Guidelines for Involving People with Intellectual Disabilities in Policy Consultations

English

Inclusion Europe

Guidelines for Involving People with Intellectual Disabilities in Policy Consultations

The Convention on the Rights of People with Disabilities (CRPD) brings about significant changes in the lives of people with intellectual disabilities and their families. Participation of civil society, in particular of persons with disabilities and their representative organisations, is a core element of the CPRD and a necessary requirement for the full and effective implementation of the Convention. This is emphasized in the preamble to the Convention, which states that "*persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them*".[1]

However, years after the adoption of the CRPD by the UN General Assembly, people with intellectual disabilities still feel left out and marginalized in these consultations, sometimes even within the organized disability movement. This is often due to the potential difficulty perceived as being difficult of accommodating specific support needs. However, without having the necessary support provided for them, people with intellectual disabilities are effectively excluded from participating as representatives of their own organisations. This often leads to the involvement of professionals or family members who speak for this group of people with disabilities, rather than consulting directly with them.

Inclusion Europe and its members hold the view that the direct involvement of people with intellectual disabilities in all policy processes is essential. Therefore, this paper aims to outline specific principles and techniques that make this possible and that would help give people with intellectual disabilities the voice they deserve.

---

[1]   CRPD, Preamble para. (o).

1.   Participation: the Lifeblood of the Convention

The participation of people with intellectual disabilities in all stages of policy-development has been formalised by the UN CRPD.

Article 3 of the CRPD sets out the general principles of the Convention. These include the principle of "full and effective participation and inclusion in society". The principles set out in Article 3 are the effectively the CRPD's value system which guides the interpretation and implementation of all other rights and obligations in the CRPD.

Article 4 CRPD requires States Parties to closely consult with and actively involve persons with disabilities through their representative organisations throughout the policy cycle, including in agenda-setting, planning and implementing the policies, and programmes and services that affect the lives of persons with disabilities. The provisions of article 4(3) state that States parties must closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Finally, the UN CRPD also includes participation of Disabled People's Organisations (DPOs) in the monitoring process as logical completion of the policy cycle. *Article 33(3)* requires that civil society shall be "involved and participate fully in the monitoring process". States Parties must ensure full participation, a much stronger obligation than mere consultation. Article

33(3) also allows people with disabilities, separately from disability organisations, to participate.

The UN CRPD further stipulates in *article 29* that people with disabilities must have effective access to political and public life, by exercising their right to vote and to be elected. It therefore ensures that persons with disabilities can become members of political parties or of non-governmental organisations. State Parties have not only the obligation to allow representative organisations of persons with disabilities or disabled people's organisations to exist, but also to "promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs", making sure that such organisations are provided with funding and/or organisational capacity to participate in civil society and political life.

2. Meaningful and effective participation

Although they has been significant progress in involving civil society in policy-making in different European countries, people with intellectual disabilities and their families still find it hard to have a voice, to be heard and to have a dialogue with the government. Their expertise and knowledge are still often not recognized, not only because they face several communicational and attitudinal barriers but also because they may lack the necessary resources to be seen as equal partners.

Participation of people with intellectual disabilities in the policy-cycle can of course be challenging and requires new measures and adaptations as well as a lot of flexibility. Meaningful participation requires that the process of involving persons with intellectual disabilities and

their representative organizations is done in an open and transparent manner.

The following principles should be respected in all policy areas as basis to involve people with intellectual disabilities.

Adequate representation

Governments as well as larger civil society groups should pro-actively seek the direct participation of people with intellectual disabilities. To make this possible, various accessibility measures must be implemented. Organisations of people with intellectual disabilities and their families should be actively encouraged to nominate self-advocates as their representatives in these consultations.

It is also important to ensure that service providers, including professional medical, social care staff, claiming to be advocating for their patients/clients, are not the main stakeholders to be consulted. Although they may do this in good faith, it is a practice to be avoided, as they cannot replace the voices of people with intellectual disabilities.

Early and continuous involvement of civil society

Persons with intellectual disabilities should be involved from the early stages of policy planning, to ensure that the methods of participation are meaningful and that people with intellectual disabilities have the time they need to valuably contribute to the policy process. It is important for governments to recognise that persons with intellectual disabilities and their families are experts in relation to their own lives.

