

**Better health, better lives: children and young people
with intellectual disabilities and their families**

Bucharest, Romania, 26–27 November 2010

EUR/51298/17/5
6 September 2010
ORIGINAL: ENGLISH

The case for change

Background paper for the Conference

Contents

	page
Introduction.....	1
Focusing on children, not disabilities	2
Failing to see the extent of the problem.....	4
Inadequately serving the health needs of children with intellectual disabilities.....	6
From institutional neglect to care in the community	8
Important lessons learned	13
Tailoring health care services to serve the right to health	15
Prevention and early interventions	16
Mainstream versus specialist health care.....	18
Final remarks	20
References.....	23

Acknowledgements

Veronika Ispanovic Radojkovic and Melita Murko are thanked for their help in preparing this background paper.

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Introduction

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.

United Nations Convention
on the Rights of the Child (1)
Article 23.1

This report briefly reviews the current situation of children with intellectual disabilities and their families in the WHO European Region, with particular regard to their enjoyment of their right to health.

Health is closely related to well-being and several near synonyms whose basic meaning is the capacity to enjoy life. It is a resource for life and for living. The right to health is therefore closely linked to the other rights of children.

There is a clearly recognized need for concerted action in the European Region to promote the health of children and adolescents with intellectual disabilities, to prevent inequality in health affecting them and to enable them to live stimulating and fulfilling lives in the community with their families, with a view to a successful transition to adulthood. They have the same rights as all children, including that of living with their families and protection from neglect, abuse and discrimination.

Recognizing the right to health and to high-quality health care is a precondition for children's effective enjoyment of their rights, including family life, education and participation in cultural life, recreation, leisure and sport. Health service interventions should serve the goal of enabling all children, including those with disabilities, to grow up in secure family environments and participate actively in their communities.

These are the principles embodied in the various United Nations conventions and other international instruments signed by most countries in the European Region. They have all ratified the United Nations Convention on the Rights of the Child (1), and most have signed the United Nations Convention on the Rights of Persons with Disabilities (2) and support the implementation of the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities (3) and the Council of Europe Disability Action Plan 2006–2015 (4).

Unfortunately, the current reality in many countries in the Region is that children with intellectual disabilities and their families remain one of the most vulnerable population groups. Too many children with disabilities in the Region continue to face barriers to participating as equal members of society and full enjoyment of their human rights, including the right to health. They are significantly more at risk than the general population for a very wide range of health problems and have significantly lower life expectancy overall while tending to enjoy less than equal access to health care, healthy lifestyles and a healthy living environment. This is in part due to the effects of the disabilities but also a result of past systems of classification, disability categorization, treatment and institutionalization.

Approaches to the special problems and needs of children with intellectual disabilities vary enormously from country to country and between the various parts of the Region. In general, the existing approaches lie between two extremes: nearly absolute reliance on segregation and institutionalization versus maximal integration in the community. The community-based approach is clearly inherently more humane and considerably more respectful of human rights.

The human rights of children with disabilities are especially important for the countries in the eastern part of the European Region, whose experience of transition from a socialist economy to a market-oriented one has been accompanied by considerable economic and social distress, in some cases leading to a partial breakdown of societal structures. Some countries in the eastern part of the Region have suffered the additional scourge of war and ethnic conflict. Overall, the quality of and access to health, education and social services has deteriorated, which has been particularly hard on vulnerable population groups with little or no voice.

The purpose of the WHO initiative to which this is an accompanying report is to bring the countries in the Region together behind a common vision of how to ensure the right to health of these particularly vulnerable children so that they may be cherished and supported in every opportunity to live their lives to the full as equal, participating and accepted members of society.

This report does not aspire to comprehensively analyse the current situation of the right to health of children with intellectual disabilities throughout the European Region. This is not possible, due to the state of the available data discussed here. Instead, limited insight into the current situation in the Region is offered, including some of the more pressing challenges facing individual countries in ensuring the highest attainable standard of health without discrimination based on disability (2).

Focusing on children, not disabilities

The key to understanding the current situation of children with intellectual disabilities in the European Region is that general attitudes and approaches towards disability, including intellectual disability, are in transition. This is taking place not just across the Region but also more generally globally. Central to this transition is a shift from models based on segregation in institutions to ones that give priority to community-based living and social inclusion. This has implications for health care services and for the whole range of social and educational services, and, in the most far-reaching of ways, for how people with disabilities, and particularly children and their families, live their lives.

The justification for this transition is that the older segregating model allows basic human rights to be violated and freedoms to be restricted. There is a growing research-based consensus that institutionalization is an active source of harm and that institutions simply do not provide a suitable environment for any child to grow up, as they foster inhumane, dehumanizing, coercive and abusive forms of experience that systematically harm physical and mental health and can result in reduced life expectancy, or in the worst cases, in early death.

This approach assumes that disabilities disqualify these children from active and equal functioning. At best, it offers palliative measures such as rehabilitation, social care and “special education” to “normalize” defective individuals and enable some degree of social participation. At worst, it defines care as referral to an institution.

The new approach marks a paradigm shift in attitudes and approaches towards people with disabilities from viewing them as objects of charity, health care and social protection towards viewing them as subjects with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent and on being active members of society (2).

This shift is reflected in changes in the terms used in relation to disability during recent decades. According to the United Nations Convention on the Rights of Persons with Disabilities (2), people with disabilities include those who have long-term physical, mental, intellectual or sensory impairment that, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

The health services and health statistics offices of most countries in the European Region apply the WHO ICD-10 Classification of Mental and Behaviour Disorders (5), which uses the classification of “mild, moderate, severe or profound mental retardation” to denote intellectual disability. This definition takes into account the criterion of the intelligence quotient (IQ) and the evidence of social impairment and limitation in the individual’s daily activities and self-care skills.

In 2001, however, WHO’s International Classification of Functioning, Disability and Health (6) adopted a new approach that recognizes disability as a universal human experience situated within a broad continuum of human functioning. This classification is an extension of the International Classification of Impairments, Disabilities, and Handicaps (7), which revolutionized the conception of intellectual disability by proposing that it no longer be regarded as a disease or even the simple consequence of disease but rather as a problem of the functioning of the whole person. In this classification, functioning is considered the interaction of the person with his or her environment. The new classification improves on the previous one by adding the factor of environmental context. In other words, disabilities arise when bodily impairments and functional limitations, including mental ones, interact with negative social and physical environmental effects.

