
Technical Report

Valerie Bradley, President
Human Services Research Institute

Presented to the Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance Abuse
October 16, 2008

An Initiative of
The North Carolina Council on Developmental Disabilities
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.

The North Carolina Council on Developmental Disabilities

NCCDD MEMBERS
Lorri Anderson, Parent Advocate
Jennifer Angyal, Parent Advocate
Sadie Barbour, Parent Advocate
Dempsey Benton, Secretary DHHS
Rosemary Bernauer, Parent Advocate
Susan Boyd, Parent Advocate
Robert Bradstock, Self-Advocate
Adonis Brown, Self-Advocate
Dan Coughlin, NC Council of Community Programs
Senator Katie Dorsett
Jonathan Ellis, Self-Advocate
Travis Evans, Self-Advocate
Wilson Finks, Self-Advocate
Monica Foster, Self-Advocate
Himabindu Gattu, Parent Advocate
Linda Harrington, Division of Vocational Rehabilitation
David Horowitz, M.D., Parent Advocate
Representative Verla Insko
Tara Larson, Div. of Medical Assistance
Matty Lazo-Chadderton, Parent Advocate
Lee McCraven, Self-Advocate
Michael McNeill, Self-Advocate
Greg Olney, Ph.D., Center for Development and Learning, UNC-Chapel Hill
Randy Powell, Self-Advocate
Robert Rickelman, Ph.D., Parent Advocate
Kevin Ryan, M.D., Division of Public Health
Lawrence Shockey, Parent Advocate
Vicki Smith, Disability Rights North Carolina
Dennis Streets, Division of Aging and Adult Services
David Taylor, Jr., Self-Advocate
Leza Wainwright, Division of MH/DD/SA Services
Mary Watson, Dept. Public Instruction
Michael Whitley, Provider Representative
Jaimie Yahnker, Self-Advocate

EX-OFFICIO
Sherry Bradsher, Ex-Officio, Division of Social Services
Laura Yates, Ex-Officio, Dept. of Corrections

NCCDD STAFF
Holly Riddle, J. D., M.Ed. Executive Director
John McCallum, Asst. Dir., Quality Management
Larry Swabe, Asst. Dir., Program Management
JoAnn Toomey, Asst. Dir., Fiscal Management
Lynell Otto, Program Manager
Cora Gibson, Administrative Support Team
Brenna Keener, Administrative Assistant
Jason Laws, Program Manager
Jill Rushing, Program Manager
Melissa Swartz, Quality Management
Yadira Vasquez, Fiscal Officer

Building Bridges to Community
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."
Person-Centered Services and Supports

Developing a service system that provides person-centered services and supports has become the overarching goal of public developmental disabilities systems across the country. To understand the attributes of person-centered services and supports, in 2000, the National Association of State Directors of Developmental Services and the Human Services Research Institute – supported by a grant from Administration on Developmental Disabilities – convened a group of stakeholders, inclusive of the NC Council on Developmental Disabilities, to arrive at a consensus regarding the characteristics of any system that lived up to this goal. The following are some of those indices:

- People and families have authority over their lives and determine their own supports
- People control the money available for their supports
- There are brokers or agents available to individual and families to assist them to plan, secure and arrange supports
- There is support for relationships and community membership
- Individuals and families are invited, welcomed, and supported as full participants in system planning and decision-making
- Public systems are accountable, understandable, and responsive to people with disabilities and their families
- There is a resolve and continuous commitment to excellence and quality improvement
- There is universal access to community services and supports for all people and families who need them
- Relevant information and training opportunities are available to individuals and families
- A person-centered system works in partnership with all networks of support

In other words, a person-centered system of supports does whatever it takes to support individuals and families to live lives in their communities in ways that mirror the lives of their neighbors and friends. To elevate these principles in North Carolina, Summit participants made the following recommendations:

- 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 intellectual and developmental disabilities (I/DD).
- Ensure the inclusion of people with I/DD and families in all inter-agency, collaborative efforts impacting I/DD service delivery.