Their participation should be sustained throughout the policy cycle: in agenda-setting, planning, implementing and monitoring, and evaluating policies and services. This consultation and
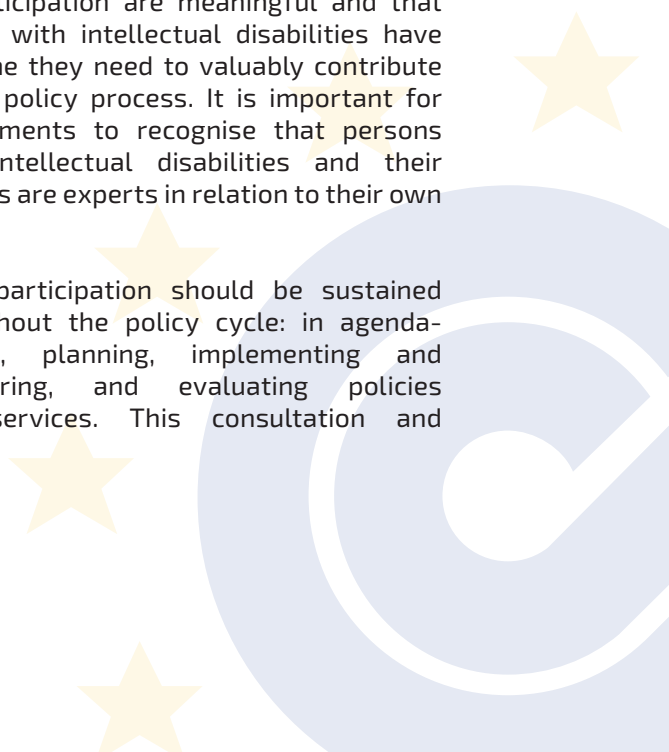
participation process should take place at all levels, whether local, regional, national, European or international, in order to fully represent the whole society.

Accessible and multiple forms of inclusion including reasonable accommodation to ensure effective participation

In order for participation to be meaningful, multiple formats need to be made available. If participation occurs only through traditional meetings, people who are unable to travel or who are not confident speaking in public places or before large groups may be excluded. There is a range of ways to make effective participation happen, for example: through individual/group interviews, focus groups with family members and/or self-advocates. Also internet-based easy-to-read questionnaires including sound and images can improve participation.

Only inviting people with intellectual disabilities to participate is unfortunately insufficient, as they may experience various barriers to participating and be excluded from discussions. For people with intellectual disabilities, regular breaks in meetings are crucial. Well-structured agendas with clear topics, easy to understand texts, as well as background material sent in advance to facilitate preparation are all important examples of reasonable accommodations. Governments should also make sure to people with intellectual disabilities directly to advise them on what type of adjustments they might need.

Capacity building, resources and advancing good practice

People with intellectual disabilities cannot equally participate if they are not informed about their rights, particularly about their right to participate in the matters concerning them. Therefore people with intellectual disabilities as well as their family members need to have knowledge about human rights, including the rights enshrined in the CRPD. They also need to learn how to engage in policy debates. Confidence and skills to participate in meetings must be taught trough different capacity-building activities.

However, in delivering capacity-building activities, DPOs should be supported by State Parties, as required in article 29. Capacity-building should be available to family members, persons with disabilities and their representative organisations. Capacity can be built in a number of different ways, including through seminars, conferences, books and online resources.

3.   Organised Civil Society in the field of intellectual disability

Moving away from the traditional medical model of intellectual disability, the 1950s saw the creation and growth of organisations of families of people with intellectual disabilities all over Europe. This movement wanted to move their children out of hospitals and asylums and instead focused on education, training and integration in society, rather than on medical treatment.

The foundation of the "European League of Societies for Persons with Mental Handicap" in 1960 showed that close European cooperation was essential during. Soon after, in 1964, this cooperation reached the world-wide level, resulting in a name change to "International League of Societies for Persons with Mental Handicap", now Inclusion International.

The roots of this family-based movement are firmly planted in the self-help philosophy. Wherever provisions for people with intellectual disabilities are not sufficient or new concepts require new kinds of support services, this movement has led the development work, lobbied the government for the necessary support, and in many cases started to provide support services on a self-help basis. This was aided by another important principle of the movement - that family members must have the majority in the decision-making bodies of organisations.

In the 1980's, the movement was also the first to recognize that people with intellectual disabilities themselves must participate in decisions that concern their lives. Since then, the past 30 years have seen a very significant recognition and growth of this principle in all European countries and people with intellectual disabilities who defend their own rights started to define themselves as "self-advocates".