In accordance with this new approach to disability, such terms as mental retardation, mental subnormality and mental handicap, which are considered pejorative, are gradually being replaced by intellectual or learning disability.

Striking differences remain, however, between countries and even within the same country in the terms used in law, health care, education and social services. Although, as mentioned, health care services in many countries continue to refer to mental retardation, education authorities tend to use such terms as “child with mild or severe learning difficulties” or “child with special educational needs”, while social services prefer “child with special needs”, which encompasses a wide range of children who need additional social support, including those with learning or other disabilities, children without parental care, abused and/or neglected children and those with behaviour disorders or in conflict with the law.

For the purposes of this initiative, “children with intellectual disabilities” refers to children with significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and to cope independently (impaired social functioning), which started before adulthood and has a lasting effect on development.

This definition encompasses children with a broad range of disabilities. Many children with intellectual disabilities also have physical and/or sensory impairments. The definition covers children with autism who also have intellectual disabilities but not those with higher-level autistic spectrum disorders, who may be of average or above average intelligence.

Failing to see the extent of the problem

The effort to bring about meaningful change in this area is severely hampered by the general lack of easily available statistical information. The data on children with intellectual disabilities and the services available to them are often subsumed within the data for the broader category of children with disability, which includes both children with physical and sensory disabilities and children with mental disabilities. The number of children with intellectual disabilities in residential institutions cannot be determined from regularly published statistics.

Even when statistics are kept, there is little or no standardization between countries, due to the variety of terms and definitions mentioned in the previous section, rendering cross-country comparison difficult and the data of little use for planning and monitoring regional and national policies. As an analysis prepared for the European Commission noted when it called for urgent action to reach consensus on terms and definitions, this fact represents “a barrier to the development of comparative analysis and policy evaluation” (8).

Presenting a simple tabulation of statistics for this group that would provide an overview of the scale of the problem is therefore difficult. The best that could be done is to provide some general parameters, rough estimates and observations as to what these suggest about some of the few statistics that are available.

Estimates of the prevalence of intellectual disabilities vary depending on the definition being used and the population in question. The disability rates reflect the complex interaction of human diversity, overall socioeconomic conditions, social equality and human rights.

Studies that use $IQ < 70$ as the criterion tend to suggest that somewhere between 1% and 3% of the general population in countries with a high Human Development Index (9) has an intellectual disability. The incidence of severe intellectual disability ($IQ < 50$) is estimated at around 0.4% (10). The prevalence of intellectual disability is expected to rise by 1% per year during the next 10 years, as better prenatal, neonatal and general health care improves the survival rate and life expectancy of children and adults with more complex needs (11).

Countries with lower income tend to have higher rates of mild to moderate intellectual disability, reflecting the impact of poverty and deprivation, which hinders the development of vulnerable children. Where rates are significantly higher, there may be public health problems affecting maternal prenatal, and neonatal health, including infectious diseases and malnutrition. Where rates are significantly lower, moderate and severe disabilities may be insufficiently recognized.

Given that official statistics treating children with intellectual disabilities as a separate category are not available for all the countries in the Region, rendering systematic international comparison difficult, the best starting-point for the current purposes is *Children and disability in transition in CEE/CIS and Baltic states* by the UNICEF Innocenti Research Centre (12), drawing on research and materials from the national statistical offices of 27 countries in the eastern part of the European Region. This study set a disability benchmark of 2.5% for comparison of rates reported by these countries. Although this is clearly towards the upper end of the range quoted above for high-income countries, the European Academy for Childhood Disability considers this benchmark the “norm” (13). This figure relates to disability overall and not just intellectual disability. It can serve as a very rough indicator of the extent of intellectual disability, because intellectual disability is by far the most common developmental disorder. Studies on the prevalence of disabilities in childhood across countries in the European Region and in the United States of America have found intellectual disabilities to be 5 times more common than cerebral palsy, 10 times more common than hearing impairment and 17 times more common than visual impairment (14).

Due to the absence of specific figures for rates of intellectual disability and considering the large proportion of intellectual disability within the total group of disability affecting children, the following text discusses the rates of overall disability among children. Such comparison is valuable, less as a way of assessing differences in the prevalence of disability between given countries than as an indicator of the degree to which disability is recognized as the precondition for providing support for children with disability.

The reported rates of disability among children in countries in the eastern part of the European Region were very low when transition began, ranging from 0.17% in the Russian Federation to 0.5% in Poland. By 2002, they had tripled in almost all the countries in the eastern part of the European Region, but only three countries have reported rates close to the 2.5% disability benchmark – Hungary, Latvia and the Russian Federation. This dramatic increase does not reflect so much an increase in congenital anomalies or impairments due to disease, trauma or social factors as greater formal recognition of disability by the state and the rise in benefit claims by parents.

As only 1.5 million children of the 102 million children in the eastern part of the European Region were receiving disability support, the benchmark of 2.5% suggests that as many as 1 million children may have slipped through the social support system.

This statistical neglect does more than simply reflect the pervasive and general neglect of this most vulnerable group. It indicates a major failure to recognize and support this group that has led to a massive hidden population of children and adults with intellectual and other disabilities who are unknown to the official systems.

This problem is sometimes referred to as hidden learning disabilities and is not specific to countries with lower income. Some calculations warn that the United Kingdom may have as many as 1 million people with a learning disability who are unknown to the learning disability services (15).

People with intellectual disabilities clearly require targeted public health interventions. This will only benefit a small minority, however, unless steps are taken to address the problem of this hidden population (16).

Inadequately serving the health needs of children with intellectual disabilities

States are required to ensure the provision of effective medical care to persons with disabilities. They must also ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.

UN Standard Rules on Equalization of Opportunities for Persons with Disabilities

Given how little is known about the number of people with intellectual disabilities in the European Region and how many of these are children, what can be said about their health needs and how well they are being met?

Unfortunately, the answer is “not much”, and even less for children than for adults with intellectual disabilities.

A growing body of reports and new research indicates striking disparities between how children with intellectual disabilities and their non-disabled peers utilize health services as well as major disparities between the countries of the European Region.

