

Outcomes measurement in the context of the UN Convention on Rights of People with Disability (CRPD)

Alixé Bonardi¹, Renata Ticha², Dorothy Hiersteiner¹, Valerie Bradley¹

1- Human Services Research Institute; 2- University of Minnesota Institute on Community Integration



Background

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) reflects an international set of agreed upon expectations about the human and civil rights of people with disabilities. The Americans with Disabilities Act (ADA) was the model for the CRPD, and the values of independence and respect and concept of reasonable accommodations are echoed throughout the treaty.

160 countries have signed the UNCRPD and the United States signed the CRPD in 2009. Signing the treaty means a country agrees to the principles of the UNCRPD. Ratifying it means that the country agrees to develop a way to monitor and report on the human rights status of people with disability and on progress toward goals. On December 4, 2012 the United States Senate considered the ratification of the CRPD but fell 5 votes short of the super-majority vote required (ratification of a treaty requires a 2/3 vote of the U.S. Senate).

The UNCRPD includes sections (Articles) describing a wide range of human rights. It also includes sections (Articles) that say countries should have systems to collect data and track outcomes for people with disabilities. Part of Article 31 states that countries should be able to 'disaggregate' data about people with disabilities. This means that countries should be able to describe the human rights situation for sub-groups of people, for example people with different types of disabilities, people of different ages, and people who live in different areas.

Article 31 – Statistics and Data Collection states that countries must:

- undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention....
- the information collected Shall be disaggregated, as appropriate, and used to help assess the State Parties' obligations....
- assume responsibility for the dissemination of these statistics...

Article 33 – the Convention requires ratifying states to have a disability policy monitoring system by designating "one or more focal points", a framework, including one or more independent mechanisms... to monitor implementation. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

National Core Indicators (NCI): an outcomes measurement tool for people with intellectual and developmental disability

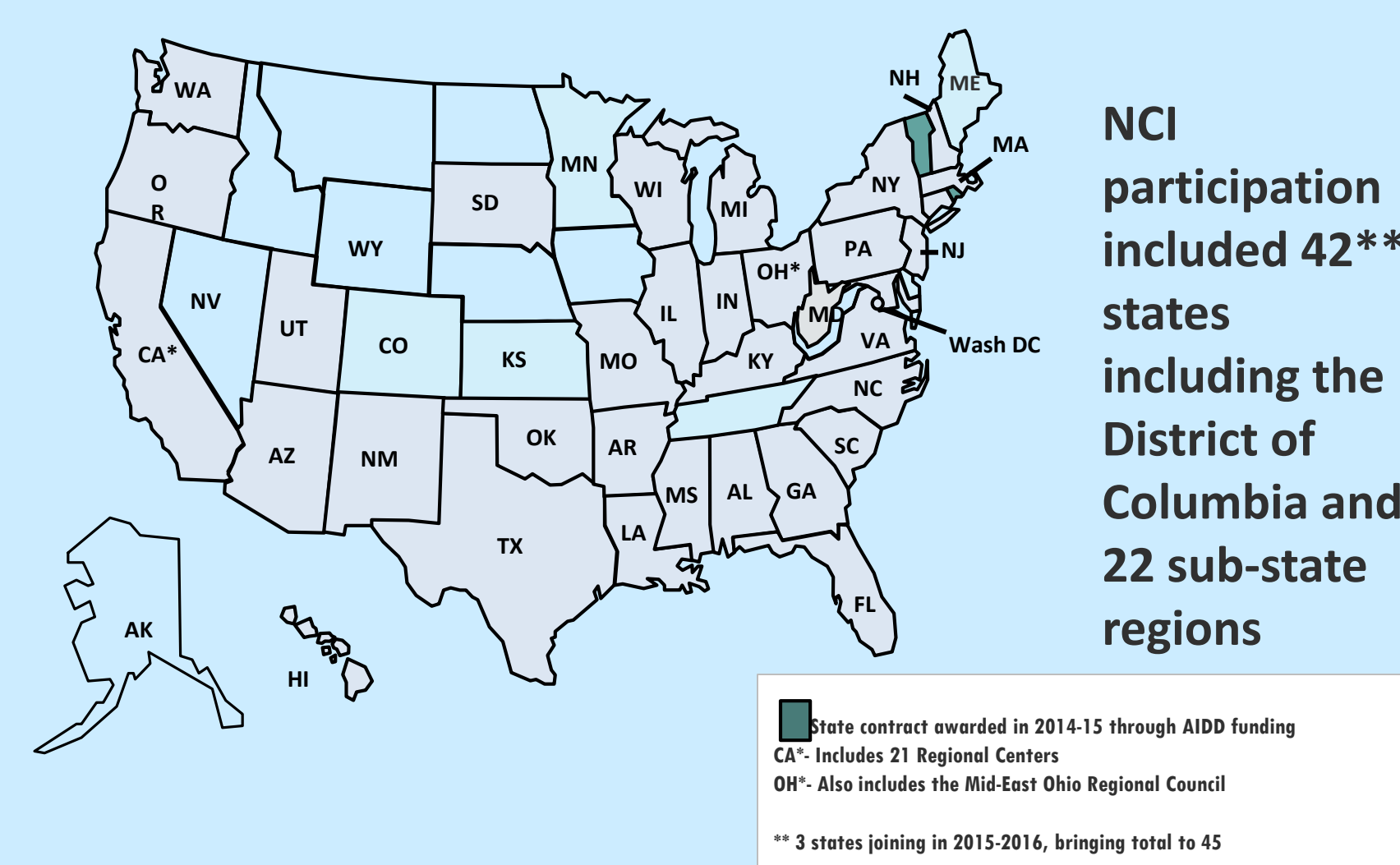
The NCI Adult Consumer Survey collects information directly from people with intellectual and developmental disability and asks them to report on their outcomes.

