A Strategic Analysis for Change

Action Steps

For Responding to the Needs of People with Developmental Disabilities in North Carolina

January 2012

Human Services Research Institute

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About the Authors

Human Services Research Institute (HSRI), a non-profit, tax-exempt corporation, was founded in 1976 to improve the availability and quality of supports for children and adults with special needs and other vulnerable populations. Working in the fields of developmental disabilities, mental health, physical disabilities, and child welfare, HSRI staff strongly support efforts to improve community-centered responses to human needs, leading to service approaches that are family and person driven and most apt to result in increased independence and self sufficiency. HSRI has assembled a fiveperson team to complete this work.

This report was prepared by the following staff:

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At HSRI since 1983, Dr. Agosta has worked under contract with state and federal agencies on a variety of projects focusing on community integration for people with developmental disabilities. He has conducted analyses of state systems and studied specific facets of the field (e.g., supported employment, family support, self-advocacy, Medicaid funding trends, and self-directed supports). He helped found the national Self Advocate Leadership Network and The Riot!, a national e-newsletter designed with and for self-advocates. Presently, he is involved with projects related to exploring innovative means for supporting individuals with disabilities and their families, evaluating what states may do to reform service systems to improve performance, and establishing resource allocation protocols to provide individualized budgets for service recipients while making systems more efficient and equitable.

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Valerie Bradley, M.S. is the President of the Human Services Research Institute. Ms. Bradley, who has a lifelong interest in public policy, has guided the Institute since its inception in 1976 to become a leading resource for public managers in human services across the country. After getting her Masters in Political Science at the Eagleton Institute of Politics, she began her work in the 1960s as a staffer to the California General Assembly where she contributed to the development of landmark legislation in mental health and developmental disabilities. Her interest in reform has been manifest in her involvement in a number of important issues including quality improvement, family support, deinstitutionalization, and performance measurement.

More recently, Ms. Bradley helped the Institute to forge important collaborations – the most important of which is with the National Association of State Directors of Developmental Disabilities. This partnership has resulted in the creation of National Core Indicators, a performance measurement system that facilitates state by state comparisons and that has generated perhaps the largest database of individuals with intellectual and developmental disabilities in the country if not internationally.

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Glossary of Key Terms

In this report, services and housing arrangements for people with intellectual or other intellectual and other developmental disabilities within the state of North Carolina are examined. Below, is a list of key terms used commonly throughout this report, as well as their meaning/definition.

Federal Definition of Intellectual and Other Developmental Disabilities

(A) The term "developmental disability" means a severe, chronic disability of an individual that:

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

114 STAT. 1684 PUBLIC LAW 106-402-OCT. 30, 2000

(ii) is manifested before the individual attains age 22;
(iii) is likely to continue indefinitely;
(iv) results in substantial functional limitations in 3 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.
(VII) Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence of 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.

(B) INFANTS AND YOUNG CHILDREN - An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

North Carolina Definition of Intellectual and other developmental disabilities

North Carolina General Statute 122C-3(12a) defines a developmental disability as "a severe, chronic disability of a person which:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age 22, unless the disability is caused by traumatic head injury and is manifested after age 22;
- is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity:
    - self-care
    - receptive (understanding) and expressive language
    - learning mobility (ability to move)
    - self-direction (motivation)
    - the capacity for independent living
    - economic self-sufficiency
- reflects the person's need for a combination or sequence of special, interdisciplinary, generic services, individual supports, or other forms of assistance which are of a lifelong or extended duration and are individually planned and coordinated;
- an individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting at least three of the above 'areas of major life activities,' if the individual, without services and supports, has a high probability of meeting those criteria later in life."

Home and Community Based Services (HCBS) WAIVERS SECTION 1915(c)

States may offer a variety of services to consumers under an HCBS waiver program and the number of services that can be provided is not limited. These programs may provide a combination of both traditional medical services (i.e., dental services, skilled nursing services) as well as non-medical services (i.e. respite, case management, environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. However, in general spouses and parents of minor children cannot be paid providers of waiver services.

Application & Approval Process

The State Medicaid agency must submit to the Center for Medicare and Medicaid Services (CMS) for review and approval an application for an HCBS waiver, and the State Medicaid Agency has the ultimate responsibility for an HCBS waiver program, although it may delegate the day-to-day operation of the program to another entity. Initial HCBS waivers are approved for a three-year period, and waivers are renewed for five-year intervals.

Program Requirements

Within the parameters of broad Federal guidelines, States have the flexibility to develop HCBS waiver programs designed to meet the specific needs of targeted populations. Federal requirements for states choosing to implement an HCBS waiver program include:

- Demonstrating that providing waiver services to a target population is no more costly overall than the cost of services these individuals would receive in an institution.
- Ensuring that measures will be taken to protect the health and welfare of consumers.
- Providing adequate and reasonable provider standards to meet the needs of the target population. Ensuring that services are provided in accordance with a plan of care.

States have the discretion to choose the number of consumers to serve in a HCBS waiver program. Once approved by CMS, a state is held to the number of persons estimated in its application, but has the flexibility to serve greater or fewer numbers of consumers by submitting an amendment to CMS for approval.

Intermediate Care Facility For Persons With Mental Retardation (ICF/MR) (1905(d) of the SSA)

An institution (or distinct part thereof) for the mentally retarded or persons with related conditions if --

1. the primary purpose of such institution (or distinct part thereof) is to provide health or rehabilitative services mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary;
2. the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and
3. in the case of a public institution, the State or political subdivision responsible for the operation of such institution has agreed that the non-Federal expenditures in any calendar quarter prior to January 1,1975, with respect to services furnished to patients in such institution (or distinct part thereof) in the State will not, because of payments made under this title, be reduced below the average amount expended for such services in such institution in the four quarters immediately preceding the quarter in which the State in which such institution is located elected to make such services available under its plan approved under this title.
4. Institution for persons with mental retardation means an institution (or distinct part of an institution) that: 1. Is primarily for the diagnosis, treatment, or rehabilitation of the mentally retarded or persons with related conditions; and 2. Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his greatest ability. (42 CFR 435.1009)r

Community integration, used with respect to individuals with developmental disabilities, means exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000
Public Law 106-402-OCT. 30, 2000 114 STAT. 1686 (17)

Inclusion means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to: (a) have friendships and relationships with individuals and families of their own choice; (b) live in homes close to community resources, with regular contact with individuals without disabilities in their communities; (c) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and (d) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

Public Law 106-402-OCT. 30, 2000 114 STAT. 1685 (15)

Supported employment services means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings, in the case of individuals with developmental disabilities: (a) for whom competitive employment has not traditionally occurred or for whom competitive employment has been interrupted or intermittent as a result of significant disabilities; and (b) who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000
Public Law 106-402-OCT. 30, 2000 114 STAT. 1688 (30)

Self-determination refers to activities that result in individuals with developmental disabilities, with appropriate assistance, having: (a) the ability and opportunity to communicate and make personal decisions; (b) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive; (c) the authority to control resources to obtain needed services, supports, and other assistance; (d) opportunities to participate in, and contribute to, their communities; and (e) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000
Public Law 106-402-OCT. 30, 2000 114 STAT. 1687 (27)

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Executive Summary

The *Strategic Path Forward: Action Steps* report offers DHHS leaders a guide for moving the service system for people with intellectual and other developmental disabilities (I/DD) to achieve financial sustainability and deliver high quality community centered supports while also serving additional citizens waiting for services.

Background and Overview of the Strategic Path Reports

In 2008, the North Carolina Council on Developmental Disabilities (NCCDD) convened a summit of developmental disabilities stakeholders to discuss areas of system change. Those meetings resulted in a report, *Looking Forward: A Summit on the Developmental Disabilities System in North Carolina,*[1] that outlined areas for system reform and proposed recommendations for solution. To assist state officials with implementation of Summit systems change recommendations, the NCCDD engaged Human Services Research Institute (HSRI) and other topic experts to provide technical assistance.

Throughout 2009 and 2010, consultants conducted technical assistance sessions with interested state officials on areas of system reform targeted in the 2001 Summit report including, maximizing utilization of home and community based waivers, individual budgets, and management of wait lists for services. Additional avenues to encourage system change were still needed. NCCDD then engaged HSRI to conduct an evaluation of the service system and prepare a guidance document on how to make these challenging system-wide reforms given strapped state budgets.

HSRI prepared this *Strategic Analysis* in two stages. The first synthesized the sagacity of key stakeholders and information about the state of service delivery across the nation to illustrate North Carolina's performance in comparison to other states. Released in August 2011, *A Strategic Analysis for Change: Planning Context* [2] is an analysis of the current service delivery system and the context within which policy makers must implement recommendations for reform. The *Planning Context* report formed the foundation for recommended action steps described in this companion report, *A Strategic Analysis for Change: Action Steps*.

This report lays out an intertwined *Action Step* agenda for North Carolina's Department of Health and Human Services (DHHS) to achieve the goals of improving system performance while promoting sustainability. NCCDD expects that these steps will be undertaken in tandem with and to complement system reforms already underway ensuing from passage of House Bill

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[1] Bradley, V., *Best Practices for Implementing the Recommendations of "Looking Forward: A Summit on the Developmental Disabilities System in North Carolina" Technical Report*. October, 16, 2008.

[2] Agosta, J., Bradley, V., Melda, K., Pell, E. & Smith, D. (2011). A *Strategic Analysis for Change Planning Context Responding to the Needs of People with Intellectual and Other Developmental Disabilities in North Carolina.* Tualatin, OR: Human Services Research Institute.

916.[3] A synopsis of the overall goal and driving principles for system reform, and the 15 action steps follow.

Overall Goal and Driving System Principles

Underscoring the strategic path to systems change is a commitment to:

Establish an efficient and sustainable system whereby people with intellectual and other developmental disabilities can live the life they want in the community with the supports they need.

Aside from making the best use of available public resources, achieving this goal is also predicated on an important proposition – i.e., there are opportunities to improve efficiency and enlist new resources in support of people with I/DD that must be vigorously pursued. Realizing these opportunities requires DHHS to re-think which services, and how services are offered, and so will likely disrupt the present ways of doing things. Unless these opportunities are pursued, however, DHHS will not be able to achieve the best outcomes possible for people with I/DD and their families.

The proposed 15 *Action Steps* are based in principles, principles that blend the supports and services that people with I/DD want with disciplined fiscal and management practices. *Action Steps* are underpinned by the following principles:

- A sustainable future requires approaches that promote community integration and self-direction.
- A sustainable future requires commitment to person-centered approaches in which individuals can choose among qualified providers of any available service, and also select where and with whom they live.
- A sustainable future requires a sustained, working partnership among service recipients, families, service providers and communities across the state.
- A sustainable future requires sufficient resources.
- A sustainable future requires allocating resources more efficiently, including accurate and reliable means of assessing individual support needs so that individuals are allocated resources that match their needs, making available a range of valued services, person centered planning for services, 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 its current division into discrete administrative entities.

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[3] In 2011 the General Assembly enacted House Bill 916 which provides for a major restructuring of the management, financing and delivery system for services for individuals with mental illness, intellectual and other developmental disabilities (I/DD), and substance abuse disorders. This restructuring will occur through the expansion of the 1915 (b)(c) Medicaid waiver, to be completed by July 1, 2013. For more information visit the DHHS website: http://www.ncdhhs.gov/mhddsas/providers/1915bcWaiver/index.htm

- A sustainable future encourages agility in service provision so that individuals can easily seek out providers who offer the highest quality services, and likewise, so that providers can alter their approach to be responsive to shifts in demand or changes in practice.
- A sustainable future requires a resilient system infrastructure. Within any system, investment in direct services must be complemented with a strong supportive infrastructure.
- A sustainable future requires collaboration across public sector systems involving health, education, human services, housing and transportation.

Recommended Action Steps

The *Action Steps* are organized into four topical areas as follows:

A. Establish clear leadership for developmental disabilities service system;

B. Serve people in the most integrated setting by reducing the role that developmental centers, nursing homes, and ICFs/MR play within the North Carolina service system;

C. Promote outcomes important to individuals and families, including emphasis on self-direction among people with I/DD, partnerships among service recipients, family members and community service organizations, as well as among public agencies, and strengthening infrastructure in support of the community services system; and

D. Expand system capacity so that by 2022 all people who have emergency or critical unmet needs will be served with reasonable promptness.

Establish Clear Leadership for Developmental Disabilities Service System

Action Step 1: Commit to a unified policy direction for community-based I/DD services

DHHS needs a coherent policy direction for services to people with intellectual and developmental disabilities (I/DD) across DHHS Divisions and offices. House Bill 916 requires a major restructuring of the management, financing and delivery system for I/DD services. Although significant, these changes do not resolve the absence of a unified systems change direction. Rather than resolving, this legislation adds pressure to leaders within DHHS to establish a cohesive approach to establishing policy direction and management of the new LME-MCOs.

The DHHS Secretary should decidedly 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 these directions. 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, state supported services. Recommendations within this report are a template for definite policy direction.

Action Step 2: Invest in self-advocacy for policy collaboration

Quality management practice today requires offering the people using the service system with opportunities to provide input -- to proposed changes to policy and practices, and on the type, accessibility and quality of services. To strengthen the voices of DHHS service recipients with I/DD, DHHS should collaborate with stakeholders to:

- ✓ Teach individuals with I/DD to take the lead in the policy arena.
- ✓ Maintain a statewide, independent self-advocacy organization that serves as the collective voice of North Carolinians with I/DD in shaping public policy and practice.
- ✓ Increase the presence of self-advocates on local service provider boards.
- ✓ Promote the role of a self-advocate leadership within DHHS, and specifically within MH/DD/SAS.

Serve People in the Most Integrated Setting

Action Step 3: Reduce the number of people served at state operated Developmental Centers to no more than the projected nationwide average by 2017

DHHS seeks to reduce its developmental center census to the legislatively mandated four percent a year, but is having a difficult time doing so because as individuals are discharged, other people with I/DD are admitted. North Carolina policymakers should now take decisive action to reduce the census of the state institutions (developmental centers and neuro-medical centers) to the projected national average in 2017.

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 currently residing in North Carolina's state institutions will need community residences. This entails moving 178 people per year over the next five years (2012 – 2017), a decrease of 44.2 percent overall.

Action Step 4: Adopt policies that facilitate transition from ICFs/MR services to HCBS-funded alternatives

Utilization of Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) in North Carolina exceeds the national average and is contrary to *Olmstead* legal decision and the national trend to de-emphasize institution-based care in favor of community-based care. In concert with assistance to offering community services first to individuals is the need to lend assistance to ICF/MR providers for transition to offering Medicaid Home and Community-Based Services (HCBS). To achieve these strategic changes, DHHS should:

- ✓ Consider action to establish "incentives" for providers to help individuals to relocate to HCBS options or to transform their funding base from ICF/MR to HCBS waiver. Incentives may take at least these three forms:
  - Eliminate barriers to transition that make it difficult and expensive for providers to move from ICF/MR to HCBS waiver funding.

  - Compensate providers for their expenses during a pre-defined transition period.
  - Assure that the HCBS waiver is an attractive option with respect to both the service array available to participants and the associated service reimbursement rates available to service providers.
- Make use of the Money Follows the Person (MFP) Program. North Carolina was awarded a MFP Demonstration Grant in May 2007 and the Centers for Medicare and Medicaid Services formally approved the NC Division of Medical Assistance (DMA)'s Operation Protocol in an award letter dated June 30, 2008. This program is designed to assist states to accelerate the transition of people from institutional settings to the most integrated setting. MFP funding provides states with enhanced federal matching funds to pay for community supports for those who transition to the community. North Carolina now receives supplemental funding and technical assistance to move 304 people who are older adults, or have an intellectual or other developmental disability, or have a physical disability. For more information go to: (http://www.ncdhhs.gov/dma/MoneyFollows/index.htm).

Action Step 5: Evaluate individuals with I/DD residing in Skilled Nursing Facilities to determine if placement is appropriate

Despite passage of the federal Omnibus Budget Reconciliation Act (OBRA) in 1987 that limits admissions to Medicaid-reimbursed skilled nursing facilities to persons requiring a high level of medical/nursing care, the number of individuals with I/DD residing in skilled nursing facilities in North Carolina is still increasing.

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:

- Complete a study by 2013 to determine: (a) what factors led to the increased number of people with I/DD residing in nursing facilities from 2008-2009, and report on whether this trend has continued; and (b) the appropriateness of the present placements of people with I/DD in nursing facilities.
- Offer individuals with I/DD living in skilled nursing facilities the opportunity to relocate to alternative community settings as appropriate, perhaps through focused use of North Carolina's Money Follows the Person program.

Action Step 6: Implement N.C. Institute of Medicine (IOM) Adult Care Home recommendations

North Carolina's use of Adult Care Homes (ACHs) for people with I/DD has drawn fire over the past several years. In May 2011, House Bill 108 was passed by the North Carolina General Assembly. The legislation calls upon DHHS to evaluate and report on IOM recommended actions, including: (a) an evaluation of residents of adult care homes to determine whether they can live independently in the community with services, supports, counseling, and transition services; and (b) submission of a Medicaid 1915(i) State plan amendment or 1915(c) Home and Community-Based Services waiver to support individuals to move to more independent living arrangements.

As DHHS undertakes these tasks, it is important that strong, clear and achievable goals be set so that change can be accomplished. To succeed, DHHS should assure collaboration among Divisions, service providers, people with I/DD and others to develop plans for establishing alternatives to ACHs as warranted.

Action Step 7: Utilize the Balancing Incentives Program

The Balancing Incentive Program, set within Section 10202 of the Patient Protection and Affordable Care Act (Pub. L. 111-148), provides financial incentives to States to offer community Long-Term Services and Supports (LTSS) as an alternative to institutional care. Specifically, states that spend less than 50 percent of their long-term care dollars on community LTSS receive a two percent (2%) increase in the Federal match they receive from participation in the Medicaid program (i.e., a state's Federal Medical Assistance Percentages or FMAP). States that spend less than 25 percent receive a five percent increase.

