

North Carolina Developmental Disability Services and Supports: Steps to System Improvement

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The category of intellectual and developmental disability (I/DD) includes a large and diverse population. Individuals with cerebral palsy, intellectual disability, autism, severe learning disability, and those with other disorders that occur within the developmental period and meet the functional criteria are classified as intellectually or developmentally disabled. In North Carolina, I/DD also includes individuals who have suffered traumatic brain injury regardless of their age at the time of occurrence. Like those without disabilities, persons with I/DD aspire to achieve optimal health and wellness, but their needs extend beyond this. They want to choose where they live and who they live with. They want to be supported to obtain and maintain jobs that are satisfying and jobs that give them a competitive wage. They want access to education and recreation and the rights of full citizenship. Thus, the goals of the state-supported system of services and supports for its citizens with I/DD must be much broader and more comprehensive than health alone.¹

In addition to medical and dental care, special therapies, behavioral intervention, assistive technology, and other specialized services, options for the I/DD population should include housing, work, recreation, and community participation regardless of where they live in the state or the extent of their disability. People with I/DD prefer these services be delivered as close to home as possible and, most importantly, they want to have the final determination of what services they receive and who delivers them. They want to count on a well-trained workforce and want to be able to review quality measures across service providers in order to make informed choices.² It is the responsibility of the state, in a transparent and fiscally accountable manner,

to construct a system that assures safety, high quality service access, consistency, and equitable distribution of resources to address these needs in a way that is congruent with the shared philosophy, values, and mission of the disability group as well as being consistent with best practices.

North Carolina has a history of providing both a strong and robust system of services for persons with I/DD and a cadre of well-trained and experienced developmental disability professionals. These individuals have acted in partnership with recipients of services and their families, service providers, advocates, sister agencies, and other stakeholders to establish a solid infrastructure. That

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infrastructure should meet the goals of safety, physical and mental health, independence, productivity, authentic community participation, and a self-determined life for all citizens with developmental disabilities in our state. The state is also fortunate to have a broad array of dedicated providers of service, an exceptional Developmental Disabilities Planning Council, an independent protection and advocacy agency, a strong self-advocacy movement, and active

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partnerships with universities and community colleges. Our state developmental disability centers have responded to the need in our state by moving from life-long residential care to the creation of model demonstration programs for the most difficult-to-serve individuals. They serve as internship, research, and training sites for physicians, allied health professionals, educators, and counselors and as an education and training resource for direct service providers. In other commentaries in this issue of the *Journal*, authors describe extraordinary efforts ongoing with and on behalf of persons with I/DD across this state.

However there is no doubt that the recent fiscal crisis and subsequent state and federal budget cuts will have a dramatic impact on persons with I/DD and their families. This is further complicated by the fact that, unlike for behavioral health, private insurance rarely covers the broad array of I/DD services, and government is overwhelmingly the sole payer for this community. Questions have been raised as to whether the state system is sufficiently equipped to navigate the upcoming rough waters in ways which will best benefit individuals with I/DD who are in need of services and supports.³

Even before the current financial downturn, mental health reform in North Carolina brought significant changes in the system of services for people with I/DD. The Reform Act of 2001⁴ declared the state's policy of advancing the dignity, rights, and responsibilities of citizens affected by disability and of maximizing their quality of life. The intent of the Reform Act was to move to a more locally-managed system with services delivered by the private sector. Implementation was left to planners in the Department of Health and Human Services (DHHS) who sought to structure a system with less dependence on institutions and more on community-based programs, and to increase consistency across the state to assure that individuals could access quality services regardless of where they lived. Private providers of services were also assured that their contracts with Local Management Entities (LMEs) would not vary from local program to local program.⁵

Prior to the reform, the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS) was structured into sections, each with its own particular focus: mental health, substance abuse, and developmental disabilities. Both community services and the operation of the state developmental disability centers were managed by the Developmental Disability Section. In 2001, DMHDDSAS moved to a cross-disability organizational model in which the sections were organized for certain functions irrespective of disability. This led to decisions that were based on the needs of one group, often resulting in a negative impact on other populations served by the Division. For example, behavioral health services for those with mental illness or substance abuse disease are, by definition, founded in a medical rehabilitation model with the ultimate goal of cure or recovery. Advances in medication management and adherence are major goals and outcomes are quantifiably

measurable by limiting the need for hospital admissions and reduction in length of stay. However, the long-term care needs of persons with I/DD are far less episodic; therefore, a system focused on triage, determination of emergent or urgent care, and recovery is not appropriate for them.⁶ While an I/DD system must include knowledgeable medical care, it must also support habilitation, life-long advancement of skills, and achievement of the ability to fully participate in a meaningful, self-determined life.