The need for a cadre of I/DD-dedicated staff at the state and sub-state (LME) level to direct and oversee the provision of services and supports to people with intellectual and other developmental disabilities is further heightened by the increased expectations at the Centers for Medicare and Medicaid Services regarding monitoring, data analysis and trending to insure that key federal assurances are met. In the past seven years, CMS has sharpened its state requirements and now expects states to generate data and evidence with respect to the performance of home and community based waiver services. Given that North Carolina currently serves more than 10,000 people in the waiver, maintaining a viable and transparent monitoring and data collection system is critical.

In light of the highly complex demands of the current I/DD system in North Carolina, there is an immediate need for knowledgeable, experienced, I/DD-dedicated staff at the state and local levels. This imperative is reflected in recommendations by Summit participants:

- 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.

Conclusion

The timing of this Summit coincides with the presence of serious and impending challenges to services and supports to people with intellectual and other developmental disabilities. The level of commitment among the diverse stakeholders who worked to generate comprehensive recommendations is testimony to their concern that the system in the State of North Carolina needs immediate reform. This confluence of consensus and events is something that policy makers and the next administration should note and use to create real change to benefit the lives of people with intellectual and other developmental disabilities and their families.
Managing funding at the person level hinges on developing funding methods that are service independent. The goal is to determine an amount of funding that attaches to the person and thereby is not contingent on “sloting” an individual into a particular type of service.

There are now a number of states that are employing assessment tools such as AAIDD’s Supports Intensity Scale (SIS) to determine an individual’s need for supports. Assessment results are then linked, via a formula, to dollars through either individual budgets or individual resource allocations (e.g., Georgia) or are linked to funding levels (e.g., Colorado, Oregon and Florida). The latter approach is being contemplated in North Carolina where the Supports Intensity Scale is currently being administered.

Summit participants addressed these concerns in the following recommendations:

- 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.

Fostering Leadership and Innovation

North Carolina’s I/DD programs have been consolidated at the state and Local Management Entity level with programs for mental health and substance abuse. The result has been the loss of a robust organizational unit whose managers are solely responsible for oversight of services and supports to people with I/DD and a series of cross-disability policy directives developed for all three target populations: mental health, developmental disabilities and substance abuse. These policies have not always been a good fit for the I/DD system. The effort to adapt policy and practice to fit all three populations simultaneously has weakened the ability of the state to provide targeted I/DD training and technical assistance to providers of these services. Further, the problems that have surrounded the mental health system over the past few years have consumed the energy and time of senior management in the Division. As a consequence, issues affecting the I/DD system – with the exception of several initiatives, e.g., the design of new HCBS waiver, the Money Follows the Person Demonstration Grant and Michael Smull’s Good to Great project – have been a low priority.

The State of Georgia reorganized the mental health, substance abuse, and developmental disabilities system several years ago in the same integrated fashion undertaken by North Carolina. Three years ago, recognizing the need for more focused attention to I/DD programs, an Office of Developmental Disabilities was created with sole responsibility for I/DD services. Since that time, the Office has developed an individual allocation formula based on individual functional characteristics and has upgraded quality assurance and quality improvement by contracting with a national Quality Improvement Organization certified by the Centers for Medicare and Medicaid Services.

Empowering Individuals and Families

The most powerful way to empower individuals and families is to reinforce and support their ability to make decisions about what services they receive and how the resources at their disposal should be allocated. This ability to direct resources to desired services and supports (participant-directed services and supports) is the embodiment of self-determination. As Tom Nerny, the director of the Center for Self-Determination in Michigan has written, the principles of self-determination are:

- Freedom to choose a meaningful life in the community
- Authority over targeted amounts of dollars
- Support to organize resources in ways that are life enhancing and meaningful to the individual with a disability
- Responsibility for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities
- Confirmation of the important leadership role that individuals with disabilities and their families must play in a newly re-designed system and support for self-advocacy.

