

# Providing Long-Term Services and Supports to Individuals with Developmental Disabilities



**NCCDD**  
North Carolina Council on  
Developmental Disabilities

## Statement of Principles

Many states, including North Carolina, have shifted from a fee-for-service model to a managed care model for the delivery of Long-Term Services and Supports (LTSS). The State of North Carolina has elected to adopt a publically managed approach that includes individuals with intellectual and other developmental disabilities (I/DD).

North Carolina Council on Developmental Disabilities (NCCDD) recognizes the positive potential and risk of a managed approach in our State. This approach can not only control costs, but can increase access to services; allow for more flexibility in the services offered; and help to “rebalance” the service system away from an institutional bias towards a greater use of home and community based supports. These goals can only be achieved if the system is designed and implemented to match existing resources with the unique needs individuals, particularly those with I/DD and their families.

The diverse health and lifelong support needs of children and adults with I/DD and their families create distinct challenges to the successful implementation of service delivery within a managed approach to service delivery. The needs of people with I/DD are often highly specialized. These needs are for daily, consistent habilitation services across the lifespan. As a result, the way people use services and the cost of those services differs significantly from people with addictive disease and mental health needs, whose services are more episodic.

Therefore, as North Carolina implements its Home and Community-Based Services (HCBS) (1915 (b)(c)) Innovations Waiver statewide, it is essential that the principles below are incorporated into serving individuals with I/DD and their families.

**Community Living:** All people have the right to live in the community. The goal of the service delivery system should be to support this. This includes the responsibility to ensure that those who live in institutions and congregate settings have the services and supports necessary to offer them the same opportunity. Nationally, North Carolina is the 10th highest user of the costly Intermediate Care Facilities/Developmental Disabilities (ICF/DD) services. Over 1,600 individuals reside in state-run developmental centers—a rate 57 percent higher than the national average (2009). The average cost of serving an individual in a developmental center is \$175,000 per year, compared to \$92,906 in a community ICF/DD and \$61,291 for HCBS waiver services. Person-centered principles in a managed approach to long-term services and supports can create incentives for valued community living outcomes.

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**Consumer choice:** Managed-care systems must be designed to support and promote person-centered planning, consumer choice and consumer-direction that honor the preferences of the person and respect the individual's right to control his or her own life. Assuring that individuals and families have choices means having a diverse array of providers in the local networks, and a flexible array of services from which to choose.

**Diverse and Qualified Provider Networks:** People with I/DD may need services from specialists who are not adequately represented in the existing local network. LME/MCO's should recruit qualified direct service providers who have the expertise and capacity to serve individuals with I/DD. These networks should have sufficient numbers of providers to allow individuals with I/DD and their families to have a real choice. Providers should be routinely monitored and held accountable to local and state agencies to prevent abuse and neglect, recruit and retain qualified staff and deliver desired outcomes. Staff should demonstrate competencies in meeting the unique need of individuals with I/DD.

**Accountability Through Measured Outcomes:** The managed care system should be designed to be accountable to people it serves and the taxpayers that fund it. Accountability at the individual level means that people have services and supports that matter (e.g., having a home, a job, transportation, education, relationships). At a system level, accountability means that all eligible individuals are served (e.g., no waiting lists), available resources are distributed fairly, rate structures keep good providers in business, and administrative costs do not unnecessarily draw funds away from direct services and supports.

**Care Coordination and Community Guide:** Persons receiving supports and their families should have access to care coordination and community guide services that are individually focused, participant directed, and build on natural supports. Care coordinators and community guides should be involved, engaged and responsive to individual needs, and should have demonstrated competencies to support the outcomes and values that matter to individuals with I/DD and family members. The long-term system of services and supports should provide the appropriate compensation and administrative structures to allow these professionals to support individuals with I/DD to achieve personal outcomes.

**Employment First:** Employment in the general workforce should be the first and preferred outcome for individuals with I/DD, in a job of their choosing with supports and accommodations provided as necessary to achieve and maintain employment and reduce the disproportionately high unemployment rate (80%) among persons with disabilities.



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Individuals with I/DD want to work in integrated settings with everyone else. They want to have the same wages, benefits, and opportunities to advance careers, and contribute to society and the economy. This includes transition support to help individual students, families, and teachers think about and plan for life after high school.

**Family Support:** In North Carolina (2009), approximately 65% of individuals receiving HCBS services were living at home with families. Access to family support services complements the Medicaid services people receive, stretching public dollars further and adding greater access to community support. The LME/MCO should offer the opportunity for families to have easy access to information they need. Families should also receive training they need to become empowered to carry out their responsibilities for advocating on behalf of individuals with I/DD.

**Involving Self-Advocates:** Leaders at the state and local level must ensure self-advocates are fully engaged in the design, implementation and monitoring outcomes of the managed care model. These self-advocates should be actively included and asked to provide ongoing feedback on plan innovations and modifications.

**Due Process:** Individuals with I/DD should have a voice in the manner in which long-term services and supports are delivered and received. I/DD have unique needs that vary from person to person; therefore, long-term services and supports cannot be delivered in a “one-size-fits-all” manner. The appeals process allows individuals to advocate for services that best support and meet their unique needs. The process for making appeals regarding Medicaid services must be accessible and easy to understand. Many service recipients would like to voice their disagreement with provider decisions; yet, they find the process to be confusing and cumbersome. There is concern that people may be forfeiting their rights or voice in the decision making process because the process is unclear.

**Lifelong Planning:** The service delivery system must have the capacity and flexibility to support to persons with I/DD and their families as they age. Specific lifelong planning areas include financial and estate planning, health care directives, and understanding guardianship. Good delivery systems create incentives and opportunities for individuals to “age in place” in their own home and plan for long-term living arrangements.

**Resource Allocation and Individual Budgets:** The goal of a managed approach to long-term services is to develop individual budgets that are participant directed and responsive to individual assessed needs. The process for developing these budgets must meaningfully involve individuals with I/DD.



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**Individuals Waiting for Services:** As directed by HB916 (NC General Assembly, 2011), specific strategies should be in place at the State and local level to reinvest any savings in public dollars achieved through this model to expand services to the more than 8,000 individuals in North Carolina who need, but who are not currently receiving services and supports. As the population and demand for services continues to grow, this number will only increase over time.

**Serving those who are Dually Eligible for Medicare and Medicaid:** Individuals who are dually eligible – those who qualify for both Medicare and Medicaid-- must navigate two complex systems that have different rules, regulations, benefits, and providers. People who are dually eligible rely on Medicare to cover acute care and drug costs and Medicaid for their long-term services and supports needs. This creates unique challenges for managed care entities and care coordinators. State leaders must ensure that changes to the service delivery system within the 1915(b)(c) structure will integrate the services of the estimated 40% of individuals with I/DD who are dually eligible.

**Expertise in I/DD at State Level:** Responsibility for the oversight of the Innovations Waiver must include state personnel who have specific expertise in providing long-term services and supports to individuals with I/DD and their families in a managed care environment. Collaboration within the Department of Health and Human Services and with other state agencies and LME/MCOs is essential.

**Promote Statewide Innovations in Service Delivery:** As articulated by the North Carolina General Assembly, (HB916, NC General Assembly, 2011) the implementation of a publicly funded managed approach to long-term services and supports should actively promote innovation. This includes improving access to services, promoting better use of community resources, fostering public-private partnerships, offering supports more efficiently and broadening services that promote meaningful outcomes.