North Carolina, using FY 2009 data (as is required) spends 42.9 percent of their long-term care funding for all service populations (i.e., developmental disability, mental health, aging and physical disability) on Home and Community-Based (non-institutional) 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, DHHS should consider applying for the Balancing Incentive Program administered through the Centers for Medicare and Medicaid Services (CMS).

Promote Outcomes Important to Individuals and Families

Action Step 8: Implement principles, structures and processes to support a self-directed system

Toward assuring a well-designed and fully implemented self-directed service 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:

- Develop specific performance measures related to self-direction.
- Assure that the LME-MCOs adopt consistent principles related to self-direction.
- Assure that the LME-MCOs have uniform operational structures in place for self-direction.
- Assure that the LME-MCOs have uniform processes in place for self-direction.

If individuals 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.

Action Step 9: Accelerate opportunities for integrated employment

In 2011, the NCCDD paid the membership fee so that North Carolina could join the State Employment Leadership Network (SELN). SELN offers member states technical assistance for systems change from reliance on sheltered work to supporting individuals in integrated work places with competitive pay. To make the most of the SELN membership, DHHS should:

- ✓ Institute Employment First policies at the state and LME-MCO levels based on a presumption that people with I/DD should work and that integrated employment at competitive wages be the *first or preferred* service option considered for service recipients.
- ✓ Embed into state and local operations practices such as: (a) offer providers funding mechanisms and contracts that emphasize employment as the preferred outcome, (b) provide for 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 utilization of natural supports on the job and while looking for a job, and (e) provide individuals with assistive technology.

Action Step 10: Promote mutual support and association among self-advocates and families

As in North Carolina, service systems across the nation are challenged to accommodate increasing demands for service while enduring difficult fiscal times. In response, states continue to support a "services first and only" approach, funded primarily through Medicaid. Lost in this response are opportunities for promoting a spirit of personal reliance and contribution, mutual support and community connection. A more favorable response requires that policy makers at all levels complement existing public services by establishing sustainable networks of mutual support for individuals with I/DD and their families.

In North Carolina, the majority of people receiving home and community-based services (HCBS) live at home with family. Recognizing a need to establish means of support to complement public services and the State's existing reliance on families, DHHS should assure that LME-MCOs work with First in Families of North Carolina to:

- ✓ Develop mutual support -- "peer connection"-- networks among families and self-advocates to promote mutual support among participants and maximize the use of available community assets; and
- ✓ Provide opportunity individuals with I/DD and their families to establish formal cooperatives or federations where participants work together to manage the services they receive.

Action Step 11: Strengthen community capacity to serve people with extraordinary behavioral challenges

A critical measure of the effectiveness of a community I/DD service system is how well it supports individuals who have especially challenging behavioral or medical conditions. The capacity to meet the needs of these individuals without resorting to unwanted and unnecessary placement out-of-home 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 will be avoided.

For DHHS to reduce reliance on developmental centers, community capacity to respond to challenging behavior must be available. The NC START (North Carolina Systemic, Therapeutic Assessment, Respite and Treatment) program is a proven model, but is spread thinly across the state. NC START must be expanded to meet demand statewide.

Action Step 12: Establish equitable resource allocation for individual budgets

Around the nation, states are acting to establish individualized service budgets for individuals to achieve greater efficiency and equity. Consistent with House Bill 916, DHHS is already moving to establish individualized budgets for people with I/DD across all the new LME-MCOs. DHHS' progress should be continued, and in ways that assure that:

- The data collected to assess individual support need is accurate and reliable;
- Stakeholders, including people with I/DD, families and service providers, are involved at the state and local levels to learn about prospective changes and provide feedback to DHHS to sharpen the process;
- The service array available to individuals with I/DD is consistent with best practices to promote community integration and self-direction;
- Reimbursement rates associated with services are fair and ample;
- The individualized budgets allocated to people with I/DD are fair and sufficient, and the aggregate funds for all budgets is within the capitation limit assigned to each LME-MCO; and
- Means are established to address complaints from service recipients, including complaints to accommodate exceptional need due to medical and/or behavioral challenges.

Action Step 13: Set standardized quality management practices and use outcome-based performance data to drive quality improvement

The adage that what is tracked and reported is what improves holds true in I/DD services. Given implementation of HB 916, it is vital that DHHS require standardized quality management practices across the new LME-MCOs. Outcomes important to individuals receiving services should be targeted for performance improvement. DHHS and the LME-MCOs should set goals, track and publicly report performance on integrated employment, health outcomes, eliminating unnecessary use of psychotropic medications, personal relationships for people with I/DD, and self-direction**.**

Expand Community System Capacity to Serve More Individuals

Action Step 14: Effective management of waitlist for services

State and local agencies in North Carolina report that 8,191 people are waiting for Medicaid-financed services. Responding to this unmet need, in 2009 the General Assembly enacted Section 1 of G.S. 122C-115.4(b) requiring each LME develop a list of persons with I/DD waiting for services. Beginning in October 2010, the LMEs 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 is still not being collected on the individuals waiting for services in a consistent fashion across LMEs.

As the State and new LME-MCOs move to collect information on individuals waiting for services, the following information should be collected through a standard process:

- Demographic information on the individual waiting (including name, current address, phone number and date of birth);
- Date of entry to the waitlist system;
- Type of service(s) the individual is waiting for (i.e. residential, vocational, etc.);
- Level of support required (using an assessment tool which measures support need); and
- Urgency of need. Are requested services critical (needed within 90 days), moderate to critical (needed within 3-6 months), moderate but not critical (6-12 months) or not critical (12 months or more)?

As this data is collected, it should be entered into a state-wide reporting database for Medicaid-financed services tracking. Doing so will allow the State and LME-MCOs to combine current service utilization data for individuals already receiving HCBS and those waiting for services. In addition, standard assessment instrument and protocols must be developed, as well as the protocols for monitoring and updating information on the individuals waiting for services.

Action Step 15: Expand system capacity at a steady pace by serving an additional 1,131 people each year between 2012 and 2022

The strategy to accommodate most, if not all, unmet demand for service is to expand system capacity at a steady pace by serving an additional 1,131 people each year between 2012-13 and 2021-22. Such action would result in 11,316 additional individuals receiving services by 2022.

There is no doubt that additional dollars will be needed for North Carolina to address current unmet service demand as well as keep pace with projected service demand through 2022. By employing the HCBS waiver authority to finance this expansion in capacity, the State will be able to secure federal Medicaid dollars to underwrite 64 percent of the cost of this expansion. Again, it is important to realize that by serving the additional 1,131 individuals per year, the State would achieve a service utilization rate of 250 per 100K by the end of the period (i.e., by 2022). There is a significant possibility that by serving this number of people, the North Carolina will sharply reduce and possibly eliminate the waitlist for specialized developmental disabilities services over time.

Conclusion

> **"When an elephant stands still, it is more bothersome for the person underfoot than for the rider on the top."**
>
> ***Indian proverb***

North Carolina faces difficult policy choices regarding the way in which it responds to the needs of its citizens with intellectual and other developmental disabilities (I/DD). Such choices are made more difficult given state budget shortfalls, chronic under-funding for the I/DD system, an over reliance on developmental centers and ICFs/MR, a stressed community service system, a growing service waitlist, and changing expectations among people with I/DD and their families for lives that mirror the general population. Unquestionably, North Carolina is at a crossroad.

To guide the way forward, in the first of two reports compiled for this effort, HSRI prepared the *Planning Context* and compared the State's performance against five benchmarks. That analysis resulted in the followingfinding:

> *Though North Carolina has worked to offer people with I/DD the services they need, the State is ill-positioned to address the present and future needs of its citizens with I/DD due to: a lack of definitive and unified leadership, insufficient resources, inefficient use of available resources, and a lack of a cohesive and full commitment to community centered service approaches.*

In response, a strategy of 15 Action Steps was compiled and is presented in this report. These *Steps* are inter-related and should be regarded as a unified, intertwined series of actions that build and depend on one another. Yes, the State will need to invest more in services for people with I/DD. After all, North Carolina's investment to date has been modest relative to what other states spend. As a result, success will depend on collaboration among many in the state, but must begin with a commitment to change from chief decision makers in North Carolina inside the executive and legislative branches, as well as the Secretary of DHHS. By enacting the proposed steps North Carolina will increase system capacity, improve efficiency, and enhance the quality of life of thousands of North Carolinians with I/DD their families.

Across the nation, people with intellectual and other developmental disabilities argue strongly for support systems that look decidedly different than the current service system in North Carolina. The time has come in North Carolina to push past its present circumstances and establish an action bias for change to assure that people with I/DD receive the supports they need to live in the community as other citizens do. Surely, people with I/DD will settle for nothing less.

Introduction

In 2008, the North Carolina Council on Developmental Disabilities (NCCDD) convened a summit of developmental disabilities stakeholders in a series of meetings to discuss areas of system change. Those meetings resulted in a report, *Looking Forward: A Summit on the Developmental Disabilities System in North Carolina*[4]*,* that outlined recommendations for policy and administrative reform reflecting the overarching issues facing the service system in North Carolina for people with intellectual and other developmental disabilities (I/DD). The Council chose to focus on advancing reform recommendations in five issue areas: Viable Direct Support Workforce; Quality Management and Quality Improvement; Improving Case Management; Empowering Individuals and Families; and Fostering Leadership and Innovation.

NCCDD engaged the Human Services Research Institute (HSRI) to develop *A Strategic Analysis for Change* to offer consultation to state staff and policy makers engaged with directing North Carolina's system for serving people with intellectual and other developmental disabilities. HSRI prepared the strategic analysis in two stages. The first report, *A Strategic Analysis for Change: Planning Context*[5]*,* released in August 2011, provides an analysis of the current service delivery system and the context within which policy makers must implement recommendations for reform. Building on that work, this second report lays out 15 *Action Steps* to achieve system reforms prioritized by the Summit stakeholders and the Council.

Overview of Planning Context Report Findings

As reported in the *Planning Context*, in some areas of performance, North Carolina's system of services for people with I/DD is on par with most other states. For instance, North Carolina is in line with the national average regarding the percentage of those receiving services that live with family. North Carolina also performs on par with the national average regarding the percentage of individuals served living in residences for 1-6 people. Likewise, regarding service quality, results generated through the State's participation in the National Core Indicators (NCI) project reveal that North Carolina places near the NCI average on many performance measures.

Yet in other respects North Carolina's system faces extraordinary challenges and has not kept pace with either national trends or performance. The strategic analysis established that:

- For most of the past two decades there has been a **lack of definitive, unified leadership and vision** at DHHS concerning I/DD services. A contributing factor is the present administrative system structure within DHHS. Along with several departmental-level positions with responsibilities involving the I/DD service system, multiple state Divisions (e.g., DMH/DD/SAS, DMA, SOHF) are called on to lead and manage pieces of the I/DD

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[4] Bradley, V., *Best Practices for Implementing the Recommendations of "Looking Forward: A Summit on the Developmental Disabilities System in North Carolina" Technical Report*. October, 16, 2008.

[5] Agosta, J., Bradley, V., Melda, K., Pell, E. & Smith, D. (2011). A *Strategic Analysis for Change Planning Context Responding to the Needs of People with Intellectual and Other Developmental Disabilities in North Carolina.* Tualatin, OR: Human Services Research Institute.

service response. While state leaders meet regularly to coordinate policies and actions, the organizational structure is extraordinarily complex, and no one agency or person seems to be in charge of setting and implementing cohesive policy. The lack of a high-level position in DHHS, responsible only for I/DD, also contributes to the lack of unified, clear direction. Without clear direction, stakeholders (e.g., provider associations, advocacy groups) are emboldened to politicize with hardened positions. The result has yielded a difficult political environment where cohesive policy direction and consensus is not apparent.

In North Carolina…

The I/DD system:

- ✓ **Lacks definitive, unified leadership and vision;**
- ✓ **Serves fewer people and spends less money than other states;**
- ✓ **Relies too heavily on developmental centers, ICFs/MR and other large facilities; and**
- ✓ **Falls short on a number of indicators of service performance or quality.**

- For its population, North Carolina s**erves significantly fewer people and spends less money than other states**. North Carolina serves 29 percent fewer people with I/DD per 100,000 (i.e., 100K) of general population with Medicaid-financed services than the national average (151 in North Carolina[6] versus 213 per 100K population nationwide). For North Carolina to have served the national average of people per 100K population in 2009, the State would have had to provide services to 5,750 more people in that year, or 62 people more per 100K of general population.
- Fueling this circumstance is a relatively modest investment in I/DD services. In 2009, North Carolina spent $104.85 per citizen for intellectual and other developmental disabilities services. The nationwide average ($121.40 per citizen) was $16.55 dollars, or 15.7 percent, per person higher. In fact, North Carolina's 2009 spending for I/DD services would have had to have been $155,253,630 higher to match the nationwide average.
- The **extraordinary reliance on developmental centers and other services funded by the Intermediate Care Facilities for the Mentally Retarded[7] (ICF/MR) option** is inconsistent with the Supreme Court's Decision in *Olmstead v. L.C.* and is fiscally inefficient.
    - ▪ The utilization rate for developmental centers in North Carolina is 57 percent higher than the national average; 1,593 individuals resided in state-run developmental centers, or 17.0 individuals per 100K in general population, compared to 10.7 nationally.

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[6] To date, North Carolina has not furnished data to the University of Minnesota on the number of people receiving services in the Piedmont Behavioral Health (PBH) LME catchment area. All data presented from Lakin, et.al excludes individuals receiving services from PBH.

[7] The authors of this report do not support the terminology "mentally retarded or the acronym MR." It is used in this report because it remains the standard term used in federal law and with regard to some Medicaid-funded services.

  - ICF/MR use in North Carolina is nearly double the national average. ICF/MR placements in North Carolina (3,854 people) comprise 27 percent of those receiving residential services, compared to 14 percent nationally. Of those in ICFs/MR in North Carolina, 1,798 individuals resided in larger community ICFs/MR (15 or fewer residents). This amounts to 14.8 percent of the 12,131 served either in community ICFs/MR or receiving HCBS. Again, this is more than twice the national average of 6.5 percent.

- In addition, 2,141 individuals, including the 1,593 in state-run developmental and neuro-medical centers, live in facilities of 16 or more people. This amounts to 21.4 percent of all those receiving residential services in North Carolina live in facilities of 16 or more people. This compares to 13.6 percent nationally who receive residential services.
- Regarding expenditures, North Carolina spends 21.3 percent more per person than the national average. North Carolina expended an average $69,331 per person for HCBS and ICF/MR services. In 2009, the national average was $57,126 per person.

  The high cost per person in North Carolina is in large part explained by the state's high reliance on ICFs/MR and the associated costs. Average costs of service illustrate that the cost of serving an individual in a developmental center is $175,000 per year, compared to $92,906 in a community ICF/MR and $61,291 for CAP/MR-DD waiver services.
- North Carolina **falls short on a number of indicators** of service performance or quality. 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 medication for behavior control. Nor has sufficient achievement been demonstrated supporting people to be in relationships beyond paid or family care providers.

In addition to these difficult circumstances, policy makers, advocates and other system stakeholders increasingly realize that resources going forward will not be plentiful, and that the system will not easily evolve on its own. DHHS must act decidedly to re-position the system to use available public funding more effectively and improve performance on service quality and outcomes.

Report Structure

To address *Planning Context* findings, HSRI prepared 15 action-oriented recommendations to guide needed system reforms. These actions embody a vision for the future (e.g., the Strategic Path Forward) that promotes community integration and self-direction for people with I/DD, improved service outcomes and fiscal efficiency and sustainability.

This report is divided into three additional parts:

1. **Strategic Path Forward**: We present the context for needed change and a series of steps which we believe North Carolina must take to improve performance and better position the state's I/DD service system. Actions are called for in four areas to:

   A. Establish clear leadership for developmental disabilities service system;
   B. Serve people in the most integrated setting by reducing further the role that developmental centers, nursing homes, and ICFs/MR play within the North Carolina service system;
   C. Promote outcomes important to individuals and families, including emphasis on self-direction among people with I/DD, partnerships among service recipients, family members and community service organizations, as well as among public agencies, and strengthening infrastructure in support of the community services system; and
   D. Expand system capacity so that by 2022 all people who have emergency or critical unmet needs will be served with reasonable promptness.

2. **Implementation Sequence.** A timeline is offered to illustrate how the 15 *Action Steps* may be sequenced and completed over ten years.
3. **Concluding Remarks:** We present a summary of our observations and parting remarks.

Strategic Path and Action Steps

North Carolina is at a crossroad. Our analysis of the present *Planning Context* shows that while the State has acted in various ways to emphasize community centered services for people with I/DD, many significant challenges remain. Modest funding that is often inefficiently applied (supporting people in segregated rather than the most integrated setting), results in a relatively high per person cost. It also yields unsatisfactory service outcomes and leaves many without services.

> **The best way to predict the future is to invent it.**
>
> ***Alan Kay***

To confront challenges such as these successfully, DHHS cannot proceed with "business as usual," but must alter policies and practices systematically to make needed reforms. Altering policies and practices challenges stakeholders in North Carolina to take a hard look at every dimension of current operations to ensure that scarce resources are put to best use, while canvassing new opportunities and looking outside the I/DD service system to support people and families.

Toward this end, DHHS is taking significant steps to modify the service system as per the mandate for change established through House Bill 916. To succeed, significant collaboration among many will be required, with DHHS playing a core leadership role. Yet DHHS should not be called upon to act unilaterally or without support to make needed system changes. Other public agencies must collaborate to coordinate efforts on behalf of people with I/DD. In addition, the NC Council on Developmental Disabilities, universities, Disability Rights North Carolina, service providers, advocacy organizations, self-advocates, families, and others must also play a part.

