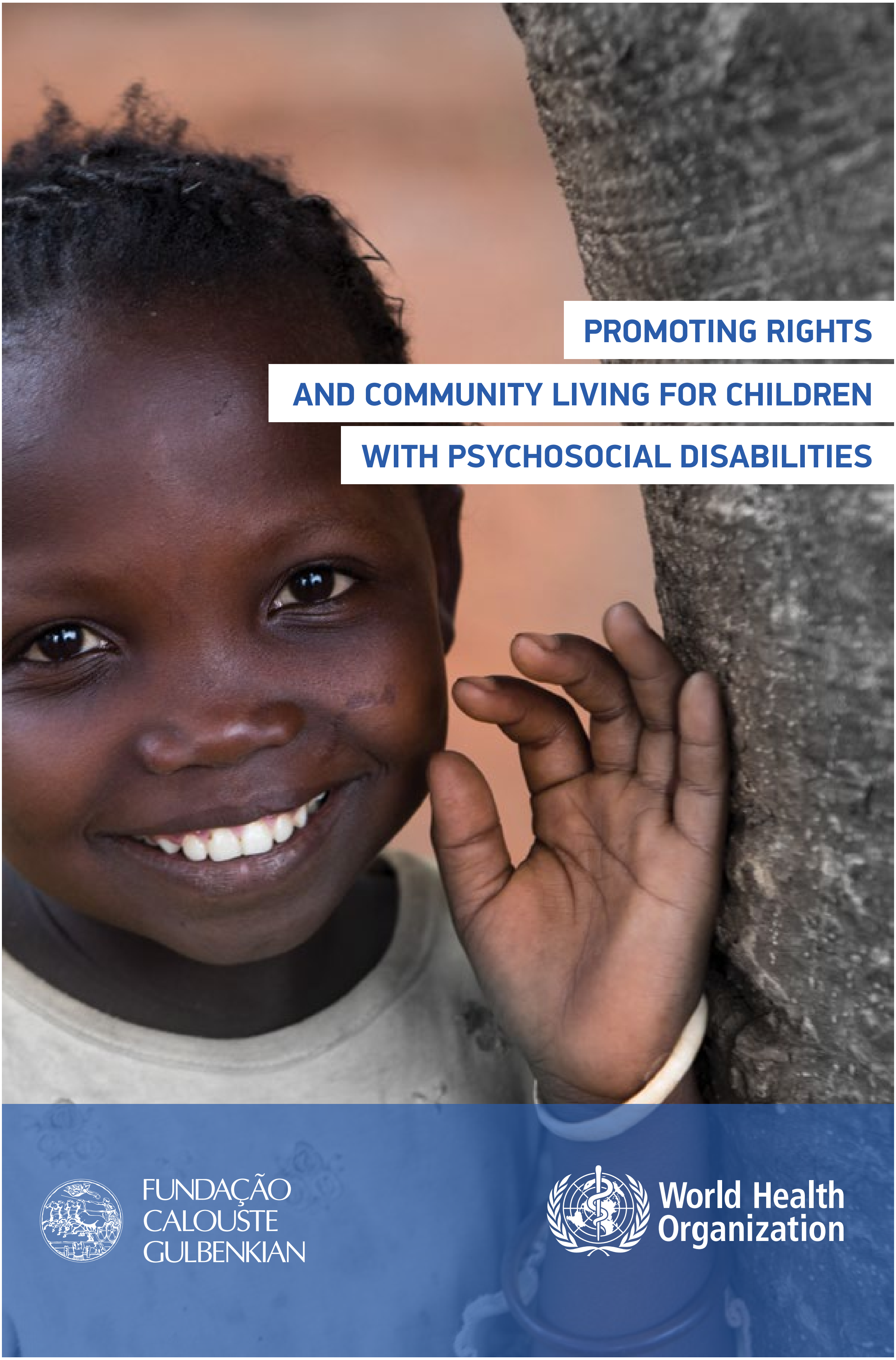

PROMOTING RIGHTS AND COMMUNITY LIVING FOR CHILDREN WITH PSYCHOSOCIAL DISABILITIES

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PROMOTING RIGHTS AND COMMUNITY LIVING FOR CHILDREN WITH PSYCHOSOCIAL DISABILITIES

This publication is part of a series of thematic papers, coproduced by the World Health Organization and the Calouste Gulbenkian Foundation's Global Mental Health Platform. The series consists of four publications covering the following topics.

- Innovation in deinstitutionalization: a WHO expert survey
- Integrating the response to mental disorders and other chronic diseases in health-care systems
- Social determinants of mental health
- Promoting rights and community living for children with psychosocial disabilities.

Examples from different countries are used throughout this report to illustrate some of the key issues, problems and solutions in relation to children with psychosocial disabilities. The information and data contained in the report are drawn from published sources which cannot be verified independently. The use of examples does not imply that these issues, problems and solutions are unique to a specific country.

These examples should not be viewed as an assessment of countries' overall performance in relation to children with psychosocial disabilities. Many countries highlighted in this report have taken corrective measures to improve the situations in which children living in institutions find themselves. Nor should the examples be taken to suggest that any country is more or less advanced than others in protecting the rights of children with psychosocial disabilities. The examples highlighted in this report are used for illustrative purposes only; they apply to many countries around the world.

PROMOTING RIGHTS
AND COMMUNITY LIVING FOR CHILDREN
WITH PSYCHOSOCIAL DISABILITIES

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FOREWORD

Those of us who are parents typically want our children to have the best start in life. And of course, we typically believe that we can provide it. We know, and the experts in childhood development also tell us, that the best start for a child is to grow up in a family group with parents or other caregivers providing security and love.

Some children are born with disabilities, and others develop disabilities in their early years. These children need security, care and love, best provided by keeping them with their parents or caregivers in their own community.

The World Health Organization published its first *World report on disability* in 2011. It emphasized the need for more attention to rehabilitative measures, medicines and therapies and the inclusion of persons with disabilities, including psychosocial disabilities, in the worlds of education, work and community living.

This present report looks specifically at the options for children with psychosocial disabilities. Many such children end up not with their families and communities but in institutions – and the decision to put them there is often taken by members of the health services and government authorities rather than parents. However, growing evidence shows that this is harmful for children. Many institutions struggle to provide the individual care that children with psychosocial disabilities need, and become places where children are subjected to demeaning treatment and forgotten by society, excluded from education, work and normal social activities.

Apart from all the scientific research that has made this report possible, extracts are included from reports by inspectors and staff of institutions. Their statements are distressing.

Evidence shows that, for children with psychosocial disabilities, community services lead to significantly better developmental, health and human rights outcomes than institutional care. Of course, it puts more responsibility on parents, and that is why this report outlines the types of community services and support, including financial assistance, that are needed – for children and for their families.

We hope that this thematic paper will not only inform but also stimulate action by all stakeholders, including governmental agencies and civil society organizations. The issue here is not just to save money; it is to meet the needs of children with disabilities more appropriately, to ensure their education and integration into society and to respect their human rights. Simply put, it is to give them the best start in life that we can.

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DEFINITIONS

Children

Refers to children and young between the ages of zero and 18 years (1).

Disability

The *International Classification of Functioning, Disability and Health (ICF)* views disability as an umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (2).

Institution

Institution, in this report, refers to any place in which persons with disabilities, older people or children live in a group setting away from their community, family and home environments. Implicitly "institution" refers to a place in which people do not exercise full control over their lives and their day-to-day activities. An institution is not defined merely by its size (3).

Psychosocial disabilities

The term "psychosocial disabilities", as used throughout this report, refers to the disabilities of children with either diagnosed or perceived mental health conditions and/or intellectual impairments, which may also be caused by stigma, discrimination and exclusion.

Intellectual impairment

"Intellectual impairment", in this report, refers to a state of arrested or incomplete development of mind, which means that the person can have difficulties understanding, learning and remembering new things, and in applying that learning to new situations. This term is also known as intellectual disabilities, learning disabilities, learning difficulties, and formerly as mental retardation or mental handicap.

Mental health condition

A health condition characterized by alterations in thinking, mood or behaviour associated with distress or interference with personal functions.

EXECUTIVE SUMMARY

Introduction

Institutionalization causes physical and psychological harm to many children worldwide. This report focuses on children who have psychosocial disabilities and describes the human rights violations they experience in institutions. The report underscores the urgent need for countries to make a policy shift from placing children in institutional settings to providing them with a range of services and support in the community.

The global picture – scope of the problem

This report on rights and community living for children with psychosocial disabilities examines the culture and consequences of institutional care and compares it to the social and health benefits of community-based services for children and families. The report focuses on the human rights, dignity, quality of life and health, autonomy and social inclusion of children with psychosocial disabilities in both forms of care.

There are an estimated 93 million children aged 0-14 years with moderate or severe disability and 13 million with severe difficulties. UNICEF estimates that some 2.2 million children around the world live in institutional settings but this figure is considered to be an underestimate due to under-reporting and lack of data in many places. The area of Eastern Europe and Central Asia, where most of the research has been conducted, has more than 1 in every 100 children growing up in institutions. Because of under-reporting, many children with disabilities remain invisible as they cannot obtain birth certificates or other identity documents in countries where they are stigmatized and their families are socially excluded. However, despite the lack of reliable numbers, evidence shows that children with disabilities are disproportionately institutionalized in most countries.

Reasons for the high prevalence rate of children with disabilities in institutions

Institutionalization of children, rather than support to parents, tends to be commoner in countries with a lower gross domestic product (GDP) and a lower proportion of GDP spent on health care. However, family poverty, stigma, discrimination, social exclusion, and a lack of community services and resources for children and families all play major roles in perpetuating institutionalization. Parents are frequently not involved in the decision to institutionalize their child, and in some cases health-care staff encourage parents to place their child in an institution.

Parents who do not have the resources to provide for their children become desperate. If the child has a psychosocial disability the situation becomes even more difficult, and many parents feel they have no choice but to place their child in an institution. At the same time, society's approach to children with disabilities often views these children as not "normal" and in need of correction in some way. On the other hand, the human rights approach to children with disabilities focuses on removing social, physical and other barriers that prevent the full inclusion of such children (and their families) in the community.

Many children with psychosocial disabilities need a range of services and supports in order to live their lives in the community. Parents require financial assistance to support their child's needs yet this is often lacking. The absence of daycare facilities and lack of education are major reasons why children with disabilities are excluded from the community. Children with psychosocial disabilities are too often judged by the capabilities they lack rather than by the capabilities they have.

Institutional environments as facilitators of violence and neglect

Many institutions for children worldwide are neither registered nor licensed, making monitoring almost impossible. Many have overcrowded rooms and wards, with little contact between staff and children, creating an environment that is more abusive than caring. Institutions that house children with psychosocial disabilities are often located in isolated areas far from families and communities. Inspections that have been carried out have reported overcrowding in poorly maintained buildings with insanitary washing and toilet facilities and poor sleeping conditions.

Institutions may easily become impersonal environments with staff who see their roles primarily as caretakers rather than sources of psychological care and support. Children often spend long periods in a crib or cot with no interaction with others, and there have been many reports of children with inadequate clothing, malnourishment and difficulty feeding themselves. The risk of physical violence is real, and children with psychosocial disabilities are especially at risk of sexual violence and emotional abuse. It is difficult to report abuse to an authority, and even more difficult to have action taken.

Children may be physically restrained by being tied to their cots, and medication – including psychotropic medication – may be given inappropriately to children with psychosocial disabilities. In some instances, children are denied medical care. The inappropriate treatment given to children with psychosocial disabilities in institutions is generally attributed to the lack of staff and to their poor training.

Consequences and outcomes of institutionalization for children with psychological difficulties

Institutionalization alone has a major impact on the mental and physical health of children. Institutions - often characterized by regimentation, lack of stimulation, poor-quality care, neglect and harm - lead to detrimental and harmful outcomes for children. Children who spend the greater part of their lives in institutions have the greatest difficulties in reaching developmental milestones. However, a child who is placed in a family-based environment in the first 6 months of life will have a substantially increased chance of optimal development. The lack of a quality relationship with a parent or caregiver leads to a higher prevalence of mental and behavioural problems. Children with psychosocial disabilities in institutions also often experience attachment disorders.

Additionally, many children with psychosocial disabilities are denied general health check-ups and immunization. The death rate among institutionalized children with disabilities, including children with psychosocial disabilities, is far higher than the rate among children in the general population.

Moving ahead: solutions and strategies

Governments have the responsibility to respect and fulfill the human rights of all citizens, including children with psychosocial disabilities. The Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities provide governments with a framework for ensuring that children with psychosocial disabilities enjoy their rights without discrimination.

Children's rights enshrined in these conventions include the right to an identity (i.e. birth registration) and the right of a child to be cared for by his or her parent. Children with disabilities are best cared for in the family environment and "should never be institutionalized solely on the grounds of disability". Other children's rights include freedom from torture or degrading treatment or punishment, the rights to live in the community and to access health-care services, the right to education and, for children with disabilities, the right to receive assistance so that they may access and receive that education.

The present report calls for deinstitutionalization of children's care by a process that phases out institutions and transfers services and supports for children and families, as well as related funds, to the community. Funding of community care for children with psychosocial disabilities has been shown to be more cost-effective in the long term than funding large-scale institutions. For several decades WHO has promoted community-based rehabilitation by local communities in low-income countries as a means to ensuring that people with disabilities are included and participate in society while having access to rehabilitation and other services.

Early childhood intervention, consisting of multidisciplinary services, is recommended for children, usually up to 3-5 years of age, facing developmental challenges. This includes psychosocial support, physical and occupational therapy, speech and language therapy, nutrition support and other interventions that involve parents or caregivers in therapeutic activities. Services may be brief and time-limited or more intensive for complex cases.

Parenting programmes exist to equip parents and caregivers to meet the needs of their child, while peer support provides opportunities to share experiences with other parents and to learn that they and their child are not alone. This is important because the shift to community-based services for children with psychosocial disabilities increases parental responsibility. Respite care services give families time off from their caregiver responsibilities and allow their children to socialize with others outside the family unit. Foster care is an alternative that is currently underused, and small group homes based in the community can be used when other community-based options have been exhausted.

When children with psychosocial disabilities are denied education, their ability to take on employment or other roles in society is diminished. It is important to provide "inclusive" education – i.e. meaningful learning opportunities for all students (with or without disabilities) provided in the mainstream school system, with additional support to the needs of children with disabilities. Creating an inclusive educational environment requires changing the educational culture from one that discriminates against children with disabilities to one that welcomes and embraces diversity and differences.

A parent of a child with disabilities often stays at home to care for the child, forfeiting paid employment. This often means that the family has difficulty paying for the necessary therapeutic services, medication or transport to appointments. Consequently, some form of financial assistance is often needed by families that have children with disabilities.

An important element of all care of children with disabilities is that it should be monitored. Monitoring of institutions should take place during the deinstitutionalization process, and monitoring of community-based services and support for children with psychosocial disabilities should also be in place. Both the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities state that all facilities and programmes for children with disabilities should be monitored by independent authorities.

Conclusion

Institutions are negative environments for children, especially those with psychosocial disabilities, causing them harm and denying them normal opportunities. Community services and support offer these children and their families better outcomes and have been shown to be more cost-effective than institutionalization. However, the fundamental justification for ending institutionalization is the need to respect the human rights of children with disabilities, including psychosocial disabilities, and to allow them the opportunity to live their lives in their own communities. All funding should be directed to this aim.

1. INTRODUCTION

The plight of children placed in institutions has been well documented. An abundance of evidence shows that institutional care causes physical and psychological harm to children, as well as to adults, both with and without disabilities. Estimates show that up to two thirds of children in institutions have a disability and that a significant number of these children have psychosocial disabilities that include developmental delay or intellectual disabilities (4, 5). The evidence shows that violence is pervasive in the institutional context (6). It also indicates that, in general, children with psychosocial disabilities are at higher risk of violence than children with no disabilities and children with other disabilities (7). Low numbers of staff, lack of training, poor quality of care, harmful treatment practices and overall neglect preclude any positive outcomes for these children. As a result, many children remain in institutional care for the rest of their lives, and many others die prematurely (8, 9, 10).

