

**North Carolina Department of Health and Human Services
Division of Medical Assistance
March 15, 2013**

**RFI-DMA100-13
Request for Information:
Improving Efficiency and Effectiveness of the State's Medicaid Program**

Submitted by:



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About the North Carolina Council on Developmental Disabilities

The US Congress created the country's Councils on Developmental Disabilities in 1970. Mandated under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act; PL 106-402), Congress directs that Councils on Developmental Disabilities conduct systems change, advocacy and capacity building activities in partnership with and on behalf of people with intellectual and other developmental disabilities (I/DD) and families. The DD Act sets forth that people with I/DD should be assisted in a manner that acknowledges the uniqueness of each person and his or her needs, within the context of family, culture and community. Services and supports for adults with I/DD and children with or at risk for I/DD and their families are to be provided in an individualized manner, building on a person's or family's strengths and a community's resources. The DD Act and the Americans with Disabilities Act (ADA), taken together, create a legal and policy framework consistent with the assertion that people with I/DD and their families must have access to the opportunities, services and supports necessary to be fully included in community life and to make contributions—through work and otherwise—to their families, community, state and nation.

One of 55 Councils in the United States and its territories, the North Carolina Council on Developmental Disabilities (NCCDD) works on behalf of over 172,000 people with I/DD and their families. The NCCDD delivers no direct services and has both a state and federal

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mandate (NCGS 143B 177-179 and PL 106-402, respectively) to advise the State with regard to the concerns of North Carolinians with I/DD and their families. The NCCDD effects systems change under a Five-Year State Plan, with a federal allocation of approximately \$2 million. Systems change initiatives are funded primarily under competitive, Requests for Application (RFAs). Collectively, the NCCDD's activities promote the adoption of innovative and evidence-based practices and policies that offer North Carolinians with I/DD and their families opportunities to exercise self-determination and to be valued, engaged members of the community.

The activities of the NCCDD and its staff are governed by a 40-member body, appointed by the Governor. The NCCDD is a composite of the State's stakeholder community in I/DD. It is comprised of people with I/DD; family members; representatives of State agencies, across three departments,¹ inclusive of seven policymakers within the DHHS;² legislators; representatives from other DD Act Network agencies;³ and representatives of providers and Local Management Entity-Managed Care Organizations (LMEs-MCOs). Under federal law, at least 60% of NCCDD's members must be families of children and adults and I/DD and people with I/DD themselves ("self-advocates"). The NC Department of Health and Human Services (DHHS) serves, under the DD Act, as the organization's Designated State Agency. As such, DHHS receives, accounts for and disburses approximately \$2 million in federal funds, allocated to the State by the US Administration on Community Living, US Administration on Intellectual and Developmental Disabilities. All Councils on Developmental Disabilities, by law, operate independently of any substantive interference by the Designated State Agency or the State.

The NCCDD appreciates the opportunity to act as a partner in the policymaking process and to submit the following response to this Request for Information. The NCCDD stands ready to assist the DHHS in improving the efficiency and cost-effectiveness of its Medicaid system, while keeping the ultimate focus on those outcomes most valued by the people and families that the DHHS serves.

Overview of the NCCDD Response

In its *Request for Information*, RFI-DMA100-13, the DHHS asked for "information,

¹Department of Health and Human Services, Department of Public Instruction, and Department of Public Safety.

² DHHS representatives to the NCCDD are: the Secretary of the DHHS and policymakers from the Division of Mental Health, Developmental Disabilities and Substance Abuse Services; Division of Medical Assistance; Division of Vocational Rehabilitation; Division of Social Services; Division of Aging and Adult Services; and Division of Public Health.

³North Carolina's DD Act Network agencies are the NCCDD (State Council on Developmental Disabilities); The Carolina Institute for Developmental Disabilities at UNC-Chapel Hill (University Center on Excellence in Developmental Disabilities); and Disability Rights North Carolina (Protection and Advocacy System).