System restructuring is a complex, challenging endeavor, especially in large service delivery systems like the one in North Carolina. To accomplish needed change, a sound plan, guided by a clear vision of the desired future system, is needed. This plan should establish overall goals, set forth the guiding principles, and outline a series of action steps to achieve desired outcomes. What follows is a road map to system change: (a) the 2011 legislative mandate that is driving present system reform in North Carolina, (b) a recommended strategic approach, including proposed guiding principles, and (c) 15 *Action Steps* within four key areas of reform.

House Bill 916 and Key Requirements for Restructuring

This report was largely compiled in the midst of planning and implementation of a major system restructuring led by DHHS. In 2011 the General Assembly enacted House Bill (HB) 916 which provides for a major restructuring of the management, financing and delivery system for services for individuals with mental illness, intellectual and other developmental disabilities

(I/DD), and substance abuse disorders. This restructuring will occur through the expansion of the 1915 (b)/(c) Medicaid waiver[8], to be completed by July 1, 2013.

Among the many requirements (or anticipated results) of the legislation are:

- The current 23 Local Management Entities (LME) will be consolidated into no more than 12;
- 11 of the 12 LMEs will convert into managed care organizations (MCOs)[9] by January 1, 2013;
- LME-MCOs will receive a capitation payment to manage the local service system and accept some measure of risk for maintaining full accountability for all aspects of waiver operations and for meeting all contract requirements specified by the Department;
- The restructured system will “maintain fidelity to the PBH demonstration model;”
- Requirement of increased coordination of care;
- Savings resulting from managed care service delivery will save money that can be reinvested into the system; and
- Stakeholders will play a major role in the design and implementation of the initiative.

The law also requires the Department to explore the feasibility of utilizing the provisions of Section 1915(i) of Title XIX to provide habilitation services for individuals with I/DD that are eligible for Medicaid but not enrolled in the 1915(c) waiver or residing in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR).

Further, the Innovations component of the waiver expansion specifies the use of a resource allocation system based on the Supports Intensity Scale (SIS) for the delivery of home and community based Medicaid waiver services to eligible individuals with I/DD. The Department’s implementation plan anticipates that the resource allocation system will be in place by January 1, 2013. Figure 1 illustrates the plan, as of October 2011, of the anticipated configuration of LMEs. Given that planning and implementation of the new system structure is continually

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[8] Medicaid is the major source of public funding for long-term services and supports provided in home and community settings for people with I/DD. A popular means for doing so involves use of a1915(c) Home and Community-based Services (HCBS) waiver. When approved by the Center for Medicaid and Medicare Services (CMS), this type of waiver typically allows states to avoid certain requirements of the Social Security Act to target a particular group (e.g., people with developmental disabilities and/or people living in particular parts of the state). Other types of waivers are possible. CMS explains that a 1915(b) waiver permits States to make mandatory the enrollment of beneficiaries in Medicaid managed care plans, use local entities to manage services, deliver additional services generated through savings and restrict providers using selective contracting.

Upon CMS approval States may utilize these two authorities together within a combination 1915(b)/(c) waiver. When both authorities are used, the State uses the 1915(b) authority to mandate enrollment in a Medicaid managed care plan and limit freedom of choice and/or selectively contract with providers, and uses the 1915(c) authority to target eligibility for the program and provide home and community-based services. By using both authorities, States can provide long-term services and supports in a managed care environment. Additionally, they could use section 1915(b) authority to use a limited pool of providers. States can implement 1915(b) and 1915(c) waivers concurrently as long as all Federal requirements for both programs are met.

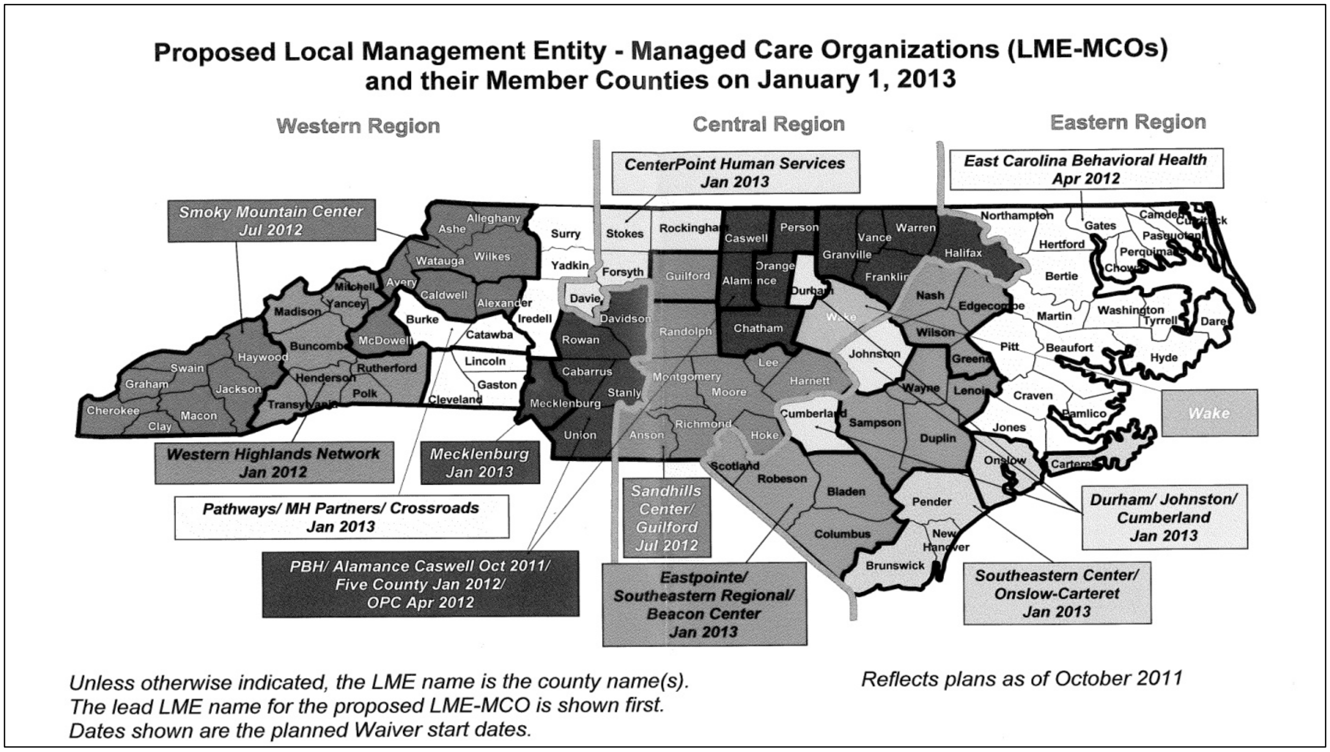
[9] The PBH LME is already a managed care organization.

evolving, stakeholders are encouraged to visit the DHHS website to review past and recent developments: http://www.ncdhhs.gov/mhddsasproviders/1915bcWaiver/index.htm.

This site provides links to reports and DHHS communications as well as news alerts. For instance, on the site one can easily locate:

- The 1915 b/c Waiver Strategic Implementation Plan (October 2011)
- A map of the proposed new LME-MCOs
- LME-MCO Tentative Start Dates (12/15/11)
- A description of the PBH Managed Care Experience (12/6/11)
- An overall description of the anticipated system changes.
    - 1915 b/c Waiver Communication for People with IDD (4/19/11)
    - 1915 b/c Waiver Communication (4/11/11)
- The Waiver Advisory Committee (DWAC) charged with advising DHHS (12/15/11)
- A comparison: NC Innovations and CAP-MR/DD Waivers (12/20/11)
- A description of the LME-MCO Appeal Process (7/15/11)
- Description of changes in case management given the new LME-MCO structure. (5/12/11)
- Various News Alerts to provide updates on the progress made toward restructuring.

Figure 1



Proposed Local Management Entity - Managed Care Organizations (LME-MCOs) and their Member Counties on January 1, 2013

Unless otherwise indicated, the LME name is the county name(s).
The lead LME name for the proposed LME-MCO is shown first.
Dates shown are the planned Waiver start dates.

Reflects plans as of October 2011

Reforms called for by House Bill 916 are significant because they dramatically revise the administrative underpinnings of the system. It changes how the system is managed and the flow of funding across the system. This bill, however, does not assure that the system will change in ways to alter or improve many of the challenging circumstances described within the *Strategic Plan for Change: Planning Context*. Consider that these reforms do not:

- Change the state level leadership structure that involves multiple DHHS Secretaries and Divisions. Coordinating the new LME-MCO structure will require cohesive policy decision making at all levels, and especially among state leaders;
- Direct DHHS to de-emphasize the present enduring, inefficient, reliance on developmental centers, community ICF/MR or other reliance on congregate facilities;
- Direct DHHS to promote practice and outcomes more consistent with contemporary practice related to self-direction, community integration or employment, or with utilizing opportunities within communities to diversify the range of supports people may receive;
- Direct DHHS to assure that ample infrastructure and collaboration exists within and between LME-MCOs to assure that extraordinary individual needs are met; or
- Direct DHHS to establish and enact a systematic plan for reducing and eventually eliminating the service wait list.

The *Actions Steps* recommended below are not meant to provide precise guidance to DHHS or the LME-MCOs about implementing House Bill 916. Instead, they offer overall targets that reach further than the Bill, challenging the department and the LME-MCOs to seize this opportunity to press past administrative revisions and change the substance of the services people receive.

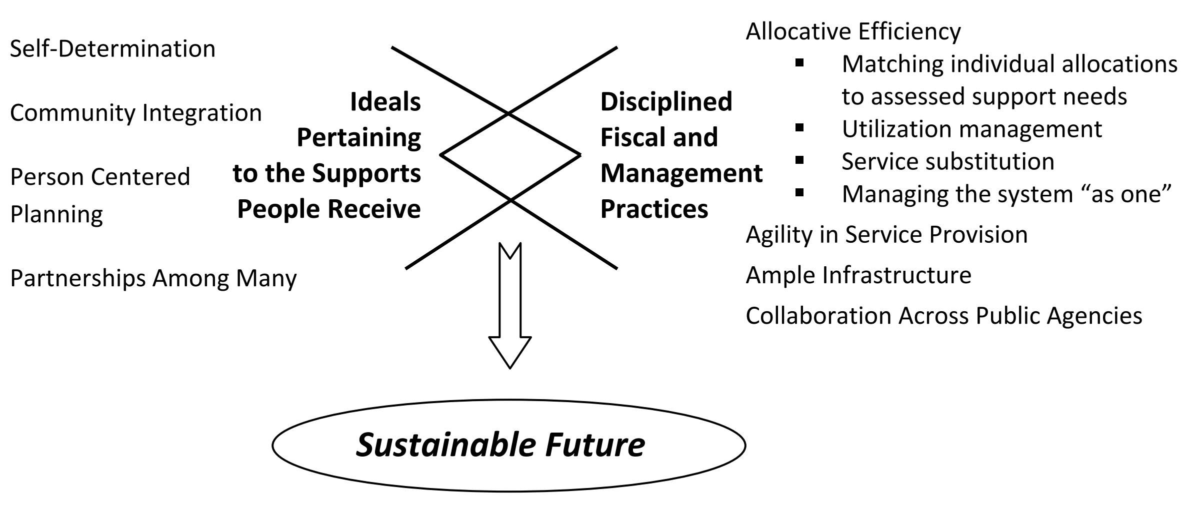
Strategic Approach and Guiding Principles

A sustainable service system is one that is funded and structured to meet the needs of all those in need over time. It must be amply funded, but it must also make most efficient use of available public resources to yield high quality outcomes. Establishing a sustainable future for North Carolina's I/DD service system must begin with an overt commitment to provide high quality supports to all citizens with I/DD who need them. All policy actions must be aimed at fulfilling this commitment.

A "strategy" is defined as a long-term plan of action designed to achieve a particular goal. Strategy is differentiated from tactics in that a strategy describes a comprehensive or high level means to an end. Tactics describe the "how to" or precise actions that must be taken to implement a strategy. Action Steps in this report are the system change tactics. Underscoring the strategic path to systems change is a commitment to:

Establish an efficient and sustainable system whereby people with intellectual and other developmental disabilities can live the life they want in the community with the supports they need.

Blending Together Ideals for Service Delivery with Management Practices to Yield a Sustainable Future
(Figure 2)



Aside from making the best use of available public resources, achieving this goal is also predicated on an important proposition – i.e., there are opportunities to improve efficiency and enlist new resources in support of people with I/DD that must be vigorously pursued. Realizing these opportunities will require us to re-think what and how services are offered, and so will likely disrupt the present ways of doing things. Unless these opportunities are pursued, however, we will not be able to achieve the best outcomes possible for people with I/DD and their families.

The proposed 15 *Action Steps* are based in principles that blend together services preferred by people with I/DD with disciplined fiscal and management practices. Doing so provides the best opportunity for yielding a sustainable future for I/DD services in North Carolina. Summary descriptions of the principles embedded within the *Action Steps* follow.

- A sustainable future requires approaches that promote community integration and self-direction. People with intellectual and other developmental disabilities (I/DD) themselves represent a primary, albeit too often neglected, group of stakeholders that must be effectively engaged. Beyond providing training resources to develop self-advocacy, policy makers must also provide opportunities for individuals to use self-advocacy skills to engage in discussions about service improvement.
- A sustainable future requires commitment to person-centered approaches in which individuals can choose among qualified providers of any available service, and also select where and with whom they live.
- A sustainable future requires a sustained, working partnership among service recipients, families, service providers and communities across the state. Making available well coordinated and efficient public services must be a primary goal. These services,

however, must be complemented by other community supports that provide individuals and families the opportunities to offer mutual support to one another through peer support networks or exchange networks.

- A sustainable future requires <u>sufficient resources</u>. North Carolina spends more dollars per person than most other states, but spends notably less overall than the national average given its state population. The state leadership must come to terms with these facts. Put plainly, not enough is spent on I/DD services. Implementing the following *Action Steps* will require that North Carolina step up its funding of I/DD services.

  Additional spending necessary to implement most of the Action Steps can be offset in large part (about 65 percent) with federal Medicaid dollars.

- A sustainable future requires <u>allocating resources more efficiently</u>. Promoting efficiency will require a variety of complementary actions:
  - Accurate and reliable means of assessing individual support needs so that individuals are allocated resources that match their needs;
  - A range of valued services must be made available to individuals regardless of the amount of their individual budget;
  - Service planning must result in individuals 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 its current division into discrete financial entities (e.g., HCBS, developmental centers, community ICF/MR).
- A sustainable future encourages <u>agility in service provision</u> so that individuals can easily seek out providers who offer the highest quality services, and likewise, so that providers can alter their approach to be responsive to shifts in demand or changes in practice. In addition, agile systems must be able 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.
- A sustainable future requires <u>a resilient system infrastructure</u>. Within any system, investment in direct services must be complemented with 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 equitable and reliable means of allocating resources on a person-centered basis.
- A sustainable future requires <u>collaboration</u>. Health, education, human services, housing and transportation systems are terribly fragmented. Rather than offering cohesive responses to need, these systems too often sort needs into categories and assign

responsibility for meeting needs to this or that public agency. As a result, people with lifelong disabilities and their families must negotiate across different service systems, cobbling together what they can 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.

Fifteen Action Steps

System redesign offers an opportunity for North Carolina to improve system performance while promoting sustainability. This report lays out an *Action Step* agenda for achieving these goals. Although not every area amenable for systems change is addressed, these steps are related to, and should be undertaken in tandem with, system reforms already underway as a result of House Bill 916. Implementation of each *Action Step* will require more detailed planning than is presented here, planning that should be conducted as a collaborative enterprise that stresses transparency. The next four sections cover recommended *Action Steps* organized by the performance and/or sustainability area the step is targeted to address:

A. Establish clear leadership for the I/DD service system;
B. Serve people in the most integrated setting;
C. Promote outcomes important to individuals and families; and
D. Expand system capacity to address the wait list and emerging service demand.

Figure 3 below illustrates the relationship of goals, guiding principles, and action steps.

A Strategic Analysis for Change

Overall Goal, Guiding Principles and Action Steps

Figure 3

Overall Goal

Establish an efficient and sustainable system whereby people with intellectual and other developmental disabilities can live the life they want in the community with the supports they need

Guiding Principles Committing to:

Ideals Pertaining to the Supports People Receive

Disciplined Fiscal and Management Practices

Action Areas	Action Steps
A. Establish clear leadership for the I/DD service system	Step1: Assure unified policy direction Step 2: Invest in self-advocacy
B. Serve people in the most integrated setting by reducing the role played by developmental centers, ICFs/MR nursing homes, and Adult care Homes	Step 3: Reduce developmental center census Step 4: Reduce reliance on community ICFs/MR Step 5: Study nursing home placements Step 6: Decrease reliance on Adult Care Homes Step 7: Consider Balancing Incentive Program
C. Promote outcomes important to individuals and families	Step 8: Offer self determination options Step 9: Promote Employment First policy Step 10: Promote mutual supports Step 11: Address extraordinary behavioral needs Step 12: Promote fair/efficient resource allocation Step 13: Promote outcome based performance
D. Expand system capacity to address the wait list and emerging service demand	Step 14: Manage wait list data effectively Step 15: Expand capacity to eliminate wait list

Action Area A: Establish Clear Leadership for the I/DD Service System

Planning Context Assessment: Leadership of developmental disabilities services lacks coherency and a commitment to long-term goals across agencies and stakeholders.

Put simply, service systems tend to generate whatever results they are designed to produce. And one characteristic of the present North Carolina I/DD system is ambiguity in policy direction. In 2001, HSRI prepared a report for the North Carolina Legislative Oversight Committee that evaluated the I/DD system in North Carolina. Published a decade ago that report[10] found that the I/DD system lacked a coherent vision:

> "*North Carolina lacks a clear vision for its system of services and supports for people with developmental disabilities. As a consequence, there is no consensus and frequent disagreement concerning the system's fundamental mission and how it will be pursued in the near and long-term*."

