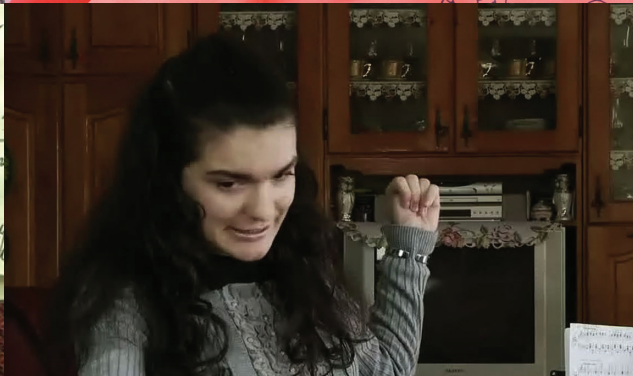


# TAKE US SERIOUSLY!

Engaging Children with Disabilities  
in Decisions Affecting their Lives



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The guidelines are intended for use by a wide audience, including governments, civil society organizations, disabled people’s organizations, and UNICEF regional and country offices, to further enhance participation of children with disabilities in policies and interventions. UNICEF does not necessarily share or endorse the examples from external agencies and organizations contained in this publication.

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Book; E-Pub and accessible HTML that can  
be found at [www.unicef.org/disabilities](http://www.unicef.org/disabilities).

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## INTRODUCTION

“We need to believe in ourselves and challenge negative opinions by showing how able we are.”

“We need to be arguing for our own rights – not just rely on non-disabled adults to do this on our behalf.”

“Disability is in the eyes of society. It is not in our eyes. If provided with opportunities, we can prove our worth.”

*(Quotes from children with disabilities in Nepal)*

The Convention on the Rights of the Child (CRC) recognises that children are not merely passive recipients, entitled to adult protective care. Rather, they themselves have rights and are entitled to be involved in decisions that affect them in accordance with their evolving capacities.

This means they can and should take on responsibility for decisions as their competence evolves. Fundamental to the CRC is respect for children as active participants in their own lives.

Although many countries are creating opportunities for children’s participation, most children with disabilities are not yet given the right to be heard and taken seriously. Children with disabilities are rarely included in such dynamic initiatives as youth forums, children’s parliaments, peer education or media projects. Nor are they involved in local and national campaigns to make rights a reality, or consulted in research concerning children’s views.

The voices of children with disabilities are largely silent in critical decisions affecting their lives – decisions about

their health, education, or where they live. Mostly due to prejudice and negative attitudes, around the world adults have low expectations for children with disabilities, doubting their capacity to develop or express a point of view. Consequently, there is widespread failure to invest in their engagement, combined with lack of knowledge, understanding and training to support their participation. The clear result, with few exceptions, is the invisibility and social exclusion of children with disabilities throughout the world.

The Convention on the Rights of Persons with Disabilities (CRPD) recognises this failure, and introduces explicit demands that governments do more. It re-affirms that the right to be heard applies equally to children with disabilities. But the Convention also demands that governments provide the necessary disability and age appropriate assistance to make it happen.<sup>2</sup> Furthermore, they must actively consult and involve children with disabilities, through their representative organisations, when developing and implementing policies and programmes to make their rights a reality.<sup>3</sup>

UNICEF’s work on disability is based on a human rights approach, with a focus on equity. It has been developed within the framework of inclusive development, and actively promotes the social model of disability. A central tenet is that legislation, policies and programmes must be informed and shaped by the children they will affect. Participation is a foundational principle of a rights-based approach. These guidelines are meant to strengthen the capacity of UNICEF and partners in creating opportunities for children with disabilities

to exercise their right to be heard and taken seriously. **It is important to:**

- clearly identify obstacles impeding the participation of children with disabilities;
- examine why participation is important for children with disabilities;
- provide practical guidance on how and where to reach out and engage children with disabilities more effectively and systematically;
- prioritize ways to measure the effectiveness of participatory initiatives with children with disabilities.

## UNICEF’S PRINCIPLES

### 01

**A human rights-based approach** recognises people with disabilities as key actors in their own development, instead of passive recipients of benefits. It acknowledges the systematic exclusion of people with disabilities from development initiatives and seeks to address these gaps.

### 02

UNICEF has adopted an **equity agenda**. Its work on disability forms a key part of achieving **equity** in local, national and international programmes and policies, which seeks to address the root causes of inequity in each society. A commitment to equity requires recognition that children with disabilities from marginalised groups face a double jeopardy. The disadvantages are not simply cumulative: disabilities magnify the difficulties children already encounter and, at the same time, are often used as justification for continued discrimination against them.

### 03

**Inclusive development** is when all groups of people contribute to creating opportunities, share the benefits of development and participate in decision-making. Under this framework, people with disabilities should be included in all

phases of any project and programme cycle and in policy and legislative design and implementation. Budgetary and administrative decisions must include a disability dimension and disability inclusiveness is considered a cross-cutting issue across the organisation.

### 04

**The social and human rights model of disability.** **The social model of disability** focuses on the high barriers created by the environment (rather than by bodily impairment), including in physical, information and communication contexts, the attitudes and prejudices of society, policies and practices of governments, and the often exclusionary structures of health, welfare, education and other systems. “Disability” is viewed as a socially created construct, not an attribute of an individual.

The Convention on the Rights of Persons with Disabilities has further developed the social model recognizing that individuals’ impairments – not only environmental aspects - also have to be taken into consideration and addressed through a human rights framework. The CRPD propounds the **social and human rights model of disability**.



**For me, children's rights mean that I and other deaf children have the same rights to go to school as all the other children**

*Nasoni Nawailagi, Fiji*

## SECTION ONE: UNDERSTANDING PARTICIPATION

**The definition of disability in these guidelines derives from Article 1 of the Convention on the Rights of Persons with Disabilities: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'**

**The term 'child' and 'children' is used to cover everyone under the age of 18 years. However, where a project or programme refers specifically to older children, the term adolescents or young people is used.**

### I. WHAT DO WE MEAN BY PARTICIPATION?

#### ARTICLE 12, CRC

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

2. For this purpose the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

#### ARTICLE 7, CRPD

1. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight

in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 12 of the CRC introduces the fundamental principle that all children capable of forming a view are entitled to express that view and have it taken seriously. It is a right that is particularly challenging in societies where children's views tend to be largely disregarded. The challenge is far greater for children with disabilities who are widely assumed to lack the capacity or experience to make a significant contribution.

The CRPD recognises that children with disabilities are commonly denied the right to be heard. Article 7 therefore obliges governments to ensure that they are *'provided with disability and age appropriate assistance to realise that right'* on an equal basis with others.

Creating opportunities for children with disabilities to express their views is only meaningful if policy makers are taking them



**I want to be a chef or a dentist**  
*Dalila Cardozo, Uruguay*

'Inclusion is not about inserting persons with disabilities into existing structures, but about transforming systems to be inclusive of everyone. Inclusive communities put into place measures to support all children at home, at school, vocational centers, sports and cultural events and in their communities. When barriers exist, inclusive communities transform the way they are organized to meet the needs of all children.'

*Source: Children with Disabilities. Ending Discrimination and Promoting Participation, Development and Inclusion, Programme Guidance Note, UNICEF, 2007*

on board. Accordingly, Article 4 of the CRPD introduces a requirement on governments to consult with representative organisations of children with disabilities in laws and policies that affect them.

Participation is a right, in the same way that inclusion is a right – and they are closely interlinked. For inclusion to be meaningful and effective, it is necessary to listen to and engage children with disabilities. This includes listening to their points of view as individuals – on decisions about where they live, the specific barriers blocking their access to school, or the support they need to participate in their local community. Effective inclusion also applies to children with disabilities as a group or constituency, for example involving them in local forums or child parliaments.

**Participation can be described as:** *'an ongoing process of children's expression and active involvement in decision-making at different levels in matters that concern them, requiring information-sharing and dialogue between children/adolescents and adults based on mutual respect, and requires that full consideration of their views be given, taking into account the child's age and maturity.'*<sup>4</sup>

**The Committee on the Rights of the Child has provided a detailed analysis of how to interpret Article 12, and has also provided guidance on its implementation with regard to children with disabilities:**<sup>5</sup>

#### 01

##### All children capable of forming a view

There is no lower age limit. Children with multiple and profound disabilities, including very young children, are able

to form views, although they may need appropriate help in expressing them. All children have experience, fears, ideas and concerns which can help contribute to decision-making.

What Article 12 requires is that adults commit to hearing those views with respect. Implementation of Article 12 requires recognition of non-verbal forms of communications such as body language, facial expression, touch, sign language, play or drawing and painting, because some children use these ways to make choices, express preferences and demonstrate understanding of their environment.

The Committee on the Rights of the Child recommends that parents, caregivers, and professionals have training in ways to support children with disabilities to express their views and take increasing levels of responsibility for decisions affecting their lives.<sup>6</sup>

#### 02

##### The right to express views freely

Children must be able to express their own views without pressure or manipulation from others. This is of particular importance for children with disabilities who are often more dependent on caregivers, and have few opportunities to explore their own ideas. **In order to express views freely, children with disabilities must be provided with:**

- **information** which is relevant, accessible, appropriate and made available in formats and at a level which they can understand. The CRPD introduces obligations to ensure that

children with disabilities are enabled to seek and impart information on an equal basis with other children.

**It requires that governments:**

- provide information in accessible formats and technologies appropriate to different kinds of disabilities;
- accept and facilitate the use of sign language, Braille, augmentative and alternative communication, and modes and formats of communication of their choice;
- encourage private entities that provide information services, including through the Internet, to provide them in accessible and usable formats.
- **‘spaces’** where they are afforded the time, encouragement and support to enable them to develop and articulate their views clearly and confidently.
- **safety** to explore and express their views without fear of criticism or punishment.

It is also important to recognise that **Article 12 does not imply any obligation on children to express their views.** It is a right not a duty, and the child can choose whether or not to exercise it.

‘The Ministry of Planning conducted a week-long workshop at which time there were many group presentations in PowerPoint, which I cannot see. The issue of accessibility, which was well illustrated by the lack of access during the workshop, was not highlighted however. The incident made me feel left out of national planning.’<sup>17</sup>

(Francis, Liberia)

**03 All matters affecting them**

The Committee on the Rights of the Child supports a very wide interpretation of “all matters affecting” children. Most aspects



**Parents shouldn't hide their children at home, they should take them to school**

Vincent Paulo, Tanzania

of decision-making from the family to the international level have either a direct or an indirect impact on children and can therefore be defined as legitimate matters of concern, for example, schooling, transport, budget expenditure, urban planning, poverty reduction or social protection.

For children with disabilities, these issues are as important as they are to other children. In addition, their experiences may influence views on, for example, physical barriers impeding access to school, negative attitudes of caregivers, or how to promote more inclusive classroom environments.

**04 Have their views weighed according to age, maturity and experience**

There is little point in listening to children if there is no commitment to giving consideration to what they say. This does not mean that children’s views may always be possible to comply with – rather that their views are not dismissed simply because they have a disability or because their views do not coincide with those of the adults involved.

Although the weight given to children’s views depends on their understanding of the issue, this doesn’t automatically mean

that older children’s views should be taken more seriously. For example, there is clear evidence of the profound impact major surgery and medical interventions can have on young children with disabilities.

Research shows they can express insights into life and death issues and the implications of related choices affecting them. Indeed, young children have proven capable of facing those choices if properly supported by the adults around them.<sup>8</sup> When it is not possible to comply with children’s views, they should always be informed of the decision and the reasons behind it.

**II. WHY IS PARTICIPATION IMPORTANT FOR CHILDREN WITH DISABILITIES?**

The Committee on the Rights of the Child clarifies the right of the child to express views and to participate in various activities, according to her or his evolving capacities. This level of participation is found beneficial for the child, the family, the community, the school, the state and democracy.

