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

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### **Build workforce capacity and commitment**

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. 8: "Build workforce capacity and commitment".

*"The well-being of children and young people with intellectual disabilities is strongly reliant on the knowledge, skills, attitudes and commitment of staff in all settings and sectors."*

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## Statement of priority

*The world health report 2000* (WHO, 2000) outlined four key functions of health care systems. One of these core functions is “generating the human and physical resources that make service delivery possible”. *The world health report 2000* further defined “human resources for health” (HRH) as the stock of all individuals engaged in promoting, protecting, or improving the health of populations. Equitable health care is a basic human right, and all health care services must be accessible and inclusive for all individuals. Health care professionals therefore must be able to respond to both the shared and additional needs of children and young people with intellectual disabilities; all professionals will require the skills, agency and motivation to do so.

## Background and action needed

The challenges of building and maintaining a quality workforce dedicated to the needs of all children, including those with intellectual disabilities, are numerous. Traditionally, health sector reform often fails to account for a major resource, the workforce (Martineau and Buchan, 2000). European countries previously undergoing reform have noted that quality service provision in new community-based services is dependent, in part, on comprehensive and collaborative efforts for workforce recruitment, redeployment and training (Mulheir and Browne, 2007). Job satisfaction is crucial to a high quality workforce and efforts to increase motivation are essential.

## Values and training

In developing any training, the primary consideration must be the incorporation and reinforcement of the rights of children with disabilities and their families. These rights are supported by the WHO European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families and enshrined in numerous European and international conventions including the Convention on the Rights of Persons with Disabilities (United Nations, 2006), the Convention on the Rights of the Child (Office of the United Nations High Commissioner for Human Rights, 1990), the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1993) and the International Bill of Human Rights (consisting of the Universal Declaration of Human Rights, two covenants on civil and political rights and on economic, social and cultural rights, and two optional protocols). Of primary consideration is any person’s right to active and full inclusion in his or her community, free from ridicule, discrimination or prejudice and with the same opportunities afforded to any member of society (European Association of Intellectual Disability Medicine, 2003).

This core value should underpin all training modules and be both actively taught and intertwined throughout all components of any training curriculum. The challenge lies in turning a shared belief in human rights into a shared commitment to human rights. This requires more than a tokenistic mention of a particular right in any training programme; it requires measurable outcomes and demonstrable rights in practice rather than rights in principle. Michael (2008) found that a lack of training in intellectual disability resulted

in negative attitudes and a failure to treat persons with intellectual disabilities with dignity and respect, negatively impacting the health care they were provided.

Rights in practice are those rights actually enjoyed and exercised by groups and individuals regardless of the formal commitment made by a government (UNDP 2006).

## **Motivation of staff**

Evidence and intuition both support the conclusion that better working conditions lead to increased motivation and performance across the workforce (Rechel et al., 2006). Strategies to motivate staff will vary according to role and context but all staff must feel valued, be given the agency and resources to do their job and have opportunities for advancement. While remuneration is only one contributor to staff's commitment, remuneration that is felt both to be fair and to value their professional role and skills will likely increase motivation and commitment.

The challenges associated with motivation and recruitment of a high-quality workforce can be compounded by the introduction of any process of reform to health and social services. Personnel will need to understand a planned reform and how it will affect them; this is especially critical in situations where their job role is likely to change, such as is the case with deinstitutionalization. A degree of opposition is to be expected in implementing any new policy, but entrusting staff with honest accounts and expectations can go a long way to ameliorate any fear or resistance surrounding reform (see the example from Albania below). Mulheir and Browne (2007) offer suggestions for how to minimize personnel's natural resistance to change and instead empower them as agents of change (for more information see Resources below). They remind us that:

The normal fear of change experienced by all humans is exacerbated for the personnel by the fear of unemployment and therefore the risk of social harm to themselves and their families. This is particularly true in rural settings, since the institution may represent one of the main employers in the village and surrounding area. ... For this reason, among others, it is important to attempt to redeploy as many of the personnel as possible in the new services. However, concerns for the personnel should not be the over-riding influence regarding the staffing structure and geographical location of the new services. It is important to remember that when planning services, the needs of the children are paramount and that those of the personnel, although important, are secondary.