Ten years later, in the *Planning Context* report, this finding stands unchanged. An array of public and private organizations are engaged in the provision of supports to individuals with intellectual and other developmental disabilities in North Carolina. Chief among them is the North Carolina Department of Health and Human Services (DHHS). Inside DHHS, several departmental-level positions have responsibilities involving the I/DD service system, and multiple state Divisions (e.g., DMH/DD/SAS, DMA, SOHF) are called on to lead and manage pieces of the I/DD service response. Within DMH/DD/SAS, there is no longer a discrete I/DD unit and no single individual within the Division is responsible for I/DD service policy direction. Multiple state agencies are in turn are joined to local service delivery involving Local Management Entities (LMEs) and a network of service providers.

In the *Planning Context* Report, HSRI noted that these complicated arrangements, with no one office clearly in charge of overall I/DD system policy, yields an enduring confusion over how the DHHS mission for valued outcomes for service recipients is carried out across state agencies and LMEs. For example, is the Department committed or not to:

Everything should be made as simple as possible, but not one bit simpler.

Albert Einstein

- Reducing census at developmental centers and reliance on other large congregate care facilities?
- Decreasing its reliance on ICFs/MR in favor of investment HCBS?

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[10] Smith, G. (2001) *Today's Choice: Tomorrow's Path – An Evaluation of the System for People With Developmental Disabilities in North Carolina.* Tualatin OR: Human Services Research Institute.

- An "employment first" service response to offer individuals the opportunity for a community job in an integrated workplace?
- Increasing substantively investment in self-directed, community centered service options?

DHHS, across its administrative divisions, provides ambiguous responses to these and other policy questions. As a result, the Divisions sometimes work at cross purposes. Emboldened stakeholders (e.g., advocacy groups, provider associations), who themselves may not agree, politicize to press their points of view. What results is a modest promotion of community-centered services while maintaining historical investments, as in developmental centers and ICFs/MR.

House Bill 916 sets forth a major restructuring of the management, financing and delivery system for I/DD services. Though significant, these changes do not resolve the lack of leadership and coherent policy direction. Indeed, the legislation adds greater pressure to leaders within DHHS to establish a cohesive approach to establishing policy direction and management of the new LME-MCOs. Establishing coherent policy direction should include the voices of service recipients and their families to the decision making process at the state and local LME-MCO levels. These individuals are the users of the services provided by the system and have experience to contribute to policy deliberations.

Action Step #1: Commit to unified policy direction within DHSS for I/DD services that embraces community centered practice

Future policy direction for I/DD services should consist of a cohesive series of goals, policy and practices implemented across DHHS Divisions and offices. Ideally, a particular office, perhaps at the secretarial level, would have overall decision making authority for coordinating policy and action and be held accountable for the outcomes that result.

DHHS may be unable to alter its present administrative organizational structure in favor of another. Yet the response called for is not complicated. After all, it is said that "things are the way they are because they got that way," and in this instance are allowed to continue.

The DHHS Secretary should decidedly embrace a position in favor of community-based services.

The DHHS Secretary should decidedly 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. Recommendations within this report are a template for definite policy direction.

This is not to suggest that the State has not already been moving in these directions. But movement has been slow and regularly competes with continued investments in contrary service options. The challenge to DHHS is to cease such ambiguity and continued investment in competing service delivery (institutional v. community) in favor of a unitary commitment to community. Responsibility for directing such a commitment rests with the Secretary.

Action Step #2: Invest in self-advocacy for policy collaboration

Quality management practice today requires offering people using the service system with opportunities to provide input -- to proposed changes to policy and practices, and on the type, accessibility and quality of services. DHHS already has two vehicles for communicating directly with individuals and their families: the North Carolina Council on Developmental Disabilities, and the Consumer Family Advisory Committees.

- North Carolina Council on Developmental Disabilities (NCCDD) The Council is funded by the US Administration on Developmental Disabilities and was established to work closely with DHHS. The Council is composed of 40 members who represent all of North Carolina; 60 percent of members are people with I/DD or their family members, 40 percent of members represent state agency, nonprofit and professional organizations. The Council directs funding and research to key policy areas including health care, housing, transportation, employment, and quality assurance. www.nccdd.org
- Consumer Family Advisory Committees (CFAC) at the state and local LME level[11] The State CFAC is a 21 member advisory organization, composed entirely of service recipients and their family members. Its role is to advise the Department (DHHS) and the Legislature on the planning and management of the State's public mental health, developmental disabilities, and substance abuse services system. Each local LME (in future, each LME-MCO) manages its own CFAC. Members include individuals and/or family representatives from each service population. State and local CFACs meet regularly to comment on policy and practice.

Organizations such as these provide significant opportunity for stakeholders, including individuals with disabilities and their families to provide input to DHHS. However, many individuals with I/DD often have a difficult time making their voices heard and need support to follow conversation and develop opinions. To engage in policy deliberations, self-advocates must know something about the policies in play and the forces that shape them. They must understand how they can be most effective in the policy arena. And they must have the opportunity to act, both individually and collectively.

Self-advocacy is not limited to promoting system change. Most of all it is relevant to individuals' personal lives. Participating in a self-advocacy group typically provides individuals with opportunities to achieve personal goals (e.g., to develop friendships, attend community events, etc.), offer one another mutual support, and opportunities to contribute to their local communities (e.g., volunteering to clean a park). From this base, self-advocates can gradually develop opinions about many matters, including the status and direction of the state's developmental disabilities service system. With time, personal experience grows and informs opinion, opinions that can coalesce and become statewide positions and collective actions.

To strengthen the I/DD self-advocate voices within NCCDD and the CFACs, and to broaden opportunities beyond these organizations, DHHS should collaborate with stakeholders to:

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[11] The Consumer Family Advisory Committees were codified into General Statute 122C-171 in 2006. For more information: http://www.ncdhhs.gov/mhddsas/services/advocacyandcustomerservice/scfac.html

- ✓ Teach individuals with I/DD to take the lead in the policy arena. If individuals with intellectual and other developmental disabilities are to live self-directed lives in the community, they need instruction and support in how to participate and thrive within a system seeking to promote community integration and self-direction. Policy makers could use the items below as a checklist for promoting individuals to be their own self-advocates.
  - Self-advocates need a working knowledge of key words and phrases, such as: developmental disability, self-advocacy and self-advocate, self-directed services, community integration, services and supports, person centered service planning, service system, providers, transition, Medicaid, in-home supports, etc.
  - Information on opportunities for self-direction within the system.
  - Information on life topics to help individuals lead balanced lives, such as nutrition and exercise, staying safe, relationships and sexuality, and developing friendships.

    Training materials on topics like these are already available nationally and could be put to use in North Carolina to train self-advocates across the state. Relevant materials can be found on the websites of Self-Advocates Becoming Empowered (www.sabeusa.org), The Riot (www.theriotrocks.org), Advocating for Change (www.selfadvocacy.com), and the National Youth Leadership Network (www.nyln.org). Other materials may already be available inside North Carolina.
  - Family involvement is not the same as the participation of self-advocates.
  - Successful self-advocate involvement requires elimination of barriers that may prevent people with intellectual and other developmental disabilities from contributing. To address potential barriers and plan supports, the first step is to consult with individuals regarding the types of supports or accommodations they need to contribute. Tailoring individual support will ensure that the talents and expertise each self-advocate has to offer will be used effectively and that meetings will be inclusive.

    One resource available to help organizations ensure that meetings are inclusive is produced by the Independent Living and Research Utilization (ILRU) Community Living Partnership and is readily available on the internet.[12] This resource includes a checklist to identify common barriers that people with various types of mobility, sensory, cognitive, and other disabilities may encounter. The checklist can assist organizations to enhance meaningful participation on their boards, task forces, and other policy shaping committees.

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[12] Independent Living Research Utilization Community Living Partnership (2006). *Checklist for Enhancing the Participation and Input of People with Disabilities.* http://www.hcbs.org/files/96/4767/ILRU_ACCESS_CHECKLIST.pdf

Another useful resource is *The Guide* available from the National Association of State Directors of Developmental Disability Services (NASDDDS). *The Guide,*[13] also available on-line, describes various issues pertaining to involving self-advocates in meetings, guidelines for involving self-advocates, an associated checklist, and a list of related resources.

✓ Maintain a statewide, independent self-advocacy organization that serves as the collective voice of North Carolinians with I/DD in shaping public policy and practice. Beyond providing training on self-advocacy, policy makers must support translation of training into collective opinions and action strategies so that self-advocates play a valued role delivering the opinion of people receiving services. Several state self-advocacy organizations include in their goals increasing participation of self-advocates on community provider boards, policy shaping task forces, and other events designed to gather public input regarding service and supports for individuals with intellectual and other developmental disabilities, or issues that affect their lives (e.g., Alabama People First, People First of California, People First of Missouri, Self-Advocacy Coalition of Kansas, Self-Advocates As Leaders in Oregon).

DHHS and other organizations should direct resources annually to further promote local and the statewide self-advocacy groups. The Association of Self-Advocates of North Carolina (ASANC) is the most visible self-advocacy organization in the state (http://www.asa-nc.org). ASANC's mission is to provide services to enable, educate, encourage, and empower people in the community. ASANC initially formed in 1987 and gained its non-profit status in 2000. It is composed of 12 active local self-advocacy groups from across the state. Over the past two years ASANC members worked through a process of reorganization to strengthen their managing structure to establish a stronger statewide voice. Members have succeeded in developing policy positions on issues important to self advocates, most notably one on the implementation of system change. (Read the ASANC Position Statement below).

Most recently, ASANC's chief source of fiscal support has been the NCCDD. The continued engagement of the NCCDD is important, but DHHS and the LME-MCOs must join in to help fund local and statewide self-advocacy. In some states the state developmental disabilities authority provides funds to self-advocacy organizations. For example, state agencies in Alabama, Illinois, Oregon, New York, Pennsylvania, New Jersey and Massachusetts have supported self-advocacy organizations. Some states (e.g., Oregon, Missouri, New York, Utah) have utilized VISTA/AmeriCorps programs[14] to complement funding for self-advocacy.

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[13] NASDDDS (2006). *The Guide: NASDDDS Handbook on Inclusive Meetings and Presentations. http://www.nasddds.org/pdf/TheGuide.pdf*

[14] Self-Advocate leadership Network (2005). *How your Organization Can Sponsor Self-Advocates as AmeriCorps*VISTA Members.* Portland OR: Human Services Research Institute (www.theriotrocks.org).

Position Statement of the Association of Self-Advocates of North Carolina on the Need to Inform People Who Receive Developmental Disability Services about Changes to Services (October 2011)

HERE IS THE PROBLEM…

- The North Carolina Department of Health and Human Services (DHHS) and its administrative Divisions are making changes to developmental disability (DD) services due to legislative action and state budget shortfalls.
- DHHS has made budget cuts to DD services and more cuts may still be made.
- People with intellectual and developmental disabilities receive services. Changes to DD services have a huge impact on our daily lives.
- People with intellectual and developmental disabilities should know about changes to DD services so they can speak up and make choices about the supports they need.
- Many people with intellectual and developmental disabilities do not know about the changes or how the changes will impact their lives. They don't know how they can get the supports they need under the new system.

WE BELIEVE ALL…

People with intellectual and developmental disabilities must have the facts about changes to DD services. These facts must be provided in clear, advocate-friendly language. We must understand the changes, educate policymakers about what is important, and participate in the new system.

THEREFORE, WE CALL ON…

- Governor Bev Purdue
- The Legislative Oversight Committee (LOC) who is responsible for making decisions about funding for services
- The Department of Health and Human Services (DHHS), including:
  - The Division of Mental Health Developmental Disabilities and Substance Abuse Services
  - The Division of State Operated Healthcare Facilities
  - The Division of Medical Assistance
- Local Management Entities (LMEs) who manage local service provider networks

TO WORK WITH THE ASSOCIATION TO:

- Develop materials in clear, advocate-friendly language.
- Inform people who receive services about current and future changes to DD services directly and in easy to understand language.
- Make sure our opinions and ideas are considered when state leaders and policy makers are making decisions. This includes:
  - Participation in temporary task forces or committees charged with informing local or state policy regarding DD services,
  - Creation of a position filled by a person with intellectual and developmental disabilities within each LME to serve as a contact with people who receive services,
  - Create an ongoing process to inform people who receive services about changes, how to get the supports they need, and what to do if they are unhappy with the services they receive.

Provider agencies must contribute as well. If providers do not have funds to offer, they can furnish indirect support by providing meeting space, office use (e.g., making copies, telephone), and staff support. Important too is assisting individuals in getting to and from meetings. Parents and family advocacy groups also can help. Parents can present to self-advocacy groups on issues from their perspective, and may also be helpful providing transportation for their family members to attend meetings. As always, in furnishing such assistance, staff and family members must work hard not to supplant, but instead encourage, self-advocate leadership in directing local self-advocacy efforts.

Agencies providing financial and other supports must take care to avoid conflicts of interest and ensure that the voice of self-advocates stay free and unencumbered by agency policy preferences.

- ✓ <u>Increase the presence of self-advocates on local service provider boards</u>. A key message that underlies this point comes directly from self-advocates, “Nothing about us without us.” Self-advocates want to have a say about decisions that affect their lives. Delivering on this goal, providers should include self-advocates in whatever decisions are being made that have a direct impact on the quality of their daily lives. Providers should inspect the common rules imposed on individuals at day programs or in community residences. Too often self-advocates are made to follow codes of behavior that make little sense to them, but are often devised for staff convenience. Examples collected from self-advocates in other states include rules such as: Bed time at 9:30 PM; Lights turned up during dances; No make-up for women; Dating only with staff escorts. Rules like these are not in all community programs, but rules imposed by others are found across North Carolina. Self-advocates refer to policies such as these as “Silly Rules.[15]” Providers and self-advocates can collaborate to eliminate such rules.

  Service providers should include self-advocates on their boards of directors. Self-advocates are experts in judging the effectiveness and quality of programs designed to support them. As a result, they can make significant contributions to the deliberations of agency boards.

- ✓ <u>Promote the role of a self-advocate leadership within DHHS, and specifically within DMH/DD/SAS</u>. DMH/DD/SAS maintains a Consumer Empowerment Team.[16] The Team gives voice to service recipients to advise the Division and offer feedback on its overall efforts. The Team is also responsible for monitoring the actions and achievements of the local Consumer and Family Advisory Committees (CFAC). In addition to this Team, DHHS should establish and fund a position for a “self-advocate liaison” and house this individual within the DMH/DD/SAS. The collective goal among all should be to prepare self-advocates across the state to play a leadership roles in their personal lives as well as to guide change within the state’s developmental disabilities service system locally and at a state level.

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[15] http://www.theriotrocks.org/blog/wp-content/uploads/2010/12/Riot_Issue_10.pdf

[16] http://www.ncdhhs.gov/mhddsas/services/advocacyandcustomerservice/consumerempowermentteam.htm

Funding this position would provide self-advocates with significant visibility and access to high level decision makers, as well as opportunity for networking and forming partnerships. Overall, this self-advocate liaison position must receive ample support to conduct activities as:

- Partner with self-advocates across the state, including emerging self-advocacy organizations, and provide meaningful linkages to the policymaking process.
- Provide leadership and promote coordination of self-advocacy groups and activities.
- Coordinate trainings, strategic planning, and other statewide activities intended to encourage people to be active self-advocates and to participate in government and civic activities that promote the rights of people with disabilities and encourage contributions to their respective communities.
- Work with the Statewide CFAC and Consumer Empowerment Team to publish an annual report for self-advocates on the I/DD system performance.

Medicaid can be used to help fund this position and its associated activities. For instance, DHHS might posit that training offered to self-advocates teaches participants be effective users of HCBS services, and so is Medicaid reimbursable. DHHS could move to include such training as a service under the HCBS waiver or claim it as an administrative expense for operating its waiver.[17]

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[17] Self-Advocate leadership Network (2006). *Using Medicaid to Fund Trainings for Self-Advocates.* Portland OR: Human Services Research Institute (www.theriotrocks.org)

Action Area B: Serve People in the Most Integrated Settings

Planning Context Assessment: North Carolina utilizes state-operated, large residential facilities at a rate much higher than the national average. Further, the State utilizes community Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), Skilled Nursing Facilities and Adult Care Homes at a high rate. These residential settings are not in line with Federal law, the Supreme Court's Olmstead decision, and the national trend to serve individuals with I/DD in the most integrated settings.

Action Step 3: Reduce the number of people served at state operated Developmental Centers to no more than the projected national average by 2017

The substantial majority of states have significantly reduced or eliminated use of large state-operated facilities and nursing homes to serve individuals with developmental disabilities. Over the past 30 years, North Carolina followed the national trend, by reducing the use of its developmental centers. In 1977, 3,753 individuals resided in North Carolina's state-operated institutions, and by 2009 that number was 1,593 (a decrease of 57 percent). Still, the State's actions have not kept pace with the national pace overall. In 2009 institutional residents constituted roughly 16 percent of the total I/DD service population in North Carolina, compared to the national average of 7.5 percent. In fact, even while legislation in North Carolina requires a census reduction of four percent annually[18], from 2008-2010 the Division of State Operated Healthcare Facilities reported that the number of people living at developmental centers actually increased by 28 people[19].

North Carolina policymakers should now take decisive action to reduce the census of the state institutions (developmental centers and neuro-medical centers) to the projected per 100K utilization national average in 2017. 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 in state population. To achieve this goal, 890 people currently residing in North Carolina's facilities will need transfer to community residences. This entails moving 178 people per year over the next five years (2012 – 2017), a decrease of 44.2 percent. These calculations are based on:

- A starting census of 1,594 which is based on 2009 reported data. This amounts to 17 per 100K state population. The present census may be slightly higher or lower than this figure.