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recommendations and suggested approaches regarding innovative system and payment reforms to the Medicaid program.” The NCCDD is not responding to all of the issues within the purview of this RFI, e.g., information technology, payment structures, and billing. The Medicaid system has bearing upon a variety of issues of concern to the NCCDD, which the Council has not specifically addressed in this response. These include, e.g., the vital importance of a skilled, frontline workforce (Direct Support Professionals); access to appropriate, primary health care services (Medical/Health Homes); accessible, affordable transportation; competency-based training for care coordinators and community guides; innovative housing options, such as shared living; assistive technologies, such as in-home sensors and remote monitoring; family-directed early intervention services; transition from school to post-secondary education and work; family support; and aging in place, among others. In this response, the NCCDD focuses on key, data-driven recommendations and policy innovations with the potential to reform the current, state system of Medicaid long-term services and supports. These recommendations are consistent with the goals of cost-effectiveness, efficiency and quality, outlined in the RFI.

Changes to the Medicaid system can improve its efficiency and administrative processes; but this is not all there is to be done. There are significant opportunities to increase access to services; allow for more flexibility in the service array; and ‘rebalance’ the system, moving it away from an institutional bias to assisting people in their homes, workplaces, schools and community. These goals can only be achieved if DHHS benchmarks outcomes for people with I/DD against the outcomes that all of us desire in life and uses these for systems drivers. It must then adequately fund the system; implement a fair and equitable approach to resource allocation; encourage more strongly the use of the generic resources and informal supports that become available when one is fully a part of a community; and recruit and retain a workforce that puts forward a cohesive system that is person- and family-centered, at all levels.

The diverse, lifelong needs of children and adults with I/DD and their families create challenges to successful service delivery that are unique to the population. Developmental disabilities, by definition, “reflect the person’s need for special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.”⁴ The availability of services and supports—or lack thereof—can affect virtually every aspect of the life of someone with I/DD. As a result, the places where people need services and supports; the ways in which people use these; and the cost of services delivered over a lifetime differ significantly from people whose needs are more episodic, e.g., people with addictive disease and mental health needs and people who are more typical recipients of aging and adult services than people with I/DD. Medicaid cost savings can be achieved for individuals with I/DD, but this

⁴ See DD Act definition of developmental disability.

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will require a holistic, population-specific strategy for reform, a strategy that takes in to account the entire population, including those receiving no services. This will also require a cultural shift in expectations, attitudes and beliefs. People with I/DD, with appropriate services and supports, can fully participate in the workplace and in community life. The NCCDD offers the following principles and recommendations as a foundation for that reform.⁵

Principles for a Sustainable Future

- 1) Promote community integration and self-direction. This includes providing opportunities for people to use self-advocacy skills to engage in discussions about service improvement.
- 2) Commit to person-centered approaches in which individuals can choose among qualified providers and select where and with whom they live.
- 3) Develop a sustained, working partnerships among service recipients, families, service providers and communities across the state. Complement services with other, community supports that provide individuals and families opportunities to offer mutual support to one another, through peer support networks, cooperatives and exchange networks.
- 4) Ensure sufficient resources. North Carolina spends more dollars per person than most other states for people with I/DD, but spends notably less overall on its developmental disabilities services than the national average, given the state population.
- 5) Allocate resources more efficiently. Promoting efficiency will require:
 - An accurate and reliable means of assessing individual support needs, so that individuals are allocated resources that match their needs.
 - A range of valued services made available to individuals, within their individual budget, regardless of amount.
 - Service planning that results in people receiving the supports they require and prefer, within the bounds of their allocated budgets and available community resources;
 - Shifting to service options that cost less and bring the highest value; and
 - Management of the I/DD system as one, cohesive system, rather than by a division into discrete entities (e.g., Medicaid waiver Home and Community Based Services (HCBS), developmental centers, and community ICFs/MR).⁶

⁵ These principles are fully articulated in “A Strategic Analysis for Change: Action Steps (January 2012), a report produced for the NCCDD by Human Services Research Institute (HSRI).