Workforce statistics, including capacity and performance, should be regularly collected and evaluated (Global Health Workforce Alliance, 2008). Advancement opportunities, salary and position should all be clearly linked to performance, and disciplinary action must be possible in the event that staff are not adequately performing their duties. In many cases, this may require depoliticizing posts so that there is no political influence or control over the maintenance of, or performance in, any staffing post (see the second example from Romania below). Whistle-blowing policies support staff in drawing attention to poor or harmful practices.

## **Multidisciplinary teams**

Quality health systems necessitate interdependence among multiple professional groups (Rechel et al., 2006). This will include thinking about the specific roles and ongoing

training needs of paediatricians, doctors, nurses, community-based nurses, school health practitioners, dentists, teachers and classroom staff, physical therapists, occupational therapist, speech and language pathologists, and child and adolescent psychiatrists. Ongoing training is essential and should include initial education, in-service training and life-long learning. The development of systematic and coordinated training curricula is one necessary step to ensuring adequate training.

Multidisciplinary teams and information sharing systems are essential to quality health care for children with intellectual disabilities. Families must be supported in their efforts to obtain services across sectors, and health professionals need to have access to previous health care services and the history of any given child (see the first example from Romania below).

## Curriculum

An independent inquiry into access to health care for persons with intellectual disabilities in the United Kingdom concluded that general health practitioners did not know enough about intellectual disability in general or the frequent health complications of this population to provide adequate care (Michael, 2008). In addition, respondents to a study by WHO reported that few undergraduate or graduate training modules in intellectual disabilities were available or incorporated into curricula within their countries (WHO, 2007).

In developing a training curriculum, it is useful to start by thinking through what competencies you wish your workforce to be able to demonstrate. These competencies are likely to include a fairly universal set of core values and skills required by all personnel, but they will need to be adjusted to ensure cultural relevance as well as to incorporate additional role-specific components. Clearly, the skills required by a nurse, teacher and psychiatrist will differ significantly, but ensuring consistency across a core curriculum will allow for greater collaboration and coordination across multidisciplinary teams. A core training curriculum is likely to include, but is certainly not limited to, the following components:

- positive attitudes: conviction of the fundamental human rights of all children and young people, as well as the belief that all children are capable of learning and have skills that can and will contribute to their society;
- understanding of what ‘intellectual disability’ (ID) is, as well as of what it is not;
- knowledge of basic child development and developmental milestones, as well as of warning signs for impairment and of screening and referral procedures, depending on role;
- strategies for communicating with children with ID;
- strategies for empowering children with ID and their families to be partners in decision-making;
- understanding and managing challenging behaviour of children with ID;
- the ability to provide practical, educational and emotional support to families; and
- familiarity with the medical complications that people with ID are at a greater risk of experiencing.

In addition to the core skills above, trainings should emphasize the importance of early intervention and be mindful of the skills and tools needed to support a child's educational and vocational transition to adulthood. Any education or training programme, whether pre- or in-service, should follow the principles of disability mainstreaming. Disability mainstreaming will mean that the specific needs and rights of people with intellectual disabilities are considered and interwoven throughout all modules for existing and incoming members of a health workforce. While some health professionals will clearly need more specialist knowledge than others, a separate training module specific to the needs of people with intellectual disabilities is insufficient in itself. Furthermore Michael (2008) recommended that people with intellectual disabilities and family members should be involved in the design and delivery of all training (see also Thacker et al., 2007, Owen et al., 2004).

As part of the Pomona Project (2008), a review was made of current training for health professionals regarding the health and health care needs of people with intellectual disabilities across 14 European countries. Findings suggested wide variation in content and depth of these elements of training curriculum, even across professions within countries. In the United Kingdom, for example, postgraduate training for general practitioners (GPs), who have primary responsibility for the health of people with intellectual disabilities, did not at that time require content on intellectual disability issues. An example of good practice comes from Slovenia, where an obligatory part of residency in paediatrics includes topics on intellectual disability (Pomona Project, 2008).

The European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities (European Association of Intellectual Disability Medicine, 2004) highlights the need for all medical practitioners to have a greater knowledge of intellectual disability and the health complications that often accompany it, as well as a need for the more specialized roles and better coordination and collaboration across regular and specialist services.

... it is necessary to pay special attention to people with complex and profound disabilities, who often also have other medical problems, such as visual and hearing impairments, cerebral palsy, epilepsy and eating problems. Their health problems sometimes require specially trained nurses, allied health professionals, psychological therapists and physicians ... .