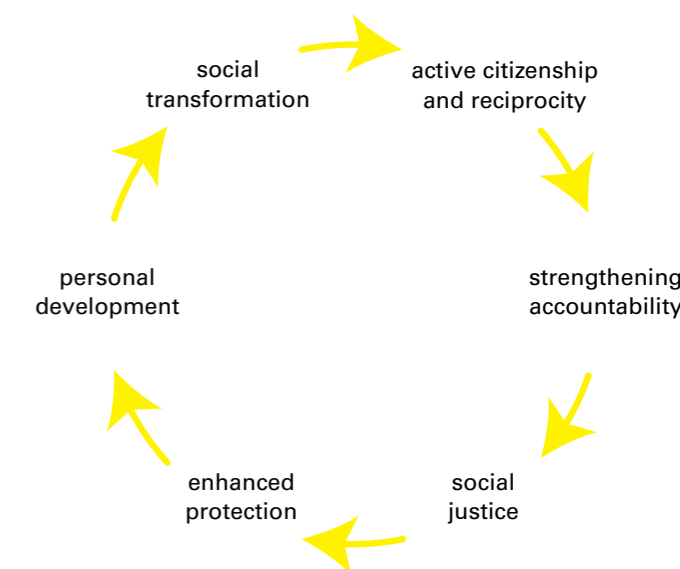
**Other reasons to make sure that children with disabilities are enabled to express their views:**

- they are subject to much greater adult intervention, leading to significant limitations on their scope for making day-to-day choices;
- their dependency results in greater vulnerability to emotional, physical and sexual abuse than children without disabilities;
- they often face a high number of medical interventions, treatments and assessment procedures from which they are denied involvement in decision-making;
- some children with disabilities are regularly excluded from consultation using written language, while others

are excluded from processes relying on spoken language;

- they are subjected to a higher level of intervention from parents and staff who are more likely to provide care than active listening;
- they are more likely than other children to be reliant on multiple caregivers who are not trained to understand their communication system.

**THE BENEFITS OF PARTICIPATION ARE MULTIPLE AND REINFORCING:**



**01 Contributing to personal development, skills and competencies**

Through participation, children acquire skills, build competence, expand aspirations and gain confidence. The more children participate, the more effective their contributions and the greater the impact on their development.

**02 Social transformation**

Children with disabilities have unique insights, knowledge, and perspectives into their own lives. Their knowledge and experience relates to matters affecting them as individuals and matters of wider concern to them as a group.

The active engagement of children with disabilities can quicken the pace of development by harnessing their experiences of, for example, barriers impeding effective and inclusive learning in schools, improving community accessibility, or expanding access to water and sanitation.

Creating opportunities for children with disabilities to be heard is also vital to improving community practices regarding adoption, placement in care, juvenile justice, health care or monitoring standards of care in institutions.

### **03**

#### **Active citizenship, reciprocity and democratic understanding**

Through experience of direct participation, children with disabilities, alongside other children, will contribute to the creation of peaceful and democratic societies which are respectful of human rights. Starting with taking part in decision-making within the family, then learning to help resolve conflicts in school, they can grow into contributing to developments at the local or national level. Participation contributes to a culture of respect in which decision-making is undertaken through negotiation, rather than conflict, and in which human rights are recognised as reciprocal and mutual.

#### **GETTING HEARD IN PARLIAMENT<sup>9</sup>**

UNICEF Montenegro supports a children's session of the National Parliament, in partnership with a local NGO "Centre for Child Rights." They organize workshops with children to enable members of school parliaments from all municipalities to identify the most urgent issues that children are facing. The job is to propose possible solutions and to prepare questions for the key decision makers. Heads of the political parties of the parliament, all Ministers, Ombudsman and representatives of national institutions participate in this children's session of the National Parliament every year on November 20th.

At the beginning of the session the children present the key problems they are faced with in Montenegro. In 2011, in line with UNICEF's 'It's About Ability' campaign, the session was dedicated to inclusion and in the following year too, inclusion was highlighted. The children especially emphasized the importance of creating conditions for inclusion of children with disabilities in Montenegrin society. Participants noted that Montenegro needs to reduce the number of children living in children homes and to increase the number of children living with families, including foster care or other alternatives to placement in institutions. The children's sessions of the Montenegrin Parliament lasted for two and a half hours and were broadcast live on the public service television TVCG.

*2011 Children's session of the National Parliament [http://www.unicef.org/montenegro/media\\_18541.html](http://www.unicef.org/montenegro/media_18541.html)*

*2012 Children's session of the National Parliament [http://www.unicef.org/montenegro/media\\_21008.html](http://www.unicef.org/montenegro/media_21008.html)*

### **04**

#### **Strengthening accountability**

The nearly universal marginalisation and exclusion of people with disabilities, including children, restricts their capacity to challenge violations of their rights. Building opportunities for children with disabilities to engage in issues of concern to them strengthens their capacity to hold governments and other duty-bearers accountable.

Learning about their rights, acquiring the skills of participation, gaining confidence in gathering and applying information, engaging in dialogue with others and understanding the responsibilities of governments – are all vital elements in creating an articulate citizenry. Similarly, to strengthen accountability, it is vital to build in these same opportunities for children with disabilities from the earliest ages.



#### **When I grow up I want to be a pilot**

*Richard Herrera, Ecuador*

### **05**

#### **Promoting social justice**

Recognition of the right to be involved in decisions and actions that impact their lives is fundamental to the creation of dignity and respect for children with disabilities. So doing represents an acknowledgement of their citizenship, and promotes their social inclusion.

Traditionally, in most societies, decisions are made on behalf of children with disabilities; the impact is to infantilise, undermine and marginalise them. Only when they are empowered to influence matters of concern to them, can they become active and effective in making their rights a reality.

### **06**

#### **Enhanced protection**

The right to express views and have them taken seriously is a powerful tool used to challenge situations of violence, abuse, threat, injustice or discrimination. The UN Study on Violence against Children highlighted the disproportionate vulnerability of children with disabilities to both physical and sexual violence. In large part, this is because they lack the information, opportunities and access to safe mechanisms for complaint, thus affording impunity to abusers.<sup>10</sup> However, if they are encouraged to voice what is

happening to them, and provided with opportunities to raise concerns, it is much easier for violations of rights to be exposed.

The self-esteem and confidence acquired through participation empowers girls and boys to challenge abuses of their rights. Furthermore, adults can protect children only if they are informed about what is happening in their lives; and often it is only children themselves who can provide that information. Violence against children with disabilities in families, schools, prisons and institutions is tackled more effectively if children themselves are enabled to talk about and report abuses.

#### **KEY BARRIERS AFFECTING PARTICIPATION<sup>11</sup>**

**A review of the research evidence on barriers to participation by children with disabilities reveals the following:**

- Persistent negative attitudes still exist towards the participation of children with disabilities in decision-making.
- Children with communication needs face barriers because of a lack of access to, for example, sign language or hearing aids.
- Children with disabilities have few opportunities to develop the skills, experience and confidence to participate.
- A lack of accessible and appropriate information disempowers children with disabilities from participating.
- The continued dominance of the medical model of disability means that barriers faced by children with disabilities to participate are ignored.
- There are few training resources dedicated to facilitating their participation.
- There appears to be too much emphasis on formal approaches to participation and not enough opportunities for informal participation, which children would welcome.

- Many mechanisms for participation, such as complaints procedures, are not accessible to children with disabilities.

### III. WHERE CAN CHILDREN WITH DISABILITIES PARTICIPATE?

The nature of and opportunities for participation of children with disabilities should be exactly the same as for all other children. They are entitled to be involved on all issues, and can engage through all approaches and at every level.

#### **BUILDING A PARTICIPATORY ENVIRONMENT AT THE LOCAL AND COMMUNITY LEVEL:**

##### **01**

#### **Child led initiatives and organisations:**

More opportunities are needed for children with disabilities to be involved in any child-led organisations. This effort requires capacity building, financial resources, review of potential barriers and awareness-raising with other children.

##### **02**

#### **Representation on local bodies with responsibility for management of local issues:**

Local committees with responsibility, for example, for education, housing, water and child protection should include representatives of child-governed organisations, and include the perspectives of children with disabilities. In addition, children with disabilities can play a role in updating information about their local community, and enrich planning and monitoring of the situation of children with disabilities by local governments.

##### **03**

**School councils** should include representation of children with disabilities as they can help build inclusive child friendly school environments.

##### **04**

**Targeted consultations on local policy issues** through which children contribute their perspectives. For example, children with disabilities have varied experience with the design of parks, school playgrounds, health facilities and local transport systems. They can help with community accessibility audits and to identify local child protection issues.

##### **05**

**Local youth parliaments and municipal children's councils** can create opportunities for participation by all children in decision-making.

##### **06**

**Research to inform policy and service provision** can be undertaken by and with children with disabilities. They can participate in identifying the gaps in knowledge about a particular dimension of their lives, developing research questions and methodology, carrying out surveys or interviews, analysing data and writing recommendations.

##### **07**

**Local media and social media initiatives** to provide opportunities for children with disabilities to contribute to children's own local newspapers, run their own radio programmes and contribute to the mainstream media. Children with

disabilities can contribute to innovative social media initiatives.

##### **08**

#### **Creative arts, music or play activities**

also provide opportunities for inclusion and creative expression of children with disabilities. Creative arts are effective advocacy and awareness tools on issues affecting all children.

##### **09**

**Peer education** to support children to provide information, support and awareness to other children. Such programmes can both involve non-disabled children to support peer education of children with disabilities and supporting children with disabilities themselves to take on a peer education role. Examples include initiatives where children take literacy programmes out to children working and living on the streets, health education programmes on HIV/AIDS and children with disabilities or hygiene and sanitation.

##### **10**

#### **Children as monitors or auditors of local services:**

Children with disabilities can be included in initiatives to investigate local hospital and health services, the police, schools, and public spaces such as shops, parks and playgrounds, to monitor whether they are complying with the CRC in general. They can help monitor discrimination or exclusion or help remove barriers keeping children with disabilities from accessing services. They can investigate or assess whether those indicators have been met, and then discuss findings with service providers including ways in which the barriers can be removed.

##### **11**

#### **Community or intergenerational dialogue:**

Involving children with disabilities in dialogue with other community members can aid in conflict resolution, building resilience and reinforcing cultural and community assets. In some cultures it

#### **CRPD AND PARTICIPATION<sup>14</sup>**

Young people with disabilities in Uganda have been using the CRPD to raise awareness about their right to education and employment, and to help their communities learn to include adolescents and youth with disabilities in their activities.

*'We have organised meetings and discussed many issues linked to people with disabilities. I have been part of a team made up of lots of representatives from different disability associations which has led advocacy and networking meetings with community leaders.'*

Francis, Uganda

*'When I got involved in a District level campaign with the (Young Voices) group, it made me feel proud. I think if it was not for this group I would not have done this on my own. This has enabled us to create awareness of disability among local authorities.'*

Maria, Uganda

Despite rejection from school on the grounds of disability, one young woman from Uganda achieved her goal of becoming a nurse. The discrimination she faced led her to join a local disability rights group and to campaign for better services.

can be particularly beneficial to have discussions with elders to explore prejudice and exclusion experienced within the community.

##### **12**

**Displaced or refugee children:** Children with disabilities are particularly vulnerable in post conflict or disaster situations, and in refugee camps.<sup>12</sup> Their perspectives are needed on the barriers they face in accessing services and next steps to take.

#### **YOUTH WITH DISABILITIES PROVIDING HIV/AIDS PREVENTION AND TREATMENT INFORMATION TO PEOPLE WITH DISABILITIES<sup>13</sup>**

In 2005/2006, 20 young people with disabilities were chosen from a township in Cape Town, South Africa to develop an educational programme in collaboration with an HIV trainer. They gained information and the trainer benefited and learned from the young people with disabilities. The trainer later became an advocate for making all 'Treatment Action Campaigns' inclusive of persons with disabilities.



## **BUILDING A PARTICIPATORY ENVIRONMENT AT THE NATIONAL LEVEL:**

### **01**

#### **Participation of children with disabilities across government:**

Children with disabilities can provide a unique lens on legislative reform, policy making, planning, data collection and resource allocation. **They can provide insight into:**

- the attitudinal, communication, physical and mobility barriers that create exclusion.<sup>15</sup>
- design, implementation and evaluation of National Plans of Action and Poverty Reduction Strategy Papers.
- online sexual abuse and exploitation, the degree and nature of risks they face, the strategies they adopt to protect themselves and the policies they would like to see put in place by governments. Little is known about their specific behaviours and vulnerabilities online.

