Good morning, my name is Inés de Araoz, and I am FEAPS legal adviser. FEAPS is a Spanish umbrella organization for persons with intellectual or developmental disabilities and their families, and a full member of Inclusion Europe, which then again is member of Inclusion International.

Firstly, I would like to thank the organization and especially Special Rapporteur on the rights of persons with Disabilities and Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, for the invitation to participate in this meeting.

1.- **What precisely do we mean by institutionalization**?  

An institution can be defined as “any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and day-to-day decisions. An institution is not defined merely by its size”. – Canadian Association for Community Living-

Inclusion International has found that when asked, people with intellectual disability choose not to live in institutions. Unfortunately, people with intellectual disability are often denied the right to decide where and with whom they want to live.

Self-advocates said: IN BARCELONA ...
 Few of us will choose an institution as a place to live. Support needs cannot override our wishes and wants of one's own life.

It is not unusual for institutionalization to include additional restrictions such non-consensual psychiatric interventions, physical and pharmacological restraints and isolation. We should not forget that in the most cases, the people in institutions are under guardianship too. It isn´t uncommon that they, specially women, are forced to use contraceptive methods, or, in extreme cases, they have been involuntary sterilized, or forced into abortion.

The institutions deny people basic rights of citizenship, personal control, personal privacy, decision-making and inclusion.

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In addition, we should not underestimate the personal cost of practices of disempowerment, segregation, neglect, maltreatment, hostility and discrimination that were described by the individuals as incalculable.2

2.- All people who live in institutions can live more successful and inclusive lives in community

Institutions do not need to exist to serve the needs of certain groups of people (There are experiences available in UK, Canada, USA, New Zealand, Norway or Sweden).

3.- But what does deinstitutionalization involve?

Deinstitutionalization is not just about closing institutions, it is not just about the removal of people from one environment to another. Deinstitutionalization is a complex process that must be based on a strong belief in the dignity of the institutionalized people.

It is necessary that States Parties develop strategies and an action plan for deinstitutionalization which provides an overall framework for guiding the reforms in social care and other systems towards3:

- The closure of institutions;
- The development of community based services; and
- Inclusive mainstream services.

Deinstitutionalization involves:

- Assisting people to leave institutions and take their rightful place in community.
- The development and provision of appropriate and adequate community and family based supports and services.
- Ensuring that people have services/programmes that are person centered, directed and controlled by the person and that are respectful of that person’s rights to make choices and take risks.
- Accordingly, States Parties must establish full recognition before the law of all persons with disabilities, prohibit the substitute decision-making and ensure that they are able to exercise, with support if needed, choice and control over their lives.

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4.- But we are concerned about:

- Institutionalization not perceived as a Human Rights violation. In fact, it is socially accepted and commonplace.
- There are many countries that are in the process of building new institutions or refurbishing and expanding existing ones. Others are increasing levels of expenditure on institutional care.
- There are countries that, despite of having a history of successful closures (i.e Canada, USA, UK), continue to invest in institutional models of supports.
- Austerity measures have reduced the budgets of local and regional authorities with direct consequences on the availability of social services. This has caused a trend towards institutionalisation in some UE Member States.
- In many countries, there is a lack of strong leadership and it is vital for a successful process.
- Persisting negative attitudes and low expectations which prevail in society, among many families, professionals and policy makers; and finally,
- Lack of adequate community-based housing and support options;

Thank you very much.

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4 Opinion of the European Economic and Social Committee on Long Term social care and deinstitutionalization (27/05/2015) http://www.eesc.europa.eu/?i=portal.en.soc-opinions.33311