⁶ The Social Security Administration signaled its intention to change all references to ‘mental retardation’ to ‘intellectual disability’ in a proposed rule, posted in the Federal Register in January 2013. The action is consistent with *Rosa’s Law*, Public Law 111-256, passed in 2010, “to change references in Federal law to mental retardation to references to an intellectual disability, and change references to a mentally retarded individual to references to an individual with an intellectual disability.” The law amends the Higher Education

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- 6) Agility in service provision, so that individuals can easily seek out providers who offer the highest quality services, and so that providers can alter their approach to be responsive to shifts in demand or changes in practice. Agility also means that people are encouraged to develop and utilize sources of support outside the public sector, including those naturally available within communities and from individuals offering support to one another.
- 7) Develop a strong, supportive infrastructure. This infrastructure should include: a viable service coordination network, an appropriate range of staff development opportunities, quality monitoring, effective response to crises, and an equitable and reliable means of allocating resources on a person-centered basis.
- 8) Promote collaboration. Health, education, human services, housing and transportation systems in North Carolina are fragmented. As a result, people with I/DD and their families must negotiate across different service systems to meet their needs. Embracing collaboration—seeking new opportunities to weave together the resources of public agencies—is essential, especially in view of the economic crisis facing the state and the nation.

Recommendations

Recommendation 1: Promote Outcomes Important to Individuals with Developmental Disabilities and Families

The long-term services and supports system should be designed to be accountable to the people it serves and to the taxpayers that fund it. Accountability to individual service recipients means that people have services and supports that matter (e.g., an accessible, affordable home; a job with a living wage and a career path; accessible, readily available, and affordable transportation; opportunities for post-secondary education, including for students with intellectual disabilities; quality health care; and meaningful relationships). At a system level, accountability to taxpayers means that all eligible individuals are served timely (i.e., there are no waiting lists and the system is adequately resourced); available resources are distributed fairly; rate structures keep good providers in business; and administrative costs do not unnecessarily draw funds away from direct services and supports.

Act of 1965, Individuals with Disabilities Education Act, the Elementary and Secondary Education Act of 1965, the Rehabilitation Act of 1973, Health Research and Health Services Amendments of 1976, the Public Health Services Act, the Health Professions Education Partnerships Act of 1998, and other related laws. *Rosa's Law* does not amend the Social Security Act, which includes Medicaid, nor does it "compel States to change terminology in State laws for individuals covered by a provision amended by this Act." However, a number of states have adopted statutes replacing ICF/MR with Intermediate Care Facility for Persons with Intellectual Disability (ICF/ID). It is likely that the federal rule change for programs under Social Security Administration is imminent. In the interim, the NCCDD encourages use of the terms "intellectual disability" and "ICF/ID."

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Specifically, to promote better outcomes, DHHS should:

- **Commit to implementing the principles, structures and processes of a self-directed system.**

North Carolina can build upon what already exists so that its model for self-direction can be utilized within the new LME-MCOs across the state. To promote self-direction, DHHS should: 1) develop specific performance measures related to self-direction; 2) assure that the LME-MCOs adopt consistent principles related to self-direction; 3) assure that the LME-MCOs have uniform *operational structures* in place for self-direction; and 4) assure that the LME-MCOs have uniform *processes* in place for self-direction. If individuals/families are to choose a self-directed option, they must be made aware of its availability and the supports they can utilize to effectively manage their services.

- **Promote Employment First principles at the state and local levels to accelerate community integration and employment opportunities for people with I/DD.**

To implement *Employment First* policies at the state and LME-MCO levels, DHHS must endorse the presumption that people with I/DD can work and that employment will occur in integrated workplaces at competitive wages. This must be the *expected or preferred* outcome for service recipients. Embed policies into state and local operations practices that: (a) offer providers funding mechanisms and contracts that emphasize employment as the preferred outcome; (b) provide training and technical assistance to providers to make this policy and service direction shift; (c) provide for longer-term supports to assist an individual with employment retention; (d) promote the use of natural supports, both on the job and as part of looking for a job; and (e) provide individuals with assistive technology.