### **02**

**Involvement in monitoring implementation of their rights:** Children with disabilities can help select and monitor indicators of progress in implementation of rights, including within the family and alternative family environments, and the impact of their participation on policy, court decisions and programme implementation. They can be directly involved in research both as respondents and researchers.<sup>16</sup>

### **03**

**Involvement of children in the reporting process to the Committee on the Rights of the Child and the Committee on the Rights of Persons with Disabilities:** In many countries, non-governmental organisations, including national alliances on children's rights, have involved children in the process of parallel reporting under the CRC, including pre-session country briefings with the Committee.<sup>17</sup> The

Committee encourages governments to include the perspectives of children with disabilities, both in CRPD reporting and parallel efforts.

### **04**

**Children's participation in national and international forums:** Involvement of children, including children with disabilities, would enrich national, regional and international conferences and children's forums.<sup>18</sup> A productive example occurred during the drafting of the CRPD where six young people with disabilities presented their priorities for the Convention text at the Ad Hoc Committee of the UN in New York.<sup>19</sup> Children with disabilities were enabled to bring their concerns to the world's leaders, a rare occasion in that they were not marginalised in the face of other powerful and competing priorities.

#### **YOUNG VOICES, LEONARD CHESHIRE DISABILITY: EXAMPLES OF PARTICIPATION BY ADOLESCENTS AND YOUNG PEOPLE WITH DISABILITIES**

A Young Voices group in China meets regularly in Beijing. To raise public awareness of the CRPD, Young Voices held two national seminars to increase the advocacy skills of young people with disabilities. This year the group will advocate to increase the number of students with disabilities attending colleges and universities.  
<http://youngvoices.lcdisability.org/china>

Young Voices in Liberia has 25 members and meets monthly in the capital, Monrovia. Partly as a result of Young Voices Liberia's tireless campaigning, their government ratified the CRPD. Power Radio, a popular station in the country, gives Young Voices regular radio coverage, greatly increasing their reach and power to influence policy and practice.  
<http://youngvoices.lcdisability.org/liberia>

Malaysia Young Voices has over 80 members in three groups, one each in

Sabah, Selangor and Penang. The groups advocate for the ratification of the CRPD and the implementation of Malaysia's Persons with Disabilities Act 2008. Their first steps have been to organise seminars, disability training courses and youth camps. They have also conducted access audits and created campaign materials.  
<http://youngvoices.lcdisability.org/malaysia>



#### **When I grow up I will be a meteorologist**

*Emmanuel Ford, United States*

#### **PARTICIPATION ACROSS UNICEF PROGRAMMING AREAS**

In all UNICEF areas of work, consideration can be given both to integrated and targeted participation activities involving children with disabilities. Their participation can advance programme objectives, for example, a consultation to identify how children with disabilities might contribute towards their own and other children's protection from violence, or to promote participation as an end in its own right, such as a more democratic school environment.

#### **OPPORTUNITIES TO ENGAGE CHILDREN WITH DISABILITIES**

##### **Child survival and health**

- Sensitisation and awareness raising on the rights of children with disabilities
- Peer education on health messages

- Training of health professionals on communicating with and participation of children with disabilities in their own health care
- Awareness raising on the human rights model of disability

##### **Education**

- Democratic school councils and committees
- Promoting inclusive schooling
- Anti-bullying campaigns
- Research into barriers to inclusion
- Mapping out-of-school children with disabilities
- Advocacy on the equal right to education
- Peer mentoring

##### **HIV/AIDs**

- Research on risk / vulnerability / prevalence
- Awareness raising of vulnerability
- Peer education on sexual and reproductive health and relationships

##### **Water and sanitation**

- Analysis of barriers to water and sanitation
- Contributing to design of accessible systems
- Peer education on hygiene

##### **Child protection**

- Peer to peer support
- Research into violence and sexual exploitation of children with disabilities
- Awareness raising of violence against children with disabilities
- Advocacy for legal reform
- Providing evidence in court
- Designing accessible reporting, complaints and redress mechanisms
- Birth registration

## Advocacy and Communication for Development

- Social mobilization and behaviour change communication interventions
- Design of media message
- Participatory monitoring and evaluation
- Strengthening communication capacity of local organizations
- Policy analysis and advocacy

## Post conflict and disaster response

- Contributing to design of new accessible and inclusive community structures
- Peace-building and community reconstruction
- Guidance on barriers in relief efforts
- Children's forums in refugee camps
- Giving evidence in truth and reconciliation commissions
- Creative and artistic activities to contribute to psychosocial support and rehabilitation

## IV. WHAT ARE YOU TRYING TO ACHIEVE?

It is helpful to be clear about why you are thinking about the participation of children with disabilities. What is it you are trying to achieve? There are a number of questions to consider which should help you tailor the participation to your goals:

### PARTICIPATION AS AN END OR A MEANS?

Participation can be an end in itself or it can be a means through which other objectives are achieved. For example:

#### 01

##### **Participation as an end:**

Examples are creating opportunities to be heard through inclusive children's parliaments, child clubs, or school councils; persuading the government to establish

consultative forums for children with disabilities; or pressing for legal and policy changes to allow boys and girls with disabilities a stronger voice in critical decisions such as placements within the community, consent to adoption, representation in courts, or involvement in health care treatments. All of these approaches are pursuing participation itself as the goal, although, of course, once established, participation will always then be used to make other rights a reality.

#### 02

##### **Participation as a means:**

Participation of children with disabilities can advance other's rights as well. For example, in a campaign to end institutionalisation, children with disabilities can play a key role in exposing violence, neglect, abuse and social exclusion that is associated with living in large establishments. When working towards inclusive education, engaging them in exploring new approaches to overcome the barriers can be a powerful vehicle for transformation.

### IT'S ABOUT ABILITY<sup>21</sup>

In 2010, UNICEF Montenegro, the Government of Montenegro and numerous partners launched a campaign, 'It's about ability' which has resulted in boys and girls with disabilities becoming more visible and accepted. A popular activity was 5-day summer camps for children with and without disability, featuring workshops on child rights and inclusion. The camps provided a first opportunity for children with and without disabilities to meet with one another and become friends. The process led to an increase in the number of child activists. UNICEF also produced the CRPD in Braille, audio and sign language as a response to a request from one of the child activists with a disability within the campaign. The first copies were given to the children by the President. The child with a disability who requested this gave

### **RWANDA CASE STUDY**<sup>20</sup>

Every year in Rwanda, UNICEF supports the Government to organize a National Children's Summit where adolescents and youth present their concerns to the highest level of policy-makers. The Government is expected to give serious responses to the topics raised by the children. Representing all districts, there are nearly 450 participants between 10-17 years of age. In 2012, UNICEF also facilitated the inclusion of 30 street children, 30 children from refugee camps, and 30 children with disabilities living in residential centres. The children with disabilities had visual, hearing, physical and intellectual impairments.

At the summit, the children spent time identifying the issues they wished to raise. One topic was the importance of being raised in loving and caring families instead of institutions. In addition, the children with disabilities argued that they should be represented at every child forum organised at the community level. Some other children initially felt this was unnecessary, as their perspectives could be represented by others. However, the children with disabilities successfully argued that they bring a unique perspective on the barriers they face in everyday life and how to overcome them. The summit was extremely constructive with a high level of acceptance and inclusion of the children with disabilities, demonstrated by the election of a deaf child as Summit President.

a speech together with the President. Children with and without disabilities were moderators at the events.<sup>22</sup>

*UNICEF is now conducting a survey with children with and without disabilities from school parliaments in the 12 least inclusive municipalities about their experience to date and recommendations for future. It draws on qualitative (focus groups and interviews) and quantitative (questionnaire) methodologies. Once available, the survey results will help with planning the new child participation activities.*

### SEPARATE OR INCLUSIVE PARTICIPATION?

Consider whether you are seeking to bring children with disabilities into inclusive opportunities for participation alongside other children or whether you want to provide a learning space specifically for children with disabilities.

#### **Both are needed:**

#### 01

**All participation opportunities and structures** provided for children need to be fully inclusive and accessible for children with disabilities so that their views can

be reflected and heard. For example, any consultative process to create a national children and youth policy should involve children with disabilities, both in their capacity as children, and also to ensure airing of their unique perspectives. Equally, in efforts to create spaces for children to be heard such as youth councils or child clubs, it takes ongoing efforts to ensure that these spaces are inclusive, accessible and disability-friendly.

#### 02

**Separate or dedicated opportunities** for participation of children with disabilities are also needed. Sometimes a forum or space specifically for children with disabilities will enable them to develop points of view and influence issues that are specific to themselves, a process unlikely to develop in a mainstream context. These opportunities should not be a substitute for inclusive participation. Children with disabilities should always be offered the choice as to whether they want separate spaces for participation. They should never be forced to go because it is the only option available to them.

## EXPLORING THE RIGHT TO PLAY <sup>23</sup>

KIDS, a project in the UK, wanted to explore the perspectives of children with disabilities in two communities on the right to play. As many of the children were unable to communicate verbally, they used art as a medium for expression. They encouraged children to express themselves in whatever art form worked most effectively for them. The groups created their ideal play spaces from a range of materials including modelling clay, drawing materials and other 'junk' materials like cork tops and straws. The project staff took care not to influence or direct the children's ideas – however unrealistic they were. They recognised that, like all children, children with disabilities have a wide range of ways they engage. The key aim was to build relationships with the children, find out how they communicate and what support they needed to participate. They examined local play provision and elements that make up a play environment – both good and bad. This enabled the children to think more creatively about what they might want or not want in their play spaces. They considered natural elements such as trees, grass and water and examined access routes to play space, and accessibility of play equipment.

The children identified elements they found important for play facilities: grass and water as features of the environment; bright colours featured strongly, demonstrating the value children place on visual appearance of the space; safe equipment for physical activities such as bouncy castles and climbing frames; spaces and equipment that children using wheelchairs could play on; a strong emphasis on inclusive space for children with and without disabilities.

The staff learned the importance of not making assumptions about children's capacities, respecting every boy and girl, recognising that children have different needs and means of communicating,

creating an inclusive environment, and making the activity fun and creative

### INDIVIDUAL OR GROUP PARTICIPATION?

Formal participation involving children as a constituency, such as consultation processes or adolescent and youth forums have been given priority by many agencies, rather than more informal individual everyday opportunities for children with disabilities to participate. However, these day-to-day decisions, which are routinely denied to children with disabilities, have wide-ranging impact on their lives. **Investment in promoting participation on both fronts is necessary:**

#### 01

**Initiatives to promote participation of children with disabilities as a group** include child clubs and councils; peer education processes; national and local consultative mechanisms; children's media; advocacy campaigns; involvement on NGO boards; involvement in organisational programme cycles at all stages; child friendly school environments; involvement in promoting inclusive community development; local child protection networks.

#### 02

**Activities to promote individual participation** on a day-to-day level could include advocacy for legal reform to



**I have the right to go to school... to have treatment, to learn**

*Siranoush, Armenia*

In 2010, UNICEF hosted a regional Media for Children workshop in Fiji. The workshop aimed to strengthen media for, with and about children and youth in the Pacific, and involved 60 participants from Fiji, Solomon Islands, Kiribati and Vanuatu. Participants represented youth and mainstream media. Good "communicating with children" practices were illustrated, including respect for diversity in all aspects, such as disability. This led the Pacific communication team to invite the Fiji Association for the Deaf to nominate 5 participants for the workshop. The workshop resulted in the production of a set of radio, TV and print materials that are all available on YouTube.<sup>24</sup> Workshop participants learned from their deaf partners about the need for subtitling of all broadcast productions. Since then, UNICEF Pacific committed to always subtitle AV productions, and in general apply the principles of producing child friendly media that is inclusive.

A year later in 2011, one of the participants from the workshop joined UNICEF as an intern and applied learning from the workshop to produce the short video together with deaf people from Fiji Association for the Deaf.<sup>25</sup> In addition, UNICEF Pacific has also hosted 3 OneMinuteJr workshops in Vanuatu, Solomon Islands and Kiribati resulting in 60 youth produced videos that are all available online and subtitled. Some of these videos have been produced by adolescents and youth with disabilities and some focus on disability.