Today, there are self-advocacy groups or organisations in all European countries. They organize peer support and training, voice concerns and are an important motor for development. At European level, they are organized in the European Platform of Self-Advocates (EPSA).

In some countries, people with intellectual disabilities have created their own national, regional or local self-advocacy organisations, which are legally independent NGOs. In other countries, they have formed groups under the umbrella of family organisations and participate at an equal level in their decision-making.

However organized, political recognition and funding are the two very difficult subjects in the area of self-advocacy. European governments very often do not provide the necessary financial support for self-advocacy, and thus make this important direct voice of people with intellectual disabilities dependent on the sporadic support of others.

European governments have an important role to play by insisting and making sure that consultations with the disability movement always include people with intellectual disabilities directly, and not only by hearing others speaking for them. This political recognition as equal citizens will strengthen their voice in all policy areas.

4. The need for accessible and timely information

People with intellectual disabilities are experts in matters affecting their lives, and could give valuable policy input, if supported to do so. In its preamble, the UN CRPD recognizes that disability stems not only from impairment, but also from barriers that hinder the full and effective participation of people with disabilities in society on an equal basis with others. The lack of accessible and timely information can thus further perpetuate social exclusion, preventing people with disabilities from making their voices heard in the policy process.

To prevent this, and comply with UN CRPD Article 9, which states that information intended for the general public should be made available to persons with disabilities in "accessible formats and technologies," policy makers should make sure they provide people with intellectual disabilities with the means to efficiently participate in all stages of policy development.

Keeping in mind that people with intellectual disabilities might find some documents difficult to understand, or might need more time to grasp complex issues, all information provided to people with intellectual disabilities should be easy
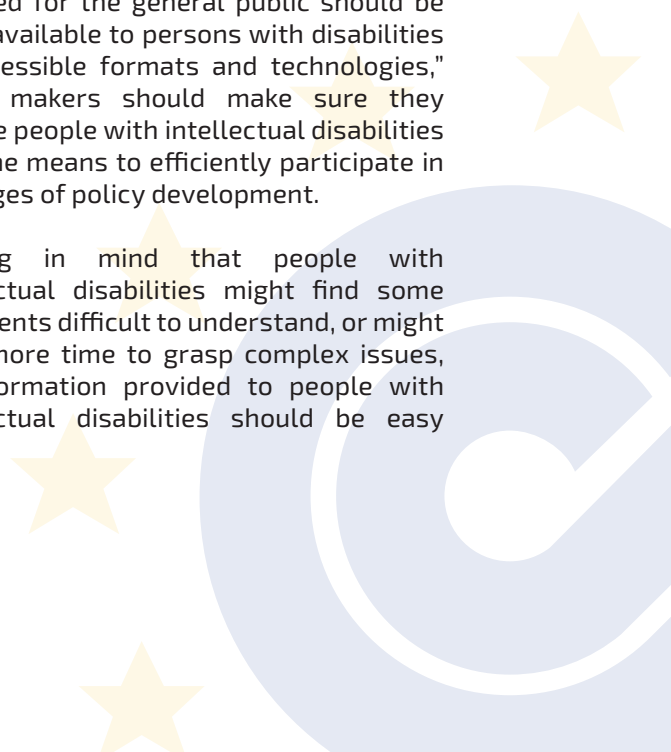
to read. While there is no legal definition of "easy-to-read" text, the European Standards for making information easy to read and understand[2] can help policy-makers in creating accessible versions of their documents.

There are several ways of going about translating regular text into easy to read, and making sure the translation is indeed understandable for people with a wide variety of intellectual disabilities. One approach would be to produce the easy-to-read translation and then ask people with intellectual disabilities to proofread it. Another more participatory approach, which is definitely preferable, would be to work with people with intellectual disabilities from the start in developing the text. In either way, testing an easy-to-read text with both individuals and with a group is necessary, as well as doing so with people with a wide range of abilities and different amounts of experience.

In either case, the end product should be adapted to the target audience, it should be clear and age-appropriate. Children with intellectual disabilities should be particularly consulted on matters important to them, as Article 7 of the UN CRPD clearly stipulates 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." Governments should make sure to select the most appropriate format of presenting any information, whether this is written information, electronic information, audio information or video.

