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

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Empower children and young people with intellectual disabilities

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 propose pragmatic steps for giving effect to priority no. 7: Empower children and young people with intellectual disabilities to contribute to decision-making about their lives.

“Children and young people with intellectual disabilities can and will make their needs and wishes known and contribute to their community, given appropriate support and a receptive environment. Family members and advocates also need encouragement and support to make themselves heard.”

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Statement of priority

Despite rights enshrined in international legislation, individuals with intellectual impairments and children in general often remain excluded from participating in decisions that directly impact on their lives, including consultation regarding policy-making and service design and delivery (Sinclair, 2004; Morrow, 1999). Children and young people with intellectual disabilities then become some of the most severely excluded within an already marginalized group. Even in countries such as England, where disabled children are consulted with some frequency on decisions regarding their own lives and needs, involvement at higher strategic levels of planning and policy remains rare (Franklin and Sloper, 2006; Department of Health, 2001). In addition, those from ethnic minority communities may be at risk of “double discrimination”.

Far too often well-meaning adults, including policy-makers, service providers, parents and caregivers, make decisions on behalf of children with intellectual disabilities without consulting them about those decisions, which have a direct impact on their lives. This is especially true for children or young people with communication or intellectual impairments (Morris, 2003). While many children and young people with intellectual impairments are currently given little control over their own lives and decisions, even the most severely impaired are capable of exercising this control with the correct and necessary supports (Department of Health 2001). It can take extraordinary effort and patience to truly listen to children and young people with profound intellectual impairments, especially those who do not use words to communicate. Morris (2003) reminds us that

“... the most important starting point is to assume that all children and young people – whatever their communication and/or cognitive impairment – have something to communicate. It is up to us to find ways of understanding their views and experiences” (p. 346).

Background and action needed

The United Nations Convention on the Rights of the Child (UNCRC) and on the Rights of Persons with Disabilities (UNCRPD) contribute to the international legislative framework for the right to full participation in informed making of choices about one’s own life for children and young people with disabilities. Article 12 of the UNCRC mandates the right of all children to participate in decisions that affect their lives. The Preamble to UNCRPD recognizes the importance of “individual autonomy and independence, including the freedom to make their own choices ...”, while Article 3 lays out one of the general principles of the Convention as “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (United Nations, 2006). Article 7.3 of UNCRPD specifically mandates the right of children with a disability to express their views freely on all matters affecting them, as well as the provision of any supports necessary to ensure they are able to realize this right. UNCRPD also secures people with disabilities the right to choose where and with whom they live (Article 19), the right to freedom of expression on an equal basis with others (including the necessity to accept and facilitate alternative

and augmentative communication) (Article 21), and the right to participate fully in political and public life, including the right to vote (Article 29).

The Council of Europe has developed a Disability Action Plan, the key objective of which is “to serve as a practical tool to develop and implement viable strategies to bring about full participation of people with disabilities in society ...” (Council of Europe, 2006).

Sinclair and Franklin (2000) provide a very helpful summary of the primary reasons for and benefits of including children in decision-making.

To uphold children’s rights	Children are citizens and service users and share the same fundamental rights as others
To improve services	To enable services to be improved and adapted to meet changing needs, which children can help define
To improve decision-making	To ensure more accurate, relevant decisions that are better informed and hence more likely to be implemented
To enhance democratic processes	Representative democracy can be strengthened as children gain new opportunities to become active members of their community, whether in schools, local authorities or organizations
To promote children’s protection	A recurring theme of successive inquiries into abuse has been the failure to listen to children
To enhance children’s skills	To develop skills useful for debate, communication, negotiation, prioritization and decision-making
To empower and enhance self-esteem	To develop self-efficacy and raise self-esteem; help (children) understand their own wants and needs

Adapted from Sinclair, 2004, p. 108

Three levels of decision-making

Meaningful participation is essential to the intellectual development of children and, in particular, to their independence and daily living skills. The participation of children with intellectual disabilities in decisions that affect their lives is perhaps easiest to conceptualize on three different levels.