Children with intellectual disabilities are disadvantaged in three ways in health care. Not only do they have greater health needs, they also experience greater barriers in accessing appropriate health care, and when treated, are at high risk of receiving poor care. Key barriers include poor knowledge and training of health professionals on disability issues, communication difficulties (poor patterns of communication with the child), negative attitudes, poor intersectoral collaboration and the lack of reliable health monitoring data for this population. These complex, multiple factors lead to negative outcomes in access to health care and inclusion in programmes that target preventive health care and health promotion but also in morbidity and mortality levels (17).

People (including children) with intellectual disabilities have consistently been found to die younger and to experience more illness and disease than their peers in the general population (18). They are more likely to have epilepsy, congenital heart problems, thyroid dysfunction, respiratory disease and sensory impairments. They are less likely to be vaccinated, more likely to have poorer dental health and likely to have more problems related to diet, weight and physical inactivity. Importantly, they are thought to be considerably and unacceptably more likely to have health problems that go undetected (19).

These problems begin in childhood. Children with intellectual disabilities are more subject to common health risk factors related to diet, weight and physical inactivity as well as impaired vision and hearing, respiratory diseases and dental problems. Up to one third have an associated physical disability, most often cerebral palsy, which puts them at risk of postural deformities, pulmonary infections, gastrointestinal problems and urinary incontinence. They are 20 times more likely to have epilepsy and are at the highest risk of sudden unexpected death in epilepsy (11). As many as 60% of such deaths may be avoidable (20).

These common and well-understood health needs of children with intellectual disabilities commonly go unrecognized or misrecognized, especially among children with severe and profound intellectual disabilities. Doctors and other professionals who are not used to communicating with people with intellectual disabilities are less likely to elicit an adequate description of their symptoms and often fail to see the illness, attributing symptoms and behaviour to the intellectual disability – a failure known as diagnostic overshadowing (21).

Their mental health problems are even more likely to go unrecognized, despite the well-established link with intellectual disability. Community-based studies suggest that 35–40% of children and adolescents with intellectual disabilities have a diagnosable mental health disorder, which is five times the rate among children in the general population (8%). The rate among children with moderate to severe intellectual disabilities is as high as 50%. Increased prevalence is particularly marked for autistic spectrum disorder, hyperkinetic and severe stereotyped movement disorder and conduct disorders (22). The reported rate for pervasive developmental disorders in children and adolescents with intellectual disabilities is between 7.8% and 19.8%, while autism, using the narrowest definition, is associated with intellectual disability in 70% of cases (23).

Another important issue is the challenging behaviour displayed by about 45% of children and adolescents with intellectual disabilities, including aggressive, destructive, attention-seeking, self-injurious, sexually inappropriate, noisy and hyperactive behaviour or other kinds of disruptive and socially inappropriate behaviour (24). This challenging behaviour is a complex mix of symptoms of multiple origin precipitated by communication difficulties, physical and mental illness and other environmental influences. Understanding the complex interplay between the factors causing or provoking challenging behaviour is a sensitive but very important task, as failure may lead to overuse of medication or unnecessary placement. Challenging behaviour is the most common reason for referral of these children to long-stay psychiatric or residential facilities, often far away from their families. Appropriate treatment requires comprehensive knowledge and appropriate assessment skills, which are not always present.

Living with and caring for a child with intellectual disabilities can have clearly adverse effects on the health and well-being of parents, siblings and extended family members. For parents, having a disabled child may increase stress, take a toll on mental and physical health and affect all aspects of family life, including decisions about work, education, family finances and social relations. It may be associated with guilt, blame or reduced self-esteem. Caregivers report a decline in physical, emotional and mental well-being, feelings of overload and poorer life satisfaction. Some mothers of children with autism, physical and intellectual disabilities or Asperger's syndrome report high levels

of stress and depression and a higher incidence of seeking professional help and taking medication (25).

Siblings of children with intellectual disabilities may be at risk too. They may have to assume extra caretaking responsibilities that can result in anger, resentment, guilt and even mental health problems, especially if this responsibility is associated with limited parental attention directed towards them rather than the siblings with disability (26).

All these potential effects can influence the quality of relationships between the family members, their living arrangements, future relationships and family structure, which in turn can affect the health care and well-being of the child with a disability (27). Thus, family members and carers of children with intellectual disabilities are a high-risk group with a significant need for support, which is all too often unmet.

From institutional neglect to care in the community

Four decades of work to improve the living conditions of children with disabilities in institutions have taught us one major lesson: there is no such thing as a good institution.

Professor Gunnar Dybwad,
founding father of the movement for inclusion,
parent advocacy and self-advocacy for persons with disabilities

Placing children and adults with severe or profound intellectual disabilities in institutions has been a traditional practice in almost all the countries in the European Region.

In the western part of the Region, the number of places in institutions for people with intellectual disability increased rapidly from 1945 to 1970. This was because of the paternalistic medical approach to disability, in which the person with disability was considered defective, unable to look after him- or herself and in need of special measures of treatment, protection or education. Interventions were directed at “correcting” the “defect” by educating children with disability in special schools or placing them in large, state-run institutions for long-term treatment and care. This normally meant isolating them from their family and social and community life.

The situation started to change in the early 1970s, as awareness of the damaging consequences of institutionalization on health and social development grew rapidly and reports started to accumulate on the massive violation of basic human rights of people with disabilities in institutions and various forms of abuse and neglect. A gradual shift ensued from a primarily medical model of disability to one rooted in commitment to universal human rights. The new social model of disability no longer emphasized dependence and assistance, focusing instead on autonomy and integration, the ultimate goal being that everyone with disabilities be fully participating members of society whose rights are respected and who receive care and support that is appropriate and proportional to their needs.

The process of deinstitutionalization became the focus of disability policy in many countries in the western part of the Region in the early 1970s. It entailed the closure of

large residential institutions, replacing them with networks of community-based alternative services.

Research into the process of deinstitutionalization has shown clearly that outcomes are better overall in the community than in institutional care. Recent publications, however, highlight that there is more to deinstitutionalization than just moving people out of institutions into community settings (28). This does not automatically improve the quality of life, whether in terms of choice and inclusion or of self-identity and access to effective health care and treatment. The way personnel provide support to the people they serve has been singled out as a key determinant of the outcome (29). This is especially true for people with more severe intellectual disabilities and complex needs, including challenging behaviour.

Some countries, including Italy, Norway and Sweden, have gradually closed all large-scale residential facilities while developing community-based alternative services provided in families, including substitute families, family-like settings, group homes and home-based care, through personal assistance. This process took three decades in those countries.