Staff training programmes will need to recognize and respond to the specific health problems which may accompany intellectual disability. People with an intellectual impairment are at greater risk of poverty and co-morbid health conditions such as visual and hearing impairments, cerebral palsy, epilepsy, eating and nutrition difficulties and poor dental care (European Association of Intellectual Disability Medicine, 2004; MENCAP, 2004). People with intellectual disabilities often have worse health than others and are doubly disadvantaged by the fact that they also often find it harder to access quality health care, even when their health needs are not related to their impairment (Michael, 2008). The exchange of students and practising health professionals between specialist intellectual disability and general services may be one way to improve training on how best to work in the health sector with children and young people with intellectual disabilities – for example, through participants having opportunities to learn from good examples of early intervention (Pomona Project, 2008).

## **Building solutions and examples of successful practice**

### **Albania: Involving personnel in reform. Increasing commitment, decreasing resistance**

It is crucially important, and in the best interests of children, that personnel involved in reform do not undermine it with resistance or by failing to provide consistency of care during transitional periods. One example of successful practice can be found in Albania, where the government decided to close a baby institution in Durres where approximately 50 children aged 0–5 years were resident. Approximately 30% of the children in the baby institution had an intellectual disability and, prior to the reform, these children would have been moved from the baby institution to another large residential institution designed for children with disabilities, where the demonstrated outcomes for health and mental development were very low.

It was clear that family- and community-based services were required to replace the baby institution and that this would involve redeployment of some, but not all, personnel from the institution. Many staff were very worried about their future, given high unemployment rates and a lack of qualifications, which left few prospects of finding similar employment. In order to reduce resistance among staff, they were informed very early on and throughout the reform about all the changes that were taking place and were empowered to participate in the process. Timely, open and honest communication went a long way towards mitigating fear.

Personnel were told that they would have the opportunity to apply for jobs in the new services, but that redeployment was not guaranteed. Critically, they were also reassured that the selection process for redeployment would be carried out in a fair and transparent manner by an external independent commission, whose members would base their judgments not only on the staff's qualifications but also on an appraisal of their work. Institution personnel were encouraged to become involved in the entire deinstitutionalization process, giving them an opportunity to demonstrate their abilities, commitment and skills, which could also help qualify them for possible redeployment. Knowing that the recruitment process would be fair was a relief to many staff and motivated them to continue delivering day-to-day care in a consistent manner.

Personnel were also trained in assessment techniques and, under supervision, they carried out initial and ongoing assessments of the children to assist with placing them in new services. Personnel were also actively involved in developing individual placement and care plans for each child. One immediate effect of this involvement was that the general day-to-day care of the children in the institution actually improved, as a result of the increased awareness of the children's needs and recognition of staff's role in meeting those needs. Personnel were then involved in preparing children to move to their new placements. Where staff would be moving with the children, for example to a small group home, this helped to strengthen the bonds between the personnel and individual children resulting in better outcomes for the children. Critically, when the children moved to their new placements, the fact that they moved with personnel they knew well eased the transition process and very little disturbance was noted in the children's behaviour.

Involving personnel in placement and care plans also served to stimulate and involve the personnel who were not moving to the new services. Even in the last stages of deinstitutionalization, when it was clear which staff would be made redundant (approximately 15%), the overall levels of care for children did not decline. Staff made redundant commented that although they were sad and worried about the future, they understood that the changes taking place were better for the children.

Resistance to the process was further mitigated by opportunities provided to personnel by a nongovernmental organization (NGO) involved in the programme, including retraining for all personnel moving to new services, as well as small retraining grants and redundancy payments of one year's salary for each staff member who was made redundant. This serves as a powerful example of the benefits to children when stakeholders collaborate in the reform process.

### **Belgium: Working together: multidisciplinary teams and parent advocacy**

A Belgian general practitioner who became the father of a newborn son with Down Syndrome observed that his colleagues who interacted with his son were unaware of specific medical conditions common in children with Down syndrome. Together with the parents' association of children with Down syndrome in the Flemish-speaking part of Belgium, he created "Down ID". This booklet discusses the medical risks that are linked to Down syndrome and gives an overview of the necessary medical evaluations within certain age periods. The booklet is given to parents who then take it with them to every meeting with a medical professional. The Down Syndrome Parents' Association also approaches medical staff (especially paediatricians) to discuss the booklet with them. Parents have also been active in sharing information about this project and the booklet through invited lectures to students in the medical faculties of Flemish universities.

