

Measuring Meaningful Outcomes for Individuals with Developmental Disabilities



Statement of Principles

The North Carolina Council on Developmental Disabilities (NCCDD) believes that individuals with intellectual and other developmental disabilities (I/DD) and their family members should receive the services and supports necessary to achieve fulfilling and productive lives. Evidence-based, person-centered outcomes that are meaningful to people with I/DD and their families must be adequately measured by providers and regularly evaluated by policy leaders in order to improve the quality and sufficiency of our state delivery system.

Every state must evaluate the manner in which services and supports are delivered. Too often, evaluation measures focus on the service delivery system in terms of what service is delivered, how much money is spent, the number of people served and whether people are “satisfied” with services received. Person-centered outcomes focus on independence and individual goals. System outcomes and person-centered outcomes must be evaluated together in order to best respond to the unique needs of people with I/DD and improve their lives.

Meaningful outcomes for individuals with I/DD include, but are not limited to:

- A home
- A job with competitive wages and a career path
- Transportation that delivers a person when and where they want to go
- Health and wellness
- Opportunities for pursuing an education
- Fulfilling relationships with loved ones, friends and neighbors
- Contribution to one’s community, including faith communities
- Receiving needed services and supports
- Safety and protection from abuse and neglect
- Choice and self-determination in life decisions
- Satisfaction with services and supports they currently receive

Measures of North Carolina’s capacity to support outcomes that matter to individuals with I/DD and families would include, but are not limited to the following service delivery system outputs:

- Access to necessary supports to find and maintain community integrated employment
- Access to accessible and affordable transportation

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- Access to needed health services and knowledgeable health professionals
- Support to participate in higher education, technical and/or vocational training
- Opportunities for social interaction, volunteering and membership in community groups
- Respect and protection from abuse and neglect in the community
- Services that are readily available to individuals who need and qualify for them
- Service coordination that is accessible, responsive and supportive of individual participation in service planning and community life
- A workforce where staff turnover ratios and recruitment and training absentee rates are low enough to maintain continuity of supports and efficient use of resources
- Listening to individual and family voice in making decisions and choices
- Assessing how supports have affected people's lives

National and state level data sources currently exist for person-centered and system level outcome measures for persons with I/DD.

The National Core Indicators (NCI) is a voluntary effort by public developmental disabilities agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcomes of services provided to individuals with I/DD and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice and health and safety.

There are also tools that focus on personal outcomes. The Council on Quality and Leadership's (CQL) Personal Outcomes Measures is an example. This set of measures asks individuals about quality of life in terms of health, housing, employment, relationships and involvement with the community.

Outcomes data drive policy and funding. State and local organizations should put the analysis of systems and individual data front and center as they make decisions about how services are provided. Involving self-advocates, family members and other I/DD stakeholders in the evaluation process will improve the state's ability to measure meaningful outcomes. With a clear focus on person-centered outcomes in the design and implementation of a statewide system, North Carolina can more efficiently and effectively match its resources with the supports people with I/DD and families need to achieve their life goals.