To ensure that the choices and preferences of individuals are at the center of any plan of supports, there are several key components. The following ingredients were identified during the evaluation of the national Robert Wood Johnson Self-Determination Demonstration pilots in 2001, by the Human Services Research Institute:

- Individual budgeting
- Personally-controlled planning process, with support from family and friends
- Help from a broker or personal assistant to locate and access supports
- Use of a financial intermediary to processes payments to support staff
- Choice of providers who work for the individual

To construct individual budgets, states – as noted above in the section on Funding Model – have created resource allocation strategies that result in assigning funding based on individual characteristics and needs. Georgia is one of the most recent states to create individual budgets using individual functional levels as part of a formula to set the level of funding. New Hampshire, for many years, has given individuals with developmental disabilities the ability to direct their own resources. In Connecticut, the state has established individual support agreements that allow people to move resources among services and supports.

To provide impetus for self-determined services and supports, states must insure that there is a regulatory and statutory foundation that supports this policy direction. The Beach Center on Disability at the University of Kansas has conducted both extensive qualitative research with disability advocates and legal research with respect to constitutional law and federal statute to identify core concepts of developmental disability policy. This work was conducted in part in North Carolina under a grant from the NC Council on Developmental Disabilities. The core concepts of disability policy are:
The Olmstead decision made clear that placing people with disabilities in institutions where they didn’t belong was not just the wrong thing to do but was constitutionally unacceptable. The work of the Beach Center in translating these concepts into practice and policy standards provides a tool that states may use to, e.g., align the statutory base with contemporary, evidence-based policy. The state should also be prepared to support self-determination and empowerment through training, technical assistance and reform of current policies and processes that constrain individual freedom and that disproportionately shift power that should reside with individuals and families to the system and to providers.

- 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.

Incentives to Reduce Use of Congregate Services

In the landmark Olmstead v. LC and EW decision, the United States Supreme Court affirmed that, under Title II of the Americans with Disabilities Act, states are obliged to operate their programs for people with disabilities in a manner that ensures that individuals receive services in the most integrated setting appropriate to their needs. As a practical matter, “most integrated setting” means that individuals are supported in community settings that are as similar as possible to typical living arrangements for people without disabilities. The decision also established affirmative expectations for the transition of people from institutional settings to the community. Not too long ago, large congregate facilities (i.e., settings where seven or more people are served) were the default setting for the majority of individuals served by public developmental disabilities systems. Twenty years ago in the developmental disabilities field, the majority of individuals served were in large congregate settings. In 1987, only 27.3 percent of all people nationally who received residential services were supported in living arrangements for six or fewer people. About one-half of all individuals were served in very large settings accommodating sixteen or more individuals.

Payments to organizations that furnish specific types of services should also take into account differences in individual support needs as well as provider costs. This funding framework goes hand-in-glove with de-emphasizing categorical approaches to service delivery to stress person-centered, individualized models of supporting people with disabilities. Smith and Fortune, 2007

According to a monograph by Gary Smith and Jon Fortune, Human Services Research Institute, published by the American Association on Intellectual and Developmental Disabilities (AAIDD) in 2007, the emerging framework for funding community services has the following elements:

- Funding should be allocated at the individual level, not the program or service level.
- Allocating funding at the person level enhances the capability to develop individualized support strategies, contributes to portability, and promotes individual choice.

Funding Model

There is growing interest in tying public funding for community services and supports for people with intellectual and developmental disabilities to the individual’s functional characteristics and support needs. This interest stems from several factors, including achieving greater equity in funding among individuals; making the most efficient use of limited public dollars; promoting flexibility in the selection of services; and, most recently, affording individuals and families the opportunity to directly manage their own resources through an individual budget. All other things being equal, people who have greater support needs require more resources to live successfully in the community than others with lower support needs. The challenge lies in developing the methodology to link support needs to the funding of community services.

Shifting to funding approaches where individual support needs play a larger, more decisive role involves decreasing the weight that “system factors” carry in the funding equation. System factors can include historical differences in payments to providers of the same type of service; inappropriate differentials in payments for similar services (e.g., higher payments for group home services versus services and supports for people who live in a home of their own); and distortions in service authorization policies and practices. The less these system factors impact the costs of services, the more weight will be given to the individual’s support needs in the funding equation.