- First, children must be given the opportunity to make decisions about the most basic aspects of their lives, such as the food they eat, the clothes they wear and when to go to the toilet. Particularly in large institutions, children with intellectual impairments often have little or no control over these aspects of their lives. This lack of daily decision-making and choice can contribute to developmental delay, lethargy and greater levels of dependence. Often, institution personnel interpret this as the children having lower capabilities than is actually the case. Without regular opportunities to make basic decisions, children with an intellectual disability will not be prepared for making more challenging decisions about their lives and will therefore continue to be more dependent on others (see example 1 below).

- The second level of choice-making provides children with the opportunity to participate in major decisions that have a significant and longer-lasting impact on their lives, such as undergoing medical treatment and choices over schooling. During a process of deinstitutionalization, these decisions might include where they would like to live and with whom. As children approach adulthood, decisions become even more complex, such as whether to engage in an intimate relationship and how and when to move out of the family home. At times, it can be challenging for well-meaning parents and carers to get the balance right in terms of fulfilling their normal role of providing guidance and protection, while doing as much as possible to encourage their children's independence skills. Ensuring that parents/carers have the skills to assist children rather than make decisions on their behalf is especially important when children reach an age at which they would typically take increasing independent responsibility for their own lives.
- The third tier involves giving children and young people with an intellectual disability the opportunity to participate in planning and policy-making that affect wider groups of people, such as children in general or people with disabilities. The self-advocacy movement of persons with disabilities (or "disabled people" in the United Kingdom) is one such example. Without support and the opportunity to participate in making decisions at the previous two levels, children with an intellectual impairment will struggle to participate meaningfully in broader planning and policy-making.

Empowering children with intellectual disabilities to participate in meaningful ways in decisions and choices that affect them should not be viewed as an abstract right or a luxury in the change process. The progression of involving a child in the three levels detailed above will not only improve the quality of life for that individual child and his or her family; it will also ensure development of daily living skills and independence, thereby ensuring children are able to contribute to the productivity of their families and wider society. The skills needed to make choices and decisions regarding one's life are dependent as much on experience as they are on age and ability, including any impairment.

Challenges to participation in decision-making

"It is no longer acceptable for organizations to view people with intellectual disabilities as passive recipients of services; they must be seen as active partners" (Department of Health, 2001).

A gradual shift towards acceptance of both the importance and the need for consultation and participation of all individuals has been fuelled by increased recognition of and commitment to the universal rights of all children, as well as of the social model of disability¹. The barriers to active and full participation in communication and consultation for children with an intellectual disability are often those that others may easily take for granted. For example, if a young person with an intellectual disability is asked to attend a consultation meeting, even if the communication reaches them in an accessible format, they may not have the support they need to attend, such as accessible transport or personal assistance, and they may not be able to pay the associated costs. If

¹ The social model of disability views "disability" as the interaction of an individual's impairment with the societal and environmental attitudes and structures that serve to marginalize, exclude or "disable".

they do manage to attend the meeting, their meaningful participation will be dependent on individualized and appropriate supports. Too often, these supports are not available when they are needed.

Building solutions

Every child and young person should be afforded equal opportunities to participate fully in his or her community with active and equal membership in society.

Every child, regardless of age or severity of impairment, should be empowered to communicate his or her wants and needs and to make informed decisions about all aspects of his or her life.

The following principles of good practice ensure active and meaningful participation by individuals or groups of children with intellectual impairments:

- consultation and participation should be a mutually supportive opportunity for learning (Sinclair, 2004);
- develop a person-centred approach² to consultation and decision-making;
- treat parents, care-workers and other adults as “gate-keepers” to the child and encourage their role as a conduit to the child’s wants and needs, rather than as a decision-maker for the child (Morris, 2003).
- ensure that national legislation requires the active consultation and participation of all individuals in decision-making;
- ensure that national policies and service information are communicated in ways that are accessible for the individual in question. Examples include “easy-read” formats, in-person one-on-one communication, audio or video recordings, or e-mail or text messaging when appropriate;
- use appropriate and accessible communication to involve children and young people with intellectual impairments and their families, in order to empower self-advocacy and encourage participation in policy-making and service planning;
- provide financial coverage of all direct and associated costs incurred by individuals, to ensure their ability to participate in any consultation process. This includes, but is not limited to, costs associated with transportation, personal assistance, communication or interpretation needs and any physical or environmental adaptations needed;
- participation should be meaningful and not done merely to comply with policies or procedures; it must always remain a choice, based on principles of informed consent and the right to refuse to answer specific questions or participate at all (Sinclair, 2004);
- never assume that a child cannot communicate or participate in decisions;

² A person-centred approach requires that planning should start with the individual, not with services, and that it uses individualized supports and communication to hear a person’s needs, wishes and aspirations (DoH, 2001).

