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**To:** "Committee, Treaties (REPS)" <JSCT@aph.gov.au>  
**Subject:** Submission to CRPD consultation

Dear Sir/Madam:

I am writing as an individual who participated in the drafting and negotiation of the Convention and am in a position to offer some commentary on the issues of legal capacity and the right to respect for integrity (Articles 12 and 17). I represented a major international organization of persons with disabilities in the negotiations, and coordinated the work of the international disability community as a whole on these articles. I continue to coordinate the Legal Capacity Task Force, now a part of the IDA (International Disability Alliance) CRPD Forum. The Legal Capacity Task Force brings together people with disabilities and allies from all over the world, including a number of lawyers, and has issued several relevant statements on Article 12. Its nearly 50 members include many who hold senior positions with the major international DPOs that were directly involved in the CRPD negotiations.

This letter also represents the collective views of the IDA CRPD Forum, established under the leadership of international and regional democratic organizations of persons with disabilities, to work for the ratification, implementation and monitoring of the CRPD.

The International Disability Caucus (forerunner to the IDA CRPD Forum) vigorously opposed the insertion of a footnote in Article 12 limiting the meaning of "legal capacity" to the capacity for rights without the capacity to act, in the Arabic, Chinese and Russian languages. Australia joined us in opposing the footnote, along with a majority of other countries, and it was eventually removed. However, the effect of a declaration stating that Article 12 permits substituted decision-making (against the will of an individual) is the same as the footnote: denying to persons with disabilities the capacity to act, i.e. to make legally valid decisions based on their own will and preferences.

The IDA CRPD Forum is also working closely with organizations of persons with disabilities in Mexico to seek withdrawal of the government's interpretive declaration on Article 12, paragraph 2, which takes a similar view that denying legal capacity to persons with disabilities could be more protective than recognizing equal legal capacity as required by that provision.

All the activity in relation to Article 12 has raised the profile of legal capacity. The UN High Commissioner for Human Rights has repeatedly emphasized legal capacity and the right to make one's own decisions as one of the key issues for implementation of this Convention. In a recent speech in New York to celebrate the CRPD entry into force, the Deputy High Commissioner emphasized both legal capacity and the right to free and informed consent. She said that disability is no longer about a person's mental or physical condition but about equal human rights. I think it is fair to say that the chief defenders

of human rights at the United Nations would not condone substituted decision-making or compulsory treatment of persons with disabilities, including psychosocial or "mental" disability.

Compulsory treatment, whether in the mental health field or otherwise, violates both Articles 12 and 17, as well as Article 25 (see paragraph d).

Substituted decision-making (against the will of the person) violates Article 12 and makes the entire Convention worthless for the most marginalized persons with disabilities, since they have no legal standing or recourse to assert their rights. Supported decision-making, on the other hand, empowers all persons with disabilities with legal independence and the support needed to equalize conditions for effective decision-making. Supported decision-making is one of the greatest advances of the CRPD and a major contribution to international human rights, building on earlier provisions dealing with legal capacity in the UDHR, ICCPR and CEDAW. The CEDAW committee, in General Recommendation No. 21, emphasized that without legal capacity, women were legally dependent on males in their families and this impacted negatively on their ability to provide for themselves and their children, as well as to function as equal members of their communities and enforce their rights in court. Analogous impacts are occurring all over the world for persons with disabilities who are deprived of legal capacity and subjected to the will of other members of their families, institutions, guardians, doctors, or even courts functioning as substitute decision-makers.

The IDA CRPD Forum has addressed some of the more technical issues on application of Article 12 in the annexed document. Please note that we are not rejecting the need to make decisions for persons who are in coma or unconscious (such as following severe injury). But we do draw a distinction between those situations, and substituted decision-making against the will or preferences of the person with a disability (which would violate Article 12, paragraph 4 as well as the recognition of equal legal capacity in paragraph 2).

