



# North Carolina Council on Developmental Disabilities

3125 Poplarwood Court, Ste. 200  
Raleigh, NC 27604

June 20, 2014

The Honorable Harry Brown, Chair  
Conference Committee, SB744: Appropriations Act of 2014  
300-B Legislative Office Building  
Raleigh, NC 27603

Dear Senator Brown:

I am writing on behalf of the North Carolina Council on Developmental Disabilities (NCCDD) to comment on the potential impact SB744 may have on North Carolina residents with disabilities, and to offer the resources of our Council to you and other policymakers on the components in this bill.

The NCCDD is part of a national network funded under the Developmental Disabilities Bill of Rights and Assistance Act (P.L. 106-402). Our federal mandate is to educate, advocate, and effect system-wide changes for the over 173,000 North Carolinians with intellectual and other developmental disabilities (I/DD) and their families. The Governor appoints the chairman and Council members, of whom 60%, by law, are people with I/DD and family members. Other Council members include representatives from the North Carolina General Assembly, and those who administer funds under federal law including state service delivery agencies, non-profit organizations and other professional groups.

We appreciate the challenges that the General Assembly faces in managing the multiple demands of the state budget. However, Medicaid is a lifeline for an estimated **283,000** North Carolinians with disabilities and is often the only source of comprehensive coverage for health care and long-term services. Already Medicaid services are limited in our state, with an estimated **13,000** North Carolina residents and families in need of long-term services and supports.

NCCDD offers the following comments on the components of SB744 as they relate to persons with disabilities. Specifically:

- **Community Based Services and Supports:** The Senate Budget (SB744, Version 3) calls for expansion of a “1915(c) waiver to create 1,000 new slots each year for 3 years, to serve a total of 3,000 additional adults with developmental disabilities from January 1, 2016, to June 30, 2019.” However, the House Budget (SB744, Version 7) does not include these additional slots. It is the goal of our Council, and other individuals and family members across all disability groups (Stakeholder Engagement Group- SEG<sup>1</sup>) to have *no waiting lists* in North Carolina. While we support the addition of these critical community-based services, adding none, or only 1,000 each

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<sup>1</sup> The Stakeholder Engagement Group (SEG) is the first statewide group comprised entirely of individuals receiving services and supports from the MHDDSA system and family members. The members focused on what they wanted--the values, principles, needs and outcomes important to recipients of services and supports--rather than how to get there, e.g., who is in charge and how the money flows. Stakeholders expect a system where there are no waiting lists, and one that produces real life outcomes including integrated employment, inclusive housing, the ability to develop financial assets, and is accountable to consumers and families to achieve these outcomes. This cross-disability group in partnership with state and national experts in service delivery models, have created a unified and informed voice coming from those most impacted by changes to the North Carolina service delivery system.



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year is insufficient to eliminate the current waiting list of estimated 13,000 residents needing support, plus those added each year due to population growth, and as our youth with disabilities leave school unprepared and not expected to earn a living wage. NCCDD has prepared a detailed report titled *“Gap Analysis and Strategic Analysis for Change: Action Steps for Responding to the Needs of Persons with Developmental Disabilities in North Carolina”* which outlines service trends in our state and comparisons to other states, and action steps North Carolina could take in the next 5 years to strategically reduce the waiting list. We welcome the opportunity to share the results of these findings with you.

- **Traumatic Brain Injury:** Individuals who experience traumatic brain injury face many obstacles in finding needed services and supports in North Carolina. Adding ‘waiver services for those eligible for Medicaid with traumatic brain injury (TBI) and the establishment of a Joint Legislative Study Commission on Traumatic Brain Injury’ is an important first step in meeting the unique support needs of this population that is currently underserved.
- **Guardianship System:** Most people with intellectual and other developmental disabilities can manage their own life with assistance and guidance from family and friends. If guardianship is necessary, it should be tailored to the person’s unique needs. Oversight and monitoring must be in place to protect the best interests and preferences of each person. The Council hopes we may be involved in the Senate’s efforts to “enhance the public guardianship system” to include the best interests of those with developmental disabilities.
- **Employment and Asset Building:** Our Council, and other individuals and family members across all disability groups (Stakeholder Engagement Group- SEG- *see footnote*) have articulated that the primary outcomes of the NC state system of long term services and supports should be *“Integrated Employment and Asset Building.”* The current budget calls for a “Study of issues related to vocational training for individuals with intellectual disabilities”. We agree that an analysis of existing barriers, policies, model programs, and partnerships are critical to achieving meaningful work outcomes for persons with disabilities. We recognize that vocational training is critical, however it is only one component of the system of services and supports that help individuals with disabilities gain integrated and meaningful employment. NCCDD has access to a federal network of model programs and policies in employment and asset building initiatives and has invested in multiple grants in North Carolina to study these issues and build models of successful employment and asset building. We welcome the opportunity to share the results of these efforts with you in hopes that our state may move quickly from “study” to becoming an “Employment First” state. “Employment First” means that the expected and preferred outcome of ALL publicly funded services shall be employment and successful careers.
- **Medicaid Eligibility:** Changing Medicaid eligibility (as proposed by the Senate in SB744, Version 3) will eliminate some individuals with disabilities from the Medicaid program. Medicaid is a lifeline for many individuals with disabilities who do not receive services from any other source. Removal from the Medicaid system could result in increased cost when persons must seek higher level, and more expensive services where they cannot be turned away – like emergency rooms.



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- **Medicaid Flexibility:** The NCCDD in addition to the Stakeholder Engagement Group (see footnote above) has expressed the expectation that our long-term service and support system is flexible to meet the needs of a diverse population. Allowing “1915(c) innovations waiver slots to be portable and recognized uniformly throughout all counties of North Carolina” (SB744, Version 7) can increase the options families have for receiving long-term services and supports in our state.
- **Reduction of early intervention funding:** –NCCDD urges the General Assembly to ensure that the resources for early intervention and diagnosis will continue to be readily available statewide, accessible to families, and delivered with the highest quality and expertise.

NCCDD’s community grant awards and systems change efforts are guided by the core values that promote independence, self-determination, productivity, integration and inclusion in community life. Through its comprehensive state plan, our Council has invested in research and model programs to create meaningful outcomes in the lives of persons with disabilities and their families. We hope that you will consider NCCDD as a resource to you on the components outlined in SB744.

Thank you for your continued efforts to improve the lives of North Carolinians with intellectual and other developmental disabilities.

Sincerely,

A handwritten signature in blue ink that reads "Ronald D. Reeve".

Ron Reeve, Chair  
North Carolina Council on Developmental Disabilities

