Inclusion International’s Right to Decide Campaign
April 2013 – April 2014

The Right to Decide: Campaign Goal
The goal of the campaign is to advance the rights articulated in CRPD Article 12 and to support families and others to understand the implications of legal capacity for people with intellectual disabilities and how to support people with intellectual disabilities to make their own decisions.

Inclusion International’s Global Campaigns
Inclusion International uses global campaigns to provide a platform for the collective voice of people with intellectual disabilities and their families around the world on issues of importance to them. Since 2006, our members have raised their voices on Poverty (2006), Inclusive Education (2009), and Living and Being Included in the Community (2012). Through these global campaigns and reports, people with intellectual disabilities and their families have identified the exclusion, isolation and discrimination that they experience. They have also identified innovative solutions, policy and legislative reforms, and strategies to promote inclusion.

Voice and Choice
A common message in each of II’s campaigns has been the lack of voice and choice that people with intellectual disabilities and their families have. Without voice, they told us, we are invisible and powerless. For people with intellectual disabilities, too often their voice is restricted because they are denied the right to make decisions in their lives. Informally or formally they are deemed “incapable” or “incompetent”; they are penalized if they need support to make decisions.

In our most recent campaign on living and being included in the community, this was particularly clear. People with intellectual disabilities did not have control about where and with whom they live; landlords or other third parties wouldn’t let them sign rental agreements or utilities contracts. They are institutionalized against their will or living in places not of their choosing. In all regions of the world, people with intellectual disabilities told us that having control in their lives was essential to achieve their right to live and be included in the community.

In many countries people with intellectual disabilities don’t get to decide how they spend their time; are not allowed to control their finances, vote or get married; they are voiceless in their own lives.

Supporting and Empowering Decision Making
For all of us, our decisions are shaped and influenced by many factors. Decisions need to be realistic and reflective of an individual’s reality; they need to take our families and loved ones into consideration. When we live as a family unit our decisions have impact on others. Individuals and families have told us that while certain cultures recognize decision-making in terms of individual autonomy, many others emphasize group and mutual responsibilities.
Article 12 of the CRPD reflects a fundamental shift in thinking: It asserts that with support, all people with intellectual disabilities are able to make decisions and have control in their lives. Support can take many forms – this could include the provision of information in plain language, support to understand the options and consequences of decisions, extra time to make decisions etc. For people with more significant support needs and/or difficulties in communicating, support could be a network of people who express and articulate a decision based on the will and intent of the individual (Supported Decision Making). We know that for people with intellectual disabilities the main support they will get in making decisions will come from their families.

Our members tell us that often people with intellectual disabilities aren’t supported to develop decision making skills as they grow; that families lack the skills and tools to understand how to support their sons and daughters to express themselves and that guardianship is a way to “protect” them; that communities lack the mechanisms (legal and otherwise) to recognize supported decision making.

Supporting people with intellectual disabilities to make decisions is not just about changing laws – it’s about changing our practices and transforming communities and societal relationships. It’s about building capacity of individuals, families and communities.

**Objectives of the campaign:**

- Raise awareness about the impact of the denial of the right to make decisions.
- Identify models of support for families and individuals that enable people to control their own lives.
- Explore models of Supported Decision Making.
- Provide tools to families and individuals to understand decision making and how supported decision making works.

Building on the findings from our previous global campaigns, and through regional discussion groups with families and people with intellectual disabilities and studying global initiatives on decision making, II will be seeking to identify how governments and communities can:

- Support people to make choices in their everyday life about where and with whom they live
- Provide support to families in planning
- Promote person centered planning
- Secure access to supported decision making.
Methodology

- Case studies on Supported Decision Making (3 to 5 case studies in different countries on supported decision making) to be developed by Natalia Angel (visiting scholar)
- Regional and national family and self-advocates discussions groups (discussion guides and webinars)
- Stories/experiences of:
  - the impact of the denial of the right to decide; and
  - how people can/are supported to make decisions in their lives
- Review current legislative reforms and the implications for people with intellectual disabilities (review of existing literature)
- Review of CRPD Committee approach to, and interpretation of, Article 12

Get involved

- Share your stories and examples (on-line format). Tell us:
  - how supported decision making is being used – what is working; what are the challenges
  - about the importance of having control in your life
  - about decisions you have made
- Join our on-line consultation and webinars (to be announced)
  - Materials available on our website
- Organize a national or regional discussion group with families and/or self-advocates (discussion guides available on-line and webinars for facilitators to be announced)