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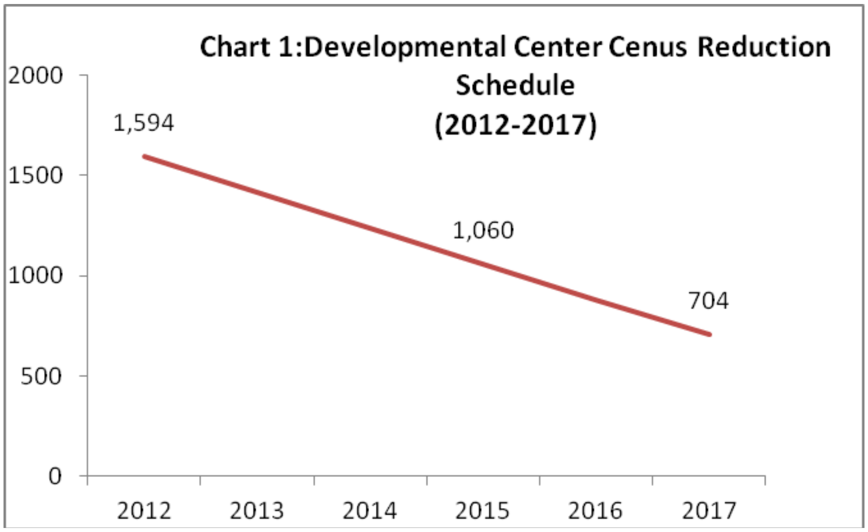
[18] General Assembly of North Carolina; Session 2007. Session Lax 2007-323; House Bill 1473. Pg. 126-127. http://www.ncga.state.nc.us/sessions/2007/bills/house/pdf/h1473v10.pdf

[19] Donin, C. Myers, A. Presentation to the Legislative Oversight Committee: *North Carolina's Developmental Centers.* December 8, 2010

- Review of the national trends regarding census reduction of similar facilities from 2005-2009, revealing that by 2017 the national utilization average will be 6.7 people per 100K state population.
- Application of these findings to indicate that to reach the projected national utilization rate, North Carolina would need to reduce its census to 704 by 2017. Using the 2009 census count of 1,594 this amounts to 890 people over the next five years.

Chart 1 illustrates the steady anticipated decline in developmental center census over this period. Success will depend on the commitment the State makes to reduce its reliance on these residential settings.



Per diem rates for individuals residing in North Carolina's state-run developmental centers have been continually increasing. As of 2009, the average annual cost of supporting an individual in a facility was $175,565. Despite past census reductions, state-run institutions continue to command a significant share of state spending on behalf of people with intellectual and other developmental disabilities.

Regardless of the reduction goal chosen, whether the four percent per year mandated by the State Legislature or 8.8 percent per year recommended here to reach the pace of national average, under either scenario, the amount of dollars that would become available for reinvestment due to downsizing is likely to be modest. The faster the pace of downsizing, however, the less overall transition cost there will be.

Action Step #4: Adopt policies that help individuals and providers transition from ICFs/MR services to HCBS funded alternatives

From its inception, the Medicaid program was structured so that individuals are more likely to have an institutional service option presented as available than a community option.[20] Institutional options include nursing facilities and large public congregate-care facilities such as "developmental centers." Typically, these large centers for people with intellectual and other developmental disabilities are funded as Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). In 1981, Congress granted states authority to establish small-community ICFs/MR

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[20] Crisp, S., Eiken, S., Gerst, K. & Justice, D. (2003) *Money Follows the Person and Balancing Long-Term Care Systems: State Examples*. Bethesda: U.S. Department of Health and Human Services; Centers for Medicare and Medicaid Services; Disabled and Elderly Health Programs Division.

housing of no fewer than four people. These smaller facilities must abide by ICF/MR rules such as a service emphasis on habilitation rather than support to live a life as is typical for the general population. In most states ICFs/MR are managed separately from community-based services, both in financial management and services. Once a person is placed in an ICF/MR, even a smaller residence located in a community setting, it is difficult to later move to a more independent living arrangement. This is because the HCBS waiver typically is capped with regard to the number served and often has a waitlist. As a result, people already served in an ICF/MR cannot easily be reassigned to the HCBS system. The difficulty would seem easy to resolve if the person receiving services could take the ICF/MR money allocated to him or her and bring it to the HCBS waiver system. But ICF/MR funding is not easily portable and cannot follow the person into a HCBS waiver program.

In response to consumer demands and legal challenges[21], states are taking steps to transition individuals who want to live in community settings, from ICFs/MR to settings in the community funded through a HCBS waiver. When individuals relocate, however, the beds they vacate are not always taken off-line. Beds may be re-filled as long as an eligible person comes forward and seeks ICF/MR services. In this way, even as individuals transition from ICF/MR services to HCBS, ICFs/MR may maintain their census.

In the *Planning Context* report, the present utilization rate of ICFs/MR in North Carolina was found to exceed national average rates and is contrary to the national trend to de-emphasize this service option in favor HCBS options. In 2009 North Carolina served 2,346 people in 305 non-state, privately run, community ICFs/MR. Eighteen of these facilities were licensed to serve 16 or more residents, while 286 served four to six residents. As noted in the *Planning Context* report, the average annual cost to serve individuals in community ICFs/MR in North Carolina amounted to $92,906 per person.

Generally, success in other states is rooted in: (a) legislative actions that set policy for system reform and create fiscal mechanisms to move funding from nursing homes or ICFs/MR to HCBS funded services, and (b) the opportunity for individuals to decline nursing facility or ICFs/MR residential placement and choose community services. Overall, the intent is to encourage

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[21] For example, in Florida, a 1999 court settlement (*Cramer v. Bush)* identified a class of 2,096 people living in private ICFs/MR. The settlement indicated that any of the individuals could, depending on their choice, continue residence in an ICF/MR or request relocation to an alternative service funded by the HCBS waiver.

In 2007, in Ohio *Martin v. Strickland* resulted in a settlement 2007 that provided funding for 1,500 additional individuals who are in an institution and who choose to move, or those who will be at risk of being institutionalized but who would choose to be served in a community setting to receive home and community based services through an Individual Options HCBS waiver. The settlement also required surveys of those residing in ICFs/DD and Nursing Facilities to assist in evaluating the need for additional community based services.

In 2005 in Illinois in *Ligas v. Maram*, advocates filed a lawsuit claiming that the State is violating the Americans with Disabilities Act (ADA) by not accommodating ICF/DD residents who would prefer to be supported in more integrated living arrangements. The resulting Consent Decree (*Ligas v. Hamos*) in 2011 gives residents of ICF/DDs the choice to move into small community-based settings with the necessary supports. The agreement also requires that an additional 3,000 people with developmental disabilities currently living at home without services be provided with community services.

increased use of community services and lessen the reliance on nursing facilities and ICFs/MR. North Carolina should follow this lead by taking action to help individuals transition from ICFs/MR services to HCBS funded alternatives. In concert with assistance to offering community services first to individuals is the need to lend assistance to ICF/MR providers for transition to offering Medicaid HCBS. To achieve these strategic changes, DHHS should:

- ✓ <u>DHHS consider action to establish "incentives" for providers to help individuals to relocate to HCBS options or to transform their funding base from ICF/MR to HCBS waiver</u>. In such instances, individuals may not need to physically relocate. Rather, by collectively choosing HCBS instead of ICF/MR services, the funding source for their residential service changes from ICF/MR to HCBS.

  When the funding source changes, however, providers must understand that they will not offer the same services, carry exactly the same administrative responsibilities or be paid the same amount as under the ICF/MR option. The change in funding source also requires a change in thinking regarding programmatic responsibilities, administration, staffing patterns, costs and reimbursement.

  As a result, the incentives for encouraging transformation should not be thought of as a guaranteed "cash award" of some kind to providers simply for participating in system reform. Nor will providers likely receive the same rates of reimbursement as under the ICF/MR program to perform the same scope of work. After all, the intent is to make the system more efficient, and so to lower the <u>average</u> cost per person for delivering services, while also promoting use of best practice community services. In doing so, however, note that for some number of individuals the cost of community services may be equal to or greater than costs in an ICF/MR. Aggregate cost savings may be achieved because some number of people may be "over-served" in an ICF/MR.

  Given this context, incentives may take at least these three forms:

  - ▪ <u>Eliminate barriers to transition that make it difficult and expensive for providers to move from ICF/MR to HCBS waiver funding.</u> In Illinois payment to providers is based on the number of residents in a home. During transition, when an ICF/MR had fewer residents, providers could not bill for the openings in the home. This lead to loss of revenue and/or an incentive to fill the openings. A solution is to compensate providers for vacancies during a transition period. Illinois has a unique means for "taxing" providers according to the number of residents. The tax is in turn used as Medicaid match. During transition of an individual even while vacancies exist, tax assessments are tied to the date that homes were initially assessed, typically without vacancies. As a result, providers again face a fiscal loss for participating in transition, creating an associated disincentive for such transition. Again, the solution is to adjust the tax, and so eliminate the barrier.

  - ▪ <u>Compensate providers for their expenses during a pre-defined transition period</u>. When individuals are being relocated, there may be associated additional costs such as meetings to plan a successful move. States can help providers offset these costs by allowing ICF/MR providers to continue to bill at their customary rates even after a person moves for a set amount of time while adjusting to the reduced census.

  - <u>Assure that the HCBS waiver is an attractive option with respect to both the service array available to participants and the associated service reimbursement rates</u>. There is no incentive to providers to switch if the perception is that the waiver has significant difficulties and/or if providers cannot offer needed services to individuals at a fair rate of reimbursement. In North Carolina, there are many six bed ICFs/MR. In this instance, transition typically may not require relocation, but instead adjustments in funding source and changes in service approach. To do so, individuals and providers will need to know that the HCBS waiver offers a fair and adequate service reimbursement.

- <u>DHHS should make greater use of the Money Follows the Person (MFP) Program</u>. In the Deficit Reduction Act of 2005, Congress set aside $1.75 billion for a new program, Money Follows the Person (MFP), to assist states in accelerating the transition of people from institutional settings to the most integrated setting. Thirty-one states received awards initially. This funding provides states with enhanced federal matching funds to pay for community supports for those who transition to the community.

  North Carolina was awarded a MFP Demonstration Grant in May 2007 and the State'sOperation Protocol was approved in an award letter dated June 30, 2008. North Carolina now receives supplemental funding and technical assistance to move 304 people who are older adults, or have an intellectual or other developmental disability, or have a physical disability. The national Money Follows the Person Demonstration Project was originally approved through September 30, 2011, but was extended through 2016 as part of the passage of Federal law, the Patient Protection and Affordable Care Act. (http://www.ncdhhs.gov/dma/MoneyFollows/index.htm).

Regardless of the policy path taken, it is important to acknowledge that transition from an ICF/MR to HCBS, while beneficial in the long haul, has budgetary ramifications. People who leave ICFs/MR may be replaced by other individuals. Unless this circumstance is avoided, there will be no reduction in ICF/MR expenditures and HCBS waiver funding will have to increase to accommodate the individuals who elect to transition from ICFs/MR to HCBS. In essence, success depends on phasing out ICF/MR capacity as the transition unfolds.

Action Step 5: Conduct a study of individuals with intellectual and other developmental disabilities residing in Skilled Nursing Facilities to determine if placement is appropriate

As depicted in the *Planning Context,* North Carolina serves slightly more people with I/DD in nursing facilities than the national average. The national utilization rate of nursing facilities is about 9.6 people per 100K in population versus about 10.1 per 100K in North Carolina. Of concern is the rapid increase in use of these facilities in the State from 2008 to 2009 when the number of individuals living in these facilities grew from 400 to 949, a 137 percent increase.

The reported numbers do not explain this increase. It may be that State staff are able to report use of this service more precisely, and as a result, the increase may not represent an actual swelling in numbers living in these facilities but a rather a proper reporting of the individuals already there. Alternatively, the increase may reflect actual heightened use of this service option.

Placement in a nursing facility may sometimes be appropriate for an individual with I/DD, just as it may be for any other American. Very often the general public thinks of nursing facilities as a residential option for seniors with extensive medical or nursing needs. To contrast, however, people with I/DD are sometimes placed in these facilities due primarily to their disabilities and the lack of available community supports. While some are older, they also include young people with disabilities, even children.

Lakin (et al) collects and reports data on Skilled Nursing Facilities. In the data report, it is noted that:

> Almost from the inception of Medicaid, states noted incentives for placing persons with ID/DD in Medicaid certified nursing facilities. Almost as soon as this began to happen, there was a sense among the advocacy community that many more people with ID/DD were living in nursing homes than were appropriately served in them (National Association for Retarded Citizens, 1975). In 1987 Congress responded to these and other criticisms of nursing facility care in the Omnibus Budget Reconciliation Act (OBRA) of 1987 (P.L. 100-203). Provisions of this legislation restricted criteria for admissions to Medicaid reimbursed nursing facilities, so that only those persons requiring the medical/nursing services offered would be admitted. Current residents not in need of nursing services were required to be moved to "more appropriate" residential settings, with the exception of individuals living in a specific nursing home for more than 30 months could stay if they so choose. In either case nursing facilities were required to assure that each person's needs for "active treatment" (later termed "specialized services") were met.
>
> Despite the intent of OBRA-87, the efforts to move persons with ID/DD out of nursing facilities as described by states in their required "alternative disposition plans," and the implementation of required preadmission screening and resident review (PASARR) provision, class action court cases established within a decade of the 1990 implementation deadline that the requirements of OBRA-87 were not always achieved (see Roland et al. v Cellucci et al., 1999, in Massachusetts; Olesky et al. v. Haveman et al., 1999, in Michigan; Gettings, 1990)." (Lakin et al 2010).

Nationally there is great concern for the inappropriate placement of people with I/DD in nursing facilities, and there has been concerted effort to relocate people with I/DD into alternative community 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:

- ✓ Complete a study by 2013 to determine:
  - What factors led to the increased number of people with I/DD residing in nursing facilities from 2008-2009, and report on whether this trend has continued; and
  - The appropriateness of the present placements of people with I/DD in nursing facilities.

- Offer individuals with I/DD living in nursing facilities the opportunity to relocate to alternative community settings as appropriate, perhaps through focused use of the state's Money Follows the Person program.

Action Step 6: Implement N.C. Institute of Medicine Adult Care Home recommendations

North Carolina's use of Adult Care Homes (ACHs) for people with I/DD has drawn fire over the past several years. As noted in the *Planning Context* report, the North Carolina Institute of Medicine conducted a review of the ACH facilities and recommended that the State reduce its reliance on this housing model for people with I/DD[22].

In May 2011, House Bill (HB) 108 was passed by the North Carolina General Assembly. HB 108 called for DHHS to review and act on the recommendations set forth by the Institute of Medicine. Specifically, the Bill reads:

> "The General Assembly of North Carolina enacts:
>
> **SECTION 1.(a)** The Department of Health and Human Services shall study Recommendation 3.1 from the North Carolina Institute of Medicine Task Force on the Co-Location of Different Populations in Adult Care Homes. The recommendation suggests that the Department develop a pilot program to evaluate the costs, quality, consumer satisfaction, and patient outcomes of a program that supports individuals who are in an adult or family care home and who want to move back into independent supported housing. The Department shall, but is not limited to, evaluate and report on the elements below that are contained in the recommendation.
>
> (1) The feasibility, fiscal implication, and appropriate timing of the submission of a Medicaid 1915(i) State plan amendment or 1915(c) Home and Community-Based Services waiver to support individuals living in adult or family care homes for 90 or more days who would like to move back to more independent living arrangements.
>
> (2) The feasibility and cost of developing and implementing a process to evaluate residents of adult care homes to determine whether they can live independently in the community with services, supports, counseling, and transition services.
>
> (3) The policy implications, impact on current programs, and cost of developing and implementing an additional Special Assistance program option that would be similar to the existing Special Assistance in-home program but exempt from the limits established in S.L. 2007-323. The Department should explore whether this program could be targeted to address concerns the Task Force raised on co-location.
>
> (4) A time line for implementing the pilot with all of the above elements in place, or a time line for phased implementation of the pilot. This time line shall include evaluation of the pilot as described in the Task Force recommendation.
>
> (5) The fiscal requirements necessary to provide technical assistance to adult care homes interested in creating financially viable models to support people living more independently as recommended by the Task Force.
>
> (6) The existence of statutory and regulatory barriers to independent living for people with disabilities.

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[22] Short- and Long-Term Solutions for Co-Location in Adult and Family Care Homes: NCIOM Task Force on the Co-Location of Different Populations in ACHs, 2011, http://www.nciom.org/publications/?colocationadultcarehomes

> (7) The goal and intended outcome of this pilot program.
>
> SECTION 1.(b) On or before October 1, 2012, the Department shall report on the elements outlined in this section to the North Carolina Study Commission on Aging and the Joint Legislative Oversight."
> (http://www.ncleg.net/gascripts/BillLookUp/BillLookUp.pl?Session=2011&BillID=H108)

As DHHS undertakes these tasks, it is important that strong, clear and achievable goals be set so that change can be accomplished. To succeed, DHHS should assure collaboration among Divisions, service providers, people with I/DD and others to develop plans for establishing alternatives to ACHs as warranted. Further, reliable and accurate tracking of the pilot phase of the plan should be consistent to ensure that changes are made to the plan as early as possible. Once the pilot is completed, DHHS and its Divisions should review what did and did not work, modify protocols as needed, and project needed funds, and extend HCBS funding for all people with I/DD residing from Adult Care Homes that wish to live in more independent settings.

Action Step 7: Consider use of the Balancing Incentive Program

To gather additional funding to support relocating individuals from ICFs/MR and nursing facilities to community alternatives, DHHS should consider applying for the Balancing Incentive Program administered through the Centers for Medicare and Medicaid Services (CMS).

The Balancing Incentive Program, set within Section 10202 of the Patient Protection and Affordable Care Act (Pub. L. 111-148), provides financial incentives to states to offer community Long Term services and Supports (LTSS) as an alternative to institutional care. Specifically, states that spend less than 50 percent of their long-term care dollars on community LTSS receive a two percent increase in the Federal match they receive from participation in the Medicaid program (i.e., Federal Medical Assistance Percentages or FMAP). States that spend less than 25 percent receive a five percent (5%) increase.

