



**World Health
Organization**

REGIONAL OFFICE FOR **Europe**

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

Bucharest, Romania, 26–27 November 2010

EUR/51298/17/PP/3
8 November 2010
ORIGINAL: ENGLISH

Transfer care from institutions to the community

The European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families: Better Health, Better Lives outlines ten priorities for action aimed at ensuring healthy and full lives for these children and their families.

The purpose of this paper is to provide background information and offer pragmatic steps in relation to priority no. 3: "Transfer care from institutions to the community".

"Residential institutions that have a negative impact on the health and development of children and young people should be replaced by high-quality community support. New admissions to such institutions should be stopped through the development of community services."

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Acknowledgements

We would like to acknowledge the help received with the preparation of this briefing paper from Ms Georgette Mulheir.

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Statement of priority

The impact of institutionalization on the health, development and life chances of children is well documented. Owing to increased awareness of the harmful effects of institutionalization over the past fifty years, most countries in the WHO European Region have begun to reform systems of care. In many western and northern European countries, these efforts have resulted in a significant reduction in the numbers of children in institutions. However across those parts of the Region, children with intellectual disabilities are still significantly over-represented in residential care (Browne et al., 2004).

The countries of central and eastern Europe (CEE) and those of the Commonwealth of Independent States (CIS) have relied heavily for decades on the placement of children in large institutions. In this part of the Region, major efforts to reform systems of caring for children began in earnest over the past decade. This delay in reform is due to a number of factors, including:

- relative isolation, during the communist era, from international research evidence demonstrating the harm caused by institutionalization;
- a lack of family- and community-based alternative services;
- economic turmoil following the collapse of planned economies and the subsequent increase in poverty;
- a lack of professionals with specialized skills to address the needs of children with intellectual disabilities;
- The current global financial crisis, which hit CEE/CIS countries harder than any other part of the world.

As a result, the desire to reform is not always matched by resources and capacity. Yet the need for reform in this part of the Region is great: with some exceptions, the poorest countries in Europe also have the largest number of children living in residential institutions.

Background and action needed

Most countries in the WHO European Region have, at some point in their history, relied upon large residential institutions to care for vulnerable and marginalized members of society. Children with intellectual disabilities were often institutionalized as a way of providing “specialized” care. They were either considered to be ill, therefore requiring constant medical care in long-stay hospitals, or seen as requiring “special” education, provided in centralized residential special schools, often sited at a considerable distance from the family home. The logical intention of these institutions was to provide care and services to children in a centralized fashion. But the effect was the arbitrary separation of children with intellectual disabilities from their families and communities, and their isolation from society.

One of the reasons why so many children with intellectual disabilities are placed in institutions across this part of the Region relates to a misinterpretation of the human

rights framework established to protect these children's best interests. Often institutions are established to facilitate specific children's rights, such as the right to education or health care. But the separation of children from their families, in order to place them in hospitals or residential schools, denies children all of their rights, including the right to live with their family.

A body of evidence now exists demonstrating good practice in deinstitutionalization across the WHO European Region, offering a source of advice on and examples of how best to manage the process. By planning and implementing reform carefully, all countries in the Region could achieve the development of sufficient high-quality, affordable and sustainable community-based services. This would make it possible for all children with intellectual disabilities to live with families, to access appropriate health, education and social protection services and to develop to their full potential, taking up their places as fully participating citizens of our European society.

Definition of an institution

Most attempts to define an institution for children with intellectual disabilities tend to focus on the number of children living together in one building. This is not always helpful, since a small group home with 15 children might have a staffing structure and ethos which means it functions in a family-like and inclusive way, whilst another with 10 children might maintain an isolated, rigid and regimented system similar to that in a large institution.

The recent report by the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (European Commission, 2009) defines institutions by characteristics such as precedence of the requirements of the organization itself over the users' individualized needs, and use of a medical model of care which carries the risk of reducing individuals to their diagnoses.

In terms of children with intellectual disabilities, institutions are therefore defined as those residential facilities that:

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

Not all residential care is "institutionalised". Many countries that have implemented deinstitutionalization have found that some children with very complex needs or challenging behaviours benefit from a placement in highly specialized, therapeutic residential care. This is ideally provided in small groups, living in normal houses, integrated into the community. A highly trained, professional workforce supports these

children and, wherever possible, strong relationships with the birth and extended family are maintained. Where deinstitutionalization has been successful, these residential placements account for a small percentage of the care provided to children with intellectual disabilities.