In written text, plain words should be the norm, and words should be used consistently throughout the text, and explained if necessary. Sentences should

be kept short and concise, ideally with one idea per sentence and one sentence per line. Passive voice should be avoided, and so should percentages and large numbers. Moreover, people with intellectual disabilities might also find written information easier to grasp if accompanied by images.

As the UN CRPD promote access for persons with disabilities to new information and communications technologies, and particularly to the Internet in Article 9, Governments should ensure that public websites are accessible for persons with intellectual disabilities. While the guidelines for written text apply to websites as well, installing software such as a screen reader could further air people with intellectual disabilities in navigating sites. Search tools are also very important for people with disabilities, and so is ensuring that website homepages clearly explain what the website is about, and that navigation bars remain consistent on all pages of a particular website.

Videos are very useful tools in sharing information with people with intellectual disabilities. However, they should be simple and kept to no longer than 30 minutes. If any subtitles are used, these should be easy-to-read. Moreover, subtitles must stay on the screen long enough for people with intellectual disabilities to be able to read them. Any audio information would have to follow similar guidelines, with presenters speaking slowly and clearly, making pauses, and repeating important information several times.

As people with intellectual disabilities might need more time to respond to a consultation, policy-makers should account for this in their planning. While self-advocates might take longer to understand information and prepare an answer, their voice is crucial in developing policy that affects their lives, and all measures should be taken to ensure they are included in discus-

---

[2]   Inclusion Europe, Brussels, 2010

sions. It is important for governments to acknowledge that persons with disabilities have expert knowledge and provide reasonable accommodation to support them in expressing their views.

5. Guidelines for involvement in consultations

People with intellectual disabilities have three main requirements when participating in consultations:

- They need information in easy to read language, which is relevant for them in their life situation.
- They need much more time to discuss and understand.
- They need independent support that helps them to make their own decisions.

In our experience it is possible to adapt all consultations and meetings with civil society in a way that enables the active participation of people with intellectual disabilities. However, if those requirements are not met – as is the case in most consultations to date – participation of self-advocates is tokenistic and may damage the self-esteem of the participants.

While we would encourage and support all efforts to make mainstream consultations more inclusive, in some situations, additional specific consultations only with self-advocates may be necessary. These may allow specific concerns to be discussed and formulated in a more appropriate way.

Guidelines for written consultations

Written consultations through the Internet are one main tool employed by policy makers at national and European levels. The Stakeholder Consultation Guidelines of the European Commission outline the principles

for the definition of the methodology that should be employed. In practice, however, people with intellectual disabilities as stakeholders are still in danger of being excluded from these consultations.

These three accessibility issues are generally to blame:

1. Accessibility of the technology: people with intellectual disabilities still have less access to online consultations than other citizens.
2. Accessibility of the content: questions are often phrased in a way that is difficult to relate to for any European citizen.
3. Accessibility of channels to respond to consultations: Many people with intellectual disabilities find it difficult to write down their opinions. They either need support from other people to respond or should be allowed to submit their contributions as voice recordings.

These issues can be avoided or better addressed, if people with intellectual disabilities are clearly identified as target group in consultations.

Guidelines for involvement of people with intellectual disabilities in mainstream consultation meetings

While more and more people with intellectual disabilities actively participate in events together with many other participants, they are often disappointed when they cannot follow and fully participate because some basic guidelines for accessibility have not been followed.

The organizer of any mainstream policy consultation should include considerations on accessibility from the beginning of the planning process. Taking care of these issues from the beginning has proven to be
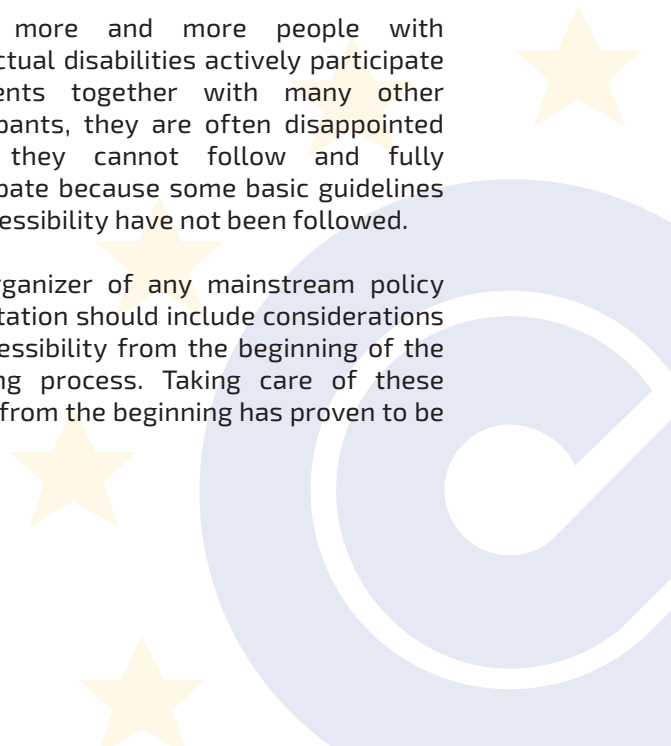
most effective and to avoid costly changes to programmes and venues. Inclusion Europe has developed three key resource materials to facilitate this work:

