

**Looking Forward:
A Summit on North Carolina's Developmental Disabilities System**

An Initiative of the NC Council on Developmental Disabilities

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Summit Co-Chairs

Senator Katie Dorsett

Representative Verla Insko

Robert J. Rickelman, Ph.D., Chairman, NCCDD

Summit Facilitators

Valerie Bradley, President, Human Services
Research Institute

Derrick Dufresne, Sr. Partner, Community
Resource Associates (CRA)

Michael Mayer, Ph.D., Sr. Partner, CRA

Preamble

We affirm that people with intellectual and other developmental disabilities are first and foremost citizens of our state and nation. We assert that all people--without exception--should have the opportunity to live, learn, work and retire surrounded by friends and family. To exclude a person from full participation in community life on the basis of disability denies individual rights, but also deprives the community of valuable talents, gifts, abilities and economic contributions.

For the common good, the State of North Carolina must extend the rights and responsibilities of full citizenship and the promise of inclusive, welcoming communities to all citizens with intellectual and other developmental disabilities. Our State motto, "Esse Quam Videri," "to be, rather than to seem," demands no less.

Purpose: The work of this Summit focused on those areas in which public policy can be changed in the near term by the Executive branch to realize the goal of full citizenship for all North Carolinians with intellectual and other developmental disabilities (I/DD).

Demographic and Economic Realities

Current Situation: North Carolina, like many other states, is facing fiscal challenges and demographic trends that will affect the state's capacity to expand community services. The stress on families and people with I/DD will likely increase as waiting lists for services become longer and more adults with I/DD find they must live longer, or even permanently, with aging caregivers. Without concerted intervention, current difficulties recruiting and retaining quality direct support

workers will be further exacerbated by the growing need for long-term services and supports of aging “baby boomers.”

Vision for the Future: Meeting these challenges will require an intensified look at the way resources are currently allocated across Local Management Entities (LMEs); an examination of whether each service provided is producing valued outcomes; and a hard look at the wisdom of continuing to support large public and private institutions. We envision a coordinated system that uses its resources efficiently and equitably to provide quality individual and family supports across the lifespan of people with I/DD.

Recommendations:

Incentives to Reduce Use of Congregate Services

- Revise statutes, eligibility and licensing rules to eliminate the connection between the place where a person lives and eligibility for and level of financial support (e.g., Special Assistance).
- Identify all individuals with I/DD living in adult care and nursing facilities and make this information transparent. Ensure that these individuals receive person-centered supports in the most integrated setting appropriate to their needs.
- Create incentives for the LMEs and the state to reduce the admissions to public and private congregate facilities.
- Prevent nursing home and “rest home” admissions of people with I/DD by supporting people to age-in-place; secure hospice care when needed; and connect with a “medical home” in their local community.

Employment and Economic Opportunities

- Assess the state’s reliance on congregate work and day settings and provide inclusive alternatives in the community, expanding Medicaid coverage as necessary.
- Afford people with I/DD control over the direction of employment supports.
- Disseminate information to people with I/DD with regard to employment and economic opportunities, e.g., information on rights and asset building strategies.
- Remove barriers to and provide incentives for public and private sector employment of people with I/DD.
- Increase coordination and collaboration among public employment and education programs--e.g., the Division of Vocational Rehabilitation Services, LMEs, high schools, community colleges and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS)--to facilitate employment, post-secondary education and other valued outcomes for people with I/DD.

Transitions from Congregate Settings to Homes in the Community

- Create financial incentives that assist LMEs and providers to transition people from ICF/MR-DD congregate facilities to homes in communities of their choice.
- Ensure availability and access, statewide, to specialized services, including: crisis; respite; behavioral; primary health; dental services; assistive technology; special vision and hearing supports; and health/wellness supports.

- Develop incentives for providers of congregate residential and day services to transition their agencies to the delivery of individualized housing and employment supports.
- Expand the availability of affordable, accessible, safe housing and home ownership.
- Ensure that the state rebalances the I/DD system in favor of a contemporary, community system of services and supports, utilizing such tools as the Centers for Medicare and Medicaid Services (CMS) “Money Follows the Person” demonstration grant. With rebalancing, provide direct support workers in institutions with opportunities and contemporary training for jobs in the community.

Viable Direct Support Workforce

- Establish statewide, competency- and values-based, portable training and certification requirements for direct support workers, front-line supervisors, and case managers. Develop a state level certification and career path for direct support workers, front-line supervisors, and case managers, based on the demonstration of these competencies.
- Fund, statewide, the “College of Direct Support” online training program to promote the mastery of core competencies by direct support workers and case managers.
- Provide financial support to providers to cover the costs of staff training; the payment of a living wage; and incentives for staff who develop specialized skills. Ensure that funds allocated for wages pass through to direct support workers.
- Work with community colleges and the university system to incorporate I/DD training into diverse, post-secondary curricula.
- Implement the recommendations in the Commission on MH/DD/SAS Workforce Development Report concerning direct support workers.

Infrastructure for Individualized and Valued Services and Supports

Current Situation: Key building blocks must be in place for a community system to be responsive, accountable, and financially sustainable. In the past several years, aspects of the state’s I/DD infrastructure—including case management, quality management, and service planning—have fallen into disrepair and have failed to keep pace with the demands of an increasingly complex and decentralized I/DD community system. Standardized expectations for case managers have dwindled; quality assurance has become generic; and service planning and resource allocation are far from being participant-directed. Strengthening these foundational building blocks is essential for an exemplary, contemporary system of services and supports for people with I/DD and their families.