The evidence base for deinstitutionalization

Over the past sixty years, research across Europe has demonstrated the harm caused by institutionalization. In the 1950s and 1960s, it was noted that children in institutions struggled to form healthy emotional attachments to their carers. This was due to the number of carers working shifts in the institutions, and the regimented regime that could not respond to the individual needs and demands of children. The lack of emotional and physical contact, together with a lack of regular stimulation and interaction, resulted in specific developmental delays and challenging behaviours common to both the British and Czech children studied (Bowlby, 1951; Matějček & Langmeier, 1964).

More recent research has found significant impairment of brain development among infants raised in institutions (Nelson, 2008), with the first six months of life being the most crucial. Most babies removed from institutions and placed in families before the age of six months recovered completely from this impairment. Those who remained longer than six months recovered only partially and demonstrated continued developmental and emotional difficulties throughout their childhood and adolescence (Rutter et al., 1998).

Experience of early institutionalization continues to have a negative impact as children grow into adults. One Russian study found severely reduced life chances for adults who had spent their childhoods in institutions: 20% had a criminal record, 14% ended up in prostitution and 10% committed suicide (Pashkina, 2001).

For children with a moderate to severe intellectual disability, the future is even bleaker. Analysis of admissions to and discharges from children's institutions in a number of countries demonstrates that the majority of these children, once they reach adulthood, are transferred to an institution for adults. The majority remain institutionalized – with all that implies – until their death (Lumos 2010, unpublished data).

In summary, the harmful effects of institutionalization include:

- impaired early brain development, leading to delayed cognitive and physical development and, in some cases, resulting in the onset of an intellectual disability;
- attachment disorders, which may result in the development of autistic behaviours, self-stimulation, self-harming, aggression to others or cruelty to animals;
- poor cognitive processing, resulting in educational under-achievement;
- poor physical health, including chronic infections;
- non-organic failure to thrive;
- unusually raised anxieties, specifically the fear of being abandoned and the fear of being alone, resulting in nightmares and sleeping disorders;
- eating disorders;

- enuresis;
- difficulty understanding right from wrong, resulting in behaviour such as lying and stealing;
- difficulties in forming healthy emotional relationships as adults; and
- significantly reduced life chances.

The argument for deinstitutionalization becomes more compelling when one considers children's ability to recover from the harmful effects of institutionalization. A number of studies demonstrate that children raised in birth, adoptive or foster families fared much better than their peers raised in institutions – not only in terms of physical and cognitive development but also of educational achievements and integration into the community as independent adults (Rutter et al., 1998; Hodges and Tizard, 1989).

The range of services required to replace institutions

Once it is agreed that institutions are not appropriate to care for children with intellectual disabilities, it is essential to understand the family- and community-based services required to replace institutions. Every country and community is different, and the range of services required to meet the needs of children with an intellectual disability varies from one country to another. Nevertheless, a minimum range of services is required to move away from reliance on large institutions, including those described below.

- *Services that support children in the family and prevent separation.* Research demonstrates that the birth or extended family usually provides the best environment to meet all the needs of children with an intellectual disability. All families require basic universal services, such as health care, education and cash benefits. Families of children with an intellectual disability require universal services to become more accessible, and also require additional specialized services. Where such services are made available to families who need them, most children are able to stay with their families, integrated into their communities.
- *Emergency protection services.* Even in countries where adequate family support services are provided, there are occasions where families cannot provide the care their children need. Children with intellectual disabilities are at greater risk of abuse than their peers without disabilities (Sullivan et al., 1997). Emergency protection services, such as emergency foster care, are therefore essential for children with intellectual disabilities who must be separated from their families.
- *Substitute family care.* For children who cannot return to their birth or extended families, substitute families are provided, including specialist foster care and adoption.
- *Specialist residential care.* For a minority of children with highly complex needs, therapeutic residential care can be provided in small homes, based in the community, ensuring full inclusion and participation in everyday life.

Challenges involved in transferring the care of children with intellectual disabilities from institutions to the community

Experience of deinstitutionalization demonstrates that children with intellectual disabilities are exceptionally vulnerable during the process. Specific challenges must be addressed, if the process of change is to succeed without placing children at risk. These include the following:

- *Lack of the appropriate legislative framework.* For instance, there may be no legislative provisions for foster care of children with intellectual disabilities.
- *Lack of capacity to manage the deinstitutionalization process.* The process is complex and requires a comprehensive management structure. This is often neglected during planning and allocation of resources.
- *Resistance to change on the part of various stakeholders.* These may include personnel who are afraid of losing their jobs, parents worried about what will happen to their children, or finance managers concerned about insufficient funding.
- *Over-stretched statutory social services.* In many countries, social work is an undervalued and under-resourced profession. Insufficiently trained social workers with high caseloads lack basic resources to support children with intellectual disabilities and their families. As a result, social workers may recommend institutional placements, because they see no alternative.
- *Outdated maternity/paediatric practices and a lack of community health nurses.* Examples of such practices include hospitals separating babies from their mothers at birth. Cases have been noted of doctors advising parents to leave children with disabilities in institutions. Some countries lack specially trained community-based health nurses.
- *Insufficient interagency working in relation to children and families.* Services for children with intellectual disabilities are often divided across different ministries or departments with little regular coordination, leading to gaps in care for children or an inefficient use of resources owing to duplication of efforts.
- *Lack of clarity over the definition of institutionalization.* In some countries, children living in residential schools and those in long-stay hospitals as a result of chronic health conditions such as tuberculosis, HIV/AIDS or mental health problems are not considered to be institutionalized. They are not included in national statistics on institutionalization and are often left out of plans for reform, despite the fact that they may have been separated from their families for long periods of time.
- *Insufficiently accessible and flexible universal services.* Examples here include a lack of inclusive education and provision of special education at the local level, and a lack of community-based therapeutic and medical services for children with disabilities or chronic illnesses.
- *Insufficiently flexible sources of funding for reform.* Some donors set unrealistic deadlines that put children at risk. Sources of funding can have significant limitations. In some cases, for example, donors will not fund capital investment. In other cases, capital is available but insufficient funds are provided for managing the process. In addition there is insufficient understanding of the

transitional costs involved in building up a new system of services while reducing the institutional system.

Discriminatory practices. Examples here include resistance to the full inclusion of children with intellectual disabilities in the mainstream community and, in some cases, families from ethnic minorities being denied access to mainstream services.

- *Financing mechanisms.* This challenge may include situations where institutions are funded and managed at national level, while community services are provided by the local budget. This acts as a disincentive for local authorities to develop and fund local community-based services for children with intellectual disabilities: it is simpler and less costly on the local budget to place children in nationally funded institutions. In some countries, many community-based services are established and funded by nongovernmental organizations (NGOs). There are cases where the state and local authorities rely too heavily on NGOs to fund services.

Building solutions

Deinstitutionalization is a programme of major change that requires careful management to minimize risks to children and maximize desired outcomes. All stakeholders should agree on the fundamental principles underpinning the process, to minimize the risk that the interests of others (such as personnel, managers, funding bodies or politicians) will take precedence over those of the children. Detailed guidance is provided in the publication *De-institutionalising and transforming children's services: a guide to good practice* (see Resources section).

Countries working to transfer care from institutions to the community need first of all to ensure that children's rights are respected. The United Nations Convention on the Rights of the Child, the United Nations Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights provide the framework for the deinstitutionalization process.

Creation of a range of services starting from the needs of individual children is essential for successful deinstitutionalization. Any decisions made during the process of deinstitutionalization should ensure that the best interests of the child always take precedence over the interests of others. Services required to replace institutions need to be designed and established on the basis of comprehensive assessments of the needs of individual children. Family support services need to be developed to facilitate reunification of families and siblings. The development of new services will be based on a thorough assessment of existing services. The new system will build on existing services, rather than being developed in parallel.

All children in institutions are vulnerable, but evidence demonstrates two particularly vulnerable groups – babies and children with disabilities. When deciding where to start the reform, these children should be prioritized. It is important to leave no child behind. All placements should be made in the best interests of each child. No child should be moved to an unsuitable placement that does not meet his or her needs or exposes the child to the risk of abuse or neglect. Institutions should be closed in their entirety and appropriate placements in families or community-based small group homes made for all children, including young adults who are about to leave an institution. No residents of

an institution should be transferred to other large institutions or be made homeless by the process of reform.

The wishes of all children and their families must be considered when planning and implementing deinstitutionalization. Special methods should be used to support children with communication difficulties to express their opinions and participate in decisions that affect them. Even where little contact exists between children and families, every effort should be made to contact families and involve them in decision-making. All placements need to be monitored and reviewed regularly, to ensure that they continue to provide the best care possible for the child.

In the process of deinstitutionalization, financial, human and material resources need to be used as efficiently as possible. Where appropriate, resources should be transferred from the institution to the community-based services, including retraining and redeploying of personnel. Institution buildings should only be reused to house community-based services if they are in an appropriate location. Investment in the current institution buildings should be avoided. Renovating the institution, or developing it into “family-style” units is not appropriate, as children continue to be isolated. Investment in buildings should only be made in emergency situations and where there is no plan to close the institution for some time.

Examples of successful practice

Belarus: Developing services to replace a residential special school

In many countries residential special schools are not classified as a form of institutional care, even though children spend the majority of the year living in the school, away from their families. In Belarus, the Ministry of Education introduced inclusive education more than a decade ago, including a special curriculum and specially trained teaching assistants to support children with intellectual disabilities and autism to learn alongside their peers in local schools.