The evidence unmistakably shows that, compared with institutional care, other forms of care and support result in better outcomes for children. Several studies also indicate that community-based alternatives are more cost-effective in the long term (4, 8, 11). The Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Rights of the Child (CRC) clearly outline the rights of children with disabilities – including psychosocial disabilities – and provide a framework for promoting the right of children with disabilities to live with their families, or in home-like environments, in the community. However, in many countries resources are not being transferred from institutional care to create community-based alternatives, and the practice of institutionalizing children with psychosocial disabilities continues.

Many of the issues highlighted in the report are relevant to all children who live in institutional settings, whether they have disabilities or not. The report focuses specifically on children with psychosocial disabilities since they are often the most invisible and overlooked, and describes the human rights violations they experience in institutions. The report aims to underscore the urgent need for countries to move from institution-based care to community-based care. It also provides guidance, based on promising practices from around the globe, on the key services and supports that need to be in place to ensure that children are able to live and thrive in the community. Examples from various countries are used throughout this report to illustrate some of the key issues, problems and solutions in relation to children with psychosocial disabilities. The examples are drawn from published information and data and are used for illustrative purposes only. The issues highlighted are by no means unique to one country or region but apply to countries throughout the world.

2. THE GLOBAL PICTURE – SCOPE OF THE PROBLEM

Children are placed in institutions in countries around the world. However, estimating the extent to which children are institutionalized in each country is challenging. For instance, data on the number of institutionalized children and the reasons why they are placed in institutions are often not collected or, if collected, are not comparable between countries. The inability to compare data across countries or continents is most often due to the absence of common definitions for types of institutions. A wide range of terms refer to institutions for children – including "formal alternative care", "social care" institutions and orphanages – but the different types of institutions are not necessarily the same in different countries and can vary in size and governance. Some institutions will accept only children while others will include both adults and children. Some countries report only data from state institutions and do not include children in institutions that are run by privately owned, faith-based or nongovernmental organizations (NGOs).

This report follows the approach of the European Commission in its *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care* which focuses on the institutional culture, regardless of the name, size or governance attributed to the facility (3). It looks beyond the surface-level qualities to examine the "human rights and dignity of users, their quality of life and health, autonomy and social inclusion" within institutions. Thus, institutions can be classified according to the extent to which they are depersonalized environments, with rigid and often arbitrary routines, lacking in privacy, failing to treat residents as individuals, and emphasizing the difference in status between staff and residents. The care provided in this kind of institution is paternalistic rather than interactive and, particularly for institutions housing children with disabilities, is based on the medical model of care where the sole focus is medical diagnoses (3).

Adopting the European Commission's definition as the basis for this report, institutions for children with psychosocial disabilities:

- are isolated from the community, providing little opportunity for inclusion in common, everyday life experiences;
- house groups of non-family members who are compelled to live with one another;
- result in prolonged periods of separation from the child's family and community;
- are organized according to regimented routines that cannot respond to the individual needs and wishes of children; and
- segregate children from the community on the basis of a determination of disability or chronic illness (4).

2.1 Prevalence rates of children in institutions

The United Nations Children's Fund (UNICEF) estimates that some 2.2 million children around the world live in institutional settings. However, UNICEF stresses that this figure is likely to be an underestimate due to under-reporting and lack of regulations in some countries (11, 12). In 2003, the WHO Regional Office for Europe carried out a survey of 33 European countries (excluding Russian-speaking countries) to map the number and characteristics of children under the age of 3 years in institutional care. Although the figures varied greatly between the countries, 12 countries had institutionalized between 1 and 10 young children per 10 000 under the age of 3 years, seven countries had institutionalized between 11 and 30 children per 10 000 under the age of 3 years, and eight countries had institutionalized between 31 and 60 children per 10 000 under 3 years of age (11). Furthermore, the number of children in institutions is stable or rising in several European Union (EU) member states – both new and old (13).

According to the Europeans Offices of UNICEF and the Office of the High Commissioner for Human Rights, the region of Eastern Europe and Central Asia has the highest number of children growing up in institutional settings – more than 1 in every 100 children. The number of children in institutions in the 20 countries in this region is the highest in the world – more than 600 000 children (13). The trend shows that more children are being separated from their parents than in previous years (14). Despite efforts for change, the rate in this region has been almost stagnant since 2000, but in 12 countries the rate of children in institutional care increased between 2000 and 2007. Furthermore, data suggest that, in 16 of the countries of this region, well over 28 000 of the children placed in institutional care were under the age of 3 years (13).

2.2 Prevalence rates of children with disabilities in institutions

The WHO *Global burden of disease* study, 2004 update, estimates that the number of children aged 0-14 years experiencing "moderate or severe disability" is 93 million (5.1%), with 13 million (0.7%) children experiencing severe difficulties (15). While this estimate is widely used, it is not considered to be fully reliable (16). Determining an estimate of the number of children experiencing disability worldwide is difficult. There are no reliable estimates of the number of children with disabilities based on actual measurement. Existing prevalence estimates of childhood disability vary considerably because of differences in definitions, limitations of census and general household surveys in capturing childhood disability, absence of registries in most low- and middle-income countries, and poor access to culturally-appropriate diagnostic services (17). Furthermore, even within a country, different ministries and organizations may use different definitions of disability and different terminology to describe impairments (18). As a result, the number of children with disabilities is under-reported and, consequently, children with disabilities remain "invisible".

Compounding this "invisibility" is the fact that children with disabilities are often not able to obtain identity documentation, such as birth certificates, when living in countries where they are stigmatized and their families are socially and economically excluded. Their births are not registered for a number of reasons: they may not be expected to survive, or parents do not want to admit to their existence, or they are considered to be a drain on public resources (16).

In some countries children with disabilities are issued disability certificates that become the only means by which the number of children with disabilities can be determined. This method is unreliable for a number of reasons:

- Some children with disabilities cannot apply for a disability certificate because they do not officially exist in the birth records.
- The certificate requires renewal, but many children and families receive no assistance to renew it, and as a result there is no record of the child having a disability.
- Children under the age of 7 years are rarely issued a disability certificate and, as a result, younger children are not included in the statistics.
- The country does not issue certificates to children with mild disabilities (19).

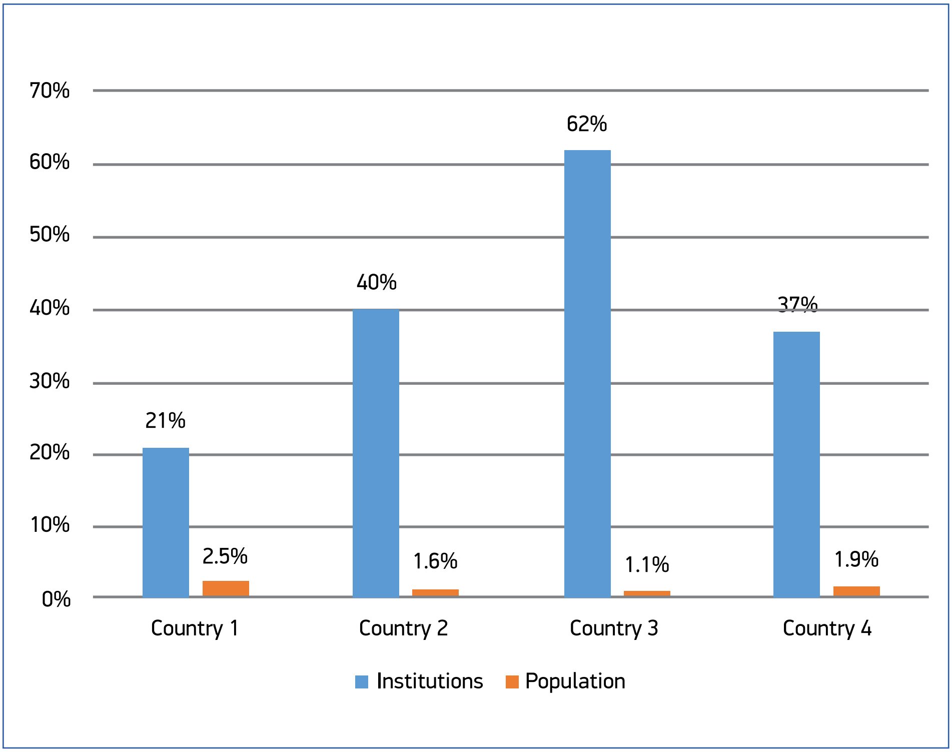
The world's institutions, including institutions referred to as "orphanages", have increasingly become dumping grounds for children with disabilities (20). Despite the absence of reliable estimates of their numbers, there is considerable evidence that children with disabilities, including children with psychosocial disabilities, are significantly over-represented in institutions (20). The estimates of the number of children with disabilities living in institutions in the countries of Central and Eastern Europe are particularly high. According to UNICEF, institutionalization remains the overwhelming policy approach across this region, with "defectology" continuing to be the academic discipline governing the care and treatment of children with disabilities (18). Data from 2007 indicate that children with disabilities make up one third of all children in institutions in the countries of Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS). This proportion has remained stable over the past 15 years, suggesting that little has been done to provide alternative forms of care (14). In 2005, UNICEF estimated that, in these countries, at least 317 000 children with disabilities lived in an institution (21). The majority of children in institutions have a developmental delay or intellectual disabilities (5).

Research conducted by Lumos, an international NGO, highlights the high prevalence rate of children with disabilities among institutionalized children compared with the prevalence rate of children with disabilities within the child population of four countries (Figure 1). It is unambiguously clear that children with disabilities are disproportionately institutionalized. In one country, Lumos found that children with disabilities accounted for 62% of children in institutions (22). For the reasons noted above, there is a strong likelihood that the actual numbers of children with disabilities may be higher.

Figure 1

Comparison between percentage of children with disabilities in institutional care found in Lumos' research compared to statistics of children with disabilities in the general population

(Lumos data based on sample of 2 864 children in institutions. Country data based on official statistics.)



Source: reference (22)
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3. HOW DID WE GET HERE? REASONS FOR THE HIGH PREVALENCE RATE OF CHILDREN WITH DISABILITIES IN INSTITUTIONS

It is a common misconception that many children with psychosocial disabilities are orphaned (4). Children who are truly orphaned account for only a small percentage of the children in institutions. It has been estimated that 94-98% of children living in institutions have at least one living parent (11) yet children, and particularly children with disabilities (including psychosocial disabilities), continue to be placed in institutions.

In its study, the EU Daphne Programme found that in Denmark, France and Greece in 2003, the reasons for institutionalization of children under the age of 3 years were abuse/neglect by parents (34%), incapacitation of parents (25%), child ill-health and disability (21%), and abandonment by parents (20%). These rates were compared with other countries in 2003 where observations were conducted – namely Hungary, Poland, Romania, Slovak Republic and Turkey – where the primary reasons for the placement of children under 3 years of age in an institution were child ill-health and disability (41%), abandonment (35%), incapacitation of parents (13%), and abuse/neglect by parents (10%). The differences between the two sets of countries were attributed to the levels of gross domestic product (GDP) and the proportion of GDP spent on health care (8). In other words, the higher the country's GDP and the more the country spent on health care, the less likely parents would be to institutionalize their young child on the basis of ill-health and disability. In countries with a lower GDP and a lower proportion of GDP spent on health care, the system tends to operate in favour of institutionalization rather than support to parents.

Many factors, including those cited above, contribute to the institutionalization of children worldwide. A review of the literature revealed that poverty, stigma, discrimination, social exclusion, and a lack of community services and resources for children and families also play a major part in perpetuating institutionalization (8, 11, 13, 20).

3.1 Poverty

There is a noticeable increase in institutional care in countries that are in economic transition, where unemployment, migration for work, and rates of family breakdown and single parenthood have increased (11). Parents become desperate as they do not have the resources to provide for their children. This situation becomes even more difficult when a child has a mental health condition or intellectual impairment. In many of these countries, families of children with psychosocial disabilities have few resources and means of social protection; this is especially important because these families often have higher living costs and lost opportunities for income. The financial cost of raising a child with psychosocial disabilities is greater due to direct expenses such as social and health care, travel, rehabilitation or assistance with care. As support is often scarce, a parent may be the only caregiver for a child and, as a result, may not be able to work outside the home, placing further financial strain on the family. Parents feel they have no choice but to give up their child and place him or her in an institution in the hope that the child will have a better life (17, 20, 23).

3.2 Stigma and discrimination

The institutionalization and abandonment of children with psychosocial disabilities is often rooted in negative social attitudes, discrimination and false assumptions of incapacity, dependency and difference that are perpetuated by ignorance (16). The medical model of approach to children with disabilities takes the position that these children are not "normal" and that the problems they have need to be corrected through clinical, physiological and pedagogical means. Taking this view, the problem lies with the child and the family, leading to blame, stigma and discrimination (18). This contrasts with a human rights approach which focuses on removing social, physical and other barriers that prevent the full inclusion and participation of children with disabilities (and their families) in the community. The stigma and shame that are associated with having a child with a psychosocial disability can be severe for some parents and often exacerbates the problem of children being hidden from view and excluded from activities that are important for their development (17). Where disability-related guilt and shame are pervasive cultural phenomena, some parents relinquish their child at birth if congenital problems are evident.

Parents of children with psychosocial disabilities who live in communities with negative beliefs about, and negative attitudes to, disability are often themselves isolated. The lack of economic and social support can in turn have a detrimental effect on their home and family life. For instance, research in high-income countries has shown that the rate of divorce among parents of children with disabilities is much higher than the rate among parents of children without disabilities in the same communities (17).

Children with psychosocial disabilities and their parents are at additional risk of discrimination because of other factors such as gender, economic status and being part of a single-parent home (11, 23). For instance, research has shown that in some countries the gender of a child can increase the likelihood that the child will be placed in an institution. In its study of European countries, the Daphne Programme found that more male children were placed in institutions than female children (8). In contrast, observations in other countries – such as Armenia, for example – found that more female children are institutionalized than male children (24). Regardless of the contributing factors, discrimination leads to greater inequalities in these children's health and development and ultimately to their exclusion from society (25).

3.3 Absence of community services and social exclusion

In many countries, community-based care and support for children with psychosocial disabilities are largely absent (26). Many children with psychosocial disabilities need these services in order to live their lives in the community, and parents require financial assistance to support their child's needs. This lack of required care, services and support in the community results in many children being placed in institutions. It also means that children are likely to remain in institutional care for longer periods of time (11).

Absence of daycare facilities (i.e. preschools) and lack of access to education and inclusive schools are key reasons why children with disabilities remain excluded from the community (14, 23, 27). Survey data from low- and middle-income countries show that children with disabilities aged 6-7 years are significantly less likely to be enrolled in school than peers without disabilities. In a study of 12 developing countries, data showed that 6-17-year-old children with disabilities were almost always less likely to attend school than children without disabilities. In some countries the shortfall is up to 60 percentage points (28). Similarly, a 2008 survey in the United Republic of Tanzania found that children with disabilities who attended primary school progressed to higher levels of education at only half the rate of children without disabilities (29). Even where some community resources do exist, parents are often not provided with information about the services, support and rehabilitation options available to them, or given advice on how to meet the needs of their disabled child. Instead the focus is solely on addressing the child's medical problems. Parents are regularly excluded from the decision to institutionalize their child, and in some cases hospital staff strongly encourage parents to place their child in an institution (14, 27).

Inclusive education refers to the provision of meaningful learning opportunities for all school-age children. It allows children both with and without disabilities to attend the same school, with individually tailored support provided to the children who need it, as opposed to segregating children with disabilities in separate schools or providing no opportunities for education at all. Inclusive schools are not the norm in many countries and, as long as this is the case, the educational needs of children with disabilities will continue to be ignored. At the root of exclusion is the way in which children with psychosocial disabilities are judged by the capabilities they lack rather than by the capabilities they have. These children are often regarded as inferior, and this exposes them to increased vulnerability to all forms of abuse and exploitation (16).