- provide training and support for parents/carers to help them communicate with their children, including strategies for listening and communicating with children with severe intellectual or communication impairments.

Examples of successful practice

Example 1: Participation in routine decisions

The regimented routine and environment of large residential institutions is typically not conducive to children contributing to routine decisions about their daily activities. This is especially true for children with an intellectual impairment, as it is often assumed that they are not able to make such decisions. In one eastern European country, personnel in an institution for children aged 0–3 years are working to give children the opportunities to contribute to daily decisions, thereby teaching them decision-making skills. As an example, a small group of children attend educational sessions at a nearby centre. Here the staff worked with the children to choose a locker space and to decorate it with the colours and materials they like. While seemingly a routine activity, these children had rarely been given the opportunity to make decisions or express their preferences in the past. As this country is undergoing a process of reforming residential services for children, the continued development of these skills will allow the children to contribute to larger decisions with a lasting impact on their lives, such as where they will live and with whom.

Example 2: Individualized coordination

In Scotland, the introduction of “learning disability liaison nurses” in the past 10 years has been one way in which children (and adults) with intellectual disabilities have been engaged in decision-making about their own healthcare. These nurses, who are based in general hospitals, act as an interface between people with an intellectual impairment and their families/carers and the general hospital staff, often addressing issues such as capacity to consent and empowering decision-making. Whereas previously there was too often an assumption that people with an intellectual impairment might not be able to make decisions, these specialist nurses have demonstrated that it is possible to involve such individuals frequently, and to allow them to take an active part in making decisions relating to them. See MacArthur et al. (2010) for more information.

Example 3: Preparation of children to move out of residential care in Romania

As part of its national deinstitutionalization plan, Romania undertook the closure of a large residential institution for 250 children and young people with disabilities. Consultation with and inclusion of the children in this process was carefully implemented. Each child had an individualized preparation programme tailored to his or her skills and needs, in order to prepare them for their new placements. During all of these sessions the children were actively encouraged to make choices.

For example, a small group of children had been previously identified to move from the institution to a community-based small group home (SGH). The preparation programme for these children included consultation with them to contribute to decisions that would directly affect their lives in the new placement. They helped to write a list of things that

they would need in the home by engaging in participatory activities such as placing photographs of things needed in each room onto a template of a house. They were also consulted and involved in decisions regarding which children would be sharing bedrooms in the new home.

Personnel involved in implementing deinstitutionalization programmes will need tailored training to ensure that they include children and young people with intellectual disabilities in decision-making. Without an understanding of the significance of child participation it would be easy, for example, to make the mistake of simply choosing bedroom assignments for the children. It is also important that governments and donors carefully consider any operational or budgetary limitations of deinstitutionalization programmes that would prevent children from participating in this process (such as the need to procure materials from only one supplier).

Example 4: Consultation on service design

In one English county, the local social services were designing a new specialist residential respite home for children with severe multiple disabilities. When developing the architectural plans, the children who would be using the service were consulted on what they would like to be included. Appropriate communication methods were used to ensure that the children understood what was being asked of them.

Taking the time to engage in consultation dramatically improved the quality of experience of respite care for the users. For example, one teenage boy with an intellectual impairment explained that when he stayed away from home at night, he struggled to sleep because he was always afraid that someone could come into his room. Together, this young man and the personnel came up with the solution of putting an alarm on the door frame, which would be triggered if the door was opened. The alarm was set once he had gone to bed and as a result, this young man now felt safe enough to sleep.