Explicit inclusion of young producers with disabilities, and a focus on inclusion of disabilities in communication materials is now a standard feature of media initiatives developed as part of broader communication for development<sup>26</sup> initiatives. Recent growth in the importance of social media has enhanced the opportunity to work with young people to apply the principles of producing child centered and inclusive media. "One world - different abilities" is a good example of all of these initiatives and principles coming together on: <http://www.facebook.com/likeunicefpacific>.

ensure non-discrimination in relation to child witnesses; or to introduce the right of children, including those with disabilities, to give consent to medical treatment when they are competent to do so; developing training for judges, teachers, doctors and nurses on how to respect the right of children with disabilities to participate; introduction of accessible and disability friendly reporting and complaint mechanisms.

### LEVEL AND NATURE OF PARTICIPATION?

There are three potential levels of engagement for children – consultative, collaborative and child-led. The extent to which children are empowered to exercise agency within an initiative will be influenced by the level at which they participate. All three are appropriate,

depending on the goals of the initiative. There is a dynamic and often over-lapping relationship between these levels. A process that begins as consultative may move on to becoming collaborative and ultimately create space for children to initiate their own agenda.

#### 01

**Consultative participation:** where adults seek the views of boys and girls with disabilities in order to learn about their lives and experience. **It is characterised by being:**

- adult initiated;
- adult led and managed;
- lacking any possibility for children to control outcomes.

Consultation can enable children to express views when undertaking research,



## Whatever conditions are in those care homes... nothing can replace having a family

Jelena Maric, Serbia

developing legislation or policies, in decisions affecting individual children within the family, in health care or in education, or as witnesses in judicial or administrative proceedings. Although it does not open up decision-making processes to children themselves, this process does recognise that children with disabilities have expertise and perspectives that need to inform adult decision-making.

### CHILDREN AND HEALTH CARE IN SOUTH AFRICA<sup>27</sup>

In a consultation with children with HIV and TB in South Africa about their experiences of health care, the children repeatedly commented that nurses and doctors did not always seem to care about them or their health. Even when they were in pain, many felt that there was no one to tell and that there was no one interested in them. The children found it difficult to ask for help, and often felt lonely and frightened, particularly at night. Many became afraid when doctors and nurses shouted at them, or treated them roughly when, for example, changing bandages.

Lack of privacy and respect for their dignity was another major concern. They commented: *'It makes us sad when we ask the doctor or nurse what is wrong*

*and he won't tell you.'* Some criticism was also focused on caregivers who refused to take them to a doctor even when they were sick or in pain. They felt that health professionals had a role to play in educating caregivers about early identification and referral. They also felt that health workers should be sensitized to the power relationship between adults and children, children's vulnerability when sick, and how to offer care in ways that acknowledge the child's feelings.

### 02

**Collaborative participation:** where there is a greater degree of partnership between

- adults and children, with the opportunity for active engagement at any stage of a decision, initiative, project or service. It can be characterised as:
- adult initiated;
- involving partnership with children;
- empowering children to influence or challenge both process and outcomes;
- allowing for increasing levels of self-directed action by children with disabilities over a period of time.

Collaborative participation can include involvement of children in research, policy development, peer education and counselling, and representation in boards or committees. Individual decisions within the family about education and health care, for example, can also be collaborative rather than consultative. Collaborative participation provides an opportunity for shared decision making with adults, and for children to influence both the process and the outcomes.

### BRIDGE OF HOPE MEDIA GROUP<sup>28</sup>

The media group promotes the participation of children with disabilities in issues concerning them. It provides them with skills in a variety of media and communication tools and introduces

### CHILDREN WITH DISABILITIES ACTING TO PROMOTE THE RIGHT TO EDUCATION<sup>29</sup>

A children's club in the Bhaktapur district of Nepal had a number of children with disabilities taking a lead role. They decided to undertake a house-to-house survey in their village to find out how many children with disabilities were not enrolled in school. Once they had identified the children, they tried to persuade the parents of the value of their children getting an education. In some cases, the obstacle was primarily poverty, in which case the children fundraised to help cover the costs of getting the child to school. In this example, the children were running their own child club and it was at their own initiative that the decision to map school enrolment was taken. Once the data had been collected, they also initiated the advocacy and support that was needed to overcome the problem facing children with disabilities in accessing the right to education.

them to their responsibilities in relation to human rights. Through classes in photography, directing, and cinematography, the children learn to use media to express their views. The members of the club create video blogs, collaborate with schools, and hold film viewings and educational events. So while the initiative is run by adults, children with disabilities gain specific skills and learn to develop their own media to present their views.

### 03

**Child-led participation:** where children are afforded the space and opportunity to initiate activities and advocate for themselves. It is characterised by:

- the issues of concern being identified by children themselves;
- adults serving as facilitators rather than leaders;
- children controlling the process.

Children with disabilities can initiate individual actions for example, in choosing a school, seeking medical advice, pressing for their rights through the courts, or using complaint mechanisms. They can also take action as a constituency through their own organisations to carry out advocacy and awareness raising; through peer representation and education; and work. The role of adults in child-led participation is to support children with disabilities

to pursue their own objectives, through provision of information and advice.

### V. IS THE PARTICIPATION ETHICAL AND MEANINGFUL?

If participation of children with disabilities is to be effective, ethical and sustainable, it is essential that certain standards are met. If not, there is a danger that children will be manipulated, placed at risk, or denied real opportunities to articulate their own views. The considerable experience since the CRC was adopted has led to a broad consensus on the basic requirements, which have to be reached to achieve quality participation. These nine requirements, which are elaborated in the CRC General Comment No.12, the Child's Right to be Heard, should be incorporated into policy and practice at all levels and, wherever possible, to be reflected in any legislative framework.<sup>30</sup> While they apply to participation for all children, particular care is necessary to ensure that they are respected appropriately for children with disabilities.

### 01

#### **Transparent and informative**

Children with disabilities must be provided with full, accessible, disability-sensitive and age-appropriate information about their right to express their views freely and to have their views given due weight. They need to know how this participation will take place, its scope, purpose and potential

impact. They will need this information in formats appropriate for children with different impairments.

## **02** **Voluntary**

Participation must always be voluntary. Children with disabilities should never be coerced into expressing views and they should be told that they can cease involvement at any stage. Adults must make every effort to ensure that children are aware of what they are being asked to do and that they have the right to say 'no' to anything. Many children will need ongoing practical support to enable them to express their views.

## **03** **Respectful**

Children with disabilities should always be afforded equal respect with other children. If representatives are being selected, the process should be democratic and non-discriminatory and inclusive of children with disabilities. It is important to speak directly to the child and not to an interpreter or adult caregiver. The privacy of children with disabilities must be respected. If there are questions about specific needs or supports, ask the child directly but away from the group. A child with a disability should not be singled out to give private information. Adults need a practical understanding of barriers impeding inclusion of children with disabilities.

## **04** **Relevant**

Opportunities must be available for boys and girls with disabilities to express their views on issues of real relevance to their lives and enabled to draw on their knowledge, skills and abilities. Children's participation should build on their personal knowledge – the information and insights that children have about their own lives, their communities and the issues that affect them.

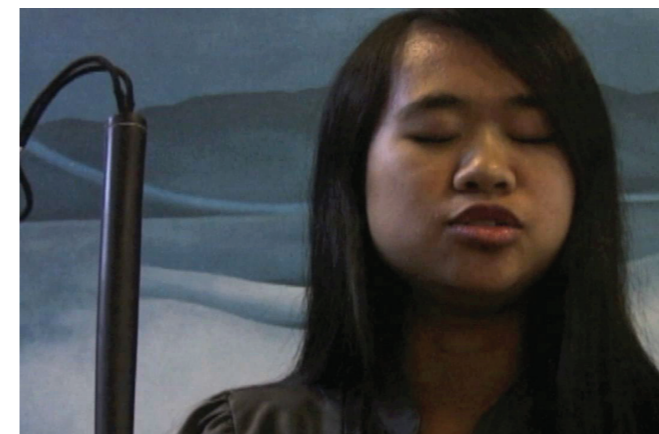
## **05** **Facilitated with child-friendly environments and working methods**

The approaches to working with children with disabilities should be adapted to their capacities. Children will need differing levels of support and forms of involvement according to their age, impairments and evolving capacities. Children will need time and resources from adults to adequately prepare and have the confidence and opportunity to contribute their views.

## **06** **Inclusive**

Participation must be inclusive, avoid common forms of discrimination, and encourage opportunities for children with disabilities to be involved. Children with disabilities are not a homogeneous group and participation needs to provide for equality of opportunity for all, without discrimination on any grounds. Some children experience multiple layers of discrimination – for example, girls with disabilities, or children with disabilities from indigenous communities. Some groups of children with disabilities are more excluded than others – for example children with intellectual impairments. Efforts to address the barriers that may prevent the participation of children with disabilities are described in more details on pages 28-37 (for more information on creating inclusive environments).

It is critical that no assumptions be made about what specific groups of children with disabilities can and cannot do. They should be given an equal opportunity to voice their opinions and contribute to any participatory process. Disabled people's organisations can be engaged to gain family and community support for the participation of children with disabilities.



**Treat us equally, people should judge us for what we can do, not for what... we can't do**

*Ann Kwong, United States*

## **07** **Supported by training**

Adults need training in how to support participation of children with disabilities effectively. Particularly needed are skills in listening and communicating, and experience in working jointly with children and engaging them in accordance with their evolving capacities. Youth and adults with disabilities themselves are often skilled trainers and facilitators in this arena.

## **08** **Safe and sensitive to risk**

In certain situations, expression of views may involve risks. Adults must take precaution to minimize the risk of violence or exploitation that may result from children's participation. A child protection strategy should be in place, which recognises the particular risks faced by children with disabilities and the extra barriers they face in obtaining help. Children should be informed of their right to be protected from harm and know where to go for help if needed. A formal and accessible complaints procedure needs to be established to allow children to make a complaint in confidence. Information about the complaints procedure should be provided in relevant languages and accessible formats.

## **09** **Accountable**

A commitment to follow-up and evaluation is essential. In any research or consultative process, children with disabilities must be informed as to how their views have been interpreted and used and, where necessary, they must be able to challenge the analysis of the findings. Listening to, and consulting children with disabilities, especially where children are communicating without speech, may involve a high level of interpretation on behalf of the listener. This raises ethical issues that need to be taken into account as part of the process of listening and consultation. For example, adults are often inclined to 'hear' what they want to hear.

Children should be given the opportunity to participate in follow-up processes or activities. Evaluation of children's participation should be done with children with disabilities themselves.

## INGREDIENTS OF HIGH QUALITY PARTICIPATION IDENTIFIED BY YOUNG PEOPLE WITH DISABILITIES<sup>31</sup>

<b>INGREDIENT</b>	<b>WHAT THIS MEANS</b>
<b>01. Participation of young people with disabilities is embedded in the culture and practices of the organisation</b>	<p>The organisation is committed to meaningful, inclusive, accessible and ongoing participation practice</p> <p>Participation is built in to the organisation's activities</p> <p>A wide range of staff are involved - not just 'participation workers'</p> <p>There is an awareness of the value and importance of participation throughout the organisation</p> <p>Learning is shared across the organisation</p> <p>There are mechanisms for communication between management and young people</p> <p>Young people with disabilities have some control of all of the above</p>
<b>02. There is a wide range of opportunities for young people with disabilities to participate within the organisation</b>	<p>Participation takes place at operational, strategic and individual levels</p> <p>(In larger organisations) participation of young people with disabilities happens in a range of different services – and not just those specifically focused on disability</p> <p>Young people with disabilities have opportunities to participate in different types of decision-making e.g. planning, service delivery, evaluation, communications</p>
<b>03. Participation opportunities are inclusive</b>	<p>Young people with disabilities have equal access to participation activities, whatever their impairment.</p> <p>All ages of 'young' people can participate</p> <p>Young people with disabilities can access 'mainstream' participation opportunities</p>
<b>04. Participation activities are accessible</b>	<p>Barriers are removed</p> <p>A range of different approaches and methods are used flexibly and creatively</p> <p>Activities are appropriate to the age, abilities and access requirements of the adolescents and young people</p> <p>Young people with disabilities have a say about the methods and activities used</p>