Placing children in institutions is, in many instances, rationalized as an attempt to "protect" children from harm, although in fact institutions themselves are often dangerous places for children with disabilities (11). The following sections describe the forms of abuse inflicted on children with disabilities, and children with psychosocial disabilities in institutions in particular, as well as the severe and long-lasting consequences of institutionalization.

4. INSTITUTIONAL ENVIRONMENTS AS FACILITATORS OF VIOLENCE AND NEGLECT

The “invisibility” of children with psychosocial disabilities makes them particularly vulnerable to all forms of exploitation and violence (16). Institutionalization isolates children from their families and communities, and it is much harder to protect children when their ties to family and community have been broken and they live in isolation far from their homes. Many institutions are not registered and not licensed, which makes monitoring of the care provided within institutions by government or outside agencies almost impossible (16). Consequently, many children’s health and lives are at great risk.

The custodial setting in institutions fosters an environment that is often characterized by neglect and violence. Many institutions consist of overcrowded rooms and wards, with little contact between staff and the children in their care, creating an environment that invites abuse. Every continent has reports of children experiencing physical violence and sexual, verbal and emotional abuse by staff, visitors and other patients in these institutions (6). This is not a phenomenon limited to middle- and low-income countries. For example, a class action lawsuit in Ontario, Canada, was recently settled and a government apology issued following allegations of physical, sexual and emotional abuse and neglect from the former residents of a large centre for children with intellectual disabilities (30, 31). The lawsuit represented children who were institutionalized at the centre between 1945 and 2009 (32).

Although a plethora of information has been collected by various NGOs, United Nations agencies and other bodies regarding the conditions in some institutions and the treatment of children in them, it seems that we have only begun to see the extent to which children with psychosocial disabilities are institutionalized and the severity of the abuse and neglect they endure. The evidence that has been documented shows a picture of extreme cruelty. These children’s voices are silenced, figuratively and literally. As is evident from the following descriptions of the conditions and treatment of children with psychosocial disabilities, the institutionalization of children is a major human rights violation.

4.1 Poor physical environment

Many institutions that house children with psychosocial disabilities are located in isolated areas far from urban centres, families and communities, and as a result they tend to be forgotten (6). The physical conditions of institutions can vary greatly according to levels of funding, donations and nongovernmental support. In countries where site visits or inspections have been conducted, the physical conditions of the institutions are often found to be poor. In some institutions that were caring for children both with and without disabilities, the physical areas for children with disabilities were in a poorer condition (19).

Many institutions are characterized by overcrowded living conditions and unsanitary bathing and toilet facilities:

> *"Building 1 was actually a one-floor school that was turned into a boarding place…inside, one could feel a distasteful smell of an unclean toilet. At the entrance, to the right, there are the toilets (4 squat toilets for 40 children) and on the same floor there are four dormitories placed in the former classrooms…The sanitary facilities were only partially working: the sinks had no pipes or faucets. At the time of the visit, only cold water was running…the first floor has the same structure but it also comprised an 8-shower room for all 80 children accommodated in this part of the building"* (19).

Typically, institutions have poor sleeping environments. As reported by one observer:

> *"Dormitories in the ward were dirty, and patients slept on thin mattresses on the floor. At the time of Human Rights Watch's visit, some children and adults were lying down naked next to their feces. The nurse said they had reacted negatively to their prescribed medications"* (33).

Interviews and observations conducted in institutions in different countries revealed that the high costs of managing the institutions were addressed through cost-saving measures such as restrictions on the use of hot water and heating. Furthermore, these cost-saving measures are sometimes justified on the false belief that individuals with mental health conditions and intellectual impairment cannot feel the cold (6):

> *"The temperature at the second floor (where the boys live) is extremely low. The hall windows on that floor are broken, and the residents from one of the rooms were using a self-made improvised electric stove for heating. The toilet and showers are completely unheated and there is no hot water. Due to the very low temperatures, it was practically impossible to use that facility"* (19).

The dormitory-style accommodation and the overcrowded living conditions mean that there is no privacy for the children and their belongings:

> *"The children go into the shared showers naked based on age groups, organized in series of 12-14 children. They don't have their own soap or shampoo as these are held by the staff who give them to the children while they are washing. Orderlies supervise all children (boys and girls) while they take a shower [at the time of the visit, the children were aged between 10 and 20 years of age]"* (19).

> *"During the monitoring visits, it was noticed that often the children didn't have wardrobes or a place to stock their personal belongings in the dormitory. When children have such items, these are locked up so that they don't get stolen by other children and staff"* (19).

4.2 Neglect and absence of care

In many cases, institutions for children are impersonal environments with highly regimented routines, with staff who see their roles primarily as providers of nursing and physical care and ignore their role as providers of psychological care, nurturing, love and support. Children will often spend significant periods in a crib or cot with no interaction. The lack of movement leads to further health problems, as noted by Disability Rights International (DRI, formerly known as Mental Disability Rights International or MDRI):

> *"Without any movement, physical disabilities worsen, and children can develop life-threatening medical complications. Some children's arms and legs atrophy and have to be amputated"* (34).

Children are often not provided with adequate clothing, with their only option being to share clothing with other children. For example, investigators for DRI and the Comisión Mexicana de Defensa y Promoción de los Derechos Humanos (Mexican Commission of Defense and Human Rights Promotion) found in Mexican institutions where children are incarcerated along with adults, "a basic lack of adequate clothing at many of the institutions. Of the people that were wearing clothes, many were dressed in identical or interchangeable garments. Residents wore clothes that were too big or too small. Many residents tied their pants up with string or simply let them fall off…one resident's pants were kept in place with adhesive tape around his waist" (35).

Observations have been made that many children, and particularly children with disabilities, living in institutions are malnourished. Children with some types of mental health conditions and intellectual impairment may have difficulty feeding themselves and may need assistance with eating. DRI reports that it has observed bedridden children, unable to feed themselves due to their disability, left inadequately fed and without assistance from staff. Investigators observed children emaciated from starvation and staff have reported children dying from starvation and dehydration.

> *"Many of the children could not feed themselves. Some were struggling to hold onto or reach the bottles and much of the contents spilled out onto beds or wasn't eaten. A little girl, who looked to be about 2 years old, was crying and squirming in her crib. A full bottle of formula was lying in the corner of her crib, just out of reach. I watched for over an hour, and no one came to feed her. She would have had nothing if I hadn't eventually helped her…Over the course of a number of feedings, I watched as staff came quickly into the room, dropped off bottles, and then picked up the bottles as they left the room. If a child could not pick up the bottle to eat or drink, she starved"* (23).

The Bulgarian Helsinki Committee, in its 2010 investigation of all the social care homes for children with psychosocial disabilities in Bulgaria, found 103 children were suffering from malnutrition and as a result were exposed to the risk of dying of hunger or diseases due to their weakened condition. The Deputy Chairperson of the Committee, Margarita Ilieva, declared that "this is a case of an institutionalized, rather than organized, crime, and it is directed against the most vulnerable group of people in this country" (9).

The consequences of malnutrition on children include poor health outcomes, missing or delayed developmental milestones, avoidable secondary impairments and, in extreme circumstances, premature death (36). The Government of Bulgaria, in an effort to improve the situation of children with disabilities, worked with Lumos (an international NGO based in the United Kingdom) to assess the needs of children with disabilities in institutions. Assessments showed that there were more than 1800 children with disabilities residing in institutions and that more than 250 of these children were malnourished. The assessment also revealed that the children were not malnourished because of a lack of food; their malnourishment was due to a lack of knowledge among institution staff regarding how to feed children with disabilities properly and a lack of time spent on feeding all the children in their care (37).

4.3 Violence against children with psychosocial disabilities in institutions

Children with psychosocial disabilities are extremely vulnerable to violence in general. In 2012, a systematic review and meta-analysis were undertaken of observational studies of violence against children with disabilities. Seventeen studies, all from high-income countries, met the criteria for inclusion in the review. Prevalence estimates of violence against children with disabilities ranged from 26.7% for combined measures of violence to 20.4% for physical violence and 13.7% for sexual violence. Furthermore, the risk of physical violence, sexual violence and emotional abuse is increased for children with psychosocial disabilities in particular, as shown in Table 1 (7).

Table 1. Random-effects pooled odds ratios for risk of violence

	ANY DISABILITY			MENTAL OR INTELLECTUAL DISABILITY		
	Studies	Odds ratio (95% CI)	Heterogeneity	Studies	Odds ratio (95% CI)	Heterogeneity
Any maltreatment	4	3·68 (2·56–5·29)	91·8% (87·7–94·1)	3	4·28 (2·12–8·62)	94·0% (90·2–95·9)
Physical violence	6	3·56 (2·80–4·52)	50·6% (0–73·0)	4	3·08 (2·08–4·57)	50·8% (0–77·2)
Sexual violence	9	2·88 (2·24–3·69)	86·9% (78·8–90·9)	4	4·62 (2·08–10·23)	84·7% (64·4–91·2)
Emotional abuse	4	4·36 (2·42–7·87)	94·4% (91·4–96·0)	3	4·31 (1·37–13·56)	96·2% (94·2–97·3)
Neglect	3	4·56 (3·23–6·43)	73·8% (27·7–86·0)	2	..	..

We used the I^2 statistic (95% CI) to estimate heterogeneity between pooled studies ..=insufficient sample.

Source: reference (7)
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Violence against children with psychosocial disabilities is pervasive in the institutional context. The situation is exacerbated by the fact that children with psychosocial disabilities residing in institutions are easy targets, often due to their powerlessness and their inability to defend themselves and to report the violence.

Children with psychosocial disabilities are disproportionately vulnerable to sexual violence compared with other children. Indeed, the 2012 review indicated that children with psychosocial disabilities are 4.6 times more likely to be victims of sexual violence than non-disabled children (7). This risk is heightened in the institutional context (19). The perpetrators of the sexual abuse can be staff or other residents of the institution.

> *"One of the girls had been sexually abused by an educator. According to the statements of the other children, the rape took place in the centre and both the staff and the children knew about the abuse…"* (19).

The use of restraints and seclusion in institutions is another form of violence against children with psychosocial disabilities. These practices are used by staff to control the movement of children either because of a lack of human resources to look after large numbers of children or because the staff do not know how to treat children with psychosocial disabilities. In other instances seclusion and restraint are used as punishments. The practices are often extreme, as observed:

> *"The resident, aged 10, was identified in one of the building dormitories where the 'vegetables' were kept (statement of a medical nurse). She was diagnosed with childhood autism and mental retardation. The resident, sedated and immobilized, was found tied up to the bed by pieces of linen and lint crossed her body…her hands were hidden, tied up behind her back at the wrist level…During the visit, there wasn't any member of the staff in the ward"* (19).

In its inspections of social care homes for children with mental disabilities, the Bulgarian Helsinki Committee found that more than eight of the homes maintained a practice of "unlawful physical immobilization of children as a means to control their behaviour" – such as binding children's limbs; fastening them to beds, wheelchairs and other objects; and using restraint jackets (9). In Greece, a 2011 report by the National Ombudsman highlighted that children in one facility were being strapped to their beds, and that children with learning disabilities were being kept in wooden cage-beds (38).

As recently as May 2014, Human Rights Watch reported that a 7-year-old boy with an intellectual disability died in a Russian orphanage after a health worker used cloth diapers to tie him to his bed (39). The boy's medical forms allegedly recommended that staff use physical restraints as treatment for hyperactivity. Following numerous visits to 10 orphanages across Russia, the author of the article encountered overwhelmed and undertrained staff who stated they restrained children "to prevent them from knocking their heads against cribs or walls, climbing out of their cribs and injuring themselves, or attempting to escape their rooms or institutions".

> *"In one orphanage, I met a thin 14-year-old girl named Lyuda with cerebral palsy who was tied to a wheelchair by the arms and torso. A volunteer explained the use of restraint: "We tie her up to prevent her from running away. We didn't want her to get beaten up by the staff as punishment. But now she has forgotten to walk"* (39).

In 2008, the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, stated in an interim report that “prolonged use of restraint can lead to muscle atrophy, life-threatening deformities and even organ failure, and exacerbates psychological damage”. Furthermore, the Special Rapporteur noted “that there can be no therapeutic justification for prolonged use of restraints, which may amount to torture or ill-treatment” (40). In a 2013 report, the Special Rapporteur added that “any restraint on people with mental disabilities for even a short period of time may constitute torture and ill-treatment” (40). The Special Rapporteur went on to state: “it is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities, should apply in all places of deprivation of liberty, including in psychiatric and social care institutions” (40).

In institutions where abuse is rampant, it is difficult to report incidences of abuse to an authority, and even more difficult to have the report acknowledged and action taken. There is a tendency for staff to cover up abuse or deny that it has occurred. More often than not, disciplinary or legal action is not taken against staff who abuse children; rather, the staff’s violent behaviour is considered normal and is accepted and tolerated by their peers and managers (19). The situation is further compounded by the lack of accountability on the part of staff and a lack of access to justice for children with disabilities. Furthermore, many children with psychosocial disabilities do not have the ability to articulate the abuse they have endured, or else their complaints are simply ignored. Even if they are able to describe the abuse inflicted on them, they are fearful to do so as they may be punished further for speaking out.

> *“The majority of the interviewed children said they were afraid to make a complaint; moreover, they were sure that their complaints were ignored because of their mental disability”* (19).

Even where mechanisms are in place to receive reports of abuse from children, they are often not appropriate. For example, one law in Romania stipulated that a child helpline must be put in place. However, many children did not know about the helpline or, due to their disability, did not have the communication skills to be able to use the service (19).

Moreover, few institutions have an internal reporting or oversight mechanism that would allow staff or visitors to report any abuse they have observed (6). External monitoring bodies that consistently inspect institutions are even fewer, making it even more difficult to expose the violence against children with disabilities. This situation is further complicated when institutions have legal guardianship over children with psychosocial disabilities. In many countries, the director of the institution where the child is placed is the child’s legal guardian which, in practice, means that children are deprived of the right to ask for redress against any act of neglect, abuse or violence. The request to bring in outside authorities to address this situation can be denied by the institution as it has legal guardianship over the child and is entitled to decide what intervention is needed (6).

4.4 Harmful and inhuman treatment practices

Children with psychosocial disabilities are often placed in inappropriate facilities such as adult psychiatric hospitals or other institutions/wards for adults. The practice of transferring children and young people from child institutions to adult psychiatric institutions is commonplace in some countries. In several cases, admission to adult psychiatric hospitals is used as a form of punishment. UNICEF has reported:

> *"In more than a third of the institutions visited, the conversations with the children and some of the psychiatric clinic staff revealed that admissions of disabled children from placement centres to psychiatric hospitals were made arbitrarily, as a punishment"* (19).

The admission of children from institutions to adult psychiatric hospitals is at times justified by staff because there are too few staff to look after the children in their care. There are documented examples of children being placed in institutions with adults, often in the same rooms and wards, which is not only socially and developmentally inappropriate but may magnify the existing vulnerability of children with disabilities.

> *"Despite its name, the Children's Ward at Accra Psychiatric Hospital houses people ranging from 14 to 40 years of age…Almost half of the patients in the Children's Ward were actually adults; those younger than 18 ranged in age from 12 to 17. A nurse said that some of the adults had been in the ward since 1980"* (33).

Staff in institutions for adults usually do not have the training and skills to address the needs of children. As a result, the children's mental and physical health deteriorates further. One observation regarding children placed in the same institution as adults indicated:

> *"These children are placed in a separate room and kept in barred beds. This treatment was justified for their 'enhanced protection'. One child, of almost two years, was laid on a fitted carpet so that we could see his level of autonomy and he wasn't even able to sit without help"* (19).