In the United Kingdom, the process is well underway, and more than half of all people with intellectual disabilities now live with their families, while fewer than 2000 adults are in long-stay hospitals. A proportionally low number (44 000) of adults with intellectual disabilities are in small residential homes, and an increasing number are in homes for three people or less (30). The use of residential care for young children in the United Kingdom also dramatically declined between 1970 and 1989, and there are no children in long-stay hospitals anymore (31).

In some other countries, including Belgium, Germany, Greece, the Netherlands and Spain, community-based services have been developed as alternatives to institutional care, although existing service structure remains dominated by institutional models (32).

Deinstitutionalization has progressed less quickly in the countries of central and eastern Europe and the Baltic countries. The number of children being placed in institutions actually increased in these countries during the 1980s and 1990s.

This is in part because these countries were struggling with worsening economic conditions and political instability, while some experienced war and ethnic conflict. Families with vulnerable members, including children with disabilities, were all too often trapped in chronic poverty and forced to abandon vulnerable family members to institutions, which were undergoing a parallel process of deterioration. Poverty drove parents to leave their children in institutions that had no rehabilitation or exit route.

An illustrative example is UNICEF data from 2005 for Romania, in which about 9000 children are given up each year – a rate of abandonment that has not changed substantially over three decades. Most of these children are left immediately after birth, in maternity or paediatric wards. The mothers who abandon their children tend to be poorer, less well educated, often illiterate, underage or in an unstable relationship (33).

A study by the UNICEF Innocenti Research Centre (12) has revealed that the main reasons many families in countries in the eastern part of the European Region surrender

children with disabilities to institutions are social attitudes that shame a family that has a child with disabilities, lack of skills or capacity to provide appropriate nursing care and lack of material and economic support. Based on national statistics, the EU-funded Daphne programme found in 2003 that some 23% of the children younger than three years of age placed in institutions in 17 countries outside the EU were admitted because of disability.

This meant that, by the end of the 1990s, institutional care was the prevalent type of care for children, young people and adults with disabilities in many countries in the eastern part of the European Region, such as Belarus, Bulgaria, the Czech Republic, Lithuania, Hungary, the Republic of Moldova, Romania and the Russian Federation. It was less common in the countries emerging from the former Yugoslavia or in countries in the Caucasus and central Asia, probably due to the tradition of strong family networks in these societies (12).

Institutionalization as a problem is not restricted to large long-stay institutions. Children with intellectual disabilities living in smaller-scale settings, including with their biological families, in foster homes or other family-like residential placements, can also be denied social, educational and economic opportunities. Kept at home, educated separately and insulated from or rejected by their communities, these children can be just as isolated “in the community” as in large-scale institutions. The proposal has therefore been made to broaden the definition of institutionalization to refer to the overall phenomenon in which an individual with a disability loses control over his or her own life (34).

The UNICEF Innocenti Research Centre has estimated that about 500 000 children with disabilities were living in institutions in 1990 in the eastern part of the WHO European Region. At least 317 000 children in this subregion still live in segregated residential institutions, excluded from the mainstream of society. This number includes children in different types of institutions, including infant homes, hospitals, boarding homes for severely disabled children administered by social services, special institutions or boarding schools run by the education ministry and children homes operated by departments of health. Institutions typically host more than 100 children, and some have more than 300 and as many as 1000 children. Determining the precise number of children with intellectual disabilities in these institutions is difficult, as they also host children with other types of disabilities (physical and/or sensorial ones), children who were abandoned or placed in care for social reasons. It is estimated, however, that at least 80% of children in institutions have some degree of developmental delay or intellectual disability. Long-term placement in the institution can further aggravate such intellectual disability or result in serious developmental delays among children who were not intellectually disabled at first. All children in institutions share the same risk, with the same serious consequences for their health, well-being and overall development.

Many of the institutions in countries in the eastern part of the European Region are insufficiently funded or staffed to provide even minimal standards of care. They have been described as “little more than warehouses, often operating on less than US\$ 1 per inmate per day, providing no rehabilitation and no means of ever transitioning out” (35). The lack of rehabilitative activities, physical therapy and nursing care in institutions is striking. The children spend most of the day in bed, without activities, movement or

physical therapy, which frequently causes atrophy of the limbs, contractures, spine deformities and breathing disorders. Self-inflicted injuries are also very frequent. The very small numbers of nurse-caregivers cannot achieve much more than to change their clothes and feed them, with no time left for individual stimulation or emotional contact. The lack of human contact is especially detrimental for babies and small children. Overuse of medication and abuse of restraints, including the use of cage beds, is not rare (36).

Poor hygienic conditions and restricted staff have led to a high prevalence of hepatitis B and D, and diarrhoeal diseases are common, as are other infections among children, especially during the summer. According to the UNICEF Innocenti Research Centre study (12), more than 15 000 cases of disease were registered in institutions in Bulgaria in 2001 alone, an average of five cases per child.

Another problem is lack of access to health care when an institutionalized child has an episode of serious or acute illness requiring hospitalization for diagnosis and treatment. This lack of access may be due to physical distance from referral health institutions and hospitals, problems providing transport or resistance by the health services to admit a child from a social care institution for hospital treatment, particularly one with severe intellectual disability. The response tends to be justified on the grounds that “there is no cure for these children anyway”, “the child can be treated in the (social care) institution” or “they bring in the child and leave it to us, and later there is nobody to take the child when he or she is discharged”. This is why many institutionalized children have huge, untreated hydrocephalus, untreated congenital heart disorders, cleft palates and other major health problems. Dental services for children with severe intellectual disability in institutions present a particular problem.

Factors contributing to the high incidence of burnout syndrome among the staff include insufficient staff, difficult working conditions, low salaries, and poor mechanisms for staff support, with a general lack of continuing or further education, supervision or temporary rotations between extremely difficult posts to less demanding jobs, putting at risk the already poor care for these children.

Other detrimental factors include lack of financial resources to provide appropriate stimulation and treatment or even maintain nutritional and hygienic standards, the use of uniform treatment programmes for all children, with a concomitant lack of individualized programmes, and an absence of legislation regulating the use of restraints on children with developmental disabilities.

In countries in south-eastern Europe, deinstitutionalization has become a central concern of child care reforms over the past 10 years, and significant efforts are being made to replace institutional care with family and community care of children with disabilities. The following examples provide some insight into the challenges involved and how certain countries have responded.