The Olmstead decision made clear that placing people with disabilities in institutions where they didn’t belong was not just the wrong thing to do but was constitutionally unacceptable.
In the 21st Century, there are five functions that case managers will play: 1) administrative (including QA); 2) problem solving and crisis management; 3) consumer empowerment; 4) individual advocacy; 5) systems advocacy. Amado, et al., 2005

Institute on Community University of MN

- 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

As systems of services and supports become more decentralized, the ability of state I/DD agencies to monitor services directly is diminished. This makes the role of the case manager a critical one in assuring the well-being of individuals; facilitating choice and decision making; and monitoring the provision of services based on approved Plans of Care. Given the centrality of the case manager to quality services and supports, it is crucial that these individuals receive sufficient training; have time to monitor the status of each person on their case load; and are free to advise individuals regarding choice of services in an unbiased fashion.

Case managers are also the “boots on the ground” to ensure that CMS quality assurances regarding the conduct of the state’s Home and Community Based Waiver(s) are met. This is particularly important function has encouraged states like Connecticut to develop standardized procedures for all case managers to use, including templates for reviewing Plans of Care, ensuring that services in the plans are delivered, and for conducting risk assessments. Such templates generate data that can be aggregated at the state and sub-state level.

The issue of case management independence is crucial given their role as the individual’s advocate and service facilitator, as well as monitor for service delivery. There continue to be some states, such as North Carolina, where individuals who are employed by agencies that provide direct services also provide case management. Such dual loyalties potentially threaten objectivity and can place the case manager in a difficult position when his or her responsibilities to the consumer come in conflict with the interests of the employer. In a recent study for the State of Colorado, conducted by Maureen Booth and Eileen Griffin at the Institute for Health Policy, Muskie School of Public Service, the authors outlined problems inherent in ceding to a provider of direct services those functions that entail monitoring, individual advocacy, and quality assurance. They recommend a variety of techniques to

including 95,000 people who resided in very large, state-operated public institutions. By 2007, 72.8 percent of all people nationwide were supported in living arrangements for six or fewer people; a comparable number of people in North Carolina are supported in such settings. However, in eleven states (AK, AZ, HI, OR, ME, MD, NV, NH, NM, RI, and VT), 90 percent or more of individuals were served in small living arrangements with six or fewer people. Nationwide, only 14 percent of all people were served in very large settings with sixteen or more beds (public and private ICFs/MR and other congregate settings). In North Carolina, the proportion of people in such settings is 20.6 percent.

Nationally, the number of people served in public institutions fell to under 36,650 in 2007—a reduction of 71.7% since 1990. North Carolina has also relocated individuals from developmental centers into community alternatives, reducing the population from 3,102 in 1980 to 1685 in 2007—only 46.4 percent decrease. The steady, marked decline across the US in the use of large and very large residential settings over the past twenty years is the product of several factors, including litigation focused on sub-standard conditions in very large public facilities, the expansion of community services, and a community integration imperative that presses for people to be given the opportunity to live in the community with the support they need, much like other citizens.

Today, in the United States, the best practice benchmark for supporting people with intellectual and other developmental disabilities in the most integrated setting are settings where six or fewer people share a living arrangement in community settings, not ICF/MR facilities. Most states have reconfigured their service systems so that the vast majority of individuals are now supported in settings that meet this benchmark.

In an analysis of factors associated with expenditures for Medicaid Home and Community Based (HCBS) waiver services (e.g., North Carolina’s CAP/MR/DD waivers) and public and private Intermediate Care Facilities for Persons with MR services (ICF/MR), researcher Charlie Lakin et al. found that HCBS services, including other Medicaid services and costs of housing, were substantially less costly than ICF/MR services for individuals with similar characteristics. Expenditures for HCBS recipients in congregate-agency operated settings were 50.7 percent less than the average expenditures for persons living in ICFs/MR. Costs were even lower for HCBS waiver recipients who were living with parents and other relatives and adults living in “host-family” (family, foster, shared living) arrangements. In addition to the social benefits that accrue to people receiving services in the community, this 2008 study suggests that substantial financial benefits accrue to states that undertake a rebalancing of ICF/MR and HCBS waiver services for people with intellectual and other developmental disabilities.