In some institutions, adult patients are forced to help care for the infants and children with disabilities; this happens most often in psychiatric institutions and institutions for children with intellectual impairments. Furthermore, in overcrowded and poorly staffed facilities, the adult patients are not supervised as they care for disabled children (19).

Medications, including psychotropic medications, are used inappropriately on children with psychosocial disabilities, often as a means of dealing with behavioural issues (41). Furthermore, a noticeable increase in prescriptions of medications, especially psychotropic medications, among children, has been seen globally in recent decades. Data from the USA's National Health Interview Survey, 2011-2012, for example, found that 7.5% of children aged 6-17 years were prescribed medications during the previous 6 months because of emotional or behavioural difficulties (42). A population-based study in the United Kingdom showed a 96-fold increase in prescriptions of stimulants to children and adolescents between 1992 and 2001 (43). Similarly, the prevalence of antipsychotic use among children and adolescents in Canada increased from 1.9 per 1000 in 1999 to 7.4 per 1000 in 2008 (44). The observed trend of increasing prescriptions is particularly concerning because many psychotropic medications are not approved or licensed for children and adolescent populations and their effects on these populations are neither well known nor well tested (45). Despite this, physicians are likely to generalize adult prescribing patterns to children (46). The use of psychotropic medications in children and adolescents may lead to adverse effects, including weight gain, movement disorder, diabetes mellitus and dyslipidemia (47, 48).

Research has shown that children in the care of the state are prescribed psychotropic medication at far higher rates than children in the general population. Results of site visits have uncovered situations in which the most "difficult" children are given antipsychotic medication as a form of chemical restraint. For example, inspectors of social care homes for children with psychosocial disabilities in Bulgaria found that over 90 children had been chemically restrained by dangerously heavy doses of damaging antipsychotic drugs (9). According to one nurse in a children's ward in Ghana:

> *"While no one on current admission has a psychiatric condition, some of them receive psychotropic drugs because they are so restless. We don't have access to alternative services that would stimulate these children. In any case, we lack the necessary skills to handle children with intellectual disabilities since we are trained to deal with psychotic adult cases"* (33).

In addition to inappropriate use of medication, children with psychosocial disabilities in institutions around the world are subjected to other severe forms of inappropriate treatment such as electroconvulsive therapy (ECT, also known as electric shock therapy) (16, 26). WHO has stated that there are no indications for the use of ECT on minors, and hence this should be prohibited (49). The United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment has remarked that ECT without anaesthesia, muscle relaxant or oxygenation amounts to torture (50). However, monitoring efforts worldwide continue to uncover instances of ECT being administered to children and adolescents.

4.5 Poor mental and physical health care and lack of habilitation and rehabilitation services

Health care for children with psychosocial disabilities residing in institutions is often neither available nor accessible. In some instances, children are denied medical care (5, 19, 51). For instance, a 2005-2006 monitoring report of institutions in Romania revealed that children may be required to go to the physician's office to receive health care although there may be no transport and support available to enable the child to go to the physician's office. It was also found that a number of institutions had a physician position within their organizational chart but that the position was often vacant. Orderlies or nurses tend to take on the roles of the physician (19). Even when children with psychosocial disabilities are taken to general hospitals for treatment, they are often refused admission because of stigma and misconceptions about their mental health condition (52). In addition, children with psychosocial disabilities are not immunized to the same extent as healthy children even though their risk of disease is the same or even greater. This leads to increased vulnerability to preventable disease, worsening of existing health conditions and in some cases even death (16).

Children with psychosocial disabilities sometimes need specialized health care. In relation to children with intellectual disabilities in particular, it has been found that although these children have greater health needs over time they encounter significant barriers to accessing health care (5). Access to specialized health care is particularly difficult for children living in institutions. Stigma associated with the children can be so pervasive that, in some cases, ambulance services have refused to come to the institution to take the child to hospital (19). According to staff at one facility, children with the most severe physical and mental health conditions and intellectual impairments are denied medical care when they become ill and are often left to die:

> *"Nurses come to the units and stand in the doorway. They ask the workers if there are any sick children; they just yell in. The workers always say no even if the children are very ill. When children get sick, they are no longer bathed and are not allowed to be taken out of bed. They are tied into their beds at times. If children are not taken care of, they do die. One is dying now"* (26).

In order to improve the quality of life and health of children with psychosocial disabilities, rehabilitation and therapeutic services need to be made available. Following an assessment of a child's needs, rehabilitation and other therapeutic services should be incorporated into the child's individual care or rehabilitation plan. However, monitors visiting institutions have often found that children's records were incomplete and in many cases did not include rehabilitation plans. This is partly because there is a lack of trained rehabilitation staff. Overall, staff appear to show little interest in the children's rehabilitation, education and socialization needs:

"The allied health personnel (orderlies) spend the most time with the residents and confirm that the planned (educational, play, therapeutic) activities are run for very short periods of time – 30 minutes – or on some days they are not carried out at all. Thus, the children are under their care for practically 24 hours a day although the institution has six full-time educators" (19).

"The psychologist said that her work consisted of counselling and evaluation of beneficiaries (children). She couldn't name the tests she was using or the type of therapy interventions used for children with behavioural disorders" (19).

4.6 Lack of staff and poor training

Substandard care provided to children with psychosocial disabilities in institutions is largely attributed to the lack of staff in these facilities and the poor standard of staff training (11, 19). One report indicated that low staff-to-child ratios in some institutions range from 1 staff person for every 40 children to 1 staff person for every 100 children (6, 23). Such low numbers of staff mean there is little or no individual care or stimulation for the children. Children are left unattended for long periods during the day, and overnight entire wards are left unattended with only minimal staff on the night shift to oversee hundreds of children (6).

In addition to overall low numbers of staff, some institutions do not have qualified personnel (e.g. child psychiatrists, psychologists, speech therapists, physical therapists) to deliver rehabilitation services. Even where such positions exist, they may be vacant because of the difficulty of recruiting qualified professionals when wages are low, working conditions are demanding, low social status is attributed to the job, and the institution is in a remote location (6, 19). When it is difficult to recruit trained staff, administrators are apt to hire persons who may not be qualified. In the haste to hire someone, background checks are often not conducted, leaving the children vulnerable to child predators (6).

Quite often, staff who work in social care institutions are not trained to care for children with psychosocial disabilities, and the result is inadequate and negligent care:

> *"Without emotional attention and support, many children become self-abusive, rocking back and forth, banging their heads against walls, biting themselves or poking their own eyes. Most facilities lack trained staff that can help children stop such behaviour. Instead, children are sometimes tied permanently to beds or held in cages"* (34).

Staff who lack proper training can lash out at children in their care because of frustration or a lack of understanding of the children's needs (19). One report revealed, for instance, that staff used physical punishment on children who were incontinent – a situation over which children have no control and which should be addressed with additional care and support rather than punishment (19). Low staff numbers and lack of qualified staff can even lead to the death of children in some instances. The 2011 report by the Greek national ombudsman, for example, reported that "the two recent deaths of minors with intellectual disabilities because of swallowing objects [were] related with the lack of scientific supervision and staff" (38).

5. CONSEQUENCES AND OUTCOMES OF INSTITUTIONALIZATION FOR CHILDREN WITH PSYCHOSOCIAL DISABILITIES

The consequences of institutionalization on children are dramatic and profound. Institutionalization alone, irrespective of a child's initial diagnosis or lack thereof, has a major impact on the mental health and physical health of children. Not only are children's pre-existing conditions likely to worsen as a result of being institutionalized but institutionalization can also result in their death.

The United Nation's *World report on violence against children* states that the impact of institutionalization on children includes "poor physical health, severe developmental delays, disability and potentially irreversible psychological damage" (53). The negative impacts of institutional care on children's development have been studied and noted for well over 50 years (54). Indeed the very nature of institutions - often characterised by regimented schedules, unstimulating environments, poor-quality care, neglect and harmful practices - does not allow for positive outcomes for any children, let alone children already experiencing psychosocial disabilities.

Research has shown that institutionalization of babies harms their early brain development, can result in developmental delay and permanent disability, and may have long-lasting effects on their social and emotional behaviour (4, 11). As a result of long periods of under-stimulation, "all areas of the cortex can be affected by early institutional care, but there is significantly reduced metabolic activity in the frontal and temporal lobes of the developing brain" (11). Perry (2008) describes different clinical reports and studies which highlight the significant impact of institutionalization on the emotional, behavioural and cognitive functioning of children (55).

The age of placement, length of stay and quality of care in an institution also directly affect the long-term outcomes for children residing in facilities (54, 56, 57). In other words, the younger the age at which a child is placed in an institution, the longer he or she resides in an institution, and the poorer the quality of care received, the more likely that the child will have physical, cognitive, emotional, behavioural and/or psychiatric problems over the long term and the less likely that these problems will improve as the child get older. Children who spend the greater portion of their lives in institutions show the greatest difficulties in reaching developmental milestones (4, 54).

Conversely, Johnson et al. found in their study that placement of a child in a family-based environment before the age of 6 months substantially increases the chances that the child will reach optimal development (56). Another study showed that young children who were moved from an institution into foster care demonstrated signs of improvement in their intellectual functioning, and the earlier the foster placement occurred, the greater the improvement (58). The Bucharest Early Intervention Project, consisting of a randomized controlled trial of foster care as an intervention for institutionalized children, found numerous benefits of early family placement and enhanced caregiving for institutionalized children, including:

- improved attachment patterns;
- reduced signs of emotional withdrawal;
- improved measures of positive affect; and
- reduced prevalence of psychiatric disorders (59).

> *"Contemporary research has documented many problems in young children adopted out of institutions in Eastern Europe. Abnormalities include a variety of serious medical problems, physical and brain growth deficiencies, cognitive problems, speech and language delays, sensory integration difficulties, social and behavioural abnormalities, including difficulties with inattention, hyperactivity, disturbances of attachment, and a syndrome that mimics autism"* (13).

5.1 Mental and behavioural health problems

One of the leading factors that contribute to the mental health of children is the quality of the relationship with the caregiver, which is characterized by confidence, support, continuity and warmth. The absence of this form of care in institutions results in a higher prevalence among children of behavioural and psychiatric disorders – including higher rates of aggressive behaviour, depression and anxiety, nocturnal enuresis (bedwetting), attention deficit hyperkinetic disorder (ADHD) and oppositional defiant disorder (60). One in-depth study of the quality of institutional care for children in four countries that were EU member states in 2003 and five other countries demonstrated that the institutions providing the least stimulation and individualized care for children had a higher number of children demonstrating behaviours indicative of emotional disturbance (8).

An extensive, systematic search of the literature published between 1944 and 2003 has been conducted regarding children who were exposed to institutional care (56). Children with disabilities were not included as a criterion for comparison; the focus was on children who had lived in an institution under the age of 5 years and for varying lengths of time. Twenty-seven research studies that used a control or comparison group were reviewed in detail. Seventeen studies measured social and behavioural problems among institutionalized children compared with other children. A majority of the studies (94%) highlighted problems with antisocial conduct, social competence and play (56).

A 2009 study which monitored behaviours indicating emotional disturbance – such as rocking and head banging among institutionalized children – found that these behaviours were significantly negatively correlated with the degree to which the child had exposure to stimulating activities, such as age-appropriate toys and books and access to a playground (11).

Children with psychosocial disabilities living in institutions also often experience attachment disorders. Indeed research studies by attachment theorists such as John Bowlby and Mary Ainsworth have shown that the lack of a one-to-one relationship with a primary caregiver is a major cause of harm to a child's development (61). In the same systematic search of the literature published between 1944 and 2003 mentioned above, studies reported that children in institutions exhibited "over-friendliness" or disinhibited behaviour that was indicative of "disorganized attachment disorder" (56). Studies by Smyke et al. (2002) and by Van Ijzendoorn & Bakermans-Kranenburg (2009) conclude that the neglectful and socially-depriving environments associated with institutions result in significant attachment difficulties in children (62, 63). In institutional environments with many children, a small number of staff and inconsistent caregiving, there are simply too few opportunities to form attachments (11).

> *"The effect of living without loving care-takers or any form of stimulation causes some children to become self-abusive. Rehabilitation centres offer no assistance for self-abusive children other than to tie them down"* (26).

5.2 Health problems, disability and death

Institutionalization also has dire consequences for the physical health of children. Many children are denied general health check-ups and immunization, leaving them vulnerable to childhood diseases and other illnesses. Specialist health care is often also denied, resulting in long-term health problems and disability in many cases. An investigation by DRI in the Republic of Georgia documented discriminatory denial of available and affordable life-saving medical care to children with disabilities because of a perception by doctors that these children would not have a high quality of life. In some cases, DRI documented cases of children with disabilities who were turned away from hospitals without being examined (10).

Reports from different countries document widespread cases of pneumonia, infections and general physical deterioration resulting from lack of care, as well as a range of injuries and self-abuse (9, 23, 34). Atrophy of arms and legs is common as a result of the restricted movement of children left unattended in their cribs or in restraints, and can lead to a need for amputation in some cases (34). Hydrocephalus is often left untreated, resulting in brain damage, convulsions, blindness and learning difficulties, as well as pain and suffering for the child (64). Malnourishment is also a feature of some institutions and may impact severely on the physical health and development of children (37).

> *"Left to languish for years in a state of total inactivity, placement in these facilities is likely to contribute to a person's disability. Children's arms, legs and spines become contorted and atrophy from the lack of activity or physical therapy"* (26).

Many children in institutions die because of the lack of attention to their physical health needs. The death rate among institutionalized children with disabilities, including children with psychosocial disabilities, far exceeds the rate attributed to children in the general population. In a study of 33 European countries, the Daphne Programme found that the most common reason for children with disabilities to "leave" an institution was because of death. A comparison of the movement of children from social care institutions for those without disabilities with the movement of children from institutions for those with disabilities showed that 28% of children with disabilities had died compared to 0.29% of children without disabilities (8).

When the Bulgarian Helsinki Committee inspected all social care homes for children with mental disabilities in Bulgaria in 2010, it was found that between 2000 and 2010, 238 children had died – an average of 25 deaths per year. Over two-thirds of the deaths were deemed to be unnecessary and avoidable (9). In one orphanage in Georgia, 30% of children with disabilities died over an 18-month period during 2009-2010. A medical analysis conducted by DRI experts at this orphanage in 2012 found that children with severe chronic pain were refused pain medication and left to die agonizing deaths (10).

Death by suicide of children with psychosocial disabilities in institutions is not discussed at length in the available literature. This is probably because there is little if any documentation when child deaths are self-inflicted. There is some anecdotal evidence, however, that suicide and suicide attempts are not rare occurrences and that staff in some institutions go to great lengths to ensure that this remains hidden.

> *[Minors] told monitors that at the beginning of November they had been threatened again with psychiatric clinic admission if they talked about a resident who had tried to kill herself"* (19).

6. MOVING AHEAD: SOLUTIONS AND STRATEGIES

6.1 Human rights conventions and obligations – frameworks that protect children with psychosocial disabilities

Placing a child with psychosocial disabilities in an institution is a fundamental violation of human rights. It is the responsibility of governments to respect, protect and fulfill the human rights of its most marginalized and socially excluded people, including children with psychosocial disabilities.

The Convention on the Rights of the Child (CRC) (1) and the Convention on the Rights of Persons with Disabilities (CRPD) (65) provide governments with a framework for ensuring that children with psychosocial disabilities are protected and enjoy their rights without discrimination. The CRC, which came into force in September 1990, and the CRPD, which came into force in May 2008, are mutually reinforcing in how they incorporate elements of key human rights standards in the protection of the rights of children with disabilities, including psychosocial disabilities. The CRC and the CRPD challenge the "charity approach" to children with disabilities by which children are seen as objects of welfare; instead, the conventions require that children are considered as members of society with the same rights as anyone else. Rather than focusing on the child's inabilities, the conventions force a shift in thinking towards the removal of barriers that prevent children from full inclusion in society. For example, to confront barriers such as the stigmatization of children with disabilities, the conventions call for support and services for children and their families in order to assist children to reach their full potential as human beings. In this sense, the onus lies on governments to create a society in which children with disabilities are not only protected but are also given opportunities to thrive.