In addition, the Parents' Association also successfully advocated for the formation of "Down syndrome polyclinics", or teams of medical specialists within university hospitals. These teams hold integrated consultation sessions where they jointly see children as a collaborative and multidisciplinary team of specialists. In this way medical doctors participate in ongoing life-long learning.

### **Romania: Recruiting and retraining staff during a period of reform. Members of staff becoming foster carers**

When reforming residential institutions for children, many of those involved often express concern about how the reform process will affect the institution's personnel. Retraining and redeployment, where possible, is critical to developing the skills of any workforce. Some deinstitutionalization programmes across central and eastern Europe have experienced success in retraining personnel from institutions for children with intellectual disabilities to become specialist professional foster carers. An extremely successful example comes from one institution which was due for closure in Romania.

Initially, personnel expressed reluctance to foster. There was no tradition of fostering in this locality and personnel expressed concern about the level of responsibility that would be involved in caring for a vulnerable child in their home. Their concerns were exacerbated by the fact that many of the children were thought to have intellectual



disabilities. Conventional practice in Romania at the time suggested that children with a disability were “sick” and required 24 hour medical care, leading many to believe it was better for these children to be cared for in a residential setting. However, a small group of staff (10 out of approximately 100) agreed to become foster parents. Within weeks of the first 10 children being placed in foster care with former institution staff members, their physical and intellectual development improved dramatically and it became evident that many of the “disabilities” were in fact effects of institutionalization. Other personnel from the institution became increasingly confident that children with disabilities could be better cared for in a family environment, and they were encouraged to visit their former colleagues at home to see fostering in action. As a result, a further 50 members of staff decided to become professional foster carers. This made it possible to close the entire institution.

During a follow-up monitoring and evaluation focus group, one foster carer who had previously worked in the institution remarked, “I used to hate working with the children in the institution. It was very hard work and the environment was depressing and because of that I resented the children. Now I love my job: watching the children develop and flourish every day because of my involvement is so rewarding”.

### **Romania: Consistency in senior management**

One of the biggest challenges in reforming services for children and families across central and eastern Europe is a lack of consistency in management of health and social services. In many countries, personnel involved in the direct delivery of services have commented on the challenges they encounter when senior managers, and therefore systems and expectations, change frequently as a result of political elections. This results in a lack of continuity across management of services and, when coupled with major reform in the delivery of these services, can hamper progress or (in the worst cases) reverse it. It is clear that when thinking about reform and workforce development, special attention must be paid to training and retaining senior and middle management. Managers of a health, education or social service should not only have a background in that field, they should also have the ability to lead and manage services. When leadership roles are not linked to political elections, it is possible to maintain consistency in the best interests of children. It is also possible, when necessary, to hold senior personnel accountable for the services they run and to ensure they are not able to secure and retain posts without the skill set and demonstrated results to do so.

An example of the positive difference consistency in management can make on outcomes for children in care can be found in one Romanian county, where the Director of Social Services has been in post since 1997. His leadership and managerial skills have resulted in additional stability across middle management personnel, resulting in stable service provision even during periods of major change and upheaval, such as multiple political administrations, national deinstitutionalization reform and entry into the European Union. Under his leadership, the county has developed a diverse and comprehensive range of services that have made it possible to reduce the numbers of children in residential institutions from approximately 5000 to less than 400. The level of stability and professionalism in the management of services in this county has also made it possible to introduce highly specialized services, while some other counties are still struggling to provide the basics. For example, in 2008 the county established specialized community-based health and support services for children with autism.