Example 5: A students' parliament

An excellent example of including children with intellectual impairments comes from a special school in a small eastern European country. Working in partnership with a local NGO, the school established a "students' parliament" with a representative from each class from grades five to nine. The students received initial training from the NGO, tailored to their abilities, which aimed to teach them about their rights and how to advocate for them. On one occasion, they met with the Mayor and asked him to finance renovation of the school's sports hall and heating system, a request that the Mayor acted on. On another occasion, the students participated in a session of the country's national parliament, where they directed questions to members of parliament on issues that concerned them. The Students' Parliament also delivered a presentation at a national children's conference and was consulted on a draft of a children's version of the Convention on the Rights of the Child. In these ways and others, children with intellectual impairments from this school have been actively contributing to decisions at all three levels of participation described above.

Example 6: Individual budgets

England has been piloting individual budgets, whereby children and young people with an impairment are given a budget, based on need, from which they can fund various activities and supports that they may require. Examples of such support can include respite care, after-school activities and support workers. When it started in 2009, the pilot scheme aimed to establish whether individual budgets would “enable disabled children and their families to have more choice and control over the delivery of their support package” and to “improve outcomes for some, or all, disabled children and their families.” The pilot scheme is due to finish in March 2011, at which time it is hoped that the pilot will have helped to establish an evidence base for lasting implementation of this strategy.

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³ All web sites accessed 1 November 2010.

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Resources⁴

Better Health, Better Lives Declaration

In line with priority no. 7, Lumos has produced an “EasyRead” version of the WHO European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families

<http://www.lumos.org.uk/files/EasyReadBetterHealthBetterLives.pdf> - not yet uploaded, but see <http://www.lumos.org.uk/what-we-do/better-health-better-lives.html>

Books Beyond Words

The Books Beyond Words series consists of specially designed books that explore various aspects of daily living without words, in an accessible picture format. In particular, the books *Michelle finds a voice* and *Speaking up for myself* both directly address the difficulty that people with intellectual disabilities can have in advocating for themselves.

<http://www.rcpsych.ac.uk/publications/booksbeyondwords.aspx>

Triangle communication guides

Triangle publishes a number of practical communication guides, including:

- *Getting it right* (2003): A guide for involving disabled children in assessment, planning and review processes.
- *How it is* (2002): An image vocabulary for children about feelings, rights, personal care and sexuality.
- *Two-way street* (2001): A handbook about communicating with disabled children and young people.

<http://www.triangle.org.uk/catalog/publications/consultation-reports-and-handbooks>

Information for all: European standards for making information easy to read and understand

Inclusion Europe has developed guidelines on how to make information in print more accessible for people with intellectual impairments. These guidelines should be considered as minimum requirements in disseminating EasyRead information but many individuals, especially children and young people, may need additional or alternative methods of communication.

<http://www.inclusion-europe.org/main.php?lang=EN&level=1&s=85&mode=nav1&n1=172>

Valuing People Now

Valuing People Now is a three year strategy in England and Wales. The resource pack contains guides and resources on person-centred planning, good practice guidelines and training materials in the areas of housing, employment, health action planning and human rights.

⁴ All web sites accessed 1 November 2010.

<http://valuingpeople.gov.uk/dynamic/valuingpeople6.jsp#ValuingPeopleNowandResourcePack>

Easy Health

Mencap and Generate have produced an accessible website making health information easy to understand. Information on common illnesses, how to stay healthy and what to do in an emergency is presented in EasyRead and audio formats on the website.

<http://www.easyhealth.org.uk/>

A Lot to Say

Scope has produced a guide for social workers and others working with children and young people with communication impairments. It is aimed at helping service providers assess the needs and seek the views of children and young people with communication impairments.

<http://www.scope.org.uk/help-and-information/publications/lot-say>.

Picture communication tool

Free to download from the website, this tool comprises various sets of drawings covering topics including personal care, feelings/emotions and medical treatment.

<http://www.picturecommunicationtool.com/>

Child participation toolkits

Save the Children International has produced useful guidelines and toolkits on child participation. While these guides are not specific to children with intellectual impairments and will need to be adapted to ensure accessibility, they provide useful suggestions, resources and examples. The toolkit *So you want to consult with children? A toolkit of good practice* may be particularly useful.

<http://www.savethechildren.net/alliance/resources/publications.html#participation>