That is, we can consider both positive and negative components of the right to have and exercise legal capacity. The positive is the right to make decisions, and the negative is the right to not have decisions made against one's own will. Even in the situation of coma or unconsciousness, a person retains the negative component of this right, while the positive component is temporarily not applicable. However, in this situation Article 12 means that, in the words of IDA Chair Lex Grandia, "We should not have to go to court to get our legal capacity back."

In addition, we recognize that for some people with disabilities who are currently without support, substituted decision-making may need to continue while adequate support is being developed. However, consistent with the analysis of a positive and negative component to legal capacity, this type of interim substituted decision-making may not be imposed against a person's will.

I hope this submission is useful to you in your consideration of issues relating to CRPD ratification, and congratulate you on moving towards ratification and on an open consultative process.

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## **IDA CRPD Forum**

### **Principles for Implementation of CRPD Article 12**

#### *Introduction*

*Article 12 accords to people with disabilities recognition equal to others as full persons before the law. To be recognized as a full person before the law means that one's legal capacity, including the capacity to act, is equally recognized. Article 12 also imposes a positive duty on the state to establish support measures to ensure that the barriers to exercising legal capacity are removed and that the supports are in place for people with disabilities to fully enjoy and exercise this capacity. Insofar as present day national laws impose barriers to the exercise of legal capacity by persons with disabilities, or deny access to needed supports for the exercise of legal capacity, it is necessary for States in accordance with their obligation under article 4 (1) (b) to modify these laws to bring them in consonance with article 12. In order to assist States Parties in their law reform activity we have outlined the implications of article 12 below.*

#### **Overarching Principles**

- 1. "Legal capacity" is best translated as the "capacity for rights and capacity to act".*
- 2. "Legal capacity" for the purpose of the Convention on the Rights of Persons with Disabilities means both the capacity for rights and the capacity to act. This applies in the legal systems of all countries for all people, including those with disabilities.*
- 3. The right to enjoy and exercise legal capacity applies equally to all people, including those with disabilities, irrespective of the nature or effects of their disability or apparent need for support. Legal capacity cannot be questioned or challenged based on disability.*
- 4. People with disabilities who need support to exercise legal capacity have a right to be provided with such support. Support means the development of a relation and ways of working together, to make it possible for a person to express him or herself and communicate his or her wishes, under an agreement of trust and respect reflecting the person's wishes.*
- 5. All people who have difficulty exercising their legal capacity can be accommodated within the support paradigm.*
- 6. All adults, including those with disabilities, have an inalienable right to exercise their legal capacity. This means they cannot be prevented from*

*doing something that they are otherwise permitted to do in the exercise of personal autonomy. They also have the corresponding duty to fulfill their responsibilities. Support and/or reasonable accommodation may be necessary to equalize the effective enjoyment of these rights and fulfillment of duties.*

- 7. All children, including those with disabilities, have an evolving legal capacity, which at birth, begins with full capacity for rights, and evolves into full capacity to act in adulthood. Children with disabilities have the right to have their capacity recognized to the same extent as other children of the same age, and to be provided with age- and disability-appropriate supports to exercise their evolving legal capacity.*
- 8. Parents and guardians have the right and responsibility to act in the best interests of their children while respecting the child's evolving legal capacity, and the state must intervene to protect the legal capacity and rights of children with disabilities if the parents do not do so, in accordance with the Convention on the Rights of the Child. The parents' or guardians' rights to act on behalf of their children cease when the child reaches the legal adult age. This must be the same for all persons to avoid classifying people with disabilities as children at an older age than others.*

### **Building Legislative and Community Structures for Supported Decision Making**

- 9. Governments are responsible for replacing existing substitute decision making laws and policies with supported decision making mechanisms that are recognized in legislation and have corresponding policies and programmes to effectively implement a system of supported decision making.*
- 10. Governments are responsible for developing, supporting, promoting and offering support services, and for establishing safeguards to ensure a high quality of support and its compliance with standards such as: respect for the rights, will and preferences of the person, freedom from conflict of interest and undue influence, and being tailored to individual circumstances.*
- 11. Support must not restrict the rights of the person or coerce the person to act in a particular way. Support must not affect his or her capacity to act. A person cannot be made to accept support against his or her will.*
- 12. Different types of support should be promoted and encouraged to meet the wide range of needs among people with disabilities and allow for personal choice among different options. Types of support may include, for example, support networks, personal ombudsperson, community services, peer support, personal assistant, and advance planning. Age, gender, cultural and religious preferences, and similar factors must be taken into account, as well*