<b>05. Young people with disabilities set the agenda</b>	<p>Young people with disabilities have choice over the decisions they participate in</p> <p>Young people with disabilities take ownership and initiate work themselves</p>
<b>06. Participation is a positive and meaningful experience for young people with disabilities</b>	<p>Young people with disabilities get something they value from their participation experience</p> <p>Young people with disabilities understand the purpose of the activities, and the ways in which their contributions will be used</p> <p>Young people with disabilities feel that their contributions are valued by others</p> <p>Activities are also enjoyable in themselves</p>
<b>07. Staff have appropriate attitudes, understanding and skills</b>	<p>Staff understand the meaning of participation – they enable young people to speak out, they do not speak for them</p> <p>Staff give young people choice, they do not lead</p> <p>Staff treat young people with disabilities as individuals and support their participation</p> <p>Staff work within the social model of disability</p> <p>Staff receive disability equality training</p>
<b>08. Participation is monitored and evaluated</b>	<p>Records are kept about participation activities and the young people who participate</p> <p>Feedback from young people with disabilities is collected and used to improve activities</p> <p>Evidence of impact is collected</p> <p>Evaluation findings are acted upon and communicated to young people</p> <p>Young people with disabilities participate in evaluation processes</p>
<b>09. Participation of disabled young people brings about change</b>	<p>Young people with disabilities' participation is seen to make a difference - to individuals, services, organisations and beyond</p> <p>These changes are communicated back to young people with disabilities</p>
<b>10. The organisation shows that it values young people with disabilities' participation</b>	<p>Young people with disabilities are recognised for their participation</p> <p>Participation is acknowledged at a senior level within the organisation, and this accurately reflects young people's own experience</p> <p>Sufficient resources enable ongoing meaningful participation</p>

## SECTION TWO: MAKING PARTICIPATION WORK FOR CHILDREN WITH DISABILITIES

### I. HOW CAN CHILDREN WITH DISABILITIES BE REACHED?

Children with disabilities are very often invisible and isolated from their peers and local communities. In some socio-cultural contexts, they may be hidden at home and not registered at birth or in school; they may be living in institutions; and are very unlikely to be part of local play, recreational, cultural or other local activities. However, in order to promote the participation of children with disabilities, it is first necessary to identify who they are and where they are.

#### IDENTIFYING CHILDREN WITH DISABILITIES

There are a number of possible methods of mapping and reaching out to them.

##### 01 **UNICEF situation analyses and surveys:**

National censuses are sources of data on children with disabilities. Analyses and surveys by UNICEF, academic institutions or governments may also provide data. These can be used to trace families, identify inclusive schools or institutions, and identify communities where there are significant numbers of children with disabilities. If surveys provide prevalence data on disability, they will indicate the proportion of children with disabilities.

##### 02 **Disabled People's Organisations (DPOs):**

While International DPOs need to drive participation in global policy discussions, local DPOs are often a source of



**There's a difference between sympathy and empathy: when people are sympathetic, I feel like I can't do anything**

*Benedictor Mokoena, South Africa*

information about families where there is a child with a disability. They can help identify families and the support needed to promote effective participation. Local DPOs tend to be community-based organisations with little funding; they may need resources to enable them to play a role.

##### 03 **Children's organisations:**

Many NGOs are working either specifically with children with disabilities or with wider groups of children including children with disabilities. They can provide a point of access to those children, as well as ideas on working with them effectively.

##### 04. **Community mapping:**

Community mapping is a tool that is used to identify specific marginalised groups and also to explore barriers and opportunities within the community. In many communities, stigma is so

deep-seated that families deny the very existence of a child with a disability. If community mapping is led by people with disabilities, families may be more willing to admit to the child's existence. Plus, involving children themselves in mapping enables them to acquire new skills. Other benefits are that participating children gain visibility in their local communities, and they may become advocates for children with disabilities. Support of health workers who are from the village is valuable as they are likely to be trusted by the community.

##### 05 **Community-based services and institutions:**

Local entities such as churches, health centres, clinics, hospitals, child protection committees, various types of schools, residential homes or institutions and early years' settings will all have knowledge of families within the local community.

##### 06. **Information Communication Technologies (ICTS) and social media:**

Online environments provide new opportunities for reaching out to adolescents and young people with disabilities and involving them in building wider networks. These networks can be engaged in developing and providing information, building connections, and campaigning.

#### WORKING WITH PARENTS AND CAREGIVERS

Parents and caregivers can play a number of different roles in the lives of children with disabilities – both positive and negative. In order to support and encourage parental involvement in facilitating the right of children with disabilities to be heard, consider the following issues:

##### 01

**Parents as experts:** Parents will have expertise on their own child, how she or he communicates, his or her needs, and how to ensure inclusion. The greatest possible degree of information from parents is needed so that the child feels comfortable, and is able to share views and feelings. One way is to involve the parents at initial meetings, so that the child begins to settle in to any group or activity.

##### 02

**Parents as partners:** Parents can and do serve as powerful advocates for their own children. They can be enlisted in support of programmes or campaigns to promote the rights of children with disabilities, alongside the children themselves. In addition, they can reinforce the skills

#### **NEW APPROACHES TO PARTICIPATION<sup>32</sup>**

Young people with disabilities feel that ICTs provide new opportunities to communicate and connect with friends, which reduces isolation and opens up more ways for them to participate. In many respects, it is improving life chances and expanding opportunities, because young people with disabilities are connecting to the world in ways that simply would not have been possible a generation ago. ICTs are a medium through which young people with disabilities can learn about their rights, meet together electronically and campaign without the barriers that make communication or physical access difficult. It often helps increase the profile of persons with disabilities, and allows them to participate actively. In addition, many young people with disabilities believe that new social media have improved their access to information, enabled them to keep up-to-date with national and international events. For those who find communication difficult, it is opening up new channels for connecting with peers and wider society.

## YOUNG PEOPLE WITH DISABILITIES SPEAKING FOR THEMSELVES<sup>33</sup>

The OneMinutesJr. is a video initiative offering children between the ages of 12-18, including those with disabilities, the opportunity to have their voices, ideas, anxieties and dreams heard by the world. It was initiated in 2002 by the European Cultural Foundation, the One Minutes Foundation and UNICEF to develop new tools for youth empowerment and social change. Through workshops, participants produce 60 second videos that are positive and powerful examples of the way visual arts communicate across cultural, geographic and national borders. Young filmmakers are equipped with the fundamental skill of self-expression that is needed to participate fully in society. The intimate nature of the videos allows close-up views despite geographical and cultural divides. More than 1000 young people from 70 countries have taken part in this successful programme, built on tailor-made collaboration between European public broadcasters and national youth and media organisations. UNICEF is working to expand the project globally.

and learning which the child is acquiring through participatory activities, by supporting those opportunities within the home environment.

### 03

**Parental protectiveness:** Many parents of children with disabilities are extremely protective of their children, recognising their vulnerability to abuse, bullying and other potential harms within the wider community. This can lead to reluctance to allow their children to engage in participatory activities. To help them support their child's participation, provide parents and caregivers with full information about any planned activities, related safety measures and who will be responsible for the safety of their child.

It is also helpful for the parent to visit locations where participation will take place, meet the staff and other children.

### 04

**Parents as barriers to participation:** Many parents, including parents of boys and girls, need more information about child development. They may not yet perceive the potential of their child to learn, communicate and contribute to decisions in their own lives. Like the rest of the world, many have prejudices or ignorance about disability. It may be easier to hide children with disabilities, than to learn how to involve them in community life. Some cultures consider an impairment to be a punishment or curse. If so, parents and other relatives will likely be ashamed of a child with a disability. Awareness raising programmes can help parents understand the causes of disability, how to maximise their child's potential, and support their participation in the family and community.

## II. PRACTICAL STEPS NEEDED TO ACHIEVE INCLUSIVE PARTICIPATION?

Although the right to participation is exactly the same for all children, there are additional barriers children with disabilities face. Children with disabilities are not a homogenous group. Different impairments and abilities, as well as factors such as gender, age, culture, language and access to education will all impact the support needed to achieve inclusive participation.

It is quite effective to engage adults with disabilities in helping to create inclusive participation. They have the greatest expertise in understanding the barriers that exist and how to overcome them. Many countries now have national networks of organisations of people with disabilities with whom partnerships can be forged to support the participation of children with disabilities.

## EFFECTIVE COMMUNICATION AND INVOLVEMENT OF CHILDREN WITH DISABILITIES<sup>34</sup>

The 'Ask Us' project (led by The Children's Society in UK) used a multi-media approach to involve children with disabilities and young people in influencing policy development. Over 200 children and young people with disabilities across England, ages 4 to 24, were interviewed about their experiences of consultation, participation and services through multi-media techniques. Young people also carried out their own consultations with other children. Some helped organise a 2 day Inclusion Festival involving all the local children from the respite unit and special schools. The Festival featured art, music, dancing, song-writing, camping and a graffiti wall. Two young researchers were 'roving reporters', asking other young people at the festival for their views about inclusion.

'Two Way Street' (led by Triangle and NSPCC) involved children with disabilities in a training video for practitioners to build skills in communicating with children with disabilities who do not use speech or language. The video shows children and young people, from ages 3 to 19, communicating through behaviour, sign, symbols, body language, eye pointing, facial expression, gesture, play, use of art, objects of reference, speech, vocalisation and physical movement.

Children and young people with disabilities from both initiatives felt that too often, the focus is on young people's impairments and not on the real barriers to their progress: that adults often fail to listen and do not try to communicate in different ways.

## ADDRESSING THE BARRIERS TO COMMUNICATION

Effective participation relies on the ability to communicate. It is how children obtain information to help them make decisions and choices. It is how they express their

experiences, ideas, perspectives, fears, concerns, suggestions, aspirations and stories.

While speech is considered the primary form of communication, people do not solely rely on words to convey meaning. Body language, facial expression, and tone of voice are also powerful means of communication. This obviously has implications for children with different impairments.

Everybody, regardless of impairment, is able to communicate in some way. However, children with disabilities can face significant barriers in communicating their views and feelings. One of the main barriers is that people without disabilities often lack a commitment to communicate with children or adults with disabilities. But it is possible to overcome these barriers. Sometimes this process can be time-consuming, but it is necessary to ensure children's right to participate.

### Some issues are:

#### 01

##### Attitudes

Many believe that children with disabilities who do not communicate in the same ways as other children are unintelligent or disobedient. This negative attitude is a major barrier to effective communication.

#### 02

##### Assumptions

Children with multiple impairments are often wrongly assumed to be unable to communicate. Their communication may be more subtle, such as the flickering of eyelids or other small movements. Good communication with children with serious impairments requires time to build a communication method. A first step is to ask others how the child prefers to communicate.

#### 03

##### Cultural expectations

It is important to understand that what might be acceptable in one culture may





**It is necessary to go outside and show others you exist, without worrying what people think of you**

*Evgeny Lyapin, Russia*

be offensive in others. Eye contact in particular is important: some children will avert their eyes from authority figures or from adults of the opposite gender as in some cultures direct eye contact is considered inappropriate or insolent.

**04 Gender**

It is usually more difficult for girls with disabilities to express their views. In most cultures, the greater expectation of passivity from girls compounds the barriers that they face due to disability.

**05 Lack of knowledge and training**

Adults working with children with disabilities may need training in how to provide communication support. For example, one useful skill is how to use photographs and graphics to aid communication and decision-making.

**06 Physical environment**

A poorly laid out area without clearly defined boundaries can be confusing to children, especially those with sensory or cognitive impairments. Lighting and temperature are also essential elements

to consider. For example, cold/warm and bright/dark places can affect mood and behaviour. All parts of the environment need to be made accessible to children with mobility impairments.

**07 Lack of confidence**

Some children may not feel confident in communicating and adults may not feel confident in communicating with some children. Training may help to address this, but a willingness to take risks and try is also necessary.

**08 Lack of time to build a relationship**

Children with disabilities who are not used to being asked their opinions or being listened to will need more time to build up confidence and trust. It may take time to explore the best ways of communicating with a particular child.