- **Promote mutual support and association among self-advocates and families.**

To promote a spirit of personal reliance, contribution, mutual support and community connection, policy makers cannot solely place the emphasis on Medicaid or state-funded services. Leaders at all levels must promote policies and practices that encourage sustainable networks of mutual support among individuals with I/DD, families and others. In North Carolina, the majority of people receiving home and community-based Medicaid waiver services (HCBS) live at home with family members. The DHHS should assure that LME-MCOs work with First in Families of North Carolina to: 1) develop mutual support, or “peer connection,” networks among families and self-advocates to maximize the use of available community assets; and 2) provide opportunity for individuals with I/DD and their families to establish formal cooperatives where participants work together to manage the services they receive.

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- **Strengthen the means for serving people with extraordinary behavioral challenges.**

If people with complex disabilities are to enjoy outcomes associated with quality of life, the capacity to meet needs without resorting to unwanted and unnecessary out-of-home placement is vital. To the extent that the needs of such individuals can be appropriately addressed in the community, their lives will be more stable and higher service costs can be avoided. The NC START (North Carolina Systemic, Therapeutic Assessment, Respite and Treatment) program is a proven model, but is spread thinly across the state and must be expanded to meet demand.

- **Establish equitable resource allocation for individual budgets.**

Consistent with House Bill 916, DHHS is laying a foundation for individualized budgets for people with I/DD across the LME-MCOs. Giving people control over an individualized budget, along with a flexible array of personalized services and supports from which to choose, lies at the heart of both maximizing available resources and achieving quality outcomes.

Resource allocation models should:

- 1) collect accurate and reliable data,
- 2) involve individuals with I/DD in the process,
- 3) have flexible service arrays based on best practices for community integration and self-direction,
- 4) incorporate fair and ample reimbursement rates for services and providers, and
- 5) include a process to address complaints.

- **Use outcome-based performance data to drive quality improvement.**

What is tracked and reported is the driver of systems change for service delivery. North Carolina is one of 34 states that participate in the National Core Indicators (NCI) Project, a voluntary effort by State Developmental Disabilities Agencies to measure and track their own performance. The NCCDD encourages the State to make NCI outcomes data readily available, annually and by jurisdiction, and to provide this data to: Consumer and Family Advisory Committees (CFACs); LME-MCOs; and the general public. The NCCDD further recommends that the DHHS particularly examine outcome indicators relative to integrated employment, health, of psychotropic medication use, personal relationships and self-direction.

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Recommendation 2: Serve People with I/DD in the Most Integrated Setting

North Carolina does not currently serve people in the most integrated setting. Consider the following data.⁷

- In 2009, North Carolina served 29 percent fewer people with I/DD per 100K of population than the national average (151 in North Carolina versus 213 per 100K population nationwide). For North Carolina to have served the national average of people with I/DD per 100K population in that year, the state would have had to provide services to roughly 5,750 more people.
- In 2009, North Carolina spent \$104.85 per citizen for developmental disabilities services. The nationwide average (\$121.40 per citizen) was \$16.55 dollars, or 15.7 percent, per person higher. North Carolina's 2009 spending for developmental disabilities services would have had to have been \$155,253,630 higher to match the nationwide average.
- Between 1999-2008, North Carolina showed a steady decrease in the number of people with I/DD served in nursing homes. Between 2008 and 2009, however, the number reported more than doubled from 400 to 949.
- NC is the 10th highest user nationally of the more costly Intermediate Care Facilities for Persons with Intellectual Disabilities services (ICF/MR; preferred term, ICF/ID).⁸
- In 2009, North Carolina provided residential services to 3,854 people in ICFs/MR and another 10,333 through HCBS waiver funding. Public and private ICF/MR placements comprised 27 percent of those receiving residential services, compared to 14 percent nationally. ICF/MR use overall in North Carolina is nearly double the national average.
- In 2009, 1,798 individuals resided in community ICFs/MR. This amounts to 14.8% of the 12,131 served either in community ICFs/MR or receiving HCBS. This is more than twice the national average of 6.5%.