Participating states draw a representative sample from among all people with ID who receive case management plus at least one service in the state.

As a survey that covers a broad range of Quality of Life Indicators, including several human rights indicators, NCI provides a large, representative dataset. Three subscales have been developed to examine Choice³, Support-Related Choice Scales³, and Community Participation⁴.

Researchers explored the extent to which the National Core Indicators could answer questions about the outcomes related to the Human Rights Articles of the UNCRPD for people with intellectual and developmental disability.

NCI State participation 2014-2015



National Core Indicators and Articles of UNCRPD

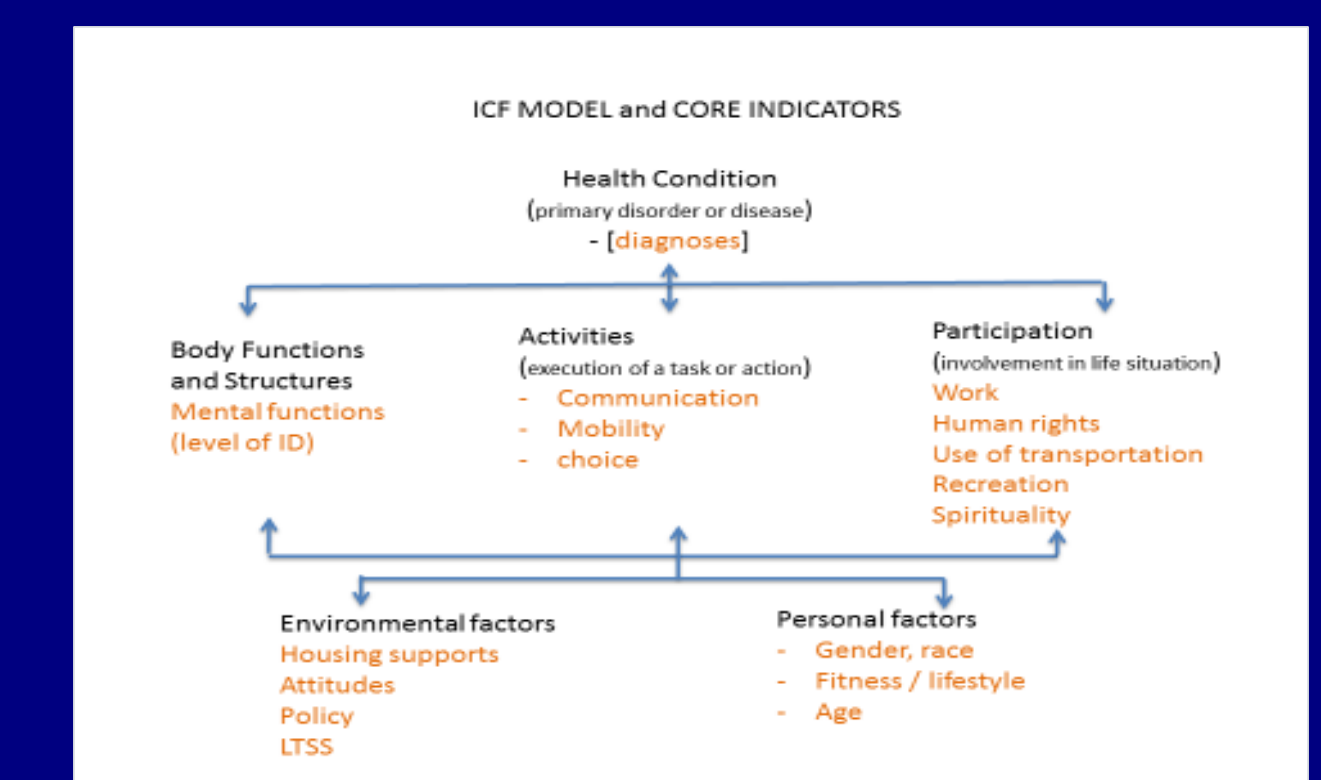
UN CRPD Article	NCI Indicator
Article 9 – Accessibility (Buildings, roads, facilities, communication)	The proportion of people who report having adequate transportation when they want to go somewhere. The proportion of individuals who report being able to use the phone/Internet without restrictions. The proportion of people who feel their support staff have been appropriately trained to meet their needs. The rate at which people report that they do not get the services they need.
Article 14 – Liberty and security of person	The proportion of people indicating that most staff treat them with respect. The proportion of people whose basic rights are respected by others. The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, what to spend money on, and social activities. The proportion of people who report that they feel safe in their home, neighborhood, workplace, and day program/ at other daily activity. The proportion of people who report having someone to go to for help when they feel afraid.
Article 19 – Living independently and being included in the community	The proportion of people who regularly participate in everyday integrated activities in their communities. The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, what to spend money on, and social activities. The rate at which people report that they do not get the services they need: If Does Not Get Needed Services Needs If Does Not Get Needed Services Needs Social/Relationships The proportion of people who can go out on a date if they want to. The proportion of people who are able to see their families and friends when they want. The proportion of people who have a close friend, someone they can talk to about personal things. The proportion of people who have friends and caring relationships with people other than support staff and family members. The proportion of people who feel lonely.
Article 25 – Health	The proportion of people in poor health The proportion of people who receive Medicare. The proportion of people age 50 and older who have had a screening for colorectal cancer within the past year. The proportion of people described as having poor health. The proportion of people reported as having a primary care doctor. The proportion of people who have ever had a vaccination for pneumonia. The proportion of people who have had a complete annual physical exam in the past year. The proportion of people who have had a flu vaccination within the past 12 months. The proportion of people who have had a hearing test within the past 5 years. The proportion of people who have had a routine dental exam in the past year. The proportion of people who have had a vision screening within the past year. The proportion of women 18 and over who have had a Pap test screening in the past year. The proportion of women over 40 who have had a mammogram within the past 2 years. The proportion of people taking medications for mood, anxiety, behavior problems, or psychotic disorders. The proportion of people who maintain healthy habits in such areas as smoking, weight, and exercise. The rate at which people report that they do not get the services they need: If Does Not Get Needed Services Needs health care The rate at which people report that they do not get the services they need: If Does Not Get Needed Services Needs dental care
Article 27 – Work and employment	The proportion of people who have a job in the community. Of people who have a job in the community, the average length of time they have been working at their current job. Of people who have a job in the community, the percent who receive vacation and/or sick time benefits. Of people who have a job in the community, the percent who were continuously employed during the previous year. The average bi-weekly earnings of people who have jobs in the community. The average number of hours worked bi-weekly by people with jobs in the community. The percent of people earning at or above the State minimum wage. The proportion of people who do not have a job in the community but would like to have one. The proportion of people who do volunteer work. The proportion of people who go to a day program or have some other daily activity. The proportion of people who have a goal of integrated employment in their individualized service plan. The rate at which people report that they do not get the services they need: If Does Not Get Needed Services Needs help finding or changing jobs

