

It's Not Independent Living Article 19 and The Declaration of Interdependence

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The heading of Article 19 of the UN CRPD “Living independently and being included in the community” is disconcerting to many families, and I think it is a misnomer.

Article 19 says “States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

Article 19's language is strong and clear, although it does not specifically call for closing institutions. However, its provisions cannot be implemented in the context of residential institutions. Article 19 (a), (b) and (c) are simply incompatible with institutionalization.

Article 19 is also interdependent with other parts of the CRPD, with everything from transportation, to respect for the person, to mobility, to education and so on. As with all people, the concept of interdependence is an important principle inherent to the CRPD. For example, Articles 3 and 26 of the CRPD support the concept of interdependence as well.

The whole idea of “independence” is culturally specific. In some societies we value the idea of an individual living alone (“making it on their own”). However, in many parts of the world, for all people in a culture, the extended family is seen as a support network and link to the community. The extended family may include people not related by blood or marriage. As with all people, people with intellectual disability experience community in a variety of ways, interacting and forming relationships with many different people.

To effectively implement Article 19 we need to stop telling families that people with intellectual disability are going to live independently. To many families, that sounds as if people will live alone and Article 19 does not call for people living alone nor does it call for people living without needed supports. Article 19 does not define independence as people living alone but, rather is about choices and control of one's life. Living alone is not the goal, though some people may prefer to live that way. But even people who want to live alone do not want to be lonely. Humans are dependent on other humans. Interdependence is a good thing, it is desirable. Multiple studies show that people with disabilities are all too often lonely. Studies also show that when you live with a lot of people who are not your family, you are more likely to be lonely than when you live with a few people. Study after study also show that we can help people with all levels of disability plan and take control of decisions large and small impacting their lives. We sometimes call this “person centered

planning and supports.” The goal of Article 19 and the CRPD is interdependence, self-governance and self-determination, not independence from other human beings. Article 19 is about people with intellectual disability being full citizens, people with meaningful and realistic choices and people with both rights and responsibilities in their community and in their nations. It is about the quality of life a person can enjoy when properly supported, not about how much support they need to live. For some people this interdependence means that they need support to exercise both their rights and responsibilities. Article 12 provides a framework for people who may need support with some or most decision making.

It is, of course, possible for people to be independent in performing tasks; e.g. dressing oneself, feeding oneself, getting around the community without support from paid staff or other people. The concept of independence as it relates to disability, comes from the tests and scales used to measure functioning: can a person dress independently, can a person make their meals without assistance, etc. Ability does not mean readiness for living in the community interdependently, however. We know how to support people to be interdependent, and in control of the major aspects of their lives, regardless of their level of disability. But for most people with and without disabilities, an important goal in life is meaningful relationships, friendships and community connections. In other words, interdependence.

The interdependence of human beings builds social capital, and social capital strengthens people and communities. Being part of a naturally occurring network, in a village, city or town, one to which people not directly connected to disability are part of, builds value for people with intellectual disability, and for families. It connects people with and without paid relationships. Being part of a community, being networked with other people fulfills so much of what the CRPD is all about.

So let's stop saying people are going to live *independently*. It scares families. It scares me.