The CRC is based on four core principles: 1) non-discrimination; devotion to the best interests of the child; 2) the right to life; 3) survival and development; and 4) respect for the views of the child. The CRC outlines the foundational rights of all children, including children with disabilities, namely: the rights to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; to grow up in a family environment; and to participate fully in family, cultural and social life, also recognizing the importance of family assistance and support. Two articles of the CRC make specific reference to children with disabilities – Article 2 outlines the principle of non-discrimination and includes disability as grounds for protection from discrimination, and Article 23 highlights the special efforts States Parties must take to realize these rights. Article 7 of the CRPD addresses children with disabilities specifically, indicating that children with disabilities (including children with psychosocial disabilities) should enjoy all human rights and fundamental freedoms on an equal basis with other children, and that all actions taken on behalf of the child are in the best interests of the child and should incorporate the views of the child whenever possible.

6.1.1 Protection of children's identity and the right to remain with their parents

Article 7 subparagraph 1 of the CRC states, "the child shall be registered immediately after birth … and as far as possible, the right to know and be cared for by his or her parents" (1). Article 8 subparagraphs 1 and 2 state "States Parties undertake to respect the right of the child to preserve his or her identity … as recognized by law without unlawful interference", and "where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity". Article 18 subparagraph 2 of the CRPD states, "Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name … and as far as possible, the right to know and be cared for by their parents" (65).

Article 9 subparagraphs 1, 3 and 4 of the CRC state "States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary in the best interests of the child … State Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests … Where such separation results from any action initiated by the State Party, such as detention of the child, that State Party shall, upon request, provide the parents, the child with the essential information concerning the whereabouts of the absent member of the family unless the provision of the information would be detrimental to the well-being of the child" (1).

Furthermore, the Committee on the Rights of the Child, which oversees the implementation of the CRC, has provided additional guidance to States Parties with regard to children with disabilities (66, 67). Thus, children with disabilities "are best cared for and nurtured within their own family environment", and they "should never be institutionalized solely on the grounds of disability" (66, 67). The former statement is supported by the General Comment 5(30) of the International Covenant on Economic, Social and Cultural Rights (68), which stipulates that "In the case of persons with disabilities, the Covenant's requirement that 'protection and assistance' be rendered to the family means that everything possible should be done to enable such persons, when they so wish, to live with their families". Similarly to Article 7 of the CRC, Article 23 of the CRPD reinforces the statement that children are not to be separated from their parents unless it is believed that doing so is in the best interests of the child. Furthermore, Article 23 subparagraph 4 states, "In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents", and Article 23 subparagraph 5 takes this further by stating that "States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care with the wider family, and failing that, within the community in a family setting" (65).

6.1.2 Freedom from torture and violence

Article 37 of the CRC states "No child shall be subjected to torture or cruel, inhuman or degrading treatment or punishment" (1). This is echoed in Article 15 of the CRPD expressly prohibiting any person with a disability from being subjected to "torture or to cruel, inhuman or degrading treatment or punishment" (65). Article 19 of the CRC requires States Parties to take all appropriate legislative, administrative, social and educational measures to protect children from "all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse" (1). This is also reflected in Article 16 of the CRPD which directs States Parties to protect persons with disabilities from "all forms of exploitation, violence and abuse" and to prevent such occurrences by ensuring "appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers" (65).

The Committee on the Rights of the Child recognized the urgency of preventing violence against children in its General Comment 13 *The right of the child to freedom from all forms of violence* (69) by stating "since the extent and intensity of violence exerted on children is alarming … Measures to end violence must be massively strengthened and expanded in order to effectively put an end to these practices which jeopardize children's development and societies' potential non-violent solutions for conflict resolution".

6.1.3 Right to live in the community

Article 23 of the CRC specifically refers to the provision of care and other resources for children with disabilities. Article 23 subparagraphs 1, 2 and 3 state: "States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community … States Parties recognize the right of the disabled child to special care … designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities" (1).

Just as Article 23 of the CRC emphasizes the need for community-based supports and services for children with disabilities, Article 19 of the CRPD emphasizes the "importance of developing good quality and sustainable alternatives to institutional care, requiring the shift of government policies away from institutions towards in-home, residential and other community support services" (65). The CRPD stipulates that living in the community with access to both specialized and mainstream services is not merely a policy goal but a matter of fundamental human rights. Article 19 of the CRPD states: "States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community … and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that … persons with disabilities have access to a range of in-home, residential and other community support services … to prevent isolation and segregation in the community" (65).

The CRC and the CRPD provide the framework for countries to develop inclusive communities for children with disabilities, including psychosocial disabilities. Both conventions emphasize the need for countries to:

- remove barriers, such as stigma and discrimination, that impede the full inclusion of children with disabilities in communities, schools and families;
- develop community-based resources, such as inclusive schools, and health and rehabilitation services that are available and accessible to all families, regardless of income level; and
- recognize that children are best cared for in family-centred environments that allow for the development of attachments that are critical for a child to reach his or her optimal development.

6.1.4 Right to education

Article 23 of the CRC states that children with disabilities should receive assistance to ensure that they are able to access and receive education. This statement is further supported by the CRC's Article 28 which recognizes the right of children to education "progressively and on the basis of equal opportunity", and Article 29 which provides a framework for the education to be delivered, including "development of the child's personality, talents and mental and physical abilities to their fullest potential".

Article 24 of the CRPD recognizes the right of persons with disabilities to education, and more specifically indicates that States Parties should ensure an inclusive educational system at all levels by not excluding children with disabilities from primary and secondary education and by providing reasonable accommodation and support (65). The United Nations Human Rights Council resolution of 24 March 2014 echoes the CRPD and calls on States Parties to adopt and implement appropriate measures, including legislative measures, to ensure that persons with disabilities, including children, have access to an inclusive educational system. The resolution urges States Parties to further this objective by:

- adopting inclusive laws and policies that prohibit rejection from the general educational system on the basis of disability;
- accommodating different needs and ways of learning by all students; and
- providing individualized support measures to maximize academic and social development (70).

6.1.5 Right to health

Articles 24 and 25 of the CRC refer to the availability of and access to health care, as well as monitoring to ensure that access is attained. Article 24 states: "States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health [and] shall strive to ensure that no child is deprived of his or her right of access to such health care services. States Parties … shall take appropriate measures: to diminish infant and child mortality [and] to ensure the provision of necessary medical assistance and health care to all children … States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children." Article 25 of the CRC emphasizes the need to monitor facilities and the placement of children in these facilities, stating: "States Parties recognize the right of the child who has been placed by the competent authorities for the purposes of care, protection and treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement" (1).

6.1.6 Accountability

Article 16 subparagraph 3 of the CRPD explicitly states that as a measure to prevent the exploitation, violence and abuse of persons with disabilities, including children with psychosocial disabilities, States Parties should ensure that all facilities and programmes that serve this population are monitored by independent authorities. Furthermore, Article 33 of the CRPD states that States Parties will designate an independent mechanism to monitor the implementation of the CRPD, and that civil society, in particular persons with disabilities and their representative organizations, will be involved and participate fully in the monitoring process (65).

Countries' ratification of the conventions to show commitment to the rights of children with disabilities is not enough. It is important that the conventions are interpreted holistically and purposefully by governments and judicial authorities when applying the principles and obligations with respect to children with psychosocial disabilities (4). Article 4 subparagraph 3 of the CRPD states: "In the development and implementation of legislation and policies to implement the Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" (65). Article 12 subparagraph 1 of the CRC states: "States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." Furthermore, according to Article 12 subparagraph 2, "the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child", emphasizing that measures must be taken to ensure that children are involved in decisions that affect them, including decisions as to where they live (1).

Thus, in order to implement the shift from a statement of rights to a change of practice, there is a need for the involvement of national and local governments, nongovernmental disability organizations, parents and children both in the area of enforcement and also in rigorous monitoring and development of new community-based options for children and families.

6.2 Deinstitutionalization as the basis of reform

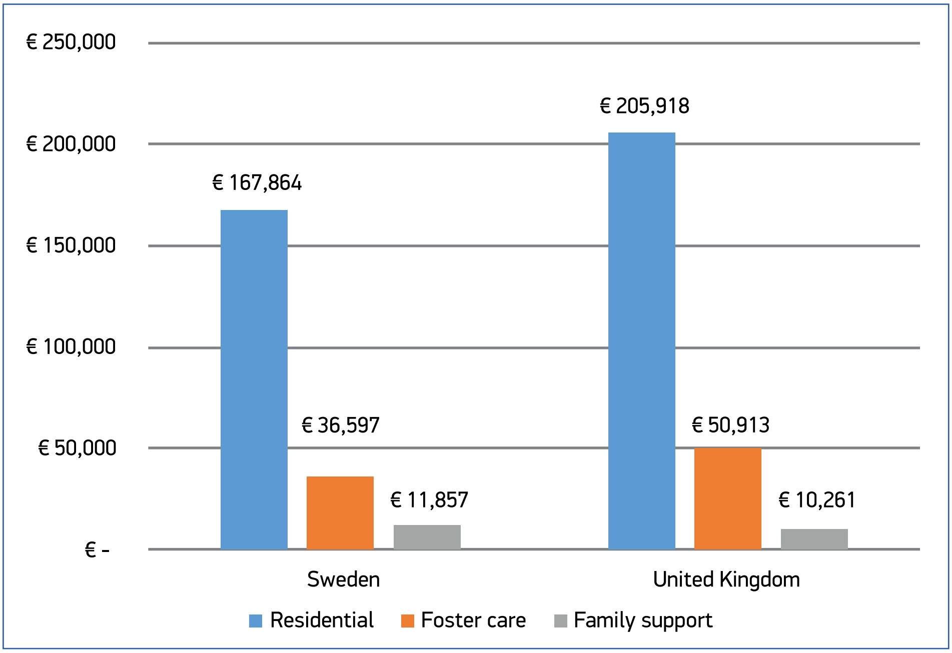
A key strategy for ending violations against children with psychosocial disabilities is to develop the necessary resources in the communities, focusing on the inclusion of children in all aspects of society in order to put an end to their institutionalization. As stated by the Chief Executive of Lumos, "institutionalization of children is the one form of child abuse that we can eradicate in our lifetime" (23). Deinstitutionalization refers to phasing out institutions while simultaneously moving treatment and care of children and families, including related funds, to the community. Mobilization of funds and reallocation of funding from institutions to community-based services and support apply not only to government funding but also to nongovernmental and foreign funding agencies that need to refrain from providing funds for the development of new institutions or refurbishment of existing ones. Instead, governments and funding agencies need to support the creation of community-based care, support and services that respect individual rights and enable people with psychosocial disabilities, including children, to live in the community (10, 71). The services and support required involve different sectors, including the Ministry of Health and also the ministries of education, social welfare, housing, employment and others. Each of these sectors has a responsibility for mobilizing and (re)allocating the appropriate funding for these community-based services. Without the mobilization and reallocation of funds for community-based alternatives, deinstitutionalization is bound to fail, as has been the case in many countries around the world.

6.2.1 Economic benefits

Respect for human rights and the achievement of better child development outcomes are the most important arguments in support of deinstitutionalization and the development of alternative well-planned, adequately resourced and community-based services for children with psychosocial disabilities (2). Additionally, it has been shown that the funding of community care alternatives for children with psychosocial disabilities is more cost-effective in the long term compared with funding large-scale institutions (4). An analysis of institutional care in Moldova, Romania, Russia and Ukraine, for instance, revealed that institutional care is eight times more expensive than providing social services to vulnerable families, 3-5 times more expensive than foster care, and twice as expensive as community group homes (72). The Daphne Programme study of 33 European countries compared the annual costs per child (under 3 years of age) in institutional placement and in foster care, as well the costs for a child with disabilities in institutional placement and in foster care. They found that the cost of institutional care was significantly higher than the cost of foster care. The average annual cost of institutional placement for a child without disabilities was €42 503 and for foster care was €13 279; for a child with disabilities, institutional placement cost €49 301 and foster care cost €31 596 (8).

Although actual costs will vary from country to country, the cost of supporting children with psychosocial disabilities in the family home, in family-based care (i.e. foster care) or in family-like environments (i.e. small group placements) have been shown to be less than the cost of institutional care. Figure 2 illustrates a comparison of costs for institutional care (referred to as "residential care"), foster care, and support provided in the home for children with disabilities (all types) in Sweden and the United Kingdom (22). While the cost for the intensive level of service provided in institutional care settings within these countries is expensive, it is offset by the fact that few children with disabilities require this level of service and most are cared for at home (4).

Figure 2
Cost of care for children in Sweden and the United Kingdom
(The National Board of Health and Welfare (Socialstyrelsen Jämförelsetal), Sweden, and The Personal Social Services Research Unit (PSSRU) Unit cost of health social care, United Kingdom)



Source: reference (22)
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6.2.2 Efforts in deinstitutionalization

There are signs of a movement in Eastern Europe to transfer resources from large institutions to community care options for children and families in order to address poverty and disability and to provide other support such as preparing institution workers to become teachers and foster parents. In Romania, the total number of children, including those with disabilities (all types), in institutions decreased from 58 385 in 2000 to 23 286 children in 2011 (73) and some family support services are now available across the country. In Moldova, the total number of children (with and without disabilities) in institutions has fallen from 12 137 in 2000 to 5711 in 2011 (73), and the resources have been redistributed to community-based family support services and inclusive schools. Action plans for change have been developed in some countries, with money being diverted to community resources (23). However, in many countries where reform efforts are being made, children with disabilities are still over-represented in the remaining institutions (10, 17).

In other countries there are actions being taken to reform the child-care system but the reform processes have been uneven and progress is fragile (15). The Mexican government recently amended its health law to create a community-based mental health system. However, DRI's Director for Mexico and other Central American countries acknowledged that Mexico must dedicate the necessary funding to the creation of services in the community for otherwise it will be impossible to enforce the new law (74).

For countries whose child-care systems consist entirely of institutions, the process of dismantling these institutions while simultaneously creating options for community-based care is a considerable challenge. The CEE/CIS countries have relied heavily on the practice of placement of children in large institutions for decades, and their subsequent delay in changing this practice is attributed to several factors, including:

- isolation during the communist era from international research evidence demonstrating the harm caused by institutionalization;
- lack of family and community-based services, including accessible health and educational services;
- lack of professionals with specialized skills to address the needs of children with disabilities; and
- economic turmoil following the collapse of the economy and a subsequent increase in poverty (4).

Further complicating matters in these and other countries is the entrenched stigma towards children with psychosocial disabilities and their families, and the lack of understanding and support for a full-scale dismantling of institutional care. It is very important that all concerned individuals, agencies and governments should be aware of the reasons behind the need for deinstitutionalization and understand its implications (75).

6.2.3 Transitioning from institutional to community-based care

The process of deinstitutionalization is highly complex and multifaceted. It often includes strategies and procedures for finding alternative care settings for children in institutions as well as "deinstitutionalizing the system itself" (75). The aim of deinstitutionalization is to prevent the need for institutionalizing children and to develop a range of non-institutional options for providing care support to children and their families. This requires careful planning which should be started well before any actions are implemented. Transitioning from a reliance on institutional care to alternative forms of care and community resources requires a reinvestment of existing resources to support children living with their families or in family-like environments. This includes reallocating funds to retraining and task-shifting of human resources to ensure that the appropriate infrastructure is in place for community alternatives. Some "double funding" of institution-based and community-based services will be required during this transitional period (2).