*as needs expressed by people with different types of disabilities.*

- 13. Interim measures may be needed when it is difficult to determine a person's wishes and it appears that the person may need support, or when support fails despite good efforts. In such cases, skilled supporters trained in establishing proper communication and the obligation to respect autonomy should be available to help. Governments should also promote advance planning for support that people may anticipate needing in the future.*
- 14. A person may agree with his or her supporter(s) that the supporter(s) can make certain types of decisions, should the supporter be unable to determine the person's wishes at a particular time. This does not mean that the person loses his or her right to make those decisions. The supporter is bound to keep making the effort to communicate and to follow the person's wishes as far as they may be known.*
- 15. If no such authorization has been made and communication has failed despite good efforts, skilled supporters should continue trying to establish communication, while a decision is made that has the least possible effect in foreclosing opportunities for later revision.*
- 16. Decisions that involve highly personal values and/or controversial measures that may violate a person's physical or mental integrity such as sterilization, cochlear implants, neuroleptic drugs, electroshock and psychosurgery, should not be permitted without the informed and affirmative consent of the person concerned.*

### **Dismantling Substitute Decision Making Systems**

- 17. Governments must act immediately to*
  - a. recognize the equal rights of all persons to have and exercise legal capacity without discrimination based on disability;*
  - b. establish a legislative, policy and financing basis for*
    - i. provision of support in decision making in accordance with the principles outlined above; and*
    - ii. the duty of all those in the public and private sectors to accommodate persons with disabilities who may require support in decision making; and*
  - c. abolish*
    - i. plenary guardianship;*
    - ii. unlimited time-frames for exercise of guardianship;*
    - iii. the legal status of guardianship as permitting any person to override the decisions of another;*
    - iv. any individual guardianship arrangement upon a person's request to be released from it;*
    - v. any substituted decision-making mechanism that overrides a*

- person's own will, whether it is concerned with a single decision or a long-term arrangement; and*
- vi. any other substituted decision-making mechanisms, unless the person does not object, and there is a concomitant requirement to establish supports in a person's life so they can eventually exercise full legal capacity.*

*18. All laws and mechanisms by which a person's capacity to act can be deprived or restricted, based on differences in capabilities, must be abolished or replaced with laws that recognize the right to enjoy and exercise legal capacity. In addition to substituted decision-making mechanisms as mentioned above, this includes declarations of incapacity, interdiction, welfare orders, commitment to institutions, and compulsory hospitalization or medical treatment.*

*19. Similarly, any laws disqualifying a person from enjoying rights or performing legal acts or responsibilities based on disability must be abolished. For example, voting, holding public office, serving on juries, giving or refusing free and informed consent, inheriting or owning property, marriage and raising children, are rights guaranteed in the Convention that also involve an exercise of legal capacity. Support and/or appropriate accommodation must be provided where necessary to exercise these rights and responsibilities. The signatures of people with disabilities are entitled to equal recognition as those of others.*

*20. In implementing Article 12, governments must address its implications for criminal responsibility and the criminal justice system. Persons with psychosocial disabilities have an equal legal capacity with others to be held responsible for wrongdoing, whether through a civil, criminal or other process, and to be provided with all needed supports and accommodations to ensure access to justice and conditions of punishment that respect human rights and dignity. The death penalty and similar harsh measures must be abolished to ensure humane treatment for all.*

*21. Implementation of all aspects of Article 12, including the development and provision of support, needs the active involvement and partnership of people with disabilities and the organizations they choose to represent their interests (in particular, organizations of people with disabilities controlled by themselves). All those who seek the protection of the Convention within an evolving concept of disability should be welcomed.*