North Carolina, using FY 2009 data (as is required) spends 42.9 percent of their long-term care funding for all service populations (i.e., developmental disability, mental health, aging and physical disability) on Home and Community-Based (non-institutional) Services, and is therefore eligible for a 2% increase in FMAP if other program requirements are met. To meet the requirements, states must ensure their systems include, or will include, the following structural features as described by the legislation:

- No Wrong Door—Single Entry Point System: Development of a statewide system to enable consumers to access all long-term services and supports through an agency, organization, coordinated network, or portal, in accordance with such standards as the state shall establish and that shall provide information regarding the availability of such services, how to apply for such services, referral services for services and supports otherwise available in the community, and determinations of financial and functional eligibility for such services and supports, or assistance with assessment processes for financial and functional eligibility.

- Conflict-Free Case Management Services: Conflict-free case management services to develop a service plan, arrange for services and supports, support the beneficiary (and, if appropriate, the beneficiary's caregivers) in directing the provision of services and supports for the beneficiary, and conduct ongoing monitoring to assure that services and supports are delivered to meet the beneficiary's needs and achieve intended outcomes.
- Core Standardized Assessment Instruments: Development of core standardized assessment instruments for determining eligibility for noninstitutionally-based long-term services and supports described in subsection (f)(1)(B), which shall be used in a uniform manner throughout the state, to determine a beneficiary's needs for training, support services, medical care, transportation, and other services, and develop an individual service plan to address such needs.

The legislation also requires states to meet certain target levels of community LTSS spending by October 1, 2015 (e.g., states that spend less than 50 percent of their long-term care dollars on community LTSS should hit the 50 percent target by this date).

Comprehensive information detailing the Balancing Incentive Program, and the process for applying can be found at the following website: http://www.balancingincentiveprogram.org.

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Action Area C: Promote Outcomes Important to Individuals and Families

Planning Context Assessment: While the State has done much to establish a community system of services for people with I/DD, there are shortcomings to the system that must be addressed.

Stakeholders in North Carolina agree that while much has been achieved to establish a community system of supports for people with I/DD, there are shortcomings that must be addressed sooner rather than later. These deficiencies affect the substance of the services that individuals receive, as well as the infrastructure needed to support these services.

From the perspective of service delivery, more could be done to promote self-direction for individuals with I/DD, to increase their opportunity for community integrated employment, and to establish means for they and their families to offer one another mutual support. Regarding infrastructure, DHHS must take action to allocate resources to individuals more efficiently and with greater equity, and to strengthen the community system infrastructure. Action Steps 8 through 13 below address these areas for reform.

Action Step 8: Commit to implementing the principles, structures and processes of a self-directed system

One of DMH/DD/SAS' guiding principles promotes the ideal of a participant-directed service system, and toward this goal, North Carolina offers a Supports Waiver Self-Direction Option[23]. Information on this waiver option can be found on the Division's website, including the core components of self-directed services (e.g., person-centered planning, individual budget control, support to access services, choice of staff, financial management), principles of self-direction (e.g., individual authority to determine needs, create support plans, budget allocated funds, select and employ staff, and monitor service quality) and opportunities that result from self-direction (e.g., building support networks, more community involvement).

Toward assuring a well-designed and fully implemented self-directed service 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. Specific strategies to address this follow.

- DHHS should develop specific performance measures related to self-direction. Performance should be tracked by LME-MCO and reported publicly through reports and the Division's webpage.
- DHHS should assure that the LME-MCOs adopt consistent principles related to self-direction. For instance, a Self-Directed System must value:

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[23] For more information go to: www.ncdhhs.gov/mhddsas/providers/supportswaiver,

  - *Individual authority to plan and pursue their own vision* - Individuals have the authority to indicate what they want, and have it be listened to and honored by others.
  - *Individual authority to direct services* – Control rests in the hands of individuals (not with programs or professionals) regarding what happens, what services/supports are received, and who provides them.
  - *Community membership* – Individuals are supported to develop and sustain their social relationships including friendships, romances, family connections, religious affiliations.
  - *Collaborative support delivery* – Individuals are supported to negotiate across several service silos, to effectively weave together their needed resources.
  - *Meaningful leadership roles for individuals* – Meaningful leadership roles for individuals are valued and assured at all levels of the service system.
  - *Flexibility in support delivery* – People's needs change. A self-directed model can bend to accommodate change, and recognizes there are many paths to achieving individual goals.
  - *Access to satisfactory support options* – The system of supports includes an array of choices that are real, available and appropriate to the needs and desires of the person.
  - *Commitment to excellence and personal outcomes* – Self-direction assures a sustained commitment to service excellence and individual outcomes.

- ✓ DHHS should assure that the LME-MCOs have uniform operational structures in place for self-direction. These include:
  - *A fair and accurate assessment of support needs* – Essential is an assessment measure providing sufficient information to differentiate among individuals accurately and reliably regarding their support needs.
  - *A fair and ample individualized budget* – With a personal assessment-based budget, individuals can consider their needs in relation to the size of the budget and the supports available to make well planned decisions about which services to choose.
  - *Fair and affordable service reimbursement rates for providers* – Budgets must be ample to purchase selected services, and providers must be reimbursed sufficiently for the services delivered.
  - *Timely pay for providers* - As a wide range of supports are developed, providers should be able to expect reimbursement for services rendered in an appropriate time frame and with reasonable requests for documentation.
  - *Means for informing and training individuals* – A self-directed model does not presume that individuals can play a leadership role within this system without training and support.

  - *Person-centered planning* – A self-directed system provides a structure for consistent and productive person-centered planning practices.
  - *A stable and qualified workforce* - A well-trained, stable workforce is central to assuring the quality of services.
  - *Quality assurance* – Effective quality assurance systems must ensure individuals are safe and secure, and services meet essential standards. Quality, for individuals, also focuses on personal autonomy, authority over resources, satisfaction and personal outcomes.
  - *Public transparency* - Self-directed models are open to public and legislative criticism concerning appropriate use (and potential abuse) of public funds. Therefore, it is imperative that the system maintain a mechanism for assuring ongoing transparency.

- ✓ <u>DHHS should assure that the LME-MCOs have uniform processes in place for self-direction</u>. These include:
  - *Individuals feel welcome and heard* - Individuals should feel welcomed, listened to, supported in their decisions, and not pre-judged.
  - *The exchange of information is adequate, yet not burdensome* - Individuals need user-friendly information, offered without hassle. Service providers' requests for information should be sufficient but not overly burdensome.
  - *Practices are culturally competent* - Self-directed services are culturally competent in anticipating and responding to people across cultures, geography, traditions and beliefs.
  - *Individuals control their budget allocation* – The individual is positioned to control a service budget, managing both the service budget and service workers.
  - *Planning is person-centered* - Person-centered planning identifies the best mix of supports to assist each individual in securing valued outcomes while assuring health and welfare.
  - *Individuals choose and manage supports and providers* – Individuals choose from an array of supports, select among qualified providers, and can change providers when dissatisfied.
  - *Money and services/supports are portable* – Funds available for support are not locked into specific service models or locations. They are connected to the individual.
  - *Supports are flexible to meet changing needs* – Service and support planning, delivery and funding is flexible to respond to changes in circumstance and need across the lifespan.
  - *Supports are available in a crisis* – Potential crises are anticipated, and effective community-based responses are available.

- *Informal community resources are utilized* – Self-directed models ripple outward from the individual, starting close and informal and branching out to more formal service options.
- *Peer support/mentoring is available* – Self-directed models assure the availability of peer support and mentoring options.
- *Quality of supports is measured* – Qualitative and quantitative mechanisms must be in place to assess satisfaction with services/supports, both individually and in the aggregate.
- *The public is kept informed* – Clear and simple public reports regarding individual needs and outcomes (in aggregate), and assurances for service quality are easily accessible.

In addition, if individuals are to choose a self-directed option, they must be made aware of its availability. Some available outreach options include:

- LME-MCOs incorporating discussion about self-direction into all service planning meetings.
- The Division modifying its existing self-direction trainings for self advocates and families.
- The Division engaging self-advocacy organizations (e.g., ASANC) to provide guidance on materials and messaging to self-advocates.
- Self-advocates with experience self-directing being paid to participate as peer trainers.
- CFAC members being engaged to spread the word on self-direction and its outcomes.

Action Step #9: Accelerate opportunities for integrated employment

People with I/DD often express a desire to work in a "real job." Self-Advocates Becoming Empowered (SABE), a national advocacy organization for people with ID/DD, plainly states, "We have been prepared enough. Get us real jobs. Close sheltered workshops." (www.sabeusa.org) SABE's resolve stems from an enduring disappointment in the lack of opportunity that people with I/DD are afforded to work at jobs in integrated settings at a competitive wages. In 2008, only 21 percent of those receiving developmental disability services across the country enjoyed an integrated work experience. In this same period in North Carolina, 20 percent of service recipients worked in the community[24].

NCCDD is committed to increasing the opportunity people have for working in an integrated job. In 2011 the NCCDD agreed to pay the membership fee so that North Carolina could join the State Employment Leadership Network (SELN)[25]. This action provides opportunity for DHHS, including several of its Divisions, to make reforms in policy and practice to promote employment for people with I/DD.

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[24] Institute on Community Inclusion (2009) *State Data: The National Report on Employment Services and Outcomes 2009.* Boston, MA: University of Massachusetts.

[25] For more information, go to: http://www.seln.org

SELN is a national initiative launched in 2006 as a joint program of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute for Community Inclusion at the University of Massachusetts Boston (ICI) to improve employment outcomes for adolescents and adults with intellectual and other developmental disabilities.

The Network promotes connections among state members so state I/DD agencies can take better advantage of other resources and partner with sister service systems, sharing costs and maximizing resources. In particular, SELN offers opportunity to: (a) maximize resources such as funding and employment services, (b) develop more effective employment systems and partnerships, (c) use data to guide program management at the local and state level, (d), improve employment-related staff competencies, and (e) share resources for systems change across states.

To make the most of SELN membership, DHHS can:

- ✓ Institute Employment First policies at the state and LME-MCO levels. Very often the first employment options offered to people with I/DD include segregated or sheltered environs. To contrast, *employment first* policies are based on a presumption that people with I/DD should work and that integrated employment at competitive wages is the *first or preferred* service option considered for service recipients. Individuals may choose a service option other than employment, but the organizing framework of the service approach presumes employability and establishes an expectation or successful employment. An Employment First policy stance provides a fundamental and necessary underpinning to a service system that seeks to increase employment outcomes for people with I/DD.

  Colorado, Florida, Oklahoma, Pennsylvania, Tennessee, and Washington State have been identified as states with significant policies or directives in place that encourage employment[26]. In 2009, Washington State reported that 87.5 percent of those in service received integrated employment services, a national high.

- ✓ Assure that use of community based non-work options are tied to gaining community employment. Complementing integrated work, many states now also encourage "community-based non work" (CBNW). The Institute for Community Inclusion defines CBNW as including all services that are focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. Volunteering and community service activities fall into this CBNW category as these kinds of community contributions are proven avenues through which individuals with disabilities can gain skills, explore career paths and develop the social networks necessary to gain meaningful employment or postsecondary education. Still, CBNW does not include paid employment, and it can be applied in ways that do little or nothing to promote later employment for participants. Care must be taken to assure that individuals do not become trapped within CBNW settings that do little more than

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[26] Cohen Hall, Allison, Winsor, J, and Hoff, D. (March, 2009). *Q&As on State Employment First Policies*. Boston MA: Institute for Community Inclusion, UMass/Boston

offer free labor to work sites, and offer little opportunity for the individual to move on to paid employment.

- ✓ Embed the following elements into state and local operations practices:
  - Funding mechanisms and contracts with providers that emphasize employment as the preferred outcome, including a service array and associated rate schedule that reimburses providers amply for employment services.
  - Service reimbursement rates that encourage service providers to expand integrated employment activities, such as establishing a higher rate of payment for integrated employment than for other day services.
  - A sustained and significant investment in employment training and technical assistance.
  - Make available to individuals with I/DD access to careers whereby an increased emphasis on the initial time that a direct service provider spends with the individual is spent to assist with the identification of career goals.
  - Provide for longer term supports to assist an individual with employment retention. At the same time, to support employment retention, develop natural and business-based supports.
  - Natural supports include supports to be provided by individuals, such as co-workers and employers, who are not hired by a human services organization.
  - Utilize assistive technology. Since the early 1970's, assistive technology or rehabilitation technology has emerged and opened unlimited employment opportunities for people with disabilities. Individuals who at one time faced enormous barriers concerning accessibility, communication, and mobility can now optimize their intellectual and physical capabilities through use of technology.

Action Step #10: Promote mutual support and association among self-advocates and families

As in North Carolina, service systems across the nation are challenged to accommodate increasing demands for service while enduring difficult fiscal times. Making matters worse, states often continue to invest in out-dated and costly service approaches (e.g., institutional services) that carry low value for the money spent and are financially unsustainable in the long term. These circumstances inevitably lead to service waitlists and tension among stakeholders with allegiances to contrasting services approaches (e.g., institution v. community). In the face of these challenges,

states continue to support a "services first and only" approach, funded primarily through Medicaid. Lost in this response are opportunities for promoting a spirit of personal reliance and contribution, mutual support and community connection.

A more favorable response requires that policy makers at all levels complement existing public services by establishing sustainable networks of mutual support so that individuals with I/DD and their families may:

- Make efficient and effective use of public services, such as those funded by Medicaid;
- Work cooperatively to achieve common goals;
- Utilize supports available from local businesses or community serving organizations;
- Provide supports to one another, as in an exchange network or peer support group; and
- Contribute in meaningful ways to the community.

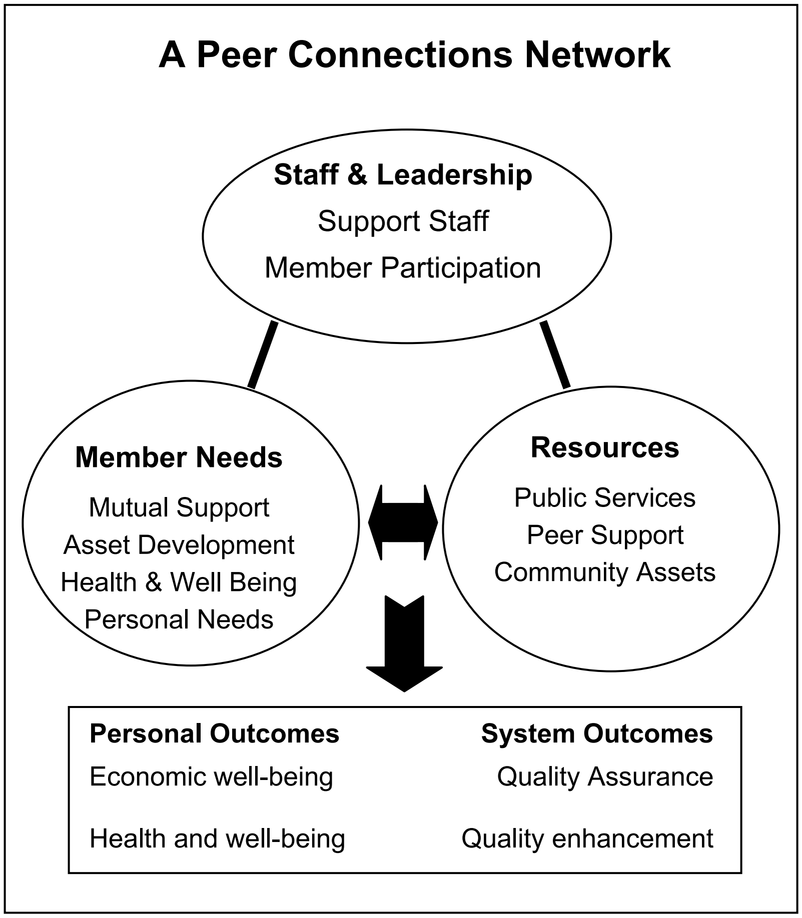
First in Families of North Carolina (FIFNC) has long acted in ways consistent with these objectives. Established two decades ago, FIFNC recognizes that people with I/DD and their families use both public and informal supports. FIFNC seeks to connect families to the public services they qualify for, but emphasizes developing and utilizing informal supports that are available from neighbors or friends, or from community businesses or other community organizations. These informal supports are often free, and are usually based upon relationships in the community.

FIFNC receives funding from DMH/DD/SAS, has 11 chapters across the State and reports that 2,543 families were supported in 2009-10; 20,535 have been served since 1998. With funding from DMH/DD/SAS, FIFNC connects families with one another and utilizes community assets in ways consistent with this *Action Step*. The State's investment in FIFNC, however is insufficient and DHHS could do more to foster mutual support.

After all, DHHS already relies heavily on families. In 2009, 6,708 of the 10,333 people (65 percent) receiving HCBS were living at home with family. All of these families should have the opportunity to participate in the approach offered by FIFNC. Going forward, a mainstay of DHHS's response to new service recipients and their families should be access to FIFNC. Providing individuals with I/DD and their families access to such services will complement the Medicaid-funded services people receive, stretching those dollars further by adding to people's lives greater access to their communities and additional sources of support.

Toward these ends, DHHS should work with FIFNC to assure that LME-MCOs act to: (a) develop peer connection networks; and (b) provide opportunity to establish formal cooperatives or federations where participants work together to manage the services they receive.

DHHS should work with FIFNC to assure that LME-MCOs act to develop peer connection networks, and provide opportunity to establish formal cooperatives or federations where participants work together to manage the services they receive.


A Peer Connections Network

- <u>Develop mutual support -- "peer connection" -- networks among families and self-advocates to maximize the use of available community assets.</u> To complement traditional Medicaid-funded services through the LME-MCO, individuals and families should be encouraged to participate in local Peer Connection Networks. These Networks are not meant to take the place of HCBS services. Rather they are intended to generate additional, complementary supports within communities across North Carolina.