Deinstitutionalization takes a great deal of time, especially if a participatory and rights-based process is undertaken that involves the affected individuals and their families in decisions regarding accommodation and care. It is of utmost importance that children and their families should be involved in development of the overall service and support system, as well as identifying, developing and evaluating the services and support that they or their child needs. Children and their families know their requirements and it is important that their opinions are consistently sought as the children grow and their needs change (5, 16).

An effective deinstitutionalization process is well-coordinated and carried out gradually. The three essential components of deinstitutionalization are (76):

1. Establishment and maintenance of a range of community-based services and support for individuals with disabilities, including children and their families.
2. Prevention of inappropriate admissions to institutions through the provision of community-based services and support.
3. Discharge to the community of long-term institutionalized residents who have received adequate preparation.

Through the process of deinstitutionalization, countries should not abandon those children with psychosocial disabilities who are living in institutions. Rather, the primary aim should be to phase out institutionalization of children with psychosocial disabilities, making efforts to monitor and protect children in institutions in order to prevent further violations, while at the same time developing community-based care options and support services. Such efforts include (77):

- registration of all institutions currently providing care to children with psychosocial disabilities;
- independent monitoring of institutions;
- prohibition of all forms of violence in institutions;
- mechanisms established for children to make complaints;
- access to independent advocates and the courts;
- appropriate safeguards on the recruitment and supervision of staff; and
- staff training on children's rights and the proper care and treatment of children with psychosocial disabilities.

Alternatives to institutionalized care should be developed within an overall deinstitutionalization strategy that has precise goals and objectives, is grounded in a policy and legislation framework based on human rights, and with a detailed implementation plan. Furthermore, opportunities should be created for children with psychosocial disabilities and their families to participate in the design and implementation of the policy, legislation and contents of the plan to ensure that they are appropriate and responsive to their needs (75).

Several publications provide steps and guidelines to help countries to deinstitutionalize their systems of institutional care and create the necessary community-based support and services for children with disabilities and their families. Some publications also include examples of specific initiatives – including the 2014 WHO and Gulbenkian Global Mental Health Platform's *Innovation in deinstitutionalization* (2, 78, 79, 80). The common elements cited regarding the process of deinstitutionalization include:

- raising awareness through a multifaceted promotional campaign on the need to dismantle institutional care for the benefit of children with disabilities, their families and the wider community;
- establishing a national strategic plan that includes a process to eliminate the need to institutionalize children with disabilities and developing alternative community-based care options;
- ensuring that the necessary infrastructure is in place – such as the financial resources to support development of new services and simultaneous closure of institutions, and retraining and redeployment opportunities for staff in institutions;
- addressing the needs of children with psychosocial disabilities and their families in order to prevent the need for institutionalization by involving them in the planning of community-based services and support, by providing them with specialist care, by providing income assistance programmes so that families can afford to look after their children, and by making transportation and respite care available;
- providing children with health and rehabilitation services so that they can reach their optimum development, and providing inclusive educational and vocational training opportunities so that they may live in the community.

The EU's *Report of the ad hoc expert group on the transition from institutional to community-based care* (3) identified several key challenges that countries overcome or avoid when reforming their institutional care systems, including:

1. Over-investment in current institutional arrangements
    - A common response to poor-quality care in institutions is to allocate funds to improve the physical condition of the institution. It is more difficult to close the institution if a great deal of money is being spent to maintain it.
2. Risk of maintaining parallel services
    - The progressive development of community-based alternative forms of care should precede the phasing-out of institutional care.
    - If children with moderate forms of disability are moved to the community first and options for more intensive community care are not developed, there is a risk that children with more severe forms of disability will remain in the institution. It is important that children with the highest needs are also transitioned to the community.
    - The transition from institutional to community-based care will require that additional funds are

budgeted to maintain the two systems simultaneously. It is important that the plans indicate an end-date for funding of institutions, for otherwise there is a risk that the institutional system will operate indefinitely.

3. Establishing alternatives that resemble institutional care

    - If there is a lack of understanding of what community-based services are, alternative facilities might be established that resemble the original institutions – such as facilities that are built adjacent to the former institution and remain isolated from the community, or facilities that perpetuate an institutional culture that provides impersonal and regimented care without retraining of staff.

4. Closure of institutions without adequate alternatives

    - Sufficient financial resources need to be made available to develop a range of services and support for children with psychosocial disabilities and their families/caregivers. The services and support must take into account those children who require intensive support – such as 24-hour personal care – for otherwise there is a risk that these children will remain in institutions indefinitely or be discharged from institutions with no care at all.

6.2.4 Leaving no child behind

Historically, children with disabilities, including psychosocial disabilities, have often been overlooked in national efforts to deinstitutionalize child-care systems. Recent reports indicate that these children are often among the last to be removed from institutions and transferred to alternative forms of care in the community, or are excluded from the deinstitutionalization reforms altogether (10, 16). Analyses conducted by Lumos of admissions to and discharges from children's institutions in a number of European countries have shown that most children with disabilities are transferred to adult institutions once they reach adulthood, and remain there until their death (4).

Any national deinstitutionalization strategy must include children with psychosocial disabilities and pay specific attention to their needs and requirements. This is underscored in the WHO European Region's Bucharest Declaration *Better Health, Better Lives* (Box 1), which calls on countries to protect children and young people with intellectual disabilities from harm and abuse, enable them to grow up in a family environment and transfer care from institutions to the community (25). A range of alternative support and service options based in the community need to be in place for deinstitutionalization of children with psychosocial disabilities to be effective (75).

Box 1. WHO Europe Bucharest Declaration – Better Health, Better Lives: children and young people with intellectual disabilities and their families (25)

Priorities for action:

1. Protect children and young people with intellectual disabilities from harm and abuse.
2. Enable children and young people to grow up in a family environment.
3. Transfer care from institutions to the community.
4. Identify the needs of each child and young person.
5. Ensure that good quality mental and physical health care is coordinated and sustained.
6. Safeguard the health and well-being of family carers.
7. Empower children and young people with intellectual disabilities to contribute to decision-making about their lives.
8. Build workforce capacity and commitment.
9. Collect essential information about needs and services and assure service quality.
10. Invest to provide equal opportunities and achieve the best outcomes.

6.3 Community-based services and supports as alternatives to institutional care

No child with a psychosocial disability has exactly the same needs as another child with a similar disability. Consequently, it is important to ensure that a full range of community-based services is available for children and their families or care providers, including: prevention services; small group and home-based care services that provide different levels of care from the least to most intensive; rehabilitation services; educational and vocational services; and income support for families. These provisions meet the requirements of Articles 19, 25 and 26 of the CRPD as well as Articles 23, 24, 27 and 28 of the CRC.

Since the mid-1980s, WHO has developed and promoted the use of community-based rehabilitation (CBR). Designed and run by local communities in low-income countries, CBR aims to ensure that people with disabilities, including children, have equal access to rehabilitation and other services, ensuring their inclusion and participation in society. Over time, the initiative has expanded from a focus on developing rehabilitation services to promoting access to education, employment, health and social services. CBR is implemented through the combined efforts of people with disabilities, their families, organizations and communities, and relevant governmental and nongovernmental health, educational, vocational, social and other services. To date, over 90 countries worldwide have developed and strengthened their CBR programmes (2, 16, 81).

WHO's 2010 CBR guidelines (81) promote and support the implementation of rehabilitation activities at the community level and the facilitation of referrals to access more specialized rehabilitation services. According to the guidelines, community-based rehabilitation services should include:

- information provided to families about the role and purpose of rehabilitation, including resource materials;
- available rehabilitation services in the community with trained personnel who receive ongoing supervision and support to provide rehabilitation services;
- individual assessments with family involvement in the development of rehabilitation plans outlining the services the children will receive; and
- referrals to specialized rehabilitation services and follow-up to ensure that these services are received and meet the child's needs

The following description of key community-based services and supports builds on WHO's CBR guidelines to identify specific elements of community-based supports for children with psychosocial disabilities and their families. How these services and supports are developed, organized and delivered will depend to some extent on the national contexts, infrastructures and systems that are already in place. It is important to note that the services and supports described are achievable not only in high-income countries. In fact, innovative and effective services and supports have been established in many low-resource settings.

6.3.1 Comprehensive multidisciplinary services for children and young people

To avoid institutionalization and ensure that children with psychosocial disabilities remain in their own communities throughout their early childhood and youth, it is critical to establish a range of comprehensive, multidisciplinary and responsive services and interventions for children. These services depend on a multidisciplinary approach involving different sectors and on strong links and coordination between actors in the health, education, social and family welfare, employment, justice and other relevant areas. Indeed, health professionals, teachers and educators, social workers and others each have a critical role in maintaining ongoing contact with children and young people and their families, and in sharing information, coordinating appropriate interventions and referring cases. Different services and types of support may be required at different times from early childhood through to adolescence.

a. Early childhood intervention

Early childhood intervention (ECI) goes by various names in different countries, and even within countries, including "early childhood education" (ECE), "early childhood care and development" (ECCD) and "early childhood development" (ECD) (82). ECI programmes address the "wellbeing and holistic development of the child and, regardless of the institutional setting, should embody a developmentally appropriate practice, which attends to health, nutrition, security and learning" (82). Brown & Guralnick (2012) highlight that multiple articles of the CRC and CRPD are particularly pertinent to the development of ECI (83).

ECI consists of multidisciplinary services designed to meet the needs of developmentally vulnerable children, usually from birth to between 3 and 5 years of age. Children who receive ECI services most commonly have a delay in physical, cognitive, communicative, social, emotional or adaptive development or have a diagnosed condition that has a high probability of resulting in a developmental delay (84). ECI services can be delivered within the home or centre, and can include (85):

- family-centred approaches, including diagnosis of health problems, needs assessment and development of an early intervention plan;
- psychosocial support and treatment for child and family;
- physical and occupational therapy;
- speech and language therapy;
- nursing care services;
- nutritional support; and
- coordination of care support.

Determination of which ECIs are needed for a child and family is based on assessment of the child's sensory-motor, cognitive, communication and social-emotional skills and functioning to enable parents and health-care providers to understand and plan interventions to facilitate the child's development. Optimally, the interventions are a combination of centre-based and home-based services that actively involve parents or care providers in therapeutic activities (based on play and training in functional skills development), provide parental education on the child's use of assistive devices, and give advice regarding modifications to the home (17).

The benefits of ECI programmes in high-income and low- and middle-income countries have been well documented (17, 86, 87). ECI programmes for disadvantaged children in the USA have shown long-term benefits in terms of improved cognitive development and reduced antisocial behaviour, depression and health-risk behaviours (88). In low- and middle-income countries, ECI programmes have been found to build child and caregiver skills during the critical period of child development. These skills form a foundation for future learning and adjustment, placing the child on a positive developmental trajectory that is protective of the child's mental health (88) (see Boxes 2, 3 and 4).

Box 2. Promoting early child development

Dr Margaret Chan, Director-General of the World Health Organization, in a 2013 article on *Linking child survival and child development for health, equity and sustainable development* published in the Lancet, stated:

"As in the case of child survival, the promotion of early child development requires common understanding, shared commitment, and united action across government sectors and by all development agencies and institutions. The first three years of a child's life are a time when a child has the greatest plasticity for growth and development, even under adverse circumstances.... WHO is making a renewed commitment to early child development as an area of work critical to a life course approach to human development.... By ensuring that all children have the best first chance in life, we can help individuals and their communities to realise their maximum potential, thereby expanding equality and opportunity for all" (89).

Box 3. Early intervention programmes

In high-income countries, there are nationwide early intervention programmes such as Head Start and Early Head Start in the USA and Sure Start and Early Support in England. Eligibility criteria are determined by the family's income and a range of services is provided based on need – including nutritional support, access to health care, playgroups, daycare and preschool groups. Parents and care providers receive support in parent-child interactions, parenting education, literacy programmes, job training, physical and mental health programmes, and community support programmes (85).

Box 4. Integrated child development in India

An example of a national programme in a developing country that serves children with psychosocial risks is the Integrated Child Development Scheme in India. It is the world's largest integrated early childhood programme with over 40 000 centres nationwide. The scheme targets expectant and nursing mothers and children under the age of 6 years. The scheme aims to provide an integrated package of services that includes health, nutrition and hygiene education for mothers, non-formal preschool education for children aged 3-6 years, supplementary feeding for all children and pregnant and nursing mothers, growth monitoring and promotion, and links to primary health-care services such as immunization and vitamin A supplementation (90).

b. Interventions and services for children and youth

Beyond early childhood interventions (which generally focus on children aged years 5 or younger) there is a need to provide a continuum of services for children and young people experiencing emotional, behavioural, developmental or mental health conditions as they develop and mature. Types of services may include brief interventions – delivered, for instance, in primary care settings – providing young people and their families with immediate access to mental health services. This type of service may be episodic and time-limited – involving, for instance, a single therapeutic session, or three sessions of therapy, or consultation sessions within a limited time frame. After brief interventions, users may be provided with information about additional services and available support and/or may be referred to more intensive services in the community (91).

Some children and young people with severe, complex or persistent needs may require more intensive services. These may include day treatment, in-home treatment or brief inpatient services provided in general hospital settings. These services should ideally be designed to reduce the severity of mental health problems, treat underlying conditions and build up coping and resilience to improve functioning at home and school and in the community. Some children and young people may need these services either for a specific period of time, or periodically throughout their lives, in order to enable them to lead full lives at home, school and in their community. Intensive services can be provided in variety of settings, including within community health services and schools, but also within the child or young person's home, foster home or small group home (91).

Crisis support services are also important for children or young persons with psychosocial disabilities who may be experiencing an urgent mental health crisis or situation that places them at risk. These child and youth services should be available in the community on a 24-hour/7-days-a-week basis and may be linked, for instance, to hospital emergency departments, telephone response services or other mental health crisis services in the community. They are focused on stabilizing and de-escalating the crisis, reducing the severity of symptoms, coordinating access to required services and interventions, and facilitating access to a range of longer-term resources and supports in the community.

Services for children, young people and their families need to offer a range of interventions of varying intensity depending on the need. Counselling and therapy are critical in order to support children and young people to address or overcome social, emotional or behavioural problems. Counselling and therapy services may be based on different clinical practices (e.g. cognitive behavioural therapy, social skills training), may be delivered in different formats (including individual, group or family sessions) and can be provided in a range of settings (including, for instance, primary care settings or the schools system) (91). Psycho-education and family skills building are also important, providing caregivers with essential knowledge, competencies and strategies to understand, support and respond to the mental health needs of their child (see the section below on *Parenting programmes and services: education, support and training for families*). A range of targeted interventions should also be available, such as interventions for suicide crisis and alcohol and substance abuse, and interventions for children and young people who have experienced physical, sexual or emotional abuse, or other trauma (92, 93).

These services and interventions must be evidence-based and child-centred and should focus on the requirements, needs and preferences of the child or young person. They must be provided close to people's homes, causing the least amount of disruption to the continuity of family, school and community life (91) (see the example from South Africa in Box 5).

Box 5. Primary care providers deliver mental health services in South Africa

In South Africa, where half of the population is under the age of 19 years and where mental health services are notably lacking, an initiative was undertaken to increase the capacity of primary care providers to deliver mental health services for children. The initiative entailed training primary health-care providers – including primary care nurses, social workers and school nurses – to identify and manage some of the basic mental health problems of childhood. The interactive training workshops were provided by clinical psychologists and addressed the following: early identification of childhood psychological problems, behaviour modification techniques, counselling principles, parent training programmes, and skills for working with physically and sexually abused children, and suicidal children and youth. The results of the initiative showed that, by training primary health-care providers, mental health services become increasingly accessible to children with psychosocial disabilities and their families. The health-care providers reported feeling more competent and confident in their ability to address childhood mental health problems (94).

6.3.2 Parenting programmes and services: education, support and training for families

Experiences in early childhood have long-term effects on brain function, cognition and social functioning. The quality of parenting (or care provision) is one of the most important factors in reducing the effects of negative childhood experiences and increasing resilience among children (88). A close child-caregiver bond is critical to the development and protection of children (17).