With the collapse of the communist system in 1989, Romania inherited nearly 100 000 children in institutional care. About 25% were considered to have some developmental delay or disability. An immediate inflow of international humanitarian aid improved living conditions in residential institutions but also allowed very inappropriate large-scale residential institutions to remain open. More than 30 000 Romanian children were

adopted abroad, which did little to alleviate the problem in institutions, which had to be addressed by Romanian society and government structures, so that a system could be created to enable families to raise their children in their communities in healthy ways, in accordance with the United Nations Convention on the Rights of the Child (1). Adoption by the government of the Strategy for Protection of Children in Difficulty (2001–2004) was a turning point. It called for the restructuring and closing of large-scale institutions, including those for children with disabilities, while simultaneously developing support services in the community for children and families in need. During the four years from 2001 to 2004, 22 000 children were deinstitutionalized back into Romanian communities. Half were returned to their biological parents and relatives. About 1000 children with intellectual disabilities are still residing in institutions.

Still unresolved is the challenge of socially reintegrating children and adolescents leaving institutional care. Few services support children with disabilities and their families. Access to education and health services is poor, while parents lack information on the legislation governing their children's education. Prospects for social integration are low, and children with disabilities and their families face multiple problems of discrimination. Of the 50 000 children of school age with disabilities, more than 13 000 are not in any form of education.

The case of Romania makes clear that deinstitutionalization must take into account the health, social and education services required to support the large number of children being returned to the community. Deinstitutionalization takes time and careful planning, carried out at a pace appropriate to the child but also to the organizational and cultural framework and the available human and financial resources.

In Bulgaria, which had one of the highest rates of institutionalization of children in Europe, the Council of Ministers adopted a Plan to Reduce the Number of Children Placed in Specialized and Residential Institutions (2003–2005). Two comprehensive assessments of all specialized institutions were carried out in 2004 and 2006 and a decision made on the future of each institution by an inter-institutional commission. Mechanisms were adopted to improve the quality of residential care and transform institutions into family and child support services or to close them. According to the Plan, the institutions were to be closed once an appropriate alternative has been found for every child, based on an individual care plan. By October 2006, 144 institutions for children had been assessed. Six institutions were proposed for closure, 118 for reform and 20 for restructuring. From 2001 to 2006, the number of children in residential care had decreased from 12 609 to 8653, including about 1000 children with intellectual disabilities and complex needs in long-term care institutions (37).

Similarly, the Government of Serbia approved a Social Welfare Development Strategy in 2005, followed by a Strategy for Improving the Position of Persons with Disabilities (2007–2015), which include programmes to be implemented to improve the position of children with disabilities. A comprehensive assessment of existing institutions for children and a transformation plan for each institution were developed along with an individual plan of alternative community care for each child in institutions planned for transformation or closure. Simultaneously, a National Agency for Fostering with regional branches was established, focusing on promoting foster family placement of children with disabilities. As a result, the number of institutionalized children with disabilities has been significantly reduced, from 2200 in 2001 to 1143 in 2008, and the

number of those in foster care increased. Of 3844 children in foster care, 790 (22%) have disabilities, mostly intellectual disabilities. The number of day care centres for children with disabilities also increased, from 5 in 2002 to 40 in 2007 (38). Measures to improve the protection of children still in institutions were also developed under a Special Protocol on Protection of Children in Institutions from Abuse and Neglect and Providing Training of Staff.

Important lessons learned

Although long-term care institutions are still a reality for many children with disabilities, so that they continue to live under difficult conditions and even suffer abusive practices (the use of restraints, low-quality health care, rehabilitation or physical therapy, lack of educational opportunities, etc.), it is heartening that the process of deinstitutionalization has already started in most countries in the Region and is well underway or nearing completion in many. As the above examples show, important lessons have been learned in many countries that can provide valuable guidance to those now embarking on or in the early stages of what will surely be a long and complex process, especially in the countries in the eastern part of the European Region, given the unstable social, economic and political conditions in many of the countries there.

One of the most important lessons learned so far is that further admissions to institutions must be stopped and alternative arrangements must be found within the community. This is the necessary first step and has proved, in combination with deinstitutionalization, capable of acting as a forceful stimulus for developing modern and effective care services for children and families in the community (39). A continuum of family and child support services in the community should be in place to avoid the need for institutional placement of children and enable them to reintegrate. Examples of such services are day care and home-based care (family outreach services), psychosocial support for children and/or parents, legal aid, respite care and others.

Providing early psychological support to parents after a child with disability is born is especially important. It can be a decisive factor that will influence the decision of parents to keep the child in the family rather than place him or her in an institution. Unfortunately, such support is often lacking in maternity wards. Paediatric practitioners are uniquely positioned to improve children's developmental outcomes through early identification and referral of children with developmental delays or risk factors for poor developmental outcomes. Unfortunately, inappropriate screening practices, high thresholds for referral, misplaced concerns about causing parental anxiety and unfamiliarity with local resources all diminish the effectiveness of many practitioners' developmental surveillance. Recent studies show that small changes in screening and referral practices have the potential to greatly improve the effectiveness of developmental surveillance. This, in turn, has the potential to improve lifelong outcomes for children (40).

Changing the attitudes and practices of health workers in maternity hospitals on these issues should be a mandatory part of their training. Services providing early childhood interventions are also particularly helpful.

Children who, for whatever reason, cannot stay with or return to their biological families should be provided with alternatives to institutional care, including family

substitutive services such as foster care or kinship care. In such cases, biological parents should be providing continuous support and contact should be maintained between the parents and any child in substitute care.

Equally important, simply closing down institutions as a quick fix, without parallel development of relevant community services for children and families, does lead to damaging effects on children and families. Transition should be actively managed to ensure that it is as efficient and quick as possible, ensuring that adequate community-based services are in place to serve the needs of all children returned to the community. During this transitional period, several institutions may need to be kept open for a clearly delimited period of time, until the community-based absorption capacity has been developed. Any such institutions should be reformed to make them acceptable, humane environments for the children placed in them, no matter how temporarily.