  In a Peer Connection Network, participants unite voluntarily to address common needs through mutual support and/or joint action. Networks can be composed of individuals with disabilities, family members or both. A staff person is typically required to advise and organize the Network, though it should ultimately be shaped by the needs and preferences of its members.

  Peer Connection Networks blend together four essential sources of support:

  - <u>Disability-oriented public services</u>: Individuals with I/DD may be receiving support services already through a community services network funded by an LME-MCO. These actions may also be complemented by other public services (e.g., local ride sharing programs sponsored by local transit agencies). These services often provide significant support, but usually are insufficient to address all of the unmet support needs among individuals with lifelong disabilities.

  - <u>Peer support</u>: Peer support associations are created to link people through a voluntary exchange of support. This can include simple forms of help that individuals offer one another (e.g., to offer temporary respite, a car ride, emotional support, information). Peer support may also be organized more formally through a "time bank." A time bank organizes participants within an exchange network where everyone's contributions are valued equally and tracked. At the Time Exchange of the North Shore (in Massachusetts), an hour of help offered equals one service credit. The hours of time a participant gives to others are credited to his or her account by computer, and hours of help the person receives are "debited" from the account. After each service exchange, the participants notify the office of how many hours were given. Quarterly statements are sent to all members. Participants e-mail each other with service offers ("I am able to provide transportation") and requests ("I need a ride to my Doctor next Wednesday"), exchange information, such as placing an ad for services or placing service requests. In this fashion, individuals reach out to others across an area to provide mutual support. (http://www.lynntimebank.org/)

FIFNC has established its own Time Bank in the Triangle - Wake, Durham and Orange counties. It is open to the entire community but emphasizes participation of people with disabilities and their families. (http://ncgives.org/news/time-banks-an-economy-of-community-giving/)

  - Community assets. The network can also collaborate with other community assets, such as faith based and other community service organizations (e.g., churches, civic or hobby clubs, recreational centers). Local chambers of commerce and community businesses may also prove helpful.

- Provide opportunity individuals with I/DD and their families to establish formal cooperatives or federations where participants work together to manage the services they receive. In the current service system, families are counted on in a number of ways to manage the supports provided to the family member with disabilities. By working together, participants can form a strong alliance within a "cooperative." Within the context of a self-directed service option, the cooperative itself may function as a provider agency, performing any number of functions collectively for its members, including:
  - Recruiting direct support staff;
  - Acting as an employer of record;
  - Monitoring paid staff and to assuring that supports are properly delivered and accounted for;
  - Purchasing services, durable equipment or other needed supports; and
  - Acting as a fiscal intermediary to ensure that providers are paid, but also to offer providers workers' compensation and other benefits.

Working on their own, such responsibilities can prove burdensome over time. If families and individuals work together, however, many of the associated responsibilities taken on by families may be more efficiently and effectively managed. This can be accomplished by promoting partnerships within the public and private sectors – for example by forming a "Human Services Cooperative (HSC)."

HSCs are recognized by the Federated Human Service Cooperative, an organization whose goal is to “assist in the creation of Human Services Cooperatives” (See http://www.federatedhsc.coop/). This national entity certifies local cooperatives that are directed by individuals and families who use disability services to provide supports which benefit its membership. Once certified, a cooperative essentially operates as a provider agency, delivering services based on policies formulated by member owners. This type of cooperative typically is built on partnerships developed between agencies and community-service organizations in the public and private sector. These partnerships create a responsive network to offer self-directed services to address member needs. Several local HSCs have been successfully implemented in Arizona and Tennessee:

- *Arizona Service Co-op Enterprise,* Flagstaff, Arizona, http://ascenthsc.org/
- *Arizona Autism United,* Phoenix, Arizona, http://www.azaunited.org/
- *Inspire HSC*, Phoenix, Arizona, http://inspirehsc.org/
- *Freedom Co-op, HSC,* Tennessee, http://www.tnmicroboards.org/

Several types of agencies are capable of establishing peer connection or cooperative initiatives. Examples include FIFNC chapters, self-advocacy groups and local Arc Chapters.

Action Step #11: Strengthen community-based supports for people with extraordinary behavioral challenges

A critical measure of the effectiveness of a community I/DD service system is how well it supports individuals who have especially challenging behavioral or medical conditions. The capacity to meet the needs of these individuals without resorting to unwanted and unnecessary placement out-of-home 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 will be avoided.

All states are facing ongoing budgetary concerns because of the global recession. Given these constraints, it is expected that more and more services will be offered to individuals in the home of family members, rather than other out-of-home service options. Already in North Carolina, about two thirds of those receiving Medicaid Home and Community-Based Services (HCBS) live with family members.

The NC START Philosophy

Services are most effective when everyone involved in care and treatment actively participate in treatment planning and service decisions. (The whole is greater than the sum of its parts.)

This change raises the question of how to meet the needs of individuals whose challenging conditions would otherwise lead to an out-of-home placement. Some states (e.g., Maine, Oregon and Vermont) recognized the need to respond quickly and expertly to the needs of individuals with challenging conditions in their home communities and avoid placement within developmental centers – placements that in some cases become permanent because of lack of community capacity.

For DHHS to act decisively to reduce its reliance on developmental centers, it is essential that community capacity be established to respond to such behavior. To do so, as noted in the *Planning Context*, North Carolina utilizes the NC START (North Carolina Systemic, Therapeutic Assessment, Respite and Treatment) program. Initiated in 2009 in North Carolina, it is based on a similar initiative originated in Massachusetts.

The program is exclusively available to serve adults (age 18 years old and above) that have a primary diagnosis of an intellectual or other developmental disability (I/DD) and challenging behaviors, often with a co-occurring mental illness. The model provides prevention and intervention services to individuals with complex behavioral needs through crisis response, training, consultation, and respite. For each person, the goal is to create a support network that is able to respond to crisis needs within the community, and so deter admission to a hospital or developmental center.

DHHS should be lauded for its initial investment, but should not shy from increasing its investment in NC START.

The NC START program is divided into three regions (East, Central and West) and each region consists of two clinical teams and one respite home. As illustrated in the accompanying text box, it offers a range of support involving emergency, at risk and short term assistance.

NC START staff report[27] that since its inception, the program has been successful. NC START has served over 500 individuals with I/DD and co-occurring mental illness or significant behavioral challenges and 74 percent of the time, individuals were maintained in their current residential setting. NC START staff also provide transition supports. To date, 280 hours of transition supports have been rendered to individuals in psychiatric hospitals. These results are a strong beginning. To strengthen this service model, critique from users will need to be addressed:

- It is not equivalently available across the state, and so does not offer a substantial enough presence in all communities.
- The model links individuals with one another for a strong response to individual and family needs. When funds to "linking" agencies are cut, as they have been, the capacity to respond is diminished; this reduces effectiveness and the perception of its impact.
- Funding for NC START has not been sufficient for the program to realize its potential.

NC START forms the core of an effective approach to serve individuals with I/DD with challenging behavioral needs. DHHS should be lauded for its initial investment, but should not shy from increasing its investment in NC START to assure that the community establishes a strong capacity for supporting individuals with higher levels of need.

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[27] Email communication, August 30, 2011 from Vivian Leon of NC START.

The NC START Program

NC START services are available to people who are at least 18 years of age and who have a developmental disability and co-occurring mental illness or significantly challenging behaviors.

Types of Services	Services Available
Emergency – a situation where, because of a person's challenging behavioral issues, there is a need for (1) immediate specialized clinical services or (2) crisis/respite service. **At Risk** – A situation where a specific or time-limited problem resulting from behaviors or situational factors disrupts a person's optimal functioning in his/her place of residence or habilitation program and causes the person to be at risk of losing his/her services. **Short-Term Assistance** – A situation where 24-hour linkage and referral services are needed for ongoing services by the family/primary caregiver to address a person's behavior or situation.	**Crisis Support Continuum** ▪ Psychological, behavioral support and crisis consultation to the treatment team and primary service providers. ▪ Psychiatric consultation to the treatment team and primary service providers. ▪ Facilitate communication across developmental disability, mental health, community and family networks. **Clinical Support – Assessment & Treatment Planning** ▪ Conduct functional behavioral assessment for planning. ▪ Develop prevention and intervention plan involving parents, caregivers, and/or providers. ▪ Facilitate emergency meetings among service providers, treatment and crisis teams, and families. **Training and Consultation** ▪ Provide training to providers, families and other community partners. ▪ Provide on-going consultation to maintain community placement. **Collaboration** ▪ Access and link families and providers to community supports. ▪ Work with case manager on planning for future needs. ▪ Maintain relationships with community partners to enhance ability of community to respond to crisis. **Short Term Respite** ▪ Planned respite is available to NC START participants living at home with their family and are unable to access traditional respite due to behavioral needs. ▪ Emergency respite is available in crisis situations that cannot be addressed in the current placement. The team member will begin transition planning upon admission.

Source: http://www.ncdhhs.gov/mhddsas/services/crisisservices/NCSTART/

Action Step #12: Establish equitable resource allocation practices to determine individualized budgets

The Center for Medicare and Medicaid Services (CMS) defines the term *individual budget amount* to mean "a prospectively-determined amount of funds that the state makes available for the provision of waiver services to a participant " (Instructions: Version 3.5 HCBS Waiver Application). Often the allocated amount is fixed, though a range may be specified. Further, the individual is typically told what amount is allocated *before* developing a service plan (i.e., prospective planning), rather than after the plan is completed (i.e., retrospective planning). Finally, to determine the individual budget, states must establish appropriate infrastructure to support the practice (e.g., a means to assess needs and allocate budgets per person, service planning protocols, reasonable reimbursement rates for providers, means for providers to be reimbursed for services rendered, and quality assurance methods).

States are acting to establish individualized budgets in response to a variety of pressures. Most notably, policymakers seek to restructure service delivery systems to achieve greater efficiency and equity. By doing so, they hope to make better use of available resources while better positioning their service systems to take on current and future challenges.

- *Efficiency* gains can be achieved by gaining a better understanding of the costs required to provide a service at a given level of quality to a particular type of recipient. Ideally, under an individual budgeting process, each recipient of service is allocated precisely the amount needed, no more and no less.
- *Equity* requires a full, well-rounded understanding of a person's support needs, and the amount required to provide these supports. Equitable budgeting also entails fairness, that people with the same level of support needs will receive the same amount of funding.

In addition, policy makers may also apply individual budgets to better position service recipients to direct their own lives. Increased self-direction can be achieved when the budget is sufficient and service recipients: (a) have ample authority over how their budget is applied to meet their needs; (b) can choose from a suitable service array; and (c) have a satisfactory choice of providers.

In North Carolina, several factors are pushing the system toward establishing individualized budgets for people with I/DD. First, the PBH LME-MCO has already undertaken this process. Since 2008, PBH has served as a pilot to inform a potential statewide initiative to develop a new resource allocation methodology that would result in an individualized budget amount[28]. Determining how much money is required to support an individual requires a reliable assessment of support needs. At PBH, this assessment of need is conducted using the Supports Intensity Scale[29]. The resulting product is that individuals are allocated an individualized budget based on their assessed level of need, but in ways relative to the needs of others served by PBH and so suitable supports may be acquired.

Another factor influencing the move to individual budgeting is the North Carolina Legislature. In 2011, House Bill 916 was passed. This legislation, titled "An Act to Establish Requirements for the Department of Health and Human Services and Local Management Entities with Respect to Statewide Expansion of the 1915(b)/(c) Medicaid Waiver", mandates DHHS to:

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[28] See: NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services (2011). *The PBH Managed Care Experience: A Comparison to Non-Managed Care Local Managed Entities.* Raleigh NC: DMH/DD/SAS.

[29] AAIDD Support Intensity Scale: http://www.siswebsite.org/

> *"Use managed care strategies, including care coordination and utilization management, to reduce the trend of escalating costs in the State Medicaid program while ensuring medically necessary care and deploy a system for the allocation of resources based on the reliable assessment of intensity of need. The Department shall design these strategies to efficiently direct consumers to appropriate services and to ensure that consumers receive no more and no less than the amount of services determined to be medically necessary and at the appropriate funding level.*

The Legislature requires that the Department shall complete the expansion of the 1915(b)/(c) Medicaid Waiver by July 1, 2013.

Third, this move toward resource allocation and individualized budgets meshes well with the State's Supports Waiver Self-Determination Option, encouraging individuals to have real control over a prospective budget, as well as more informed service planning and a more tailored response to individual needs.

Consistent with House Bill 916, DHHS is already moving down a path toward establishing individualized budgets for people with I/DD across all the new LME-MCOs. DHHS' progress should be continued in ways to assure that:

- The data collected to assess individual support need is accurate and reliable;
- Stakeholders, including people with I/DD, families and service providers, are involved at the state and local levels to learn about prospective changes and provide feedback to DHHS to sharpen the process;
- The service array available to individuals with I/DD is consistent with best practices to promote community integration and self-direction;
- Reimbursement rates associated with services are fair and ample;
- The individualized budgets allocated to people with I/DD are fair and sufficient, and the aggregate funds for all budgets is within the capitation limit assigned to each LME-MCO; and
- Means are established to address complaints from service recipients, including complaints to accommodate need for extraordinary medical or behavioral challenges.

Action Step 13: Set standardized quality management practices and use outcome-based performance data to drive quality improvement

The adage that what is tracked and reported is what improves holds true in I/DD services. Given implementation of House Bill 916, it is vital that DHHS require standardized quality management practices across the new LME-MCOs.

Standardized quality management starts with setting system performance goals and prioritizing achievement of outcomes considered vital by people receiving services. Outcomes then drive development of appropriate structures and processes, rather than be driven by them.

Standardized quality management entails not only targeted outcomes and performance measures, but also standardized practices for data collection, aggregation of data and analysis, reporting, and tracking data over time on progress to achieve outcomes at the LME-MCO and statewide levels.

Outcomes important to individuals receiving services, and to all adults, include having meaningful things to do with their day and an ample amount of money to live modestly, to be as healthy as possible, to have relationships with others, and to make important decisions about their life and supports.

Specific action steps for tracking and reporting on outcomes important to individuals receiving services and their families follow.

- ✓ <u>DHHS and the LME-MCOs should set goals, track and publicly report performance on integrated employment</u>. As illustrated above within Action Step 9, North Carolina recently joined the State Employment Leadership Network (SELN). The next level of commitment is to become an Employment First state, a designation that entails creating integrated employment incentives and infrastructure, and tracking results. Action steps for creating a culture that stresses employment include the following:
    - ▪ Make integrated employment the preferred service outcome regardless of level of disability. Develop a clear definition of integrated employment of people with I/DD as the priority for funding and ensure this outcome is incorporated into Division guiding principles, regulation, policies and practices and funding incentives.
    - ▪ Set integrated and supported employment goals for numbers of individuals served, statewide and per LME-MCO. Ensure there is method to track employment status data such as full time versus part time, wages and benefits.
    - ▪ Report employment progress publicly by posting goals and progress made to a website, sharing with advocacy groups, and CFACs.
- ✓ <u>DHHS and the LME-MCOs should set goals, track and publicly report performance related to health outcomes</u>. One of the DMHDDSAS guiding principles is a prevention-focused service system. As noted in the *Planning Context* report, North Carolina collects information on preventive health care through its participation in the National Core Indicators (NCI) project. Although many health indicators for North Carolinians are consistent with the average performance across NCI participating states, performance in several health care measures is below levels expected by individuals and families. More people in North Carolina are described as in poor health and as overweight and obese. Performance is signficantly lower too in areas of preventive screenings (vision and hearing), than performance of other NCI states. High use of pyschotropic medications impacts health as well; steps to address psychotropic medication use are presented separately below.

    To make a stronger positive difference in health outcomes, the DHSS and LME-MCOs should:

- Establish uniform, statewide expectations for preventive health care including annual physicals, cancer screenings, vision and hearing exams, flu shots, and dental exams. For example, a standard for mammograms could read, *Females between the ages of 40 and 74 years old will receive a screening mammogram at least every two years. Females at high risk will receive mammograms as recommended by their health care practitioner.* Performance can be tracked at the individual level by case managers and system-wide using National Core Indicator (NCI) data the State collects annually.
- Advise individuals, families, case managers, providers and health care practitioners of the required preventive screenings. Consumer and family advocacy organizations can be useful conduits for spreading the word. Collaborate with the Division of Public Health and State Board of Education on educational campaigns.
- Establish expectations that providers will support individuals to engage in sufficient physical activity, to extent possible, in community settings to meet and maintain healthy lifestyles. Hold providers accountable for supporting people to exercise in integrated environments and exercising in ways that are individualized to preferences.
- Track performance and publicly report on preventive care. NCI data shows statewide achievement of preventive screenings and integrated exercise. With NCI data the Division can run specialized reports such as gynecological exams by type of residence to determine if where a woman lives is correlated to whether she receives this examination. In most states, women with I/DD who live with family members have lower rates of compliance with gynecological exams than women living in other residential settings. Knowing this, the Department can tailor outreach and education to improve performance. Along with statewide performance tracking, monitoring at the individual service delivery level is also necessary, such as a case manager’s review of whether an individual received preventive health care services when due[30].

✓ DHHS and the LME-MCOs should set goals, track and publicly report performance related to reducing and eliminating unnecessary use of psychotropic medications. As reported in the *Planning Context*, NCI data from North Carolina found that nearly half of adults with I/DD receiving services (47 percent as of 2009-10) are prescribed at least one medication for mood and/or behavior control. Although this is not unique to North Carolina, this high use of medications for mood and/or behavior control is under scrutiny in many states as potentially indicative of chemical restraint and human rights violations. North Carolina should investigate the extent and reasons for such

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[30] Consistent with this theme, NCCDD is working with the Mountain Area Health Education Center to develop the National Curriculum Initiative in Developmental Medicine. The work involves collaboration with the WalMart Foundation, the American Academy of Developmental Medicine and Dentistry, and IASIDD. Go to: http://www.aucd.org/itac/detail/event.cfm?event_id=2474&parent=655&parenttitle=

widespread use and create safeguards to reduce unnecessary use of psychotropic medications.

