Inclusion International
Submission to the UN CRPD Committee of Experts Re:
draft General Comment No.1 on Article 12 CRPD
Inclusion International is the global network of people with intellectual disabilities and their families working towards inclusion. The issue of legal capacity and the right to make decisions about our own lives is a fundamentally important issue to our members and regional groups. The Committee will receive submission from our regional groups which reflect their particular perspective and issues and from national member organizations in different regions. These submissions will reflect the vibrant discourse that is underway throughout our movement on the importance of Article 12. Inclusion International’s Global Campaign on the Right to Decide (which will culminate in a Global Report on the Right to Decide) has highlighted the need to raise awareness by governments and by communities that Article 12 must be understood as a crosscutting commitment which impacts on the implementation of all aspects of the Convention. Without it people with intellectual disabilities will be excluded from exercising the other rights articulated in the Convention. This submission by Inclusion International reflects some of the priority issues raised by our members and is an attempt to summarize the feedback received on the Draft General Comment on Article 12.

The movement for the inclusion of people with intellectual disabilities and their families very much welcomes the draft General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities. We are pleased that the Committee has taken such strong and positive positions in its draft General Comment and we applaud the ambitious work of the Committee. This authoritative interpretation of Article 12 will be extremely useful for our work towards a better implementation of the rights of persons with intellectual disabilities. The draft General Comment reflects many of the positions that people with intellectual disabilities, their families and their organisations have developed in the past years.

We welcome the holistic interpretation of Article 12 and consider all the elements of the draft General Comment as essential to ensure the full implementation of Article 12. The following comments are intended to supplement the General Comment and build on the strong base of the committee’s work.

We strongly support the statement that all persons with disabilities have legal capacity and have the right to enjoy their rights (§11 of the draft General Comment), as well as the statement that in the absence of legal capacity the realization of many other rights guaranteed by the Convention cannot be achieved.
We welcome the useful distinction made in §23 about the characteristics of substitute decision-making models bound by the perceived “best interests of the individual – as opposed to the individual’s own will and preferences” which defines supported decision-making.

We also welcome the key statement that Article 12 is not subject to progressive realization and that “the development of supported decision-making systems in parallel with the retention of substitute decision-making regimes is not sufficient to comply with Article 12.” However, the Inclusion movement would like to raise concerns about the danger that some States Parties might abolish substitute decision-making regimes without ensuring at the same time the availability and accessibility of supported decision-making systems for all who need them, including adequate support for people with significant impairments and complex needs.

Furthermore, Inclusion International consider § 14 to 17 on suitable arrangements to be made to ensure the exercise of legal capacity as absolutely crucial and indispensable for understanding the nature of the duty imposed by Article 12(3). It is essential to require from States Parties to provide a range of initiatives and arrangements (including the possibility to not wish to exercise the right to support) in order to fulfill their duty to provide access to support.

Our movement has always highlighted that supported decision-making does not only require legal support, but a whole range of formal and informal arrangements, starting from training decision-making at schools, to informal support by peers, friends, family or neighbors, up to making mainstream support services (like debt counseling, consumer protection, etc.) accessible and available to people with disabilities in all life situations.

We also welcome the clear statement that the support described under Article 12(3) is the basis to enjoy the substance of the other rights provided for in the Convention. These supports are of particular relevance for people with intellectual disabilities to exercise informed consent to medical treatment, to exercise financial autonomy and to choose where and with whom to live.
In relation to Article 12(4) of the Draft Comment we would welcome a more detailed interpretation by the Committee about necessary safeguards. We would encourage the Committee to clearly state in the final Comment:

- that the restriction of legal capacity cannot be considered to be a safeguard under Article 12.
- that safeguards shall never limit the full and equal enjoyment of all rights and respect the persons’ autonomy, including the freedom to make one’s own choices in line with the principles of the Convention.
- that safeguards are suitable measures to prevent abuse and exploitation of persons with disabilities. Such measures should, whenever possible, be disability-neutral.
- that wherever disability-specific measures are needed to support the exercise of legal capacity, it is appropriate to devise them under Article 16 and Article 17 as measures to prevent from abuse and for the respect for personal integrity.
- that a clear distinction shall be made between legal capacity and supported decision making on one hand and social care services and social support on other hand. It should be made clear that the existence of social care and support does not relieve the Member States from their duty to provide for measures for supported decision making which shall ensure the enjoyment of rights through supporting the capacity to act. Very often even legal experts confuse the support for full and equal enjoyment of all rights through autonomous actions with the social support, ensured through the social care system.
- to add the right of association to the list of rights mentioned in §25(f) of the General Comment. The right of association as the freedom to join with others who share the same goals and values to achieve common aims has a huge potential to create safeguards for the person in its own right. This fundamental right is intensely connected with the individual personality, identity and uniqueness and therefore fully depends on the will and preferences of the individual.

In addition we propose to include the following examples as possible safeguards in the sense of Article 12:

- The individualised approach and person-centred methods and solutions are safeguards, as they provide a guiding structure to respect the personal choices and preferences of each individual.
- The involvement of several supporters (trusted persons chosen by the concerned person) is a safeguard, especially if they support the person in different areas of life or if a person is appointed as Monitor (a person
whose role is to make reasonable efforts to determine whether the support persons are complying with their duties).

- Another important safeguard is to make information and tools available and understandable to people with disabilities to complain or to report about a disagreement with their supporters. Similarly, third persons should be encouraged to report in case they believe a supporter is not acting on the basis of the will and preferences of an individual. Mediation or counselling services accessible to ALL people with disabilities may also be a safeguard.

- A safeguard may further be the definition of clear steps and principles to be followed when a decision has to be taken (see British Columbia Representation Agreement Act).

- Experience shows that the execution of rights for people with limited mental capacity is heavily depending on the acceptance of contracting partners (shops, banks, doctors, public authorities, service providers, etc.). Therefore, for decisions which have a strong legal impact, a certificate could be provided to confirm that the decision has been taken according to official quality standards for supported-decision making in order to be accepted by third parties.

We would also encourage the Committee to include a clear statement on the right to reasonable accommodation or measures of affirmative action to achieve equality for persons with disabilities. In particular, we propose to add in the General Comment that:

- disability-specific measures can be taken to allow persons with disabilities to exercise their legal capacity. These measures are covered by the right to reasonable accommodation.

- any special measure which results in the exclusion of persons with disabilities on grounds of “severity”; “nature of impairment” or “difference in functioning and communication” cannot be considered as affirmative action or reasonable accommodation under article 5(4) of the Convention.

While we acknowledge the complexity of the issues around the topic of medical decisions, we would appreciate guidance by the Committee on the issue of informed medical consent, in the sense of Article 25 (d) and its relations to Article 12. Indeed support to exercise informed consent to medical treatment is of particular relevance. Specifically, the General Comment should state that
• measures to prevent abuse of people with disabilities and safeguards for medical decisions are allowed under Article 16 and 17.
• in the case of complex medical decisions, a third independent authority should testify that the decision is taken on the basis of the will and preferences of the person, to prevent abuse of people with disabilities.

Finally, we would like to draw the attention of the Committee to the crucial importance of the accessibility of information for people with intellectual disabilities in relation to legal capacity and access to justice. Without the provision of easy-to-read or easy-to-understand information, people with intellectual disabilities cannot access basic information about their right to take decisions and about the supports available for decision-making. We encourage the Committee to
• include a statement that is in keeping with CRPD Article 9 and 21. The provision of easy-to-read or easy-to-understand information is crucial to the exercise of legal capacity for people with intellectual disabilities. This includes general information about rights, access to justice, consumer’s rights, public and disability specific services, banking information and others which relate to decisions which have legal effect.

We would like to thank the Committee for the possibility to share our views and remarks and we are looking forward to reading and using the final version of the General Comment.