Admissions to residential special schools fell and the government decided to deinstitutionalize. This met with considerable resistance, but one institution director pro-actively managed the closure of her own institution, and resistance to change from the personnel was minimal. They developed community-based support services, which reunited more than half the children with their families. Other children were placed in foster care and small group homes. All children were integrated into mainstream schools to be educated. Most institution personnel were retrained and redeployed in the new services.

Bulgaria: Government, donors, experts and nongovernmental organizations working together

In Bulgaria in 2010, the government developed a 15-year national action plan for comprehensive de-institutionalization of services for children and families. The plan was developed in consultation with the European Commission and a national group of experts, including representatives of all relevant ministries, national NGOs and local authorities. The involvement of all stakeholders, including funding bodies, made it

possible to identify obstacles to paying for the reform to be carried out and to develop strategies to overcome these obstacles.

The Bulgarian government decided to prioritize the most vulnerable children and to begin the reform by developing services needed to replace institutions for children with severe disabilities, including children with intellectual disabilities. Because many of the children were placed at some distance from their families, planning of the services required to replace the institutions was complex and required a national mapping process. The Bulgarian government, with support from experts, developed an assessment tool and involved local social workers, institution personnel and professionals from NGOs in assessing the needs of 2000 children with disabilities. The planned new services are based on these assessments.

Romania: Preparing children with intellectual disabilities to move from an institution

In 2001, one county in Romania decided to close an institution for 250 children and young adults with severe intellectual disabilities. Staffing levels in the institution were inadequate – often one member of staff looked after 20 or more children. Severely institutionalized behaviours were common, including self-stimulation, and some children were physically or chemically restrained on a routine basis to prevent aggression towards others or self-harming. Children rarely left the institution and were unfamiliar with the world outside.

The local authorities had few qualified personnel to prepare all the children for their new placements, so they worked with a local NGO to develop preparation programmes for each child. Children with intellectual disabilities need concrete rather than abstract explanations of new situations. So the professionals working with the children used play, special communication methods, photographs and actual experience to understand the changes that were happening. Children who had never lived outside institutions did not understand concepts such as “family”, “home” and “community”. Children were prepared individually, and those who wanted to live together in groups undertook joint activities to develop relationships. Activities were aimed at increasing self-esteem and self-identity, stimulating the children’s abilities to make choices and state their wishes for the future.

Children with severe behavioural difficulties, such as aggression to others or self-harming, were involved in regular one-to-one therapy with skilled professionals. Techniques such as intensive interaction were used to develop other means of communication, reduce self-harming behaviours and help children to form healthy relationships. The institution personnel learned alternative methods to help children with behavioural difficulties, reducing the use of physical restraint.

When the children moved to their new homes, the vast majority demonstrated little or no disturbed behaviour. They settled into their new environments quickly and rapid improvements were noted in their health, development, behaviour and independence skills.

Romania: Recruiting, supporting and financing specialist foster parents

In many countries foster care has been slow to develop. Yet this service is essential to reduce reliance on residential institutions. In many CEE/CIS countries, there is a belief that people will not foster children with intellectual disabilities. Despite this, there are excellent examples of specialist foster care in this part of the Region.

In one Romanian county, the director of social services developed a specialist foster care service to facilitate the closure of a local institution for children with severe disabilities. The director believed that such foster carers should receive a higher salary than mainstream foster carers. At that time, there was no provision in the law on foster care for this expenditure, but the director persuaded the county council to prioritize specialist foster care and to provide additional funds from the local budget. Within two years, the county had managed to place more than 100 children with moderate to severe intellectual disabilities in local, long-term specialist foster families. Improvements in children's health, development and behaviour were dramatic. Although the local authority provided additional funding to foster parents, the cost per child of placement in foster care was still considerably cheaper than the institution.

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Resources

Deinstitutionalisation and Community Living: a network for change [web site] (www.kent.ac.uk/tizard/research/DECL_network).

The Portage Project (www.portageproject.org). A method of early assessment and intervention, which empowers families to support children with intellectual disabilities to develop to their full potential.

Intensive interaction (www.intensiveinteraction.co.uk). This is an approach to teaching the pre-speech fundamentals of communication to children and adults with severe intellectual difficulties and/or autism.

Springboard for children (www.springboard.org.uk). This approach encourages literacy for young children with intellectual disabilities, to help prepare them for integration into mainstream education.

Lumos RESponse (Remote Expert Support Service) (www.lumos.org.uk). Provides detailed support on every stage of the deinstitutionalization process.