Specifically, to serve people in the most integrated setting, DHHS should:

- **Reduce utilization of developmental centers.**
Review of the national trends regarding census reduction of similar facilities from 2005-2009 reveals that, by 2017, the national utilization average will be 6.7 people per 100K state population. To achieve this goal, 890 people residing in North Carolina's state institutions will need community residences. This entails moving 178 people per year over the five year period of 2012 to 2017, a decrease of 44.2 percent overall.

⁷ See "Strategic Analysis for Change: Planning Context (HSRI, August 2011).

⁸ See footnote 1.

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- **Adopt policies to help individuals transition from ICFs-MR services to HCBS funded alternatives.**

Utilization of Intermediate Care Facilities for Persons with Intellectual Disabilities (ICFs/MR; preferred term, ICFs/ID)⁹ in North Carolina exceeds the national average and is contrary to the US Supreme Court's *Olmstead* decision and the national trend to de-emphasize institution-based care in favor of community services and supports. In concert with building its reliance on Home and Community Based Services (HCBS), North Carolina must lend assistance to ICF/MR providers to support their transition to offering HCBS through the 1915(b)(c) waiver.

- **Conduct research on individuals residing in Skilled Nursing facilities with intellectual and other developmental disabilities to determine if individuals are being served properly in the settings.**

Because North Carolina reports nearly a thousand people with I/DD living in nursing facilities and a recent increase of 137 percent over one year, DHHS should 1) complete a study to determine: (a) what factors led to the increased number of people with I/DD residing in nursing facilities from 2008-2009, and whether this trend has continued; and (b) the appropriateness of the placements of people with I/DD in nursing facilities; and 2) offer individuals with I/DD living in skilled nursing facilities the opportunity to relocate to alternative community settings as appropriate, perhaps through use of North Carolina's Money Follows the Person program.

- **Implement North Carolina Institute of Medicine Adult Care Home Recommendations for People with I/DD.**

North Carolina's use of Adult Care Homes (ACHs) for people with I/DD has raised concerns over the past, several years. An evaluation of residents of adult care homes (ACHs) with I/DD is needed to determine whether they prefer to live independently in the community with necessary services, supports, counseling, and transition services. A Medicaid 1915(i) State plan amendment or Home and Community-Based Services waiver to support individuals to move to more independent living arrangements should be considered. The DHHS should assure collaboration among divisions, service providers, people with I/DD and others to develop plans for establishing alternatives to ACHs for people with I/DD.

- **Utilize the Balancing Incentives Program.**

The Balancing Incentive Program, Section 10202 of the Patient Protection and Affordable Care Act (PL 111-148), provides financial incentives to states to offer community, long-term services and supports as an alternative to institutional care. North Carolina, using FY 2009 data, spends 42.9 percent of its long-term care

⁹ See footnote 1.

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funding for all service populations (i.e., developmental disability, mental health, aging and physical disability) on Home and Community Based Services, and is therefore eligible for a 2 percent increase in FMAP if the program's requirements are met. To gather additional funding to support relocating individuals from ICFs/MR and nursing facilities to community alternatives, the DHHS should consider applying for the Balancing Incentive Program, administered through the Centers for Medicare and Medicaid Services (CMS).¹⁰

Recommendation 3: Expand Community Systems to Serve More Individuals

All people have the right to live in the community with people of their choice. The goal of the service delivery system should be to support this. This includes the responsibility to ensure that those living in publicly funded, ICF/MR institutions and private, ICF/MR congregate settings have the services and supports necessary to offer them an equal opportunity for community life.

Consider the following data:¹¹

- The average 2009 cost in North Carolina of serving an individual in a developmental center was \$175,565 per year, compared to \$92,906 in a community ICF/MR and \$61,291 for Home and Community Based (HCBS) waiver services. North Carolina spent 21.3 percent more per person than the national average for ICF-MR and HCBS combined.
- The state falls short of achieving outcomes for integrated employment, promoting healthy lifestyles and prevention of chronic diseases. It also oversees a high use rate of prescribed medications for behavior. Further, the state has not demonstrated sufficient achievement in supporting people to be in relationships beyond their frontline service providers (Direct Support Professionals).