Parenting programmes and services should aim to provide parents and caregivers with the knowledge, skills and support to meet the needs of their child. It is recommended to include two elements in these support services, namely: 1) teaching children's parents and caregivers new skills, including how to provide a cognitively stimulating and emotionally supportive environment with a strong focus on promoting positive social and emotional interactions between caregiver and child; and 2) attending to the caregivers' mental health, social support and self-efficacy in an effort to strengthen their capacity to care for the child (17, 88). Examples from Belarus and Australia are included in boxes 6 and 7.

Box 6. Positive parenting programme in Belarus

In Belarus, three ministries helped to develop a comprehensive nationwide parenting movement called the Positive Parenting Programme that targets pregnant women and the parents of children from birth to school entry. The Ministry of Health offers flexible parenting programmes to vulnerable children through home and centre-based ECI services and close coordination with polyclinics. The Ministry of Education provides "mother's clubs" in preschools for children aged 0-3 years who are not yet enrolled in preschool. "Parent universities" and other parenting programmes are also offered in preschools as well as through development centres providing special education to children with developmental delays or disabilities.

New, flexible rural preschools also feature parent education and counselling. To assist high-risk families, the Ministry of Labour and Social Protection offers parenting services combined with family therapy, referrals and counselling. All three ministries provide child-centred and family-focused parenting programmes with linked case management services. The ministries share professional training activities as well as common methodologies and a wide variety of educational materials on parenting for professionals and parents (95).

Box 7. Triple P positive parenting in Australia

The Triple P Positive Parenting Program (96) is a parenting and family support system designed to prevent and treat social and emotional problems in children and adolescents. Originating in Australia and available in 25 countries, Triple P is an evidence-based private-sector programme that aims to enhance parenting skills and reduce the risk factors associated with severe behavioural and emotional problems in children. The Stepping Stones Triple P programmes focus specifically on parents of children under the age of 12 years with disabilities. The programmes offer positive parenting support that:

- builds positive relationships with the child, praising and encouraging behaviour that they like;
- teaches children new skills;
- sets rules and gives instructions that their children will follow;
- responds to misbehaviour immediately, consistently and decisively;
- uses discipline strategies that work;
- plans ahead to avoid or manage potentially difficult situations; and
- helps parents to develop self-care strategies.

Programmes similar to these are needed in the public sector.

6.3.3 Peer support for parents and children

Peer support is another means by which parents and caregivers of children with psychosocial disabilities can be assisted. Peer support among parents and caregivers provides opportunities to share experiences in dealing with stressful circumstances and to learn that they and their child are not alone (17). The shift towards community-based services for children with disabilities, including psychosocial disabilities, results in a marked increase in parental responsibility. This is particularly significant in countries that have historically placed most children with disabilities in institutions. A community-based system of care depends on the willingness and ability of parents to care for their children with disabilities, and consequently resources are needed to support and sustain parents in their role as long-term caregivers (97) (see boxes 8 and 9).

Peer support can take many forms, including one-on-one mentorship, community-based parent networks, technology-enabled parent networks, and peer support groups (97). One-on-one mentorships can be formed through a formal introduction – through, for instance, a health-care provider – or informally – through, for instance, a chance meeting in a doctor's office. Evidence suggests that the potential for positive adaptation to a child's disability or illness is increased when parents have a confidant who understands the private aspects of their experience (98).

Community-based parent networks commonly use nonprofessional lay counsellors who mentor parents who have had similar experiences to their own. Outcome evaluations have shown that community-based parent networks have led to improved attitudinal changes, as well as increased parental acceptance of their child's disability (97, 99). Technology-enabled parent networks such as chat rooms and computer-mediated support groups are increasingly being used and are particularly beneficial to parents living in remote, rural areas. Peer support groups can be led by a professional or by the participants and are associated with the following positive outcomes (97):

- acquisition of relevant knowledge and skills by parents receiving support;
- improved physical and psychological health in parents receiving support; and
- improved coping and decreased isolation in parents giving and receiving support.

Peer support groups and networks for and of children are also important. They can enable children to share their experiences, provide support to one another, communicate their perspectives and have their voices heard. Such groups are few and far between in most places but they are beginning to emerge in certain countries where they enable children with psychosocial disabilities not only to have access to support from their peers but also, through self-advocacy, to become more aware of their rights and to participate in national decision-making processes on issues that affect them (100) (see Box 10).

Box 8. MyTime Peer Support Groups for Parents of Young Children with Disability, Australia

The Department of Social Services of Australia funds the Parenting Research Centre to deliver the MyTime Peer Support Groups for Parents and Carers of Children with Disability. MyTime began in April 2007 and provides peer support groups for parents and carers of children with disabilities or chronic medical conditions up to and including 16 years of age. Groups are provided at 262 locations in the community and just over a third of the groups are in rural/remote locations (97).

MyTime:

- gives parents and carers the chance to socialize and share ideas with others who understand the rewards and challenges of the caring role;
- provides an opportunity for parents and carers to find out about available community support services and research-based parenting information;
- provides groups with a facilitator for parents and carers and a play-helper for children. The play helper organizes play activities and provides support for the children while parents and carers participate in activities and discussions.

Source: https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/mytime-peer-support-groups-for-parents-of-young-children-with-disability, accessed 22 May 2015.

Box 9. Canadian Mental Health Association – peer support guide for parents of children or youth with mental health problems

As part of its Strengthening Family and Youth Voices project, the Canadian Mental Health Association has developed a peer support guide for parents of children or youth with mental health problems. The guide provides "practical information and resources on the ways in which parents can learn from and support each other in a group setting" and on how to organize and develop a peer support group for parents. It outlines the planning required prior to the launch of the peer support group, as well as step-by-step guidance on conducting the first and second meetings of the group and ideas for future meetings.

In addition, the guide discusses how to build up and sustain momentum for the group, including how to create opportunities for feedback from parents, how to reach parents who are not members, and how to disseminate information about the group through service providers. The guide also includes practical sample resources that include a pre-launch checklist, an invitation flyer, a meeting agenda and an evaluation questionnaire (101).

Box 10. Turning Words into Action – making lives better for young people with intellectual disabilities

The Turning Words into Action project, funded by the European Commission and managed by Lumos through a steering group, started in 2011. The project brought together multiple stakeholders, including children and young people with intellectual disabilities and their families, service providers, NGOs and policy-makers from various levels of government. The aim of the project is to ensure that the 2010 Bucharest Declaration *Better Health, Better Lives: children and young people with intellectual disabilities and their families* is put into practice with meaningful results.

The Turning Words into Action project was implemented in three countries – Bulgaria, the Czech Republic and Serbia. As part of the project, networks of children and young adults were established. Support was provided to these groups to increase their capacity and skills to make decisions for themselves, to empower them and build their self-esteem, and to give them confidence to speak up for themselves and others. The children and young adults had the opportunity to provide support to, and learn from, one another and to express their views and talk about their experiences and needs. The groups participated in national working groups and transnational meetings during which they had the opportunity to contribute to decision-making processes and to interact with policy-makers and others in order to share their perspectives and opinions and raise awareness about their rights.

The groups of children and young adults who were involved in this project continue to meet regularly. Significantly, the project has established the idea of peer-to-peer support for children, as well as self-advocacy and child participation in shaping practices and informing policy-making (100).

6.3.4 Inclusive education

Education is a key factor in the full participation of children with psychosocial disabilities in society. Access to education is a right of all children (1, 65) though it is often denied for children with psychosocial disabilities around the world. As a result, their ability to take on valued roles in society – such as gainful employment – is undermined (16). The inclusion of children with psychosocial disabilities in the educational system is vital as it provides opportunities for child-focused learning, play, participation, peer interaction and development of friendships (17).

Nevertheless, it is important to distinguish between the mere provision of some form of education and inclusive education. The former may mean that children with disabilities receive education in segregated classrooms, schools or institutions. In contrast, inclusive education means the provision of meaningful learning opportunities to all students (with or without disabilities) within the regular mainstream school system and with additional support tailored to the needs of children with disabilities. These two concepts are not always clearly distinguished from each other and are often used interchangeably (18).

In 2014 the United Nations Human Rights Council passed a resolution calling on countries to ensure that all persons with disabilities enjoy the right to education by developing an educational system that is inclusive at all levels (70). Inclusive education is considered to be a more cost-effective approach than segregated schools; however, it is critical that this educational model includes increased levels of support for children with psychosocial disabilities (17) (see boxes 11 and 12). Special preparations for children with psychosocial disabilities include staff trained in inclusive educational principles and teaching methods and with the ability to develop child-centred individual programmes based on the child's learning needs. Furthermore, the children are taught in small classes where they receive individual attention and are included in all activities, including playtime (16, 17).

To create inclusive environments in schools successfully, there must be a shift in the school culture from one that stigmatizes and is discriminatory towards children with disabilities and their families to one that is welcoming and embraces diversity and differences. An inclusive environment for children with disabilities and their parents includes (18):

- School systems and teachers understand and accept the concept of inclusive education.
- Parents of children with disabilities actively participate in the school.
- Awareness programmes are launched to promote and support inclusive education.
- The local community and private sector actively support inclusive education.
- Inclusive education is seen as an important factor for economic and social development.

Box 11. Developing a sustainable model of inclusive education for children with disabilities: the Samoa experience

The inclusive education project in Samoa was coordinated by an NGO, SENESE, in partnership with the Ministry of Education, Sports and Culture, from 2006 to 2009. The primary goal was to develop a sustainable community-based system of support for school communities that included children with disabilities. Attitudes were considered to be a significant barrier because of the prevalent traditional superstitions regarding disability. The project activities aimed to increase the knowledge of teachers and parents, promote inclusive attitudes in communities, develop government policies that would ensure schools were accessible to children with disabilities, and share stories of significant changes in order to sustain and extend the enthusiasm for inclusive educational environments. Parents became increasingly empowered and the project strengthened their confidence that they had a right to advocate for their children to attend school. Together with an effective media campaign, the project was powerful in changing negative attitudes towards children with disabilities in the home and the community.

Raising the level of professionalism of teaching staff was considered essential. Support activities included: special training for principals, teachers, curriculum staff and parents; the training of teaching assistants to give support in classrooms with the special needs students; and a trial placement of four salaried assistants in government schools. In addition, mentors were appointed to visit the schools, reassure the teachers that they were doing a good job, and suggest other activities teachers could try. This helped in boosting confidence, encouraging and stimulating innovation and initiative, and in building teachers' involvement and sense of self-worth. In addition, three national workshops focused on how to support children with different types of disabilities. A special workshop was also conducted on identifying each child's stage of development and tailoring an individual education programme to that child's needs.

The programme has begun planning and exploring further possibilities for sustainability. Samoa's Education Act of 2009 now provides the legal mandate for compulsory education for all children, including those with special needs within inclusive education. The formulation of a national disability strategy and the creation of a disability self-advocacy group have promoted ownership and sustainability of the programme, and the National University of Samoa has begun training specialist inclusive education teachers (102).

Box 12. Parents support children with disabilities in mainstream education: the Moldova experience

In Moldova, in May 2014, a network of parents who had children with disabilities was established with the support of the United Nations Human Rights Office and financial assistance from the European Union.

The chief aim of the network is to promote inclusive education for children with disabilities. Advocacy activities were undertaken to foster a more supportive political environment for inclusive education. Actions included sending petitions to the ministries of education, health, labour, social protection and family, calling for inclusive educational systems and highlighting the need for a personal assistant as a support service in schools. The United Nations Human Rights Office helped families within the network to find placements in the mainstream educational system and supported their children's integration in schools. The Office also provided technical support to help schools incorporate the core principles of inclusive education in their curriculum.

As of February 2015, the network had 80 families with children with special needs. At the beginning of the 2014 school year, 22 children from families in the network joined mainstream kindergartens and schools.

In addition, the Ministry of Education has developed legal and policy tools for inclusive education. The government programme for inclusive education was enacted in 2011 and psycho-pedagogical assistance is currently provided in 35 districts, with trained staff supporting children with special needs.

Advocacy by parents and increased engagement to promote inclusive education at policy level were shown to be crucial ingredients for the success of the project (103).

WHO's *World report on disability* (2) outlines recommendations for countries establishing inclusive educational systems, including:

- Develop a clear national policy on the inclusion of children with disabilities (including psychosocial disabilities) in education, with an agreed definition of inclusive education and outlines of the resources required.
- Identify, through the involvement of children and families, the level and nature of the needs so that the appropriate support and accommodations are available.
- As far as possible, provide inclusive education in mainstream schools that are accessible for all students, including the provision of transportation to the schools.
- Build and improve the skills of teachers to teach children with disabilities, including psychosocial disabilities.
- Support teachers in using flexible teaching models to meet the needs of a diverse group of students.
- Make available specialist services within the school, such as speech and language therapy, occupational therapy, and physiotherapy to students with moderate or significant disabilities. If these resources cannot be made available within the school, link with the existing resources in the community.
- Make available teaching assistants to provide one-on-one support to children with disabilities, while maintaining children's inclusion in all aspects of school activities.

6.3.5 Financial assistance and support for families

Financial support for families with children with psychosocial disabilities is necessary in order for the children to be cared for in the home and community and to prevent institutionalization (see Box 13). A parent often stays at home to look after a child with disabilities and is unable to work outside of the home. A low income means the family struggles to pay for the required medical and therapeutic services, medication or transportation to appointments.

A growing number of governments of low- and middle-income countries – including Bangladesh, Brazil, Chile, India, Lesotho and Mozambique – have begun targeted social protection initiatives that include cash transfers specifically for children with disabilities (16). In CEE/CIS a form of social allowance is provided to families with children with disabilities. Eleven CEE/CIS countries offer some form of social cash transfers, ranging from more comprehensive systems differentiated by disability (Uzbekistan) to general allowances given to socially vulnerable families (Turkey). The methods of distributing the allowances differ, with some requiring comprehensive paperwork, and many are attached to specific conditions such as requiring the registration of a child on a national disability register. The registration process, however, acts as a barrier to receiving payment as the registration process is lengthy and cumbersome and families are reluctant to register their child as having a disability due to stigma (18).

Box 13. Disability living allowance for children in the United Kingdom

The United Kingdom introduced a "disability living allowance" (DLA) for children in 1992 to help cover the extra costs that families may incur while caring for a child with a disability.

This tax-free benefit is made up of two parts – a care component and a mobility component – and children may qualify for one or both of these. The care component relates to the level of care and support a child requires, ranging from help for part of the day/night (lowest rate) to help throughout the day/night (highest rate). The mobility component relates to level of help a child requires to get around, ranging from the lowest rate (the child requires minimal assistance with mobility) to the highest rate (the child requires substantial assistance with mobility).

Children with disabilities who qualify for the care component may receive the lower (£21.80), medium (£55.10) or higher (£82.30) weekly rate. Children with disabilities who qualify for the mobility component may receive the lower (£21.80) or higher (£57.45) weekly rate. The distribution of DLA payments has been improved by creating an automatic payment system, whereby payments are directly deposited every 4 weeks once a child is entered in the disability registry.

Additionally, families or caregivers spending at least 35 hours a week caring for a child who receives the middle or higher DLA rate may also qualify for a "carer's allowance" (£61.10 a week, taxed) (104).

6.3.6 Respite care

Respite care is temporary child care offered for designated periods of time to allow a caregiver to tend to other family members, alleviate a personal crisis or take a break from the stress of caring for a child with high needs (105). The rationale for providing respite care services is that families need time away from their caregiver responsibilities in order to restore and maintain their own physical and mental health (see boxes 14, 15 and 16). Respite care is also important for children as it allows them to take a break from their home life and socialize with others outside the family unit. There is evidence to indicate that respite services can enhance the capacity to cope with stress and can improve family functioning, satisfaction with life and attitudes to the family member with a disability (105).