Such an approach may spark objections that it results in parallel funding of institutions and community services (double funding). It has been argued that spending funds on upgrading institutions will reduce the funds available for developing alternative services in the community and slow down the process of deinstitutionalization. It is also argued that improving conditions in institutions could contribute to the general public and policy-makers falsely perceiving that abuse and neglect in institutions have been eradicated and there is no need for deinstitutionalization. Although such concerns are far from unfounded, limited transitional use of institutional settings is a necessary aspect of any humanely managed transition, particularly in an environment where community-based services are not already in existence. The process being embarked on aims at improving the situation for all children with intellectual disabilities so that they can enjoy their right to health. There is thus no excuse for allowing the suffering of some children currently in institutions and the gross violation of their rights to continue. Much can be done with modest resources to create better conditions for them, while adequate structures are being established to shift them to the community as soon as possible.

In such cases, children should be enabled to live together in small family-like groups even within the institution, pending transfer to the community, with responsible carers acting as surrogate parents, in units made to resemble a family home to the degree possible. This is both a matter of principle and useful in preparing them for life in the community. Institutions scheduled for later closure should nevertheless be provided with properly staffed and equipped educational facilities, to ensure that the children whose transfer to the community is delayed for whatever reason can still enjoy their right to an equal education. Strict professional ethics codes should be drawn up for all currently employed staff of the institutions as well as complaint filing procedures and consequences for failure to abide by codes of professional standards.

Providing training and support to staff in the institutions is of paramount importance, both to improve current practice pending their closure and because many of these professionals will have to provide services for people with disabilities in the community in the future, after deinstitutionalization. Education, training and similar organizational measures are an efficient tool for preventing burnout. Staff should therefore receive intensive training in implementing best practices in work with individuals with disabilities, with a series of workshops and mandatory courses. The workshops should be focused on developing their understanding of the social model of disability,

internalizing the code of ethics and providing training on child-centred approaches to care. The treatment, education and activity planning in existing institutions for children with disabilities should be organized in accordance with best-practice methods and techniques – children should be provided opportunities for making choices in everyday matters, while behavioural problems should be addressed through functional behaviour assessment and positive behavioural planning. Educational and milieu activities should take children’s preferences, needs and abilities into account.

Finally, deinstitutionalization is not the responsibility of one profession or agency but of all together. It has to be recognized as a multidisciplinary effort and priority, especially of those working in social care, social assistance, health, education and housing. Providing education and health services for children with disabilities in the community is a key factor ensuring that children can remain in or return to the communities to which they belong.

Tailoring health care services to serve the right to health

Modern health care systems can improve the quality of life of those they serve. Problems, for the most part, arise in ensuring equitable delivery of these services to those who most need them and are most likely to benefit from them. As noted above, children with intellectual disabilities in the European Region face several barriers accessing health services, largely due to (41):

- learning and communication difficulty among children with intellectual disabilities;
- lack of awareness among caregivers and professionals of the health needs of children with intellectual disabilities and discriminatory attitudes towards them; and
- physical barriers and inflexible administrative and care procedures.

It is particularly important in this regard that “equal” or “equitable” does not mean “the same” and that “reasonable adjustments” are needed to make services equally accessible to children with intellectual disabilities (11).

Caring for children with intellectual disabilities means adjusting standard approaches to gathering information on children’s conditions and symptoms, including good knowledge of relevant risk factors, awareness of atypical presentations to diagnostic screenings and appropriate methods of treatment, care and referral.

The role of family and carers in this process is crucial. They are an important source of information, as they are in a unique position to observe changes in the child’s behaviour and how they may be related to environmental influences. They also play an important role in implementing and monitoring treatment (42). If such knowledge and skills are absent, the health needs of children with intellectual disabilities may remain unmet and there may be unnecessary referrals to secondary or tertiary services because primary health care workers are not comfortable treating children with disabilities within the primary health care system. It is crucial that communication with carers be fostered and their views respected (43).

The services involved include health promotion, primary health care services and specialist health services, when required, but preventive and early intervention services are especially important.

Prevention and early interventions

The scope for preventing developmental disorders and, more specifically, intellectual disabilities has increased enormously in recent decades (44). Organic syndromes that can result in intellectual disabilities prenatally can increasingly be diagnosed based on blood tests, ultrasound scans and amniocentesis. Rubella vaccination can prevent congenital rubella, and folic acid supplementation in early pregnancy can prevent neural tube defects. Continuing advances in obstetric and neonatal care may further reduce the rate of early brain damage related to complications of prematurity. Neonatal screening for phenylketonuria, galactosaemia and hypothyroidism can enable early treatment before irreversible brain damage has occurred. Immunization can protect children against diseases that cause meningitis and encephalitis, which often result in intellectual disabilities.

The examples of evidence-based interventions for preventing developmental disorders given in the WHO Mental Health Gap Action Programme (mhGAP) (45) are:

- measures within the health sector such as providing skilled care at birth, effective community-based services for maternal and child health care, prenatal screening for Down's syndrome and preventing alcohol abuse by mothers;
- multisectoral measures that relate to public health such as fortifying food with iodine and folic acid and interventions to reduce child abuse;
- identification and initial care in primary health care settings; and
- referral and supervisory support by specialists.

The question is to what extent these measures are actually available and applied in the various countries. The significantly higher incidence of congenital disorders and organic brain syndromes in the countries in the eastern part of the European Region suggests that relevant preventive measures are not sufficiently used, and in some cases not at all (12).

The risk of birth complications, of premature delivery and of low birth weight has increased in many countries in the eastern part of the European Region since 1989. This outcome can be attributed to the many physical, mental, social and economic stresses associated with transition. Evidence also indicates a deficiency of folic acid, vitamin A, iodine and iron in maternal and infant nutrition in many of these countries, and particularly in the most impoverished ones, such as Kyrgyzstan and the Republic of Moldova. Rubella, hepatitis and measles are still endemic in some of these countries.

States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment.

This could prevent, reduce or eliminate disabling effects.

(Rule 2, Standard Rules)

Harmful maternal lifestyle practices, including using alcohol, tobacco and drugs during pregnancy, are more widespread than before transition, increasing the risk of fetal damage, premature birth and other impairments associated with intellectual disability. The situation requires a more vigorous public health response to eliminate or at least reduce the high risk of preventable intellectual disability in these countries.

Another powerful tool of prevention is early intervention. The rationale for early intervention is that it enhances the development of young children already exhibiting intellectual delays, both by altering their developmental trajectories and by preventing secondary complications from occurring (46). There is a consensus that the success of an intervention is related to the age at which it starts: the earlier behavioural intervention begins for a child, the better the prognosis (47).