The National Core Indicators align with many of the sections (Articles) of the UN Convention on the Rights of Persons with Disabilities

- NCI can be used as a resource for monitoring status of rights of people with intellectual disability.
- As a tool that collects information directly from people with disability, it provides important validation of national or secondary data.
- National policy and cultural factors should be considered for widespread use beyond the United States.

How do NCI outcomes align with ICF?

The International Classification of Functioning, Disability and Health (ICF) is an internationally recognized framework for examining the interrelationships between the person, their social and physical environment, and how this relates to their ability to participate in their community. This interrelationship has been recognized as an important consideration in monitoring the rights of people with disability⁵.



Discussion and Next Steps

As a next step, researchers are considering the development of a 'Rights' scale for the NCI, incorporating NCI measures that align with human rights articles.

The NCI is developed to monitor service outcomes. In the US, it does not collect information from people with ID in the US population who are not receiving services. Monitoring on a national level would need a *sample frame* to include those who receive services and those who do not.

The NCI was developed for people with Intellectual Disability. The NCI-AD includes the ageing population and people with physical disabilities who are receiving services. These surveys have the same domains, and have a portion of overlapping questions and can serve as a companion tool, broadening the population being included in survey. Additional next steps involve developing an NCI-AD to UNCRPD crosswalk to further explore the NCI surveys as a potential source for monitoring of the UNCRPD.

References

³Lakin, K.C., Doljanac, R., Buyn, S., Stancliffe, R., Taub, S., & Chiri, G. (2008) Choice-making among Medicaid HCBS, and ICF.MR recipients in six states, American Journal on Mental Retardation, 113(5), 325-342
⁴Lakin, K.C., Ticha, R., Stancliffe, R.J., Larson, S., Taub, S., Engler, J., Bershadsky, J., & Mosley, C. (2014) Community participation of adults with intellectual and developmental disabilities receiving residential support in 19 states (submitted for publication) ⁵ Bickenbach, J. (2011) Monitoring the United Nations Convention on the Rights of Persons with Disabilities: data and the International Classification of Functioning, Disability and Health. PMC Public Health 11(Suppl4)S8