To heighten oversight that these powerful drugs are utilized appropriately, DHHS and LME-MCOs should:

- Set a goal that psychotropic medications are prescribed with safeguards in place: a) full informed consent that includes a doctor's assessment of interactive effects and effects on health overall, both short term and long term, b) after a comprehensive functional evaluation has been completed, and c) after trials of positive behavior supports. Examples goals: (a) Reduce the number and percent of those prescribed psychotropic medications for behavior control; (b) Reduce the numbers and percent of individuals prescribed more than one psychotropic per year.
- Conduct a study to determine the extent of use of psychotropic medications. Potential research questions could be: How many psychotropic drugs are people prescribed? What informed consent process was followed? Does medication appear to be utilized for staff convenience? Are psychotropics used more extensively in larger congregate settings than in smaller residences? Are consumer protections in place such as review by a Human Rights Committee of plans to prescribe a psychotropic medication? When more than one psychotropic is recommended, is there an analysis of potential interactive effects and effects with other non-psychotropic medications prior to prescribing? How long are people prescribed psychotropic medications?

  Research questions could be added to North Carolina's NCI Adult Consumer Survey. Data could be useful for evaluating statewide psychotropic usage. Over time, NCI data could indicate the impact of quality improvement initiatives.
- Ensure that there are multiple oversight and monitoring methods evaluating psychotropic medication utilization, such as treatment team review of psychotropic medications, review by Human Rights Committees external to a provider, state quality monitoring, etc.
- Share findings from the study with a stakeholder group that includes individuals and family representatives (CFACs, ASANC, etc.). Use stakeholder input to design a quality improvement initiative to reduce and eliminate unnecessary psychotropic medication.
- Publicly report on progress made to eliminate unnecessary use of psychotropic medication.

✓ <u>DHHS and the LME-MCOs should set goals, track and publicly report performance related to personal relationships for people with I/DD</u>. It is well established that connection to others translates into better health and mental health outcomes. North Carolina has taken steps to stress the importance of relationships, one of which was the revision of the service planning process to require consideration of a person's natural and community supports. Through participation in NCI, North Carolina collects information on relationships, e.g., the proportion of people who are lonely, who talk to neighbors, and who have friends and relationships with people that are not staff or family.

To further heighten achievement on relationships and connections, DHHS and LME-MCOs should:

- Establish goals for increasing individual's connections to non-paid community members.
- Reward providers that demonstrate excellence in facilitating community connections for those they support.
- Share performance data on relationships with stakeholder groups. Collaborate with self advocates and other policy partners on strategies to improve performance.
- Publicly report on progress made to enrich people's lives through relationships.

✓ DHHS and the LME-MCOs should set goals, track and publicly report performance related to self-direction**.** One of DMH/DD/SAS' guiding principles is a consumer-driven service system. Consistent with Action Step 8, DHHS and LME-MCOs should:

- Adopt fundamental performance measures that include setting targets to significantly increase both the number and percent of individuals self-directing. Targets should be set both statewide and within each LME-MCO.
- Adopt additional performance measures to track the number and percent of each LME-MCO's I/DD service clientele that received information about self direction and were offered support (such as a support broker's assistance) to experiment with this service option.

Action Area D: Expand Community System to Serve More Individuals

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Planning Context Assessment: North Carolina does not furnish services with reasonable promptness to its citizens with intellectual and other developmental disabilities. Compared to the national average, North Carolina provides Medicaid-funded services to 29 percent fewer people. State and local agencies report a waitlist of 8,191 people and HSRI's analysis of projected unmet demand also suggests significant wait lists.

Action Step #14: Establish effective means for tracking and managing the waitlist for services

As illustrated in the *Planning Context* report, North Carolina serves significantly fewer individuals per 100K than the national average (151 in North Carolina compared to 213 nationally). Typically, states that serve 250-300 people per 100K have little to no waitlist for services. Not surprisingly, state and local agencies in North Carolina report that 8,191 people are waiting for Medicaid-funded services.

Responding to this unmet need, in 2009 the North Carolina General Assembly enacted Section 1 of G.S. 122C-115.4(b) which reads:

> "The General Assembly of North Carolina enacts: SECTION 1. G.S. 122C-115.4(b) is amended by adding the following new subdivision to read: (b) The primary functions of an LME are designated in this subsection and shall not be conducted by any other entity unless an LME voluntarily enters into a contract with that entity under subsection (c) of this section. The primary functions include all of the following:
>
> Each LME shall develop a waiting list of persons with intellectual or intellectual and other developmental disabilities that are waiting for specific services. The LME shall develop the list in accordance with rules adopted by the Secretary to ensure that waiting list data are collected consistently across LMEs. Each LME shall report this data annually to the Department. The data collected should include numbers of persons who are:
>
> a. Waiting for residential services.
>
> b. Potentially eligible for CAP-MR/DD.
>
> c. In need of other services and supports funded from State appropriations to or allocations from the Division of Mental Health, Intellectual and other Developmental Disabilities, and Substance Abuse Services, including CAPMR/DD."

All states struggle to keep pace with rising service demand. Not all people waiting for services require the same kinds of support or at same intensity. But all people waiting for home and community-based services meet the federal guidelines of having intellectual or other developmental disabilities that affect the person's ability to perform activities of daily living to such an extent that they qualify for an ICF/MR level of care. Some people waiting for HCBS may need residential services, and some may need this support urgently (such as when an older parent who has been providing round the clock care dies). Others waiting for services may need non-residential services, such as personal care workers to get them out of bed and assist with meal preparation. Some people waiting for services have been abused or neglected by caregivers. The circumstances that bring each person to the attention of DHHS are different, and assessment of need for services and when those services should start is an important function. Thus, forecasting demand and the intensity of services needed in future to reduce waitlists are top priorities in most states.

At issue, always, is the accuracy of the information collected and the biases that may be inherent within the data. For example, individuals may express a service need whether the requested service is presently needed or not, simply to "get on the list", so that when the service is necessary, the individual has already been found eligible. Such behavior tends to overstate the number of individuals waiting for services. This is why good assessment of need and estimation of when services are needed are important evaluations for prioritizing who will move off the waiting list into services and when.

Beginning in October 2010, the LMEs 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 is still not being collected on the individuals waiting for services in a consistent fashion across LMEs (i.e., LME-MCOs given the new local organizational structure).

As the State moves forward in collecting information on individuals waiting for services, the following information should be collected through a standard process:

- Demographic information on the individual waiting (including name, current address, phone number and date of birth);
- Date of entry to the waitlist system;
- Type of service(s) the individual is waiting for (i.e. residential, vocational and/or other services);
- Level of support required (using an assessment tool which measures support need); and
- Urgency of need. Are requested services critical (needed within 90 days), moderate to critical (needed within 3-6 months), moderate but not critical (6-12 months) or not critical (12 months or more)?

As this data is collected, it should be entered into a state-wide reporting database for Medicaid-funded services tracking. Doing so will allow the State and LME-MCOs to combine current service utilization data for individuals already receiving CAP-MR/DD waiver services and those waiting for services. Standard assessment instrument and protocols must be developed, as well as the protocols for monitoring and updating information on the individuals waiting for services. Once the statewide waiting list is in place, the State and LME-MCOs can utilize the data for projecting future support needs and preparing budget requests for the Legislature, reconcile open waiver slots with individuals waiting, and have a central data system for waiver services. This could include information per person related to their demographics, changes in life, service preferences and urgency of need.

Action Step #15: Expand system capacity at a steady pace by serving an additional 1,131 people each year between 2012 and 2022

An important goal for North Carolina's system is to have sufficient capacity to respond with reasonable promptness to the legitimate needs of people it is charged with serving. Yet, North Carolina faces a major strategic challenge, keeping pace with the rising demand for developmental disability services while simultaneously adding new capacity. There already is a substantial shortfall in North Carolina's current system capacity to meet the expressed demand for services.

To develop a sound strategy to address demand for services, a realistic projection of service demand is necessary. Owing to the difficulties in interpreting present waitlist data in North Carolina (see Action Step 14), projections and recommendations on North Carolina's utilization rates are compared with national utilization rates.

Projected Service Demand in North Carolina

Total service demand is the sum of people who are receiving services and people who seek services and have emergency or critical unmet needs. To estimate year- to-year service demand in North Carolina, consider these three factors:

1. *North Carolina's general population will continue to grow.* Projections of general population within the state show year over year growth. Between 2009 and 2022 the population is projected to grow from 9,380,884 to 11,350,784 or by 21 percent (North Carolina Office of State Budget and Management, http://www.osbm.state.nc.us/index.shtm).

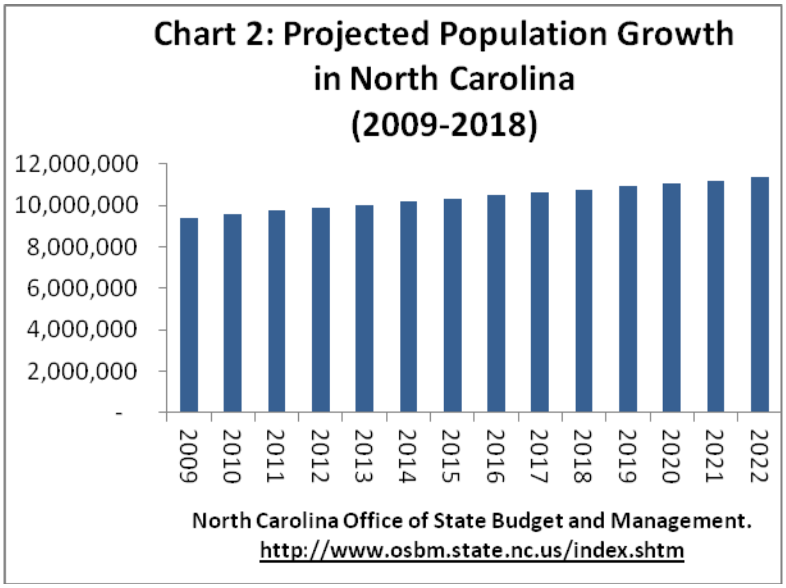
Chart 2: Projected Population Growth in North Carolina (2009-2018)

North Carolina Office of State Budget and Management. http://www.osbm.state.nc.us/index.shtm

2. *The rate of growth in demand will exceed the rate of population growth.* The specific demand for developmental disability services is influenced by several factors. At a minimum,

demand will grow at about the same rate as the general population. However, there is considerable evidence from other states that the demand for services is growing at a rate that exceeds the rate of general population growth. For example, California has experienced yearly increases in service demand that are two to four percent above the rate of population growth.

3. *Uncertainty over service utilization targets*. North Carolina recently re-established a system for measuring unmet demand. Due to the relatively limited amount of information being collected, however, service demand projections for this report are founded in measures of service utilization rates in North Carolina and nationally. More specifically, service demand estimates derive from:

    - The difference in 2009 between the number per 100,000 in population that North Carolina serves (i.e., 151 people per 100K) and the number it would serve per 100K if it were to serve the people at a level commensurate to the national average of 212 people per 100K; and

    - The service penetration rate that North Carolina would have to reach to address, meaning reduce or eliminate, the waitlist. This approach would require North Carolina to serve about 250 people per 100K in the general population. This estimate is not a firm, failsafe number. It is based on HSRI's review of national service utilization patterns and reported waitlists. As some states that serve 250 people or more per 100K population have waitlists, a number closer to 300 per 100K could have been used.

      It seems, however, that when states serve near 250 per 100K in population, minimal waitlists result. Lakin et al. (2009) reports service use patterns and residential waitlists by state: Connecticut serves 272 people per 100K and has a residential waitlist of 482 people; Rhode Island serves 314 people per 100K and reports no waitlist; while Pennsylvania, a more populous state, serves 270 people per 100K and has a waitlist of 2,095. To meet the demand for services in Pennsylvania would require an 8.6 percent growth in service capacity[31].

To forecast the rate of demand for services in North Carolina, HSRI assumed demand will grow at a pace somewhat faster than state population alone, a rate of increase of two percent each year above the rate of population growth. This is a relatively conservative assumption. Other states are experiencing higher year-to-year rates of increase in service demand, and so, a "Population Plus 2%" assumption is reasonable.

Based on the Plus 2% population estimates, two scenarios were developed, one keyed to a 212 person per 100K service utilization pattern, and the other to a 250 person per 100K rate. Both scenarios factor in that:

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[31] North Carolina did not furnish data for the Lakin report on the number of people waiting for residential services in 2009.

- In 2009, a total of 14,187 people were served in ICF/MR-certified settings or were HCBS waiver service recipients. These individuals are counted as "satisfied demand."
- The state population in 2009 was 9,380,884 with estimated growth to 11,350,784 in 2022 (Source: North Carolina Office of State Budget and Management). http://www.osbm.state.nc.us/index.shtm).

Projection #1: Service Use Rate of 212 people per 100K population. North Carolina serves 151 people per 100K in the general population. If it were to serve people at a level commensurate to the national average in 2009, it would need to serve 212 people per 100K. This is a difference of 62 people per 100K in general population. Given the State's population in 2009 of 9,380,884 this would have amounted to serving 5,837 more people in 2009. As a result, the North Carolina level of total service demand in 2009 would be 20,023 (i.e., 14,187 + 5,837).

Projecting these numbers forward from 2012 to 2022, to reach the present national average utilization rate of 212 people per 100K in population, North Carolina would need to serve an additional 6,973[32] people by 2022. This amounts to 697 new people added to the service rolls each year from 2012 to 2022.

Projection #2: Service Use Rate of 250 people per 100K population. Under this scenario, the target is set higher, at 250 people served per 100K. Again, noting that in 2009 the service utilization rate in North Carolina was 151 people per 100K, pushing to 250 people yields a difference of 99 more people per 100K. Given a state population in 2009 of 9,380,884 this would amount to 9,287 more people having been served in 2009. Using this service use target, the North Carolina level of total service demand in 2009 would have been 23,474 (i.e., 14,187 + 9,287).

Again, projecting these numbers forward from 2012 to 2022, to reach a utilization rate of 250 people per 100K in population, North Carolina would need to serve an additional 11,316[33] people by 2022. This amounts to 1,131 new people added to the service rolls each year from 2012 to 2022.

This is the better projection for DHHS to pursue because it offers the best chance to eliminate the I/DD service waitlist.

Resources Needed to Meet Projected Service Demand

There is no doubt that additional dollars will be needed for North Carolina to address current unmet service demand as well as keep pace with projected service demand through 2022. Resources should not be garnered from reductions in current HCBS waiver services. Federal Medicaid dollars can underwrite 64 percent of these additional outlays.

To estimate the dollars that might be necessary, we assume that North Carolina will employ the Medicaid HCBS waiver authority exclusively to expand system capacity. The baseline figure

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[32] This assumes a 2% yearly increase over population.

[33] This assumes a 2% yearly increase over population.

used under this scenario is $47,191 per person[34] (the average HCBS expenditure of 2009 in North Carolina).

Table 1 illustrates this cost scenario by two the service utilization standards, the first at a rate of 212 people per 100,000 in general population, and the second at 250 people per 100K. As shown:

- Given a service use rate of 212 people per 100K, resources must be allocated to serve an additional 6,973 people by 2022, an additional $329.05 million by that date. Given the state's Medicaid matching ration (64.05 percent), the cost to North Carolina would be 34.95 percent of this amount, or $118.29 million.
- Given a service use rate of 250 people per 100K, resources must be allocated to serve an additional 11,316 people by 2022. The estimated cost under this projection would be $534.03 million annually by 2022. The cost in state general revenue would be $191.98 million.

As illustrated in Table 1, North Carolina policymakers can choose between two policy options to address the unmet needs of people with intellectual and other developmental disabilities to varying degrees. A conservative choice would involve expanding capacity gradually until a service utilization rate commensurate with the national average is achieved. While attractive from a cost savings perspective, this approach would still leave thousands of individuals with intellectual and other developmental disabilities without services.

The strategy to accommodate most, if not all, unmet demand for service is to expand system capacity at a steady pace by serving an additional 1,131 people each year between 2012-13 and 2021-22. Such action would result in 11,316 additional individuals receiving services by 2022. By employing the HCBS waiver authority to finance this expansion in capacity, the State will be able to secure federal Medicaid dollars to underwrite 64 percent of the cost of this expansion. Again, it is important to realize that by serving the additional 1,131 individuals per year, the State would achieve a service utilization rate of 250 per 100K by the end of the period (i.e., by 2022). There is a significant possibility that by serving this number of people, North Carolina will sharply reduce and possibly eliminate the waitlist for specialized developmental disabilities services over time.

When considering this *Action Step* and the associated costs, past system growth must be taken into consideration. From 2001 through 2009, North Carolina added 4,303 people to its developmental disabilities service system, or about 478 per year[35]. This raises concern about the system's capacity to absorb the addition of 653 more new enrollees per year. If the State wants to ensure that more individuals with I/DD receive the services they need, however, decided action must be taken. By utilizing the HCBS waiver program, and not the higher cost ICF/MR model, the State will be better equipped for this proposed growth.

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[34] Lakin et al (2010)

[35] 4,949 individuals were added to the HCBS waiver program, however, there was a reduction of 666 people from the ICF/MR program averaging to a system increase of 4,303 (4,949 + (-666)).

In summary, two options are presented to illustrate how the State might serve individuals on the waitlist who are in need of and likely to accept services if offered at the time. It is prudent to add individuals from the waitlist each year, since serving everyone currently on the waitlist at once presents huge challenges financially and administratively. These options are for bringing individuals with I/DD into the service system over time since (a) new people will present themselves for services every year, (b) there are costs differences depending on how the State elects to serve people new to the system, and (c) the current waitlist information is insufficient to determine when each person on