1. "Guidelines for Organizers of Meetings and Conferences" which help in the planning processes.
2. "Rules for Speakers" which can be distributed well before the event to all speakers.
3. "Rules for Meetings" which should be distributed together with the accessibility cards at the event to all participants.

The most important recommendations are as follows:

Papers and Materials:

Those materials, which are crucial for understanding and following a conference, should be translated into easy-to-read language. They should be sent to the participants at least two weeks before the event. Since those texts are short summaries of the contents of the full papers they help all participants and they are easily translated into other languages.

Preparation Meeting:

A meeting that takes place before the conference actually starts. All the participants with intellectual disabilities should be invited to participate with their supporters. The aims of this meeting are:

- Explaining the way the conference will be run and which sessions will be accessible and what measures people can expect in terms of accessibility.
- Explaining the themes and the contents of the different sessions in easy-to-understand words.
- Helping the participants with intellectual disabilities to have their own ideas and formulate their questions on the different topics.

- Reminding participants about the proper use of the accessibility cards and the general rules for meeting.

Accessible sessions:

Especially at large events, it might not always be possible to have all sessions accessible for people with intellectual disabilities, for example during scientific presentations. Please make sure that in these cases there is an alternative programme and/or that the inaccessible sessions are equally distributed during a conference day. It is also very important to clearly indicate accessible sessions in the programme and to announce at the start of each session if it will be accessible or not.

Breaks:

Participants with intellectual disabilities may find it difficult to follow a long session without any breaks. Accessible sessions should therefore not be too long. To increase the participation and the understanding of the people with intellectual disabilities, a short break after a presentation and before anyquestion and answer session might be very useful. During the break, supporters have the opportunity to explain once more some ideas developed during the presentation.

Working groups:

All participants to the meeting or conference (including participants with intellectual disabilities) might find it interesting to have working groups of maximum 20 persons at some moments. Sharing experience and exchanging information is important for the participants, and it is often easier for everyone to do so in small groups than in plenary sessions.

Interpretation:

In international meetings, it is very important to think about facilitating

understanding by providing interpretation. Usually, people with intellectual disabilities do not speak other languages. However, sometimes their supporters can translate for them. But that takes time and requires the speaker to deliver his/her presentation very slowly.

The Rules for Speakers:

It is very important for all speakers to be aware that you are planning an accessible event before they start preparing their presentations.

Visual aids:

"One picture is worth more than 1000 words" and it helps people with intellectual disabilities follow presentations much better. Please encourage all speakers to prepare support material that also use pictures and communication symbols. Power Point presentations, overhead slides or video may be of help to support their speech. Make sure that the necessary technical equipment is available.

Developing specific consultations with people with intellectual disabilities and their organisations

Focus groups designed according to the specific needs of people with intellectual disabilities may be an effective tool for involving them in consultations. It is, however, necessary to ensure a representative selection of participants. Special attention should be given to people with severe disabilities or complex needs in the selection process.

A good way to organize this kind of consultations is to involve representative self-advocacy organisations or groups. Given enough preparation time, they can discuss the issues with their members and thus bring the opinion of more people to the table.

In organizing such consultation Focus Groups, one should provide participants with enough time to prepare, as well as with enough an experienced independent facilitator for the discussions.

Inclusion Europe
Rue d'Arlon 55 – B
1040 Brussels – Belgium
secretariat@inclusion-europe.org
Tel.: +32-2-502 28 15
Fax : +32-2-502 80 10
www.inclusion-europe.org

Co-funded by the European Commission