

Looking Forward:
A Summit on the Developmental Disabilities System
in North Carolina

An Initiative of
The North Carolina Council on Developmental Disabilities



Thursday, August 7, 2008
3:00 PM to 5:00 PM
Hilton North Raleigh

Letter from the NC Council on Developmental Disabilities

Over the next six months, the political landscape in North Carolina will change. There will be a new Governor, new members in the General Assembly, and new leadership in state agencies. The past few years have seen turmoil and change in the state's mental health, developmental disabilities and substance abuse system. With more change on the horizon, it is time for leadership concerned about the future of services and supports for people with intellectual and developmental disabilities (I/DD) to unite. We must work together to ensure the development, accountability and sustainability of a contemporary system that supports quality of life for people in communities across our state. In the recommendations of the Summit on Developmental Disabilities, "Looking Forward," we have an opportunity to create a pragmatic agenda for foundational change - an agenda for a new Administration. The NC Council on Developmental Disabilities seeks the support of leadership at all levels in establishing a common ground for going forward together.

In hosting the Summit, the North Carolina Council on Developmental Disabilities engaged key stakeholders from the advocacy, provider, and public sector in a series of discussions aimed at uniting leadership around a shared vision and common goals.

Summit participants have produced a pragmatic document offering core recommendations to the next Administration on the delivery of the high quality, responsive and sustainable services and supports that North Carolinians with intellectual and developmental disabilities (I/DD) and their families deserve.



Robert J. Rickelman, Ph.D.
Chair

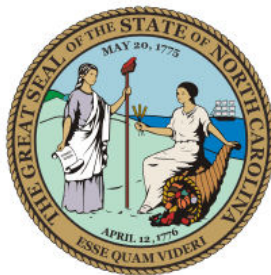


Holly Riddle, J.D., M.Ed.
Executive Director

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.



"To be, rather than to seem"

Summit Co-Chairs



Senator Katie Dorsett



Representative Verla Insko



Robert J. Rickelman, Ph.D.

Summit Participants

Rusty Bradstock*
 Adonis Brown*
 Carol Clayton, Ph.D.
 Connie Cochran
 Senator Katie Dorsett
 Jonathan Ellis*
 Sam Hedrick, J.D.
 Representative Verla Insko
 Joan Johnson
 Pat Keul
 Karen Luken
 Betsy MacMichael*
 George McCoy
 Stephanie Moultrie*

 Duncan Munn
 Ellen Perry*
 Patricia Porter, Ph.D.

 Azell Reeves*
 Dave Richard
 Robert J. Rickelman, Ph.D.*
 Holly Riddle, J.D., M.Ed.

 John Rittelmeyer, J.D.*
 Pam Shipman
 Rebecca Sorensen*
 Jack St. Clair
 Peggy Terhune, Ph.D.
 Martha Thompson
 John Whittle, J.D.

Member, NC Council on Developmental Disabilities
 Member, NC Council on Developmental Disabilities
 Member of the Public
 Executive Director, Easter Seals UCP NC
 NC General Assembly
 Member, NC Council on Developmental Disabilities
 CEO, RHA Howell
 NC General Assembly
 Charles Hines and Sons
 NC Assoc. for Persons in Supported Employment
 Project Director, Office on Disability and Health, UNC-CH
 Chairman, Developmental Disabilities Consortium
 Member of the Public
 Advisory Board, Center for the Study of Development and Learning, UNC-CH
 Member of the Public
 Association of Self Advocates of NC
 Director of Community Outreach, Allied Health Sciences, UNC-CH
 Chairman, Exceptional Children's Assistance Center
 Executive Director, Arc of NC
 Chairman, NC Council on Developmental Disabilities
 Executive Director, NC Council on Developmental Disabilities
 Disability Rights North Carolina
 Deputy Area Director, PBH Local Management Entity Board, Arc of NC
 Director, Cherry Hospital
 CEO, Monarch Services
 Executive Director, Liberty Corners
 NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services

*People with developmental disabilities or family members

Summit Facilitators



Valerie Bradley
President, Human Services Research Institute

Ms. Bradley has been the President of the Human Services Research Institute since its inception in 1976. She has headed numerous projects aimed at assessing and improving the quality and delivery of services to persons with intellectual and developmental disabilities. She acted as a principal investigator for the Pennhurst project, a longitudinal effort designed to assess the impact of system change, namely the closing of a state institution in favor of community placement. In conjunction with John Ashbaugh and Bruce Blaney, she edited a book on system change in the field of developmental disabilities titled *Creating Individual Supports for People with Developmental Disabilities*.



Derrick F. Dufresne
Founder and Senior Partner, Community Resource Alliance

As founder and senior partner of Community Resource Alliance (CRA), Mr. Dufresne has been offering insightful training and consultation services since 1982. Over the course of his career, he has delivered conference presentations, trainings, strategic board planning retreats, workshops, and management consultation to over thirty thousand people in forty-nine states. In 2003, Mr. Dufresne was named President and CEO of the Institute Public Policy for People with Disabilities. The Institute is a membership organization that focuses on promoting best practice and quality community supports for people with disabilities throughout Illinois.



Michael Mayer
Senior Partner, Community Resource Alliance

Prior to joining CRA, Senior Partner, Michael "Mike" Mayer, Ph.D. was the Executive Director of the Institute on Complex Disabilities for 12 years. He also has been providing cutting-edge training and consultation services internationally since 1990. Mr. Mayer is an internationally known speaker, consultant, and trainer. Over 400 local, state, and national organizations have benefitted from his unique approach, compassionate drive, and enlightening and dynamic presentations.

SUMMIT RECOMMENDATIONS

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.

SUMMIT RECOMMENDATIONS (Continued)

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.

SUMMIT RECOMMENDATIONS (Continued)

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.

What is a developmental disability?

According to the Developmental Disabilities Assistance and Bill of Rights Act (P. L. 106-402), section 102(8), "the term 'developmental disability' means a severe, chronic disability of an individual 5 years of age or older that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the individual attains age 22;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in three or more of the following areas of major life activity;
 - (i) self-care;
 - (ii) receptive and expressive language;
 - (iii) learning;
 - (iv) mobility;
 - (v) self-direction;
 - (vi) capacity for independent living; and
 - (vii) economic self-sufficiency.
5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided."

The North Carolina Council on Developmental Disabilities

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Sadie Barbour, Parent Advocate
Dempsey Benton, Secretary DHHS
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