Summit participants addressed these concerns in the following recommendations:

- 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

The goal of achieving integrated employment and economic opportunities for people with developmental disabilities is still an elusive one. However, we have, in the past few years, begun to understand some of those contextual factors that contribute to success. John Butterworth from the Institute on Community Inclusion in Boston completed a case study last year in which he highlighted the components and conditions that were present in states that had accomplished better than average achievements in creating jobs and economic independence for people with developmental disabilities. The states studied were Colorado, New Hampshire and Washington. According to Butterworth, each of these states posited clear goals and objectives regarding employment; had an unwavering commitment to training and technical assistance in support of the goals; offered flexible and individualized supports; had explicit values about the importance of employment; and included a cadre of leaders at all levels of the system that were committed to supporting community inclusion and employment.

With respect to policies, there were several factors that appeared to explain the progress these states had made toward their employment goals. Specifically, each of these states had policies that gave providers the flexibility to innovate and initiate new ways of providing employment supports. Such flexibility made it possible for providers to explore new ways of providing employment supports through such approaches as microenterprises—an approach that assists individuals with developmental disabilities to create their own businesses. This approach is undergirded by the primacy in each of these states of the goal of employment and economic self-sufficiency. Flexible policies were also coupled with flexible funding. Such flexibility in allocations— including start-up funding— allowed providers in the case study states to shift funding as needs changed and to move funding over time from segregated sheltered settings to more integrated, individually tailored employment supports. In addition, these exemplary states also found ways to provide informal and formal incentives to reward providers that were successful in meeting the state’s goals. Such incentives included expanded flexibility as well as increased block grant funding.

These states also matched their rhetoric regarding goals with systems designed to measure the outcomes of their policies. In each state— particularly in Washington— benchmarking of progress was a powerful goal to continued improvement. Finally, all of these states made a concerted effort to disseminate information on best practice, to provide technical assistance and to mount continued training regarding the implementation of employment supports. All in all, this overview of successful practices strongly suggests the importance of a coordinated effort at the state level to emphasize the goal of employment while putting in place the policies and supports that will stimulate best practice at the provider level. It should be noted that these practices are being disseminated as part of the Supported Employment Leadership Network initiative of the National Association of State Directors of Developmental Disabilities Services.

In its oversight role, CMS will focus on each state’s system to assure and improve quality. As such, CMS’ approach will use information provided by the states, derived from their [states’] internal self-monitoring activities, as a primary source of information. This approach provides a more efficient and effective assessment of waiver programs by CMS. CMS, 2004

Because Medicaid Home and Community Based Services (HCBS) Waiver funding is critical to the support of services to people with intellectual and developmental disabilities, recent changes in expectations from CMS regarding quality management have meant that state Medicaid and I/DD agencies have been challenged to increase the rigor of their monitoring and their ability to track and trend system performance. I/DD agencies must, for example, show that problems have been ameliorated and demonstrate that providers are competent to provide services.

Further, as systems of services and supports become more complex, there is a need to use performance and other data to project needs for services over time. Such performance and data sets establish the extent to which funded services supply the expected value and whether access to services is equitable across the state. One important data element for future planning and to ensure equity is the maintenance of a waiting list that contains accurate and up-to-date information about service need. Best practice suggests that a tested instrument be used, such as the Prioritization of Urgency of Needs Survey (PUNS) in Pennsylvania, a tool that ranks people in terms of the immediacy of their needs for services.

Another rich source of information for future planning and for monitoring system performance is that data collected as part of National Core Indicators (NCI). North Carolina is currently a participating state in the NCI and collects data from consumers and families using standardized instruments. The results can be compared to national norms. There are also additional NCI indicators that could be used in North Carolina to assess the status of the system, including indicators specific to systems performance, staff turnover, mortality rates and employment. In some states, consumer advisory groups have used such data sets to assist in their work with policymakers.

The recommendations, below, from Summit participants speak to the impact of these national trends for North Carolina.