Theories and practice in early intervention have evolved in the past two to three decades. There has been a shift from intervention focused on the child to a much broader approach, in which attention is not placed solely on the child but on the family and the community too – the ecological systems approach.

This change was influenced by two streams of increased knowledge: evidence from neurobiology highlighting the importance of early experience for the development of the brain and its functions and theories and data highlighting the role of family and caregivers in the child's development (attachment theory) (48) and the influence of interaction with others and the environment on development (human ecology theory) (49). The ecological systems approach is widely applied and can be considered the reference model for early childhood intervention.

A UK-based charity, MENCAP, active in the area of learning disabilities, has made a number of valuable practical recommendations to improve the health care provided to people with ID, including children. Their principles include:

- fair access to mainstream services,
- better training in learning disability for all health care staff,
- annual health checks for all people with ID,
- longer appointments to allow patients to explain their health needs,
- accessible information to be provided in all health care settings, and
- all health records to show that someone has an intellectual disability.

The Early Childhood Intervention study (50) carried out during 2003–2004 in 18 European countries¹ that conduct early childhood intervention and offer services following early detection of developmental delay or disability found that there were considerable problems and made the following recommendations regarding the quality of care services:

- available: the same quality of service should be provided to all children and families (such as urban versus rural or marginalized groups);

¹ Austria, Czech Republic, Denmark, Estonia, Finland, France, Greece, Germany (Bavaria), Iceland, Lithuania, Luxembourg, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and United Kingdom.

- accessible: services should be near to the family and family centred;
- affordable: services should be free of charge or at minimal cost; and
- interdisciplinary: the roles and responsibilities of different professionals should be clear.

How professionals involved in early childhood intervention are trained is especially important. In addition to initial training to develop a shared understanding of common concepts, there must be further training and in-service training, which should strengthen the competencies of staff working with and in families: such as working in a team, cooperation between services and developing personal abilities such as self-reflectivity, communication skills and problem-solving strategies (51).

Mainstream versus specialist health care

There is a longstanding debate among professionals and policy-makers as to the best way of providing health services to people with intellectual disability and mental health problems: mainstream versus specialist health care. Advocates of the mainstream approach argue that specialist services lead to stigmatization and labelling and perpetuate the marginalization and social exclusion of people with intellectual disabilities. The others argue that assessing and treating people with intellectual disabilities require special expertise that is difficult to provide within the mainstream services (52).

In this context, the provision of mental health care to people with intellectual disabilities has faced particular challenges. For example, the closing of long-stay hospitals for people with intellectual disabilities in the United Kingdom was followed by the creation of multidisciplinary community teams tasked with managing the physical and mental health of people with intellectual disabilities and a wide range of their social needs. Specialist mental health provision for these people, however, remained fragmented and outside of mainstream mental health services, even as reports piled up of their unmet mental health needs (53). Research data and pressure applied by stakeholder groups influenced a change towards the provision of comprehensive mental health services that would "... identify the needs of this group but keep its roots within mainstream mental health services" (54). Staff members on the community intellectual disability teams were given the role of facilitators responsible for facilitating access to health care from both primary and mainstream secondary health services (55).

Regardless of where care is provided, continuity between child and adult services for people with intellectual disabilities represents a major problem. As noted above, this can be dealt with by introducing a designated key worker (health facilitator) to serve as the point of contact between parents and caregivers and the service system and to coordinate the delivery of services.

The role of primary health care is crucial to ensuring the success of care in the community. In most countries in the European Region, children with intellectual disabilities still have limited access to primary health care services, which are designed with the general population without disabilities in mind.

Even when the children with intellectual disabilities have access, primary health care workers (general practitioners, family doctors and community paediatricians) are often insufficiently trained to ensure that the health needs of these children are being recognized and met. Even if they are diagnosed, treatment is often of poor quality, involving overmedication, with unnecessary and often unrecognized side effects. A recent survey of general practitioners found that 75% had received no training on how to treat people, including children, with intellectual disabilities (56).

Most countries in the eastern part of the European Region deliver primary health care through extensive networks of health centres, but not for children with intellectual disabilities and their families, who are streamed towards health institutions specializing in particular types of impairment for general health care as well as rehabilitation services. This reinforces the segregation of care, mostly of an institutional type (34).

Although the overspecialized approach of countries in the eastern part of the European Region generally applies in the countries emerging from the former Yugoslavia, they have developed several alternative health care settings for children with disabilities in the past two decades.

Developmental counselling centres have been established in Serbia and the former Yugoslav Republic of Macedonia, which provide outpatient services for the families of children born with developmental difficulties. This aids early diagnosis and prevention and referrals to relevant specialized institutions and long-term follow-up. These services are generally located within primary health care and give parents access to multidisciplinary support for their child's development within a local setting. The multidisciplinary staff members, comprising a paediatrician, a psychologist, a special teacher, a social worker and community nurses, have received training in prevention and early intervention on (developmental) issues, backed by the regional mental health services for children and adolescents.

In most countries in the European Region, paediatric services, mental health services for children and adolescents or life-long disability services are predominantly responsible for providing services for children with intellectual disabilities and mental health problems. Each model has advantages and disadvantages, and no universal model would suit all countries. A full-scale cross-country comparison of the models applied would throw much needed light on this issue.

The model of a children's disability team embedded within generic mental health services for children and adolescents has the advantages of cross-fertilization of ideas and joint training and work. It prevents teams from becoming isolated, while retaining staff with more experience and training in the area (57). Generic mental health services for children and adolescents are, however, very unevenly developed and vary between countries in the European Region in capacity and quality (58). Based on the ratio of psychiatrists specializing in children and adolescents to the population 0–20 years old, the best provision is in Switzerland (1:5300), followed by Finland (1:6600), France (1:7500), and Sweden (1:7700). Learning disability units are rare even in countries with well-developed mental health services for children and adolescents. For example, in England and South Wales, 80 mental health units for children and adolescents (900 beds) serve a total population of 12.5 million children (aged 0–18 years) but only five learning disability units, with 79 beds (59).