Respite care can be provided in the home or outside of the home. Daycare centres are one option that can provide parents with respite from child-care responsibilities. Daycare centres can also provide therapeutic services, thus eliminating the need for additional appointments with health-care professionals (11). Another form of respite care can assist families with children who have more intensive needs or behavioural issues and can provide care over a longer term; this form of respite care involves placing a child in a community-based home with trained care providers for a week or longer (80).

Respite care programmes have been established in high-income countries and countries in transition, although high unmet needs for respite care are reported in these countries (106, 107).

In the course of research conducted by the Child and Family Research Centre of the National University of Galway, Ireland, key principles of practice in the provision of respite care emerged (108):

Principle One:	That respite services be person-centred and family-centred
Principle Two:	That respite services be provided on a rights basis
Principle Three:	That respite be defined as a support service and regarded among a system of support services
Principle Four:	That there be a single point of access to respite care services in a given administrative area
Principle Five:	That respite services be designed in consultation with families in acknowledgement of their expertise in providing care
Principle Six:	That respite be designed to facilitate the service user in building relationships in their community
Principle Seven:	That respite services be age-appropriate and develop as the service user develops
Principle Eight:	That respite care services have clear goals and that systematic and regular review ensure achievement of those goals.

Box 14. Respite support for carers of young people with severe or profound disability, Australia

The Australian Government provides AUD 8.9 million annually in funding for the Respite Support for Carers of Young People with Severe and Profound Disability programme. The programme:

- provides immediate and short-term respite to carers of young people with severe or profound disability;
- facilitates access to information, respite care and other support or assistance appropriate to the individual needs and circumstances of both carers and care recipients;
- focuses on carers' needs and allows carers to exercise choice and control over their respite care arrangements;
- supports carers whose needs are not being met through existing Australian Government or state/territory government initiatives; and
- expects to alleviate unmet demand for short-term and unplanned respite care that currently causes significant stress to carers (109)

Box 15. The "Short Breaks" scheme, England

The "Short Breaks" scheme in England is a service which allows children and young people (aged 0-19 years) who have disabilities to spend time away from their families and enables families to have a break from continuous caring. Activities can take place at the family's home or at an approved carer's home, in the community or in a residential setting. Residential short break centres are family-based settings adapted to meet the needs of the children and young people. Overnight breaks are delivered in a flexible way and may include weekends, weekdays and holiday periods.

The scheme offers "universal services" for children and young people who qualify for a lower-rate disability living allowance (see Box 13), "targeted services" for those who qualify for a higher or middle rate allowance, and "specialist services" for children and young people with a severe learning or physical disability or complex health need and who meet the United Kingdom's Children's Disability Service criteria and require a high level of service in emergencies.

Short Breaks help children widen their social circle, have fun and develop their independence and confidence. They can give children with disabilities the opportunity to make new friends and have new experiences. Nonresidential services may include support workers, enabling children with disabilities to participate in community-based activities such as sports and leisure, play and creative arts. Other services include sibling support groups for brothers and sisters of disabled children and family activities (110).

Box 16. Short-break services for children with disabilities, Russia

Short-break services for children with disabilities have been developed in order to prevent these children entering institutional care. The service was developed in St. Petersburg and provides respite care in a family that has received training in supporting children with disabilities. The service is flexible in meeting the needs of each individual family and the care can be provided in the child's own home or in the carer family's home.

An evaluation of the programme has shown that it has successfully prevented admission to institutional care. To date, all of the 61 children with disabilities involved in the programme have remained in the care of their families. In addition, the evaluation has identified significant benefits to the quality of life of the child with disabilities. Benefits to the parents and other children in the families involved in the programme include: continued care of the child at home when normal caring arrangements within the family are disrupted due to illness or family conflict; assistance to parents isolated from extended family members; practical support for exhausted parents at times when they need it most; improved confidence of the parents when caring for the child with disabilities; and practical assistance in facilitating health-care visits and treatments essential to the child's well-being (75).

6.3.7 Foster care

Maintaining children within their family unit should always be the primary goal and preferred option. However, in situations where children are not able to stay with their family, the option of foster care should be available.

The use of foster care varies widely across countries. Some countries use foster care purely as a caretaker provision until the child can be provided with a more permanent adoption placement, with little attempt to rehabilitate parents who are in difficulty. Other countries use foster care more therapeutically to provide treatment for the child and/or a role model for parents in difficulty as a part of family rehabilitation (8). The latter is the recommended form of foster care that should be made available to parents with children affected by psychosocial disabilities (see boxes 17 and 18). However, the option of foster care as an alternative to the institutionalization of children is underused in many countries (4).

In 2010 the United Nations General Assembly adopted Resolution 64/142 on *Guidelines for the alternative care of children* (111) which outlines specific expectations of foster care as an alternative form of care for children with disabilities. In order for foster care to be a credible option, it is recommended that:

- A pool of accredited foster carers is identified in each community to provide children with care and protection while maintaining ties to the family, community and cultural group.
- Appropriate training, supervision, support and counselling services should be made available to foster carers at regular intervals before, during and after the placement.
- Carers should have the opportunity to share their opinions and influence policy, as well as to receive peer support through means such as associations of foster carers.

Box 17. Foster care network in Paraguay

In Paraguay, some 5000 children are living in institutions. Since 2006, with the support of the Latin American Foster Care Network (RELAF), persons and groups active in the field of child care and protection have been cooperating to develop and promote foster care as an alternative measure to institutionalization.

A Paraguayan Foster Care Network has been set up, comprising civil society organizations and the State government, represented by the Centre of Adoptions of the National Childhood and Adolescence Secretariat. A key step forward was the publication of a presidential decree in 2010 establishing a foster care programme for children and adolescents in need of protection and support. Ongoing work revolves around creating awareness among judges responsible for determining the setting for care of children deprived of parental care, the promotion of foster care in the wider society, and the recruitment, training, support and monitoring of foster families (75).

Box 18. Minimum standards for foster care in Namibia

In order to strengthen alternative care services for vulnerable children in need of protection, care and support in Namibia, an alternative care assessment was undertaken in 2008. The assessment identified large numbers of children in unregulated care. As a result, standards for foster care were developed. Training took place countrywide with all NGOs and government social workers, and a task force was formed to facilitate implementation. The new standards included guidelines for foster care, a social work training manual for assessing prospective foster parents, a training manual for training prospective foster parents, and a toolkit for support groups for foster parents. A database was established for potential foster care service providers and foster children (75).

6.3.8 Small group homes based in the community

Small group homes may also need to be considered when children cannot stay with their families or in foster care. These settings should be considered an option only after all other community-based options have been exhausted (80). This type of service should be provided for children in small groups, living in normal houses, integrated into the community. Small group homes require a highly trained, professional workforce to support the children and meet their individual needs. It is also important that, wherever possible, these services maintain and encourage ongoing links with the family (4).

This type of service can be provided on a 24-hour basis by specialized carers or in specialized group care settings in the community. In such settings, strong relationships with the birth family and extended family should be maintained (4). Where deinstitutionalization has been successful, placements in small group homes account for only a small percentage of children with disabilities (4).

Research has shown that, when children are placed in such settings with highly trained care providers who are supervised in the implementation of the child's care plan, the children have higher rates of success in maintaining their placement and achieving a "normalized" quality of life than children living in hospital-like settings (112). The *Guidelines for the alternative care of children* (111) recommend that: these residential care settings should be small and organized around the rights and needs of the child; national or local authorities should establish rigorous screening procedures to ensure that only appropriate referrals are made; and governments should ensure that there are sufficient numbers of carers to provide individualized attention to the child, allowing for a bond to develop between the child and carer (see boxes 19 and 20). Failing to do so would result in the care settings becoming another form of institutionalized care.

Box 19. Foster mothers initiative, OAfrica, Ghana

Since 2003, OAfrica has been running a small group home in Achimota, Accra, Ghana. The home consists of several “foster mothers” who provide specialist care and support for eight children with disabilities (including cerebal palsy, autism and psychotic disorders) who have special needs. Children are referred to the home through a variety of sources, including the police, the Department of Social Welfare and NGOs.

Three of the foster care mothers provide care for two children each, while another two provide one-on-one support to children with more intensive needs. An additional foster mother is available to provide respite to the full-time foster mothers.

The mothers provide for all the care needs of the children – including their general care, medical support, physiotherapy and education. They also accompany the children to their school, the New Horizons Special School, where they receive tailored education.

The foster mothers have been trained in physiotherapy and encourage the children to do small daily exercises as a part of their daily routine in order to increase their muscle strength. They are also responsible for taking the children to medical appointments. A physiotherapist visits the home every two weeks to assess the progress of the children and provide ongoing support and advice to the foster mothers.

In addition, each child also has an OAfrica social worker who visits them every week, rotating between school and home visits, to ensure that all care being provided is appropriate and is meeting the children’s needs (113).

Box 20. SOS children's villages

SOS Children's Villages International is the umbrella organization for the global federation of 116 national associations of SOS children's villages. Through its family strengthening programmes, the NGO provides direct support, education and counselling to families who are experiencing hardships, so that parents can cope and children can continue to grow up in their own families.

In situations where children have lost parental care, SOS Children's Villages provides long-term, quality alternative care in a family setting to children who need it. Usually this alternative care means an SOS family, with an SOS mother and other children in her care. In other cases, it can mean facilitating another form of family-based foster care or short-term care that is better suited to the individual child and the situation (114).

Many "villages" in different countries provide a home and support to children with physical and psychosocial disabilities. For instance, the SOS children's village in Khajuri Kalan, India, provides a home to 80 children and young people with a range of disabilities, including psychosocial disabilities. The children and young people are looked after in 14 family houses with specially trained SOS mothers and co-workers. The village has a well-equipped medical centre which includes special units for physiotherapy, speech therapy, hydrotherapy and music therapy. Children at Khajuri Kalan attend local schools, special-needs schools or the local SOS school. Each child is encouraged to play an active role in "village" life while at the same time being encouraged at times to shed responsibilities and be a child (115).

6.3.9 Monitoring the care of, and services for, children with psychosocial disabilities

Several international reports recommend that monitoring mechanisms should be in place to prevent further violence against, and violations of, children with psychosocial disabilities (6, 19, 111). The monitoring mechanisms should address institutions during the deinstitutionalization process, and community-based services and support for children with psychosocial disabilities (see Box 21).

UNICEF, in its summary report *Violence against disabled children* (6), outlined a number of recommendations related to the oversight and monitoring of services for children with disabilities, including:

- People responsible for, or working with, children with disabilities should be appropriately trained. Thus, support staff, teachers, medical staff, police and others should be made aware of the risk of violence towards children with disabilities and how to identify and intervene when violence occurs.
- There should be oversight of administrators and professionals working with children with disabilities, with controls such as background checks.
- A functioning reporting mechanism should be established to ensure that violence is reported in a timely and confidential manner, and all reports are addressed.
- Professional standards and licensing requirements should be developed.
- Guidelines should be established for the oversight of schools, community programmes and workplaces in order to ensure not only that children with disabilities are included but that, when included, they are kept free from harm.
- Data should be collected on the prevalence of children with disabilities through birth registries, school registries and institutions as a means of tracking and monitoring incidents of violence against children with disabilities.

Both the CRC and the CRPD state that all facilities and programmes that serve children with disabilities should be monitored by independent authorities (1, 65). The Committee on the Rights of the Child, in its General Comment No.9 (66), outlines the necessary elements of an independent oversight body, such as an ombudsman or commissioner, including:

- independent and provided with adequate human and financial resources;
- well known to children with disabilities and their caregivers;
- accessible not only physically but also in a way that allows children with disabilities to communicate their complaints or problems easily and confidentially; and
- having the appropriate legal authority to receive, investigate and address the complaints of children with disabilities in a manner sensitive both to their childhood and to their disabilities.

Box 21. WHO QualityRights: assessing and improving quality of care and human rights in facilities

In 2012, WHO launched the WHO QualityRights project. As a part of this project, WHO works with countries to assess and improve the quality of care and human rights conditions in mental health and social facilities – including those used by children – and aims to empower people with psychosocial disabilities and their families to advocate for human rights (116, 117).

The specific objectives of QualityRights are to:

- improve service quality and human rights conditions in inpatient and outpatient services and facilities;
- promote human rights, recovery and independent living in the community for children and adults with psychosocial disabilities;
- develop and strengthen organizations of people with psychosocial disabilities, as well as peer and family support groups, in order to enable them to provide mutual support, conduct advocacy and influence decision-making processes on issues affecting them;
- reform national policies and legislation in line with international human rights standards, in particular the United Nations Convention on the Rights of Persons with Disabilities.

As part of this project, WHO developed the WHO QualityRights Toolkit (118). This resource provides guidance on how to assess and improve the quality of care and human rights conditions in mental health and social care facilities. Using the Convention on the Rights of Persons with Disabilities as its framework, the toolkit establishes the key standards that need to be met in all inpatient and outpatient services for people with psychosocial disabilities. The specific themes covered in the QualityRights Toolkit include:

- the right to an adequate standard of living and social protection;
- the right to enjoyment of the highest attainable standard of physical and mental health;
- the right to exercise legal capacity and to personal liberty and security of person;
- freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse;
- the right to live independently and to be included in the community.

WHO QualityRights has already achieved results in countries. In Somaliland, in Northern Somalia, an assessment of Hargesia Hospital led to the establishment of specific measures to address poor standards of care and living conditions. Furthermore, many long-term service users were released from the hospital and several went on to find employment, additional health professionals were appointed, hygiene standards were improved and the practice of chaining service users ceased (117). Assessments in a number of inpatient and outpatient facilities in Asturias, Spain, led to the development of a mental health strategic plan to improve services as well as a “bill of rights” for people with psychosocial disabilities. In Brazil and Greece, QualityRights assessments of facilities also led to the identification of gaps needing to be addressed in order to improve the quality of care and human rights conditions.

In India, the QualityRights project was launched in July 2014 by the Ministry of Health and Family Welfare of Gujarat. Activities are focused on assessment of quality of care and human rights conditions in facilities throughout Gujarat, and on developing an individualized improvement plan for each facility. Additionally wide-scale capacity-building (on the rights of people with psychosocial disabilities, quality care issues and on recovery) is being undertaken for health-care staff, service users and families. As part of the project, peer support groups for service users and families are being established throughout Gujarat (119).

7. CONCLUSION

The placement of children with psychosocial disabilities in institutions is based on the false belief that there is something fundamentally wrong with them which can only be “managed” or “corrected” in these settings. The evidence shows us that this is not true, that institutions are damaging environments for all children, causing them untold emotional, psychological and physical harm and denying them any possible opportunity of a decent life. Evidence also shows that alternative community services and community supports better provide for children with psychosocial disabilities and their families and lead to better developmental outcomes.

There are, as highlighted in this report, economic arguments for transitioning from institutional to community-based care. But there is a more fundamental human rights justification for ending the suffering experienced by children in institutions and ensuring that they are given a chance to live fulfilling lives in their own communities.

Governments, and also foreign funding agencies and the wider international community, have a responsibility to ensure that all future investments are redirected towards community-based alternatives, thereby ending the ineffective and harmful institutional model which currently predominates across the world.

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PROMOTING RIGHTS AND COMMUNITY LIVING FOR CHILDREN WITH PSYCHOSOCIAL DISABILITIES

The world's institutions have increasingly become dumping grounds for children with disabilities, including psychosocial disabilities. An abundance of evidence shows that these settings cause extensive physical and psychological harm. Low numbers of staff, lack of training, poor quality of care, harmful treatment practices, violence, abuse and overall neglect preclude any positive outcomes for children and as a result, many remain in institutional care for the rest of their lives, and many others die prematurely. This report underscores the urgent need for countries to move from institution-based care to community-based care. It provides guidance, based on promising practices from around the globe, on the key services and supports that need to be in place to ensure that children are able to live and thrive in the community. A firm commitment to redirecting investments towards community alternatives is critical, if we are to end these institutional abuses, and provide children with the best possible start at life.

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