- Enhance planning by reinstating a comprehensive, statewide waiting list that is transparent and based on published criteria.
• Meeting the need for comprehensive training of DSPs to ensure knowledge, skills, and competence in provision of care to consumers and families.

Drawing on best practices implemented in other states, Hewitt et al. suggested several immediate steps to ensure a stable workforce in the future. First, they recommended that the state create a permanent interagency/stakeholder group to collect data, monitor turnover and recruitment, and set goals for wages and benefits. In addition, the consultant team suggested that North Carolina develop a voluntary certification program for DSPs based on national education and training requirements. In this vein, the NC Council of Community Support Providers is piloting the internet- and competency-based DSP curriculum, the College of Direct Support under funding from the NC Council on Developmental Disabilities. The College of Direct Support has a proven track record of reducing staff turnover, thus reducing hiring and training costs for service providers. Similar efforts have been mounted in Ohio and Kansas. Further, the team recommended that North Carolina assure that DSPs make a living wage including the creation of a built-in, yearly cost-of-living increase for DSP salaries.

To publicize the importance of direct support work, the report recommends that the state renew its commitment to a public awareness campaign to both improve understanding of the contributions and value of direct support work and also to encourage people to seek careers in direct support. The consultants further emphasize the importance in introducing providers in the state to evidence-based practices in retaining and recruiting staff as well as training managers and supervisors regarding proven and productive supervisory techniques.

The report also urges North Carolina to find ways to empower DSPs by including them in policy-making efforts and giving them access to state-level and national professional organizations. Also stressed are the importance of providing DSPs with health insurance and the potential of emerging self direction approaches to make it possible for individuals to choose to direct their own staff. The Summit recommendations are a strong endorsement of the Workforce Report and include additional complementary proposals.

• 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.

Quality Management and Quality Improvement

Public managers at the state and sub-state level are responsible for the management of systems of services and supports for people with intellectual and developmental disabilities. A critical aspect of this responsibility is the assurance that such services provide value for money spent, meet the needs of the individuals and families who receive them, and are in keeping with statutory and policy

With respect to economic security, some states are employing asset-based strategies that are tailored to disadvantaged individuals generally, not just people with developmental disabilities. Specifically, states are beginning to look at the possibility of using Individual Development Accounts (IDAs). IDAs are part of a federal program that, coupled with state funding, allows disadvantaged individuals to set aside funds for such expenditures as housing, starting a business, and education. In addition to these federally sanctioned applications, states may expand the potential use of IDAs to other purchases. These savings are not counted against public benefits eligibility and are matched by federal and state funds. North Carolina is, with a growing number of other states, exploring strategies to expand opportunities for people with disabilities to acquire and preserve assets through a grant from the NC Council on Developmental Disabilities to the state’s IDA and Asset Building Collaborative.

In line with these national trends, Summit participants recommended the following:

• 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

“Deconstructing” congregate settings means insuring that the necessary supports and specialized services are available across the state. One key resource is housing. Best practice requires us to think differently about the role of housing in relationship to people with disabilities. It is important that we separate housing from supports instead of funding “one size fits” all residential services. We need to view housing as an issue that affects all people in communities not just people with disabilities. This requires the development of regular houses in regular neighborhoods. In multi-family settings, the proportion of residents with disabilities should not be kept out of proportion to other residents in the complex nor should people with developmental disabilities be segregated with other disadvantaged groups such as low-income elderly.

There have been significant innovations in housing that can be modeled and expanded upon in North Carolina. For instance, Bob Laux from Creative Housing in Maine developed hundreds of units of housing for people with (People with disabilities) have a potentially much wider range of housing options available to them than is recognized by most human service agencies... . These options are attainable through a vast array of ownership arrangements and financing alternatives... . the same ones available to the (people without disabilities). Bob Laux, 1986

Bob Laux, 1986
developmental disabilities using generic housing funding such as Section 8, low-income housing tax credits, and Community Development Block grants. Sid Blanchard, a provider in New Jersey, has made creative use of low-income housing credits to provide integrated housing scattered throughout the community. Jean Bowen of Connecticut has worked with local affordable housing developers to develop affordable condominium projects that allow people with disabilities both physical integration and social integration in typical community housing. We need to build on examples such as these and work with affordable housing advocates, state housing agencies, banks and other generic committee providers who understand housing as housing.