**HINTS AND TIPS FROM YOUNG PEOPLE WITH DISABILITIES ON COMMUNICATING**<sup>35</sup>

- We do have feelings.
- We're just like other children.
- Show respect, and don't patronise us.
- Take your time and make sure you understand.
- Talk directly to us, not just to our parents or our caregivers.
- Don't be scared to ask questions.
- Really listen and understand.
- Make sure you really understand us. Take time to find out how we say yes or no.
- Keep calm and get on with it.
- Don't be scared.
- Learn from young people.
- Show an interest in us, make it more than just a job

**09 Lack of funding**

Lack of funding is often a barrier to meeting children's individual requirements. For example, interpreters might be crucial to effective involvement in decision-making. Some children may need a specific piece of equipment to communicate. Creative thinking helps as this need not mean an expensive solution; it could be as simple as using symbols and pictures.

**10 The impairment**

While in-depth knowledge of all impairments is not required, it is important to understand if and how the child's ability to use speech and body language is affected, and what specific methods of communication best suit the child.

**CREATING INCLUSIVE PARTICIPATION**

**The following practices can help create environments in which young girls and boys with disabilities feel more accepted, included and confident:**

**01 A welcoming introduction**

- Check whether the environment allows everyone to participate equally – ramps, wide enough doorways, no intrusive or dangerous hazards, effective lighting, accessible toilets, and the space to allow children with different types of impairment to move freely.
- Always ask children with a disability how best to meet their needs: consider the child as the best expert about her or his disability.
- Always ask if and how a child wants or needs to be assisted. Do not insist or be offended if your offer is not accepted. Always address the child with a disability and not the child's assistant or sign language interpreter.

- Help children to develop ground rules to resolve issues that might lead to exclusion or withdrawal.
- Create time to help the children get to know each other. If the group comprises children with and without disabilities, engage in activities and games, which help them, learn about each other and about disability - children may come with many preconceptions and misunderstandings, which need to be worked through.
- Introduce consistent, predictable routines so children know what to expect

**EXAMPLE**

In a group of children with and without disabilities, there will be some children who are unfamiliar with disability and its implications. This might lead to language being used, or attitudes expressed which are hurtful or inappropriate. One solution is to introduce a rule where children choose a word that can be called out whenever something is said or done which causes offence or upsets them. The word might be 'stop' or 'ouch.' As soon as someone calls out the word, all activity must stop. The child then explains why what has been said is upsetting. There can be a full discussion of the issue. This process helps everyone gain a better understanding of what it feels like to be excluded or made to feel different, why it is important to be sensitive to others' feelings and how to build an environment where everyone feels accepted equally.

**02 Equal opportunities for every child**

- Recognise that every child has a contribution to make to the group or activity – but that they will make contributions in different ways. Encourage the children to understand and value each others' differences.
- Encourage children with disabilities to contribute equally and to share

the same obligations – for example, volunteering to be involved in specific activities, asking for feedback from the group, speaking to the media, meetings with policy makers.

- Allow children with disabilities to take the same risks as other children in order to help them to gain confidence. Over-protection denies them the chance to explore, discover what is possible and learn how to keep themselves safe.
- Do not help children with disabilities unless they need it. Too much support denies them the chance to become independent and can feel patronising.
- Be open and flexible to change to accommodate the children involved.
- Introduce activities leading children to understand the experience of disability.

### EXAMPLE



Russian children with and without disabilities vote on the best children's films about disability issues at the film festival known as "Breaking Barriers." Held every other year in Moscow and other Russian cities, the festival is organized by Perspektiva, a national disability rights organization. In 2012 the festival, which attracts films from all over the world, was attended by hundreds of children and youth, who enjoyed a whole weekend of films just for them. Perspektiva, based in Moscow, then packages the 10-15 winning films and organizes screenings in other cities to help reduce stigma and discrimination by showcasing good examples of disability portrayals. One favorite of children and adults is "About

Love," an internationally acclaimed documentary consisting of revealing interviews of Russian children about their loves.

### 03

#### Building on children's strengths

- Focus on reinforcing each child's strengths and abilities rather than those things they cannot do, for example, a wheelchair user might have strong arms and hands, a deaf child might be great at drawing.
- Use peers and encourage teamwork and child to child activities which can contribute to overcoming difficulties and exclusion.
- Encourage children to pair up to support each other – a wheelchair user can help read flip charts to a blind child, a deaf child can facilitate the wheelchair user to engage in activities involving movement, a non-disabled child can help explain idea or concepts to a child with learning difficulties
- Encourage an inclusive environment by praising children who say, "I don't understand" or ask for help or thank them for asking and then offer help or an explanation.

### EXAMPLE

You can use puppets as a means of helping children share their ideas, feelings and experiences. You can make puppets out of any available materials, such as old socks. Each child chooses a sock and you then provide buttons, thread etc. to make the faces. They each give their puppet a



name and the puppets can then introduce themselves. The children can then talk on behalf of, or as the puppet. This tool can be particularly helpful with younger children and those with learning disabilities.

Children can feel more comfortable using puppets to talk about issues where they feel vulnerable, insecure or embarrassed, or involving criticism of adults. It can also be a way of getting children to explore what issues are important to them, or to give feedback about a project or programme. As the children take on the identity of the puppet, it can be easier for them to answer the following type of questions:

- Which activities do you like most in this project? Why?
- Are there any activities you do not like? Why?
- In the project, who decides which activities children will do?
- Do adults ever ask you or your friends about what you want to do? How?
- Do adults ever ask you or your friends about what you like or do not like about the activities?
- How does it make you feel when adults listen to you?
- How does it make you feel when adults do not listen to you?
- Do you have any suggestions for adults to listen to you more?
- The children can also use the puppets to create role plays to share their ideas.

### 04

#### Accommodating difference

- Give children plenty of time to both understand what is being talked about and to formulate their responses.
- Respond to individual needs of a child and listen to them.
- Be flexible and adjust your level of language to different children.

- Recognise that children with different impairments will access information in different ways. Documents are more accessible if they are clearly written, as concise as possible and as legible as possible by using slightly larger typeface.
- Use pictures and images to help children communicate ideas and views.
- Allow children themselves to decide where they sit and take part in activities – a child with low vision may need to sit at the front of a room; one using a wheelchair may find it difficult to work in groups of children on the floor, a child who is deaf may need to be away from windows or external noises that distract from hearing.
- Use smaller groups, allowing for different patterns of language exchange.
- Model good communication so that children learn from what they see and hear.

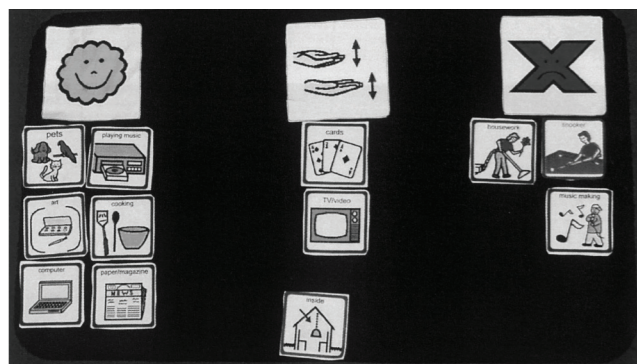
### TOOLS FOR PARTICIPATION WITH CHILDREN WITH COMMUNICATION DIFFICULTIES <sup>37</sup>

A broad range of methods can be used to support children with disabilities to express their views:

- **Photography and videos** to enable children to articulate their world, highlight places, objects and people who are important for them, and explore fears, challenges and barriers.
- **Pictures** cut out from magazines, or cartoon images can be used to help children highlight good and bad things in their lives, and stimulate their views on identify preferences, concerns and changes they would like to see happen.
- **Questionnaires** which include sad, neutral and happy faces can further children's understanding and enable them to respond more readily. Pictorial images can be used to guide

semi-structured conversations and interviews.

- **Talking mats** is an inexpensive, low-tech visual communication resource that helps people with communication difficulties express their views. It uses three sets of symbols – topics, options and visual scale – and a mat on which to display them. The topic covers what is being talked about (for example, school, health); the options include symbols specifically relating to each topic (such as types of activities); the visual scale includes symbols which enable the children to indicate their feelings or attitudes about each option – for example, whether they are happy, unhappy, or unsure. Once the children have chosen the topic, each child is given the relevant options one at a time and asked to think about what they feel about them. They are then asked to place the symbol under the appropriate visual scale symbol to indicate what they feel. For example:



## **SPECIFIC GUIDANCE FOR DIFFERENT IMPAIRMENTS**

In addition to the general guidance, there are particular strategies that can be employed to overcome the barriers faced by children with different impairments.

### **01** **Visual impairments**

Some children are born with the impairment (congenital) and others get it later in life (acquired).

#### **Tips for inclusion:**

- Provide additional explanations for children who have visual impairments. If you are showing a picture, describe what it looks like.
- If you are handing out text, see if it can be provided in Braille. Or have the text read out loud. Information can also be provided in audio format, or into digital formats that can be read out loud by their own computers. Websites are increasingly accessible for children with visual impairments. The Web Accessibility Initiative (W3C) is evolving internationally recognized standards on website accessibility.<sup>38</sup>
- Consider pairing children who are blind with children who can see so that they can work together in activities that require writing, drawing or responding to visual images.
- Always talk directly to children, not to adults assisting or accompanying them.
- At the outset of any activity, ask everyone in the room to introduce themselves so that the child knows who is there, and can begin to recognise their voices.
- Suggest that in group activities, rather than indicating with a hand that someone wants to speak, they say their name, so that children who are blind can enter discussions on an equal basis with others.
- Speak to the child directly using a normal speaking voice; there is usually nothing wrong with a blind person's hearing.
- When children are all in a group, always address a child who is blind using her/his name, otherwise they may not know she or he is being addressed. Avoid using expressions like "he said that" and mention names, so that the child can understand who you are referring to.
- If you leave the room, let a child who

is blind know so that they will not be talking to an empty room.

- Make sure the child knows where doors, windows and furniture are, how to find the toilet, etc.
- Remove any unnecessary obstacles – for example, chairs, plants, footstools, piles of papers, or alert the child who is blind to these obstacles and ask if they want them moved. Do not move objects around without alerting them to the change.

### **02** **Hearing impairments**

Children can have many different types of hearing loss, from mild difficulty in hearing to profound deafness. They may use a number of ways of communicating, for example, a hearing aid or hearing loop, sign language, lip reading, speaking or a combination of these methods.

#### **Tips for inclusion:**

- Always ask the child what mode or modes of communication would work best for them – for example, Sign Language interpretation, subtitling or text messaging;
- If the child uses a hearing aid, hearing loop or other assistive hearing device, avoid holding activities in places with lots of background noise. The devices usually pick up this noise making it difficult for the child to focus on what is being said.
- Remember, it can be hard for children who are deaf to follow conversations when several people are talking at once, or when the conversation is going on at some distance. Try to ensure that only one person talks at a time and encourage children to talk slowly and clearly.
- Ask children where they'd like to sit to enable them to hear as effectively as possible.
- If the child uses sign language it is

important to use a sign interpreter. Even very good lip readers will often understand only about 30% of what someone says to them.

- It is common for parents or siblings to interpret for a child who is deaf. However, sometimes to be able to speak openly and safely, a deaf child will need privacy and confidentiality. In these situations, it is necessary to provide a sign language interpreter.
- If the child is lip reading, speak slowly and clearly, but normally. Always look directly at them, do not cover your mouth, or place anything (a hand, a cup) in the way.
- Never shout at a deaf child. This will not help a child who is completely deaf, while shouting will distort sound uncomfortably for a child using a hearing aid.

### **03** **Speech impairments**

Children who stutter or who have speech impairments resulting from cerebral palsy, for example, often speak slowly or with difficulty, and may be difficult to understand for people who are not used to listening to them.

#### **Tips for inclusion:**

- Take time to listen to what the child is seeking to say and avoid cutting them off.
- If you do not understand, then it is fine to ask the child either to repeat or to say 'if I understand you correctly, you would like to...' but then give them time to reply or correct what you have understood.
- Consider alternative forms of communication, for example, using symbol boards or computer-assisted systems.

#### 04

### Mobility impairments

Mobility or physical disabilities often mean a child uses assistive equipment such as a wheelchair, cane or prosthetic limb. Children with physical disabilities may have difficulty with movement or self-care.

#### Tips for inclusion:

- Make sure the facility that you are using is accessible, in particular that the toilets can accommodate a wheelchair, that ramps are in place where there are steps, and that doorways are wide enough to fit wheelchairs.
- During hands-on activities, check for any physical difficulties. Pair children up if they need help.
- Check with the child to see what their needs are. Remain flexible and willing to adapt an activity for different abilities.

