

# Strengthening Supports for Home and Community Living

## Statement of Principles



The North Carolina Council on Developmental Disabilities (NCCDD) believes that individuals with intellectual and other developmental disabilities (I/DD) should receive the support necessary to live full lives in the community that include choices about housing, education, employment, social and recreation and volunteering.

Individuals with intellectual and other developmental disabilities can be included in all aspects of community life when adequate and appropriate supports are available. Therefore, North Carolina must allocate the requisite resources to build a coordinated, cost-effective, participant directed, local system of services and supports.

### **Rebalancing the State System:**

Cuts to the Medicaid reimbursement rates, changing system infrastructure (for example, the 1915(b)(c) waiver expansion) and institutional bias continue to create significant barriers for individuals and their families to receive support. In order for North Carolina to meet the current and future needs of individuals with I/DD, state leaders must take action to:

### **Reduce Utilization of Developmental Centers:**

- The utilization rate for developmental centers in NC is 57% higher than the national average.
- Close to half of all states have reduced or eliminated their use of large, state-operated facilities and nursing homes. By the end of 2009, ten states and the District of Columbia no longer operated large, state institutions. 11 other states now have fewer than 200 people living in these facilities.
- In 2009, a total of 1,666 people resided in North Carolina's developmental centers: that year only 16 individuals were moved to other residential settings. To achieve the national average, North Carolina needs to move 178 persons from developmental centers each year for the next five years (2012-2017).

### **Adopt policies to help individuals transition from ICFs/MR and Adult Care Homes to Home and Community-Based Services (HCBS) waiver-funded alternatives:**

- Funding for ICFs/MR services should easily follow the person from a facility into a home and community based waiver funded setting.
- A strong, community-based system should have limited reliance on ICFs/MR to provide services.
- North Carolina should create policies and incentives for providers to successfully transform their funding base from ICFs/MR to HCBS waiver services and maintain viable business operations.

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### **Address the waitlists for state delivered services:**

- North Carolina currently does not serve every person in need. Today, over 8,000 individuals are waiting for, but not receiving, Medicaid-funded services.
- Greater understanding of current and future needs is required to plan and cost effectively and accurately project delivery of services.

### **Commit to implementing the principles, structures and processes of a participant-directed system:**

- North Carolina should build on the existing framework for providing services in a more participant-directed manner. Principles of family and self-direction include:
- Individual capacity to communicate needs and have it be heard and honored by others;
- Control over what services and supports are received and who provides them;
- Authority to negotiate across service definitions and 'silos';
- Ability to develop and sustain social relationships with friends, partners, family and community organizations;
- Flexibility to accommodate changes over time and the recognition that there are many methods to achieving individual goals;
- Access to a full array of choices that are available and appropriate to the needs of the individual;
- Work with providers and staff who are adequately trained to navigate the system with the needs of the individual as the primary goal;
- Focus on service excellence and quality with meaningful, individual outcomes;
- A system that provides fair assessments of needs and allocation and management of corresponding budgets;
- Strengthens informal community and family supports;
- Maintains the rights of the individual by providing access to due process and appeals;
- Ongoing and accessible communication between state and local leaders, providers and the public.

With continued population growth, budgetary deficits, service reduction and new service delivery models being introduced, the North Carolina long-term services and supports system will face ongoing challenges. In this climate, focused leadership on intellectual and other developmental disability services is essential.