Prior to the reform, there was a coordinated organization from the state level through a regionally supported network of I/DD specialists to local programs (the former Area MHDDSAS Authorities) that was designed to assure seamless system management. The structure included a single portal of entry/exit at the local level which provided identifiable community access and a local point of contact that ensured that the needs and preferences of each individual would be assessed, therefore resulting in a multiagency process for person-centered planning and delivery of needed services. Well before the reform, the Area Authorities had been divested of service delivery for the vast majority of individuals with I/DD and were on their way to becoming local hubs with clear management and coordination responsibilities for the planning and delivery of services provided by the private sector. However, with the reform, rather than strategically assessing and revising while maintaining and expanding the successful components of the I/DD service system infrastructure as well as the many points of excellence throughout the state, much of the system was changed to fit a newly established behavioral health model. While some excellent results have been achieved in the health and behavioral health system as a whole, unintentional consequences have, to some extent, led to a lack of operational coordination, fragmented management, and disjointed accountability.⁷ There is evidence that I/DD stakeholders are unclear about the ever-changing roles and responsibilities of state agencies and LMEs in their interaction with the critically important private service provider industry.⁸

We are a number of years past the initiation of the reform, and it is a good time to look at the current I/DD system of service outside of the construct of behavioral health. We should evaluate and shore up what works and change what does not. This must be managed with a "big picture" perspective; changing one part of the system will affect all parts.

System change decisions in North Carolina should be informed by a number of independent studies that have already been conducted to evaluate the impact of the reform on the I/DD service system.⁹⁻¹¹ These have been uniform in describing the I/DD system as fragmented and overwhelmed by the breadth and depth of the simultaneous "one size fits all" changes proposed in the reform effort. Studies also stress that thousands of persons with I/DD remain waiting for services.^{3,8}

The purpose of this commentary is not to provide a comprehensive, research-based view of how the I/DD system should be structured in North Carolina; rather, it is to identify several key issues and to recommend changes to address these issues with the goal of system improvement. The issues listed below are found in some form in the studies referenced above; the recommendations are those I believe are the best and most practical solutions to these key issues.

Organization and Operation

The cross-disability organization of the Division of MHDDSAS described above has been further divided by action of the Secretary of DHHS this year. The Division of MHDDSAS will now focus on community services and supports and a new division has been established to focus on the state-operated facilities: the state psychiatric hospitals as well as the developmental disability, alcohol and drug treatment, and neuro-medical treatment centers. While the purpose of this as a mechanism to assure the improved operation of the facilities is understandable, it is conceivable that this may further fragment a system whose abiding mission has been to reduce the admissions of individuals to state facilities in favor of service delivery in home communities and to discharge individuals into communities prepared to receive and support them in a seamless and coordinated operation.

Recommendations:

- Establish a discrete unit focused on I/DD within the DHHS. North Carolina is one of very few states in the country without such an identifiable unit; many states have created separate departments of disability services or divisions of long-term care and disability services.
- Actively recruit and hire state-level I/DD leadership with state-level I/DD experience. The excellent and experienced I/DD staff currently within the Division are simply insufficient in numbers to manage the unique budgetary accountability and programmatic requirements of the system of services for I/DD. The mandate of these staff members would include establishment of measurable individual and system outcomes valued by persons with I/DD as well as quality standards for I/DD services based on national benchmarks.
- Re-establish a regional presence for I/DD. Expertise for training, monitoring, technical assistance, standards compliance, data collection and management, team building, information exchange, and accountability closer to the local delivery of service would maximize consistency and transparency, reduce miscommunication, and provide critical, identifiable, and accessible technical contact with individuals with I/DD and their families, LMEs, and other local agencies.
- Develop senior management positions within each LME with expertise in training, case management

coordination, I/DD funding streams, desired outcomes, and best practices. These individuals would take the lead in the coordination of services and supports for persons dually diagnosed with mental illness and I/DD and would be the chief contact for persons moving from state and community intermediate care facilities to less congregate community settings.

Planning

Because of the diverse needs of the population and the extensive list of service options, service planning for I/DD differs from behavioral health and acute care in a number of ways. Key to this planning is comprehensive information on who is in need of services. For I/DD, waiting lists are stable and reliable; the majority of needed services are long-term in nature and change slowly over time. Issues such as recidivism, readmission to hospital, rapidly occurring crisis needs, and residence changes that impede the management of waiting lists are not issues for I/DD services. North Carolina no longer maintains and manages an active list of those persons eligible and waiting for I/DD services. Determination of numbers of persons in need of services by age and geographic location are currently based on national prevalence data which have been shown in the past to be inconsistent with actual need. There are currently no reliable figures for state and local planning, budget development, legislative requests, and preparation of Medicaid and Medicaid waiver applications.

Recommendations:

- Re-establish a systematic statewide I/DD waiting list system. During the 2009 session of the North Carolina General Assembly, session law was established to direct the Department of Health and Human Services to establish such a systematic waiting list for I/DD.¹²
- Employ waiting list data at the state agency and local management level for the purposes of development of clearly defined services that are responsive to actual needs, for fiscal planning, and for monitoring to assure qualified provider availability for all services.

Equitable Resource Allocation

As resources become more limited, it is critical to ensure that decisions on the allocation of available resources are made based on reliable and valid measures of relative intensity of need. That is, comparing the needs of each individual to the needs of all individuals with I/DD across the state for the purpose of ensuring justifiable and equitable allocation of resources. Many states have elected to employ intensity scale instruments for this purpose. These assessment scales can be used to achieve meaningful efficiency in the fair allocation of resources when reliably administered by well-trained individuals who are independent of the providers of service.

Recommendations:

- Establish a funding allocation formula based in a reliable and valid assessment of each I/DD-eligible individual that is consistently administered, and that identifies the intensity and complexity of the needs of each person compared to all other persons with I/DD regardless of the source of service funding. The selected assessment should be administered by well-trained assessors who are independent of the provision of services.

Assessment and Case Management

With the advent of reform, case management was transferred from the Area Authorities to the private sector. Because most individuals with I/DD need and receive a list of services and supports which may be most appropriately delivered by more than one provider, case management is a critically important service for people with I/DD. Currently, in order to avoid conflict of interest, the same private provider agency is not allowed to provide case management and also deliver services to the same individual. However this has proven to be a weak firewall. For example, case managers are put in the position of denying services requested from another agency then requesting services for their own service recipient from that same agency. The vast majority of case managers are conscientious and dedicated to the individuals they serve, but they have many incentives to draft service plans that may exceed the actual needs of the individual and no incentives to deny unnecessary services. They should be protected and supported with the

training and authority that would come with independence and a better ability to distribute restricted resources fairly and equitably.

Recommendations:

- Eliminate potential conflicts of interest by ensuring that case management is independent of service coordination for persons with I/DD. This can be accomplished by returning it to the LMEs or by establishing independent provider agencies whose sole responsibility is case management.
- Assure that case managers have manageable case loads, are well-trained, and are well-compensated for the comprehensive responsibility they have with multiple vendors and individuals with complex needs.

It is not surprising that in the flurry of activity associated with mental health reform there have been unintended negative results. The unique situation of citizens with I/DD has made them particularly vulnerable. It is the responsibility of state government to organize and manage an effective and fairly compensated network that is programmatically and fiscally accountable and that proves optimally desirable for persons with I/DD, their families, and service providers. We must take advantage of the points of excellence already present in the system and build on those. I believe this can be achieved by following the recommendations set out above and that North Carolina can be justifiably regarded as a model system for citizens with I/DD. **NCMJ**

REFERENCES

1. North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. *Core Indicators Project: Statewide Report*. Raleigh, NC: North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services; 2001.
2. North Carolina Council on Developmental Disabilities. *Looking Forward: A Summit on the Developmental Disability System in North Carolina*. Raleigh, NC: North Carolina Council on Developmental Disabilities; 2008.
3. Turnbull HR, Blue-Banning M, Klein S, Stowe MJ. *Innovation and Outcomes in Developmental Disabilities in North Carolina: Bottom-Up Innovation in Response to Top-Down Mandated Transformation*. Lawrence, KS: Beach Center on Disability, University of Kansas; 2007.
4. Mental Health, Developmental Disability and Substance Abuse System Reform Act. HR 381, Session Law 2001-437 (NC 2001).
5. North Carolina Department of Health and Human Services. *State Plan 2001: Blueprint for Change*. <http://www.dhhs.state.nc.us/MHDDSAS/stateplans/sp2001/sp01-main11-30.pdf>. Published November 30, 2001. Accessed October 20, 2009.
6. Gettings R. Reassessing the impact of managed care in the developmental disabilities sector. *Insights Bulletin: The National Leadership Consortium on Developmental Disabilities*. 2009;1(1).
7. Lin AP. *The Implementation of Local Management Entities in North Carolina*. Raleigh, NC: North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services; 2007.
8. *Life in the Community: A Roadmap for System Success*. The Arc of North Carolina website. http://www.arcnc.org/action_alert/Roadmap%204.17.07.pdf. Accessed September 1, 2008.
9. Bradley VJ, Day S. *Proposed Indicators of Progress Toward Reform in the North Carolina Mental Health, Developmental Disabilities, and Substance Abuse Systems*. Raleigh, NC: North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services; 2006.
10. Cooper R, Harkins D. *Going Home—Keys to Systems Success in Supporting the Return of People to Their Communities from State Facilities*. Raleigh, NC: People Can't Wait Project of the North Carolina Council on Developmental Disabilities; 2006.
11. Porter P. *A Strategic Partnership: The University of North Carolina and the North Carolina Developmental Disability Service System*. Chapel Hill, NC: Department of Allied Health Sciences, University of North Carolina; 2008.
12. HR 673, Session Law 2009-186 (NC 2009).