#### 05

### Psycho-social disabilities

In many societies, people with psychosocial (mental health) and intellectual (cognitive or learning) disabilities are confused with each other and grouped as though they have the same conditions. In fact, they are very different and require different adaptations. Psycho-social disabilities are not obvious or visible, and take many different forms, for example, depression, schizophrenia, or bipolar disorders. The health and behaviour of a child with a psychosocial disability will depend on the attributes of their condition, the personality of the individual, and the surrounding environment. The biggest barrier such children face is not their disability, but the lack of understanding and acceptance they often experience in the communities where they live.

#### Tips for inclusion:

- Treat the child with dignity and respect at all times and include their opinions and thoughts in discussions.
- Be flexible and allow for choice and

autonomy. Children may feel anxious, worried or stressed when placed in situations where they lack control or where they feel that people anticipate they will be difficult.

- Keep discussions calm, speak in a normal tone of voice and do not make them feel as though you are anxious to end the conversation or exclude them from interactions.

#### 06

### Intellectual disabilities - Cognitive, learning disabilities, Autism

Intellectual disabilities can vary significantly but often children with intellectual disabilities take more time to learn and may have difficulty communicating. Many children with intellectual disabilities can learn to read and write, grow up to have jobs, and have a family of their own. Even children with more severe intellectual disabilities can be supported to participate in school and in their community and will benefit from inclusion. Children with a learning disability may have difficulty understanding, remembering and communicating information. Learning disabilities come in many different forms, such as difficulties with letters, numbers or using print in general.

#### Tips for inclusion:

- Simplify language, summarize information and use a variety of communication methods including gestures, and pictures. But, do not infantilize children: communicate in ways appropriate to physical age as well as level of cognitive development.
- Use visual images – photos, drawings, videos – to promote communication, especially when discussing abstract ideas or to help children explain their feelings.
- Consider the use of audio, audio description, easy access, subtitles, simplified (or plain language) and other adaptations.

- Be willing to repeat points, questions or answers several times to be understood.
- Give children adequate time to express themselves.
- Check in to make sure that the person understands the topic or activity to be completed.
- Incorporate hands-on learning activities into routine.

#### 07

### Autism

Most children with autism have difficulty interacting with others. They may have difficulty responding to approaches by others, as well as in initiating interactions. They may use less interaction to socialise with other people. It is important to remember that communication and interaction do not have to involve the use of language and speech. Many autistic children are delayed in their use of language and avoid speech. So, other communication methods are used prior to speech and language.

#### Tips for inclusion:

- If a child is not using any sound or speech, try using gestures instead of communicating through words. For example, a child may communicate with you by directing your hands to something they want, using pictures, or reaching out to objects.
- Persist in engaging with the child's activity. Sometimes, children may express anger with this. Anger is a type of interaction can be better than none at all and can help the child realise that social engagement with another person can be fun.
- Follow the child's lead and respond to what they do.
- Reward any attempt to understand and communicate. In this way you increase the likelihood that they will try and do it again. By praising anything children



**I want people to see me as a girl who is vulnerable physically but can be hard to break mentally at the same time.**

*Nguyen Phuong Anh, 16, Vietnam*

have achieved, they can learn to make connections between their actions and your words.

- Try to create opportunities that encourage children to communicate. For example, if you place something the child values in a visible but out of reach location, you can encourage them to ask for help, and in so doing stimulate communication.
- Offer activities likely to provoke high levels of interest, such as playing with bubbles or balloons in ways which involve more than one person – blowing up a balloon and letting it go, partly blowing it up and waiting for a response from the child before blowing it up the rest of the way, and blowing bubbles towards the child – can all be effective.
- Once the child engages in an activity with you, continue until the child indicates that they want to stop. This will encourage the child to communicate when they want to finish the activity.

## TWO EXAMPLES OF APPROACHES TO HELP CHILDREN COMMUNICATE WITH OTHERS

### 01

#### Examples of visual images to help children communicate feelings



I feel sad



That hurts



Go away



Please stop

### 02

#### Examples of actions to help children communicate feelings

##### When I do this:

Smile

##### People think I mean

*I am saying 'yes'*

*I am happy*

*I like what I am doing*

Lift up my left hand, scream and/or bang the table

*I am trying to say 'no'*

##### You should do

Give me time to smile and act according to my answer of 'yes'

Ask me the question again and act according to my answer of 'no'

Close my eyes and moan or scream

*I am uncomfortable*

*I am sad*

*I am bored*

*I don't like what I'm doing*

Ask me if I am uncomfortable, if I smile, move my position; for example, if I am in my wheelchair, take me out and let me stretch out on a mat. If I'm on the mat, sit me back into my chair properly  
If I don't smile, just talk to me and see if you can cheer me up

If I don't smile, see if I would like to do something else; offer me a choice

Keep letting my head fall forwards, sit on the floor and refuse to move

*I am tired*

Let me rest, stretched out on the mat, or on my side

Stick my tongue out

*I am thirsty*

Give me a drink of water

Cry but there are no tears or screaming

*I am cross*

Check to see if I need anything, change my activity or include me in an activity  
Move me from sitting next to someone who may be upsetting me

Screw up my hands

*I feel very unsafe*

Give me more support and help

Screw my nose up and twist my head

*I have a tummy ache*

Help me change my position  
Give me sips of warm water to drink

## III. HOW DO YOU KNOW IF PARTICIPATION OF CHILDREN WITH DISABILITIES IS EFFECTIVE?

It is important to monitor and evaluate the participation of children with disabilities.

This can be undertaken at two levels by<sup>39</sup>:

- mapping the extent to which children with disabilities are able to participate in all aspects of their lives;
- evaluating the nature of children's experience of participation and its associated impact.

Both dimensions are necessary to:

- be able to review the extent to which the legislative and policy environment protect and promotes the right of children with disabilities to participate in all aspects of their lives;
- enable children to gain a greater understanding of what they hope to achieve;
- assess the strengths and weaknesses of initiatives, and clarify which procedures and practices are helpful and which are redundant or obstructive;
- identify what support and resources are needed to strengthen child participation;
- provide evidence to support the case for political commitment to the realisation of children with disabilities' participation rights;
- encourage donors to see the benefits of investment in strategies to promote the right of children with disabilities to participate.

Monitoring and evaluation of participation should always be undertaken with children with disabilities themselves, as well as with other stakeholders. Appropriate methodologies should be used to enable them to communicate those experiences.

*The following section provides an overview of a framework for monitoring and evaluating children's participation.*

*The complete framework, together with a set of matrices and a toolkit for undertaking the process of monitoring and evaluating, can be found on the CRIN website:*

*<http://www.crin.org/hrbap/index.asp?action=theme.infoitem&item=25808>.*

### MAPPING THE PARTICIPATION ENVIRONMENT

In many countries, the legislative, policy and cultural contexts do not encourage the participation of boys and girls with disabilities. Unless efforts are undertaken to challenge the barriers, participation initiatives with children with disabilities will continue to be short-term, isolated and ad-hoc pockets of good practice. The following standards provide a framework for monitoring the extent to which respect for the participation rights of children with disabilities and a child and disability friendly environment exist. It is an overview of what should be in place if children's right to participation is respected, and enables you to map how a given country rates with regard to those rights. They can be applied for all children but need to be considered specifically through a 'disability lens' to ensure that they apply equally to children with disabilities.

This process should highlight the major gaps or weaknesses. It can be a tool to determine programme priorities, or an advocacy tool with governments. Specific indicators can be developed from these standards at an individual country level - for example, to introduce target numbers or percentages against those standards where there is a commitment to programming.

### 01

#### Measuring legal entitlements to participate

- Child and disability-friendly court procedures are introduced for child victims and witnesses, e.g. courts are obliged to consider children's views when deciding matters affecting them, and no discriminatory provisions

exclude children with disabilities; legal information and education is provided for children in forms accessible to children with disabilities.

- Representation for children, including for children with disabilities, is provided through legal aid mechanisms.
- Respect is given to children's evolving capacities e.g. minimum ages of consent to treatment have been introduced; children with disabilities are entitled to confidential medical counseling.
- Confidential, safe and accessible mechanisms are in place for boys and girls with disabilities to complain and to seek redress in cases of abuse, without fear of reprisals.
- Children with disabilities are entitled to be heard at all stages of child protection procedures.
- Children with disabilities in public care or institutions are entitled to be involved in decision-making processes affecting their lives.
- All schools are required to establish democratic school councils that are inclusive of children with disabilities.
- Family law includes provisions on parental obligations to involve children in decisions affecting them, irrespective of disability.

## **02** **Measuring the right of access to information**

- Education is compulsory and free for all children without discrimination on grounds of disability.
- Information from a wide range of sources is readily available in child-friendly and accessible formats that are appropriate for boys and girls of different ages and disabilities: radio, television, libraries, books, press, Internet, and helplines.

- Human rights education is included in the school curriculum for every child – including the CRC, CRPD, and CEDAW.
- Human rights education is provided in outreach programmes for children with disabilities out of school.
- Children with disabilities know about their rights, and how to make them a reality

## **03** **Measuring awareness-raising on children's participation rights**

- Child rights training, including a focus on participation of children with disabilities, is introduced at pre and in-service levels for all professionals working with and for children, including teachers, school governors, doctors, nurses, lawyers, judges, police, psychologists, social workers, prison staff, and staff working in institutions.
- Programmes of education for parents, including parents of children with disabilities, on child rights and participation are developed and made widely available.
- Policy makers are sensitive to the participation rights of children with disabilities.

## **04** **Measuring opportunities to influence agendas**

- Children with disabilities are included in consultations on legislation, policies, services and resource allocations.
- Children with disabilities have opportunities to provide feedback on the quality, accessibility and appropriateness of public services for children.
- Boys and girls with disabilities are represented in governance bodies.
- Children, including those with disabilities, have the right to establish their own organisations.

- Democratic and inclusive child-led organisations are supported at the national and local levels.
- Children with disabilities have the opportunity to use broadcast and online media to communicate their own views.

## **05** **Measuring respect for children's participation in their daily lives**

- Children with disabilities, from babyhood upwards, are listened to, and, in accordance with their evolving capacities, their views are taken into account within family decisions.
- Schools provide a child and disability friendly, participatory, inclusive learning environment.
- Children with disabilities are involved in decision-making about their own health care, consistent with their evolving capacities.
- Children with disabilities can access confidential health care services, including reproductive health care.
- Children with disabilities participate in local community actions or decision-making processes.
- Child and disability friendly cities and communities are introduced.

## **MEASURING THE NATURE AND IMPACT OF CHILDREN'S PARTICIPATION**

It is also necessary to measure how effective and ethical participation programmes are in practice. **There are three distinct dimensions to measuring participation:**

- **Scope** - what degree of participation has been achieved and at what stages of programme development - in other words – **What is being done?**
- **Quality** - to what extent have participatory processes complied with



**In sport or anything you do, the most important thing is to work hard and then, you will get better at it!**

*Azril, Malaysia*

the agreed standards for effective practice – in other words – **How is it being done?**

- **Outcome** - what has been the outcome – on adolescents and young people themselves, on families, on the supporting agency, and on the wider development of young people's rights within families, local communities and at local and national governmental level – in other words – **What has been achieved?**

## **01** **Scope of participation in programmes**

To assess the scope of participation by children with disabilities, **two perspectives are to be addressed:**

- **Point of engagement** – Children with disabilities can be involved at different stages in the process of developing a programme: situation analysis, strategic planning, programme design and implementation, and monitoring and evaluation. The earlier they are involved, the greater their degree of influence.
- **Level of engagement** - At each stage of developing a programme, there are three potential levels of engagement

EXAMPLE 1

	<u>Children with disabilities are not involved</u>	<u>Consultative</u>	<u>Collaborative</u>	<u>Child-initiated, led or managed</u>
<b>Situation analysis</b>		Views of children with disabilities are solicited but the design and process for information gathering as well as the analysis are undertaken by adults	Children with disabilities are invited to contribute to the design and methodology, their views are sought for both the data collection and the data analysis	Children with disabilities undertake their own research with other children to identify issues of concern
<b>Strategic planning</b>		Planning takes account of the issues raised by children with disabilities in the identification of key issues	Children with disabilities are involved in contributing to what programmes are to be prioritised and developed	Children with disabilities identify and determine what programmes they would like to see developed
<b>Programme development and design</b>		Children with disabilities are consulted on ideas conceived by adults	Children with disabilities work with adults on the design of the programme, and deciding what activities will take place and who should be involved	Children with disabilities work together to design their own programme
<b>Implementation</b>		Children with disabilities are invited to participate, for example, delivering a peer education programme	Children with disabilities work with adults and are involved in the implementation of the programme, for example, communicating what the programme is seeking to achieve, taking part in programme activities	Children with disabilities organise and manage the programme and have full responsibility for its implementation
<b>Monitoring and evaluation</b>		Children with disabilities are consulted on whether the programme has been successful in achieving its objectives	Children with disabilities collaborate with adults in developing the criteria for evaluating the programme and they are consulted on whether the programme has been successful in achieving its objectives	Children with disabilities determine what should be evaluated and, with adult support, undertake the evaluation of the programme

EXAMPLE 2

		<u>Standard has not been considered</u>	<u>Awareness of the standard but not reflected in practice</u>	<u>Efforts made to address the standard but no systematic procedures in place</u>
<b>Requirement 1: Participation is transparent and informative</b>	Children with disabilities understand what the programme is about and feel confident and informed about the nature and scope of their participation			
	The roles and responsibilities of all involved are clearly defined and understood			
	Clear goals and targets are agreed upon with the children involved			

for children – consultative, collaborative and child-led (see pages 19-21 for an explanation of these three levels).