Vision for the Future: We envision strong, knowledgeable I/DD leadership and enhanced collaboration among the public developmental disabilities system, private providers, LMEs, people with I/DD, and families. Collaboration will support the delivery of flexible and individually tailored supports that result in outcomes valued by people and their families. Improvements in the structure of the system will produce, e.g., more accountability and transparency; heightened outcome expectations; more efficient funding and allocation decisions; system-wide, coordinated monitoring and oversight; and the expansion of services and supports that are crucial to the stability of the community system.

Recommendations:

Quality Management and Quality Improvement

- Enhance planning by reinstating a comprehensive, statewide waiting list that is transparent and based on published criteria.
- Review licensure, endorsement, and provider quality standards to determine whether they adequately identify sub-standard provider performance and recognize excellent performance; delineate steps to improve performance; and, when necessary, eliminate sub-standard providers.
- Ensure that quality standards support the development of individual choice, person-centered practice, and self-determination.
- Create capacity at all levels of the system (DHHS and other state agencies that deliver services to people with I/DD, LME, provider, Consumer and Family Advisory Committee, individual) to use performance information to improve the delivery of services and supports; to track progress toward desired outcomes; and to support individuals and families in making informed choices about services and supports.
- Ensure that provider monitoring makes the most efficient use of resources and is not redundant or duplicative of other state or national accreditation or monitoring requirements.
- Ensure paperwork requirements maximize efficiency and that there is added value in these for people with I/DD and their families.

Case Management

- Establish case load standards for I/DD case managers that correspond to the recommendations of the National Case Management Association.
- Eliminate potential conflicts of interest where waiver and state-funded case managers are employed by direct service providers.
- Enhance accountability by ensuring strong communication and coordination between case management entities and LMEs.
- Explore new ways of organizing case management to standardize practice, increase accountability and eliminate conflicts of interest.

Funding Model

- Develop a funding allocation formula that takes into account population, inflationary increases and the long-term nature of I/DD services and supports.
- Establish an individual funding allocation model that accounts for all funds; corresponds to the intensity and complexity of an individual's needs; and allows for multiple funding tiers.
- Give individuals and families the support and tools necessary to control, within CMS guidelines, the use of an individual resource allocation or individual budget.

Person-Centered Services and Supports

- Ensure that service definitions for state-funded and Medicaid waiver services are designed to support individual outcomes and cost-effective service delivery.

- Review intake, access, and authorization procedures to determine whether these are user-friendly and result in the provision of services and supports that match individual needs; ensure that service authorizations and related decisions are made as close to the individual and family as possible.
- Ensure that resources are available to individuals to secure and maintain affordable, accessible homes in the community, along with the services and supports necessary to remain there.
- Promote inter-agency collaboration between the Department of Transportation and the Department of Health and Human Services to improve access to transportation across the state for people with I/DD.
- Ensure the inclusion of people with I/DD and families in all inter-agency, collaborative efforts impacting I/DD service delivery.

Intellectual and Developmental Disabilities Leadership, Expertise and Partnerships

Current Situation: Over the past decade, North Carolina’s I/DD programs have been consolidated, at the state and LME level, with programs for mental health and substance abuse. While coordination and collaboration is valuable, cross-disability system organization has resulted in the loss of a robust organizational unit whose managers are solely responsible for oversight of services and supports to people with I/DD. It has also weakened the ability of the I/DD system to empower and support people and their families. Given the highly complex demands of current I/DD systems, including the increased expectations of the CMS, and the life-long supports needed by people with I/DD and their families, there is a critical and immediate need for knowledgeable, experienced, I/DD-dedicated staff at the state and local levels.

Vision for the Future: With the strengthening of leadership and partnerships among professionals, families and people with I/DD at the state, provider and LME level, the recommendations envisioned in this consensus document will be more likely to be implemented. Further, strengthened leadership and partnerships will re-energize the I/DD system and community; assist with the dissemination of crucial information and knowledge regarding best practices; and help build the political will necessary to effect positive change.

Recommendations:

Empowering Individuals and Families

- Support revisions to the statutory base and regulations that reflect core concepts of intellectual and developmental disability policy and advance community inclusion and full citizenship for people with I/DD.
- Strengthen self- and family-advocacy through user-friendly training and information on access to services and supports, including entitlements and benefits. Ensure the full and meaningful participation of individuals with I/DD and their families in the state and local Consumer and Family Advisory Councils (CFACs).
- Review guardianship laws to ensure that the rights of individuals with I/DD are not unnecessarily abridged and that alternatives to guardianship are pursued whenever

possible. When guardianship is warranted, the principles of least restrictiveness should apply and guardians should be fully trained in laws applicable to guardianship, rights, and the principles of self-determination.

- Expand the opportunity for all people receiving services, regardless of their level of disability, to direct their own services.
- Employ people with I/DD as mentors to others with disabilities around such issues as self-determination; rights; employment; community inclusion; health and wellness; and training/mentoring for professionals.

Fostering Leadership and Innovation

- Actively recruit and hire state-level I/DD leadership with a proven track record in a state I/DD system of effectively implementing those practices and policies that result in outcomes valued by families and people with I/DD and that achieve accountability to funders.
- Develop, within each LME's senior management structure, a dedicated position for an I/DD specialist who is knowledgeable about core I/DD concepts and values; program access and eligibility; funding; and the provider network.
- Review, update and upgrade, as necessary, the personnel classifications for I/DD managers at both the state and local level.
- Provide substantial funding to expand and demonstrate competency in emerging and best practices within the field of I/DD and to develop new, or support existing,, "home grown" innovations that have an evidence base.