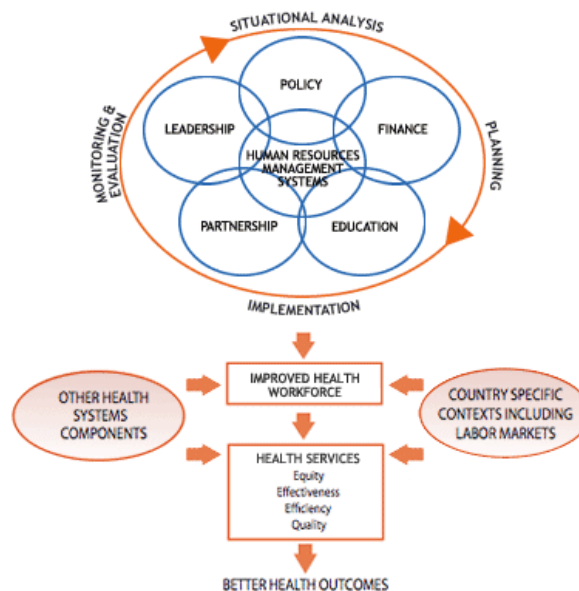
Other services of this kind exist in Romania, but they are usually established, run and funded by NGOs, where consistency across personnel is sometimes easier to maintain. In addition, due to the knowledge and respect the Director has gained over many years in post, he was able to convince local authorities to finance ongoing training for personnel, implementing this well before the national government made it a requirement.

## Resources

### Human Resources for Health Framework

The USAID Capacity Project outlines three components essential to strengthening the capacity of the workforce, namely, planning, developing and supporting the workforce (USAID, 2009). Each of these steps is essential and their consideration in isolation from each other is unlikely to result in sustainable capacity-building of a health care workforce.

**Fig. 1: HRH Action Framework**



The Capacity Project has developed a “Human Resources for Health Action Framework” which is “designed to assist governments and health managers to develop and implement strategies to achieve an effective and sustainable health workforce. By using a comprehensive approach, the Framework will help ... address staff shortages, uneven distribution of staff, gaps in skills and competencies, low retention and poor motivation, among other challenges”. The entire framework, online tools and resources to accompany implementation of this framework can be found at <http://www.capacityproject.org/framework/>.

## Resource Requirements Tool

The Resource Requirements Tool (RRT) is a practical Excel-based tool which allows countries to estimate the detailed costs associated with increasing the capacity of a workforce. The RRT has been successfully used in pilot countries to:

- estimate and project the resources required for meeting their human resources for health (HRH) plans;
- analyse the plans' affordability;
- simulate "what if" scenarios;
- facilitate the monitoring of scale-up plans;
- contribute to development of the costing and financing component of human resource management information systems.

The RRT was developed by the Financing Taskforce of the Global Health Workforce Alliance (GHWA) in collaboration with the World Bank Group. The toolkit and instructions for use can be found at <http://www.who.int/workforcealliance/knowledge/publications/taskforces/ftfproducts/en/index.html>

## Deinstitutionalization manual

The manual entitled *De-institutionalisation and transforming children's services: A guide to good practice* (Mulheir and Browne, 2007) is a comprehensive guide for countries looking to transform residential services into inclusive and community-based alternatives. After first exploring what is meant by the term 'institution', the progress made in Europe to date and the values and principles which underpin the reform process, the manual then outlines a series of 10 steps in this process. Each step is carefully explained and pragmatic "how to" suggestions are offered alongside case studies and examples. These steps are:

1. raising awareness of de-institutionalization
2. managing the process of de-institutionalization
3. analysis at country/regional level
4. analysis at institution level and assessment of individual children
5. design of alternative services
6. planning the transfer of resources
7. preparing and moving children
8. preparing and moving staff
9. logistics of transforming services
10. monitoring and evaluation.

Step 8, preparing and moving staff, is particularly relevant to building the workforce capacity and commitment.

## Health and disability: Partnerships in action

*Health and disability: Partnerships in action* is a digital learning and teaching package in disability health which is produced by the Centre for Developmental Disability Health Victoria (CDDHV) at Monash University, Australia. It was produced through interprofessional collaboration and is aimed at improving the health and health care of people with developmental disabilities.

The package consists of six DVD-based video stories, study guides and a knowledge base, and focuses on a) Disability health: exploring issues in the health and health care of people with developmental disabilities, including intellectual disability, cerebral palsy and autism spectrum disorders; and b) Interprofessional education and practice: providing a platform for interprofessional education and a springboard for appreciating the value and importance of interprofessional practice.

The package and some helpful fact sheets on topics and issues related to developmental disability medicine are available at <http://www.cddh.monash.org/>

## Understanding intellectual disability and health

*Understanding intellectual disability and health* is a web site designed and regularly updated by St George's University of London for medical, nursing and other health care students and professionals. It is available free of charge at <http://www.intellectualdisability.info>

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