- These two dimensions can be analysed through a matrix to assess the scope of children with disabilities’ participation. Use this matrix to assess what your programme has achieved and what it aims to achieve. [See Example 1.](#)

**02 Quality of participation of children with disabilities**

As outlined on pages 24-29, there is an emerging consensus as to the requirements for achieving quality standards for effective participation. It is important to obtain feedback from children on the extent to which they feel these requirements have been met. This matrix indicates how feedback can be analysed and recorded.<sup>40</sup> [See Example 2.](#)

**03 Outcomes of participation of children with disabilities**

The outcomes associated with participation of children with disabilities ought to be assessed in accordance with the objectives for involving them. For example, the objective might be to promote their self esteem and build skills and confidence. It might be to develop ways to enable boys and girls with disabilities to make complaints or seek redress when their rights are violated. It might be to change a law or policy to strengthen child protection. Or, it may include all these and other objectives. Objectives need to be clear at the outset, and will determine what indicators are selected to measure achievements.

Following is an overview of dimensions that might be used to measure change, outcomes and effectiveness. They are

EXAMPLE 3

		<u>Negative change/harm arising from participation</u>	<u>No change</u>	<u>Immediate change/change only in some stakeholders/lack of sustainability</u>	<u>Significant and sustained change acknowledged by children and adults</u>
<b>On children</b>	Acquisition of skills and knowledge				
	Enhanced self esteem and self confidence				
	Greater rights awareness				
	Sense of efficacy and empowerment				

illustrative, and have been developed as a guide to stimulate ideas and suggest possible outcomes. Each initiative will require distinct objectives and desired outcomes. Across these dimensions, the outcomes will be assessed by the various participating groups: children with disabilities, parents, staff, and community members. It's important to identify concrete evidence of any changes asserted or effects claimed.

**Types of outcomes**

The outcomes fall into two broad categories:

- **Behavioural or attitudinal outcomes:** outcomes of project work which have influenced those affected directly or indirectly by the initiative:
- **Outcomes for children with disabilities** e.g. greater self esteem and self confidence, acquisition of skills (communication, problem solving, negotiation, etc), greater awareness of rights, sense of efficacy and empowerment
- **Outcomes on parents' attitudes or behaviour** e.g. higher level of awareness of and sensitivity to the rights

and needs of boys and girls with disabilities, quality of relationships with children, greater understanding of the capacities of children with disabilities, willingness to consult with and take account of their views

- **Outcomes on staff attitudes and behaviour** e.g. changing practice towards including and respecting the rights and needs of children with disabilities, enhanced commitment to creating inclusive participatory practice, improved quality of relationships with children with disabilities, and greater understanding of their capacities
- **Outcomes for services/programmes/organisations/institutions** e.g. change in organisational culture towards greater respect for inclusion of children with disabilities, willingness of staff to recalibrate power balances and relinquish control in favour of greater power sharing, participation of children with disabilities built in to all programme areas, changes in programmes to reflect their concerns and priorities
- **Outcomes within the local community** e.g. greater awareness of children

EXAMPLE 4

		<u>Negative change/harm arising from participation</u>	<u>No change arising from participation</u>	<u>Immediate change/change arising from participation but no sustainability</u>	<u>Significant and sustained change arising from participation acknowledged by children and adults</u>
<b>Legal/policy reform</b>	% children with disabilities in inclusive education				
	Implementation of a disability-friendly complaints and reporting mechanism				

with disabilities and attitudes towards them, improved status of children with disabilities within the local community, increased willingness to act in their best interests. The outcomes can be tracked on a matrix. See Example 3.

- **Structural or external outcomes:** outcomes impacting a wider constituency of children in the realisation of their rights. These outcomes will vary widely, for example, some might be directed to advocacy for legal reform, others on community development, media access or promoting a more inclusive school. Some of these objectives will have child participation as a means while others will have participation as an end in itself. Where the participation is used as a means to achieving a wider goal, one must measure the extent to which that goal has been achieved, and the role that participation by children with disabilities contributed to that outcome. This might be assessed using the following matrix. See Example 4.



## CONCLUSION

Neither the right of children with disabilities to be heard, nor the obligations of governments to create opportunities to listen to their voices, are in dispute: they are firmly established in both the CRC and the CRPD. As has been illustrated in this publication, children with disabilities, like all other children, have experiences, ideas and views to contribute to decisions affecting them.

The most direct path to improving policies and services impacting their lives is to draw on the views of children with disabilities—they are the experts on their lives. And with appropriate support and commitment, they are as able as all other children to communicate, advocate, collaborate, undertake research and policy analysis, organise, and claim their rights. Most importantly, they passionately want to be heard, acknowledged and taken seriously.

As they have both the right to be heard, and the capacity to contribute, why are so many millions of children with disabilities still excluded and silenced?

In principle, the answer is very simple: children with disabilities continue to be perceived as incapable of participating or too challenging to include. And because it is not possible to change children, or remove their impairments, the barriers are considered to be insuperable. This perception must be confronted repeatedly until there is universal recognition that the problem rests not within the children but rather within the attitudes of wider society.

As these guidelines demonstrate, by investing in efforts to remove the physical, attitudinal, communication and cultural barriers,



**I am moving together with the world because disability is not inability.**

*Dennis Komakech, 17, Uganda*

the participation of children with disabilities becomes no harder to achieve than the participation of any other group of children.

For all of us, being heard and taken seriously is fundamental to our sense of dignity, self respect, belonging, and our common humanity. Most of us can recall a time in childhood when our needs and wants were ignored, when we were shamed or scared into silence. We can still remember how isolated, alone and powerless that treatment made us feel. Yet this is the daily, damaging experience of millions of children with disabilities around the world.

It is time to commit to change, to create incremental changes that will add up to participation of children with disabilities in decisions affecting their lives. Please let us know if these Guidelines are a useful contribution to this process, or what suggestions you have to make them more effective.

## ADDITIONAL RESOURCES:

The state of the World's Children Report 2013 that focused on children with disabilities, including a range of supporting materials is available at <http://www.unicef.org/sowc2013/>. There are also several additional UNICEF resources which you may find useful while engaging with and consulting children with disabilities: Children and Young People with Disabilities Fact Sheet; Using the Human Rights Framework to Promote the Rights of Children with Disabilities: Discussion Paper; Communicating with Children Resource Pack; and the All Staff Disability Orientation Video.

These and other valuable resources are available at [www.unicef.org/disabilities](http://www.unicef.org/disabilities).

In addition to the print version, the Guidelines "Take Us Seriously! Engaging Children with Disabilities in Decisions Affecting their Lives" is also available on our website in a range of alternative formats: Easy-to-Read; DAISY Book; E-Pub and accessible HTML.

The following list details various popular forms of alternative communication. To learn more, visit the websites of the organisations mentioned.<sup>41</sup>

**Accessible web design:** Creating web pages according to universal design principles to eliminate or reduce barriers, including those that affect people with disabilities.

**Adaptive technology:** Hardware or software products that provide access to a computer that is otherwise inaccessible to an individual with a disability.

**Alternative keyboard:** A keyboard that is different from a standard computer keyboard in its size or layout of keys.

**Assistive technology:** Technology used to assist a person with a disability, e.g., wheelchair, handsplints, or computer-based equipment.

**Braille:** A method of reading by touch that is used by people with visual impairments. Braille letters are made of raised dots and are usually written on a braille.

**Captioned film or videos:** Transcription of the verbal portion of films or videos displayed to make them accessible to people who are deaf.

**Captioning:** Text that is included with video presentations or broadcasts that enables people with hearing impairments to have access to the audio portion of the material.

**Closed Circuit TV Magnifier (CCTV):** Camera used to magnify books or other materials to a monitor or television.

**Communication device:** Hardware that allows a person who has difficulty

using their voice clearly to use words or symbols for communication. May range in complexity from a simple picture board to complex electronic devices that allow personalized, unique construction of ideas.

**Compensatory tools:** Assistive computing systems that allow people with disabilities to use computers to complete tasks that they would have difficulty doing without a computer, e.g., reading, writing, communicating, or accessing information.

**Deaf-Blind Manual Alphabet** is designed for use by people who are deafblind. Sometimes wrongly known as fingerspelling, it is a method of spelling out words onto a deafblind person's hand. Each letter is denoted by a particular sign or place on the hand.

**Fingerspelling** is used for names, to spell words for signs that the signer does not know, or to clarify a sign that is not known by the person reading the signer.

**Easy Read** is an accessible information format. It is mostly used by people with learning difficulties, as well as other groups like older people and speakers of other languages. Easy Read does two main things - makes the words used simpler and uses pictures such as PhotoSymbols alongside the words.

**Electronic Communication Aids** may be used alongside, or instead of, other systems, such as paper-based charts, signing systems, etc. Few people with communication impairments will use only one particular method of communication, in most cases somebody using an electronic aid will reinforce its messages with gesture, head movement, etc. Many

users of electronic aids use a symbol or pictorial system to associate the images with larger messages. For those users who are able to spell, more complex machines allow them to type in messages which the machine then turns into speech using speech synthesis. Increasingly, portable computers are being used as electronic communication aids by running specialist software. This operates in much the same way as the purpose-built communication aids.

**Lipreading** is 'reading' the visual cues of the spoken message: the movements of the lips, the tongue, the lower jaw, the eyes, the eyebrows, the facial expression and gestures. They are all clues for the lipreader. The lipreader will also observe the syllables, the natural flow, rhythm, phrasing and stress of speech. It is not possible to distinguish all speech from lipreading alone, therefore it is easier to lipread if another system is used as well.

**Reading system:** Hardware and software designed to provide access to printed text for people with visual impairments, mobility impairments, or learning disabilities. Character recognition software controls a scanner that takes an image of a printed page, converts it to computer text using recognition software and then reads the text using a synthesized voice.

**Refreshable Braille Display:** Hardware connected to a computer that echoes screen text on a box that has cells consisting of pins that move up and down to create Braille characters.

**Screen enlargement:** Hardware and/or software that increases the size of characters and text on a computer screen.

**Screen reader:** Software used to echo text on a computer screen to audio output, often used by people who are blind, with visual impairments, or with learning disabilities.

**Sign language:** Manual communication commonly used by deaf. The gestures or symbols in sign language are organized in a linguistic way. Each individual gesture is called a sign. Each sign has three distinct parts; the handshape, the position of the hands, and the movement of the hands. Deaf people from different countries speak different sign languages.

**Total Communication** is about having lots of communication methods available. Sometimes one method of communication cannot provide total understanding. It is better to use an additional method to assist or replace the first. Total communication stresses the equal importance of all communication methods to gain an understanding of language. Typically, signing and speech are used together.

**Universal design:** Designing programs, services, tools, and facilities so that they are useable, without modification, by the widest range of users possible, taking into account a variety of abilities and disabilities.

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