In countries with less favourable ratios of child psychiatrists, such as Romania, the Russian Federation and Ukraine (1:30 000), or Bulgaria, Hungary and Serbia, where it is between 1:40 000 and 1:50 000, the few existing mental health services for children and adolescents are not able to provide the mental health care needed by children with intellectual disabilities (60). Children with intellectual disabilities in these countries are mostly diagnosed and treated by extensive networks of inpatient and outpatient paediatric services. The problem is that treatment at paediatric services is traditionally more biologically oriented, often failing to meet the mental needs of the child and family. Psychologists, social workers, and special teachers are rare in paediatric services, especially inpatient ones. Strengthening the capacity of paediatric services for mental health intervention, introducing multidisciplinary teamwork, training staff and providing continuous support by mental health professionals specializing in children and adolescents would be a promising investment.

Some experts have warned that replacing the specialist model tailored to the needs of people with intellectual disabilities with generic models that must also apply to other client groups (de-differentiation) may lead to poorer recognition of special issues and greater competition for resources. The risk is lower in countries where universal public services are provided as a right, such as the Nordic countries (61).

Regardless of health care model, there is a consensus in the countries of the European Region that the team providing health care to children with intellectual disabilities should be multidisciplinary and that there must be a high level of planning, collaboration and cooperation between social services, child health, education, voluntary agencies and mental health services for children and adolescents for both community and inpatient services. The vision is to “ensure effective access by children with disabilities and children with special needs to integrated services, including rehabilitation and health care, and promote family-based care and appropriate support systems for parents, families, legal guardians and caregivers of these children” (62).

Final remarks

This review of the current situation of children with intellectual disabilities and their families makes clear the effort being made across the European Region by governments, service providers, civil society and other stakeholders to achieve a common vision of promoting, protecting and ensuring the human rights of everyone with disabilities.

Unfortunately, it also makes clear that too many children with intellectual disabilities in Europe:

- still live in segregating institutions and have little, if any, family contact;
- continue to face barriers to participation as equal members in society and full enjoyment of their human rights, including the right to health;
- remain significantly more subject to common health risk factors related to diet, weight and physical inactivity, as well as epilepsy, cerebral palsy, sensory impairment, mental health problems and challenging behaviour, resulting in significantly lower life expectancy overall; and

- experience greater barriers in accessing appropriate health care and, even when treated, are at high risk of receiving poor care, including for their frequently unrecognized or misrecognized mental health needs.

It is also true that the family members and carers of children with intellectual disabilities are a high-risk group with a significant need for support, which is all too often unmet. Having a disabled child can result in parents suffering from increased stress, taking a toll on their mental and physical health, and can affect all aspects of family life, including decisions about work, education, family finances and social relations.

The reasons this situation persists include professionals and caregivers' lack of awareness of the health needs of children with intellectual disabilities, discriminatory attitudes towards them, the poor communication skills of children with intellectual disabilities and their caregivers and of the relevant professionals, physical barriers, inflexible administrative and care procedures, poor intersectoral collaboration and the lack of reliable health monitoring.

At highest risk are children with intellectual disabilities placed in long-term care institutions. It is therefore welcome that the process of deinstitutionalization has already started in many countries in the European Region and is well underway or nearing completion in some. Much, however, remains to be done, before one can be satisfied that adequate progress is being made. The countries facing the greatest challenges in this regard are those in the eastern part of the European Region, where institutionalization is still a common practice and institutional conditions are poor, especially because of underfunding and the survival of outdated and abusive practices.

Several countries in the eastern part of the European Region have adopted national deinstitutionalization strategies or policies for children with disabilities, and the number of children with intellectual disabilities in institutions has been declining. Serious concerns remain, however, that these processes have not been accompanied by an adequate increase in the quantity and range of the community support services needed to serve the needs of children returned to the community.

One of the most important lessons learned during ongoing processes is that further admissions to institutions must stop but that a continuum of family and child support services in the community must be in place first.

During any transitional period, it may be necessary to keep open several institutions for a clearly delimited period of time while the community-based absorption capacity is being fully developed. Any such institutions should be reformed to make them acceptable, humane environments for the children placed in them, no matter how temporarily. Training and support to their staff is of paramount importance, both to improve current practices pending closing and because many of them will continue to work with people with disabilities in the community in the future, after deinstitutionalization.

Such reforms must include instituting strict codes of professional ethics and effective complaint, inspection and disciplinary procedures.

The most important lessons learned include the following:

- Primary health care has a crucial role to play in ensuring the success of health care for children with intellectual disabilities in the community. This is particularly important because not all children with intellectual disabilities currently have any, much less adequate, access to their country's public primary health care systems.
- One approach to care provision does not suit all. Suitable adjustments are required in how care is provided by both primary and specialized health care systems to meet the physical and mental health needs of children and adolescents with intellectual disabilities.
- The International Classification of Functioning, Disability and Health (6) provides a useful framework for thinking about the health of children and adolescents with intellectual disabilities and planning interventions on behalf of this population group.
- Community-based services for children with intellectual disabilities and their families should be available, accessible, affordable and interdisciplinary.
- A high level of planning, collaboration and cooperation is required between social, child health and education services, voluntary agencies and mental health services for children and adolescents regarding both community and inpatient services.
- The parents of children with intellectual disabilities play an important independent role in providing appropriate community services. Family organizations can make a major contribution by lobbying the relevant authorities and promoting mass-media awareness.
- The capacity of mainstream health professionals to provide adequate health care for children with intellectual disabilities needs to be strengthened, and training and education on intellectual disability needs to be provided to undergraduates and postgraduate clinical staff in primary care and in hospital services.
- As evidence continues to surface of the survival of abusive practices across the European Region, even in countries that pride themselves on having carried out far-reaching reform processes and despite the clear consensus on the nature and feasibility of the reforms needed, there is no justification for further delay in implementing them.

A final and particularly important point for any attempt to improve the situation of children with intellectual disabilities and their families, whether regarding the right to health or anything else, is the difficulty of bringing about meaningful change due to the absence of a clear common understanding and definition of the issues and the consequent lack of easily available and comparable statistical information. Although the situation has improved compared with even the recent past, children with disabilities remain largely hidden from the public view.

No initiative has any real prospect of benefiting more than a small minority unless steps are taken to address the problem of the hidden population of children with intellectual disabilities. Once the target group has been properly identified and mapped and a common vision developed of how best to ensure their right to health, it is imperative that it be followed up by investment in implementation of evidence based services and the evaluation of their effectiveness research locally to inform the understanding of the

impact of changes in health policy and interventions on children with intellectual disabilities and their families.

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