In North Carolina, there is a promising housing initiative. Since 2002, the state’s Housing Finance Agency (HFA) has partnered with the state’s Department of Health and Human Services (DHHS) to facilitate the inclusion of persons with disabilities and homeless populations within Low-Income Housing Tax Credit (LIHTC) developments. In 2002 and 2003, substantial bonus points were made available through the Qualified Allocation Plan (QAP) to housing developers that targeted 10% of the units in their developments to these populations. In 2004 and 2005, the QAP made the 10% set aside of units for extremely low-income persons with disabilities, including homeless persons with disabilities, a threshold requirement.

To receive the bonus points, developers were required to partner with a Local Lead Agency (LLA) to develop and submit a Targeting Plan (this became a post-award requirement in 2005). The Targeting Plan must outline how the development will work with the LLA and other local human services agencies to make the units available to the target population. DHHS staff has been working in local communities since the spring of 2005, bringing together local partners to implement Targeting Plans for each development.

Another important resource to maintain individuals in non-congregate settings is community crisis supports. Best practice requires a community-wide strategy that covers multiple entities. One such services is the Commonwealth of Kentucky Crisis Services. The intent of these services is to provide the supports in the least restrictive/most integrated setting appropriate to meet the needs of individuals. The target population is those at risk of being deemed unable to remain in their home or community due to a behavioral or psychiatric emergency. These services are extraordinary supports to be used when other supports have been attempted or exhausted. Some of the elements of the approach include: state-wide training for all providers on crisis prevention; early intervention and first responder training; prevention services, including training and technical assistance as well as a 24-hour crisis line in each region to provide assessment and triage; development of working relationships with first responders; intensive case management; and 24-hour crisis response.

North Carolina has taken a positive step forward towards building a state-wide crisis intervention system by initiating implementation of Joan Beasley’s START model in key sites around the state. START is a systematic approach to crisis intervention that mobilizes an individual’s community network to support resolution of difficulties. START employs diagnostic work and crisis prevention, specific to both an individual’s environmental and psychiatric support needs, to prevent crises from occurring while improving quality of life. START’s credo is that crisis prevention plans are the key to proactive intervention. The crisis prevention plan serves additionally as a working agreement among providers that clearly delineates roles and responsibilities.

In the white paper "Going Home - Keys to Systems Success in Supporting the Return of People to Their Communities from State Facilities," Dennis Harkins of A Simpler Way and Robin Cooper of NASDDDS outline a variety of resources and strategies North Carolina might consider as it continues to work towards supporting people to return to community from state facilities. The purpose of the paper, funded by the NC Council on Developmental Disabilities, was not to suggest that North Carolina emulate any particular state’s strategy. Rather, the report illustrates that states with no greater and, arguably, less capacity than North Carolina have been successful in effecting significant census reductions in large ICFs/MR. The report, which builds on the research of Susan Parish, UNC-Chapel Hill, outlines potential strategies the state may consider as it continues its efforts to assist individuals to transition from state facilities and private ICF/MR facilities to their communities and to enhance quality of life while doing so.

The recommendations from the Summit touch on these issues:

- 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

One of the lynchpins of a sustainable system of services and supports to people with developmental disabilities and their families is the presence of a robust and competent workforce of direct support professionals (DSPs). That goal in North Carolina and elsewhere is proving to be elusive. In a report prepared under funding from the NC Council on Developmental Disabilities by Amy Hewitt, The Institute on Community Integration in Minnesota, and her colleagues, several workforce challenges were noted:

- The ability to retain existing DSPs.
- The projected significant increase in the demand for DSPs in the face of employee shortages.
- A high turnover rate that compromises care for consumers, adds to provider costs, and increases the demand for replacement workers.
- Low wages and extremely limited access to health care insurance and other benefits for DSPs. Direct support workers are paid near poverty level wages and make less than the federal poverty level for a family of four; many do not have health insurance or depend on Medicaid.