Specifically, to expand community services, DHHS should:

- **Effectively manage the waitlist for services.**
State and local agencies in North Carolina have, in previous years, reported that over 8,200 people are waiting for Medicaid-financed services. Responding to this unmet need, in 2009, the General Assembly enacted Section 1 of NCGS 122C-115.4(b), requiring each LME to develop a list of persons with I/DD waiting for

¹⁰ Applications for the Balancing Incentives Program are being accepted on an ongoing basis until August 1, 2014, or until the full provision of the \$3 billion has been projected to be expended, whichever date is earlier.

¹¹ See "Strategic Analysis for Change: Planning Context" (HSRI, August 2011).

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services. In October 2010, the LME-MCOs started reporting data to the State on the number of people waiting for services. The data, however, is limited in the type and amount of information collected. Critical information, such as priority of utilization of need for services, is still not being consistently collected, across LME-MCOs, on the individuals waiting for services.

- **Set goals for annual enrollment in services.**

To accommodate most, if not all, unmet demand for service in North Carolina, the state would need to expand system capacity at a steady pace by serving an additional 1,131 people each year between 2013 and 2022. There is no doubt that additional dollars would be needed for North Carolina to address current, unmet service demand, as well as keep pace with projected demand through 2022. By employing the HCBS waiver authority to finance this expansion, the State could secure federal Medicaid dollars to underwrite 64 percent of the cost of this expansion. By serving the additional 1,131 individuals per year, there is a significant possibility that North Carolina could, over time, sharply reduce and possibly eliminate the waitlist for developmental disabilities services.

Recommendation 4: Strengthen Leadership for the I/DD Service System

Responsibility for the oversight of long-term services and supports in the Medicaid system must include adequate numbers of state and regional personnel who have specific expertise in providing and managing long-term services and supports to individuals with I/DD and their families.

Specifically, to strengthen leadership, DHHS should:

- **Commit to a unified policy direction within DHHS that embraces community-centered practice for I/DD services.**

The DHHS Secretary should embrace a position in favor of community-based services, direct others in leadership positions within DHHS to take action consistent with this commitment, and reject decisions contrary to this commitment. This is not to suggest that the state has not already been moving in this direction. But movement has been slow and regularly competes with continued investments in facility-based service options. The challenge to DHHS is to cease ambiguity in favor of a unitary commitment to community life for those with I/DD in North Carolina using, or in need of, services.¹² The NCCDD’s recommendations, summarized in this response, are a template for a more definitive policy direction.

¹² See “A Strategic Analysis for Change: Planning Context” and “A Strategic Analysis for Change: Action Steps” (HSRI, August 2011 and January 2012, respectively).

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- **Invest in self-advocacy to teach individuals with I/DD to take the lead in shaping their lives and increase their presence in policy-shaping councils and boards.**
Quality management practice today requires offering people using the service system opportunities to provide input--to proposed changes to policy and practices, and with respect to the type, accessibility and quality of services. To strengthen the voices of DHHS service recipients with I/DD and their families, DHHS should collaborate with stakeholders to:
 - 1) teach individuals with I/DD to take the lead in the policy arena,
 - 2) maintain a statewide, independent, self-advocacy organization that supports the collective voice of North Carolinians with I/DD in shaping public policy and practice,
 - 3) increase the presence of self-advocates on local, service provider boards, and
 - 4) promote the role of a self-advocate leadership within DHHS and, specifically, within the Division of Mental Health, Developmental Disabilities and Substance Abuse Services.

The Developmental Disabilities Assistance and Bill of Rights Act directs the North Carolina Council on Developmental Disabilities to serve as an advisory to the State in the design and implementation of its system of services and supports for people with intellectual and other developmental disabilities and their families. The NCCDD looks forward to discussing this response in greater detail, including how these recommendations may be implemented in the context of broader, Medicaid system reform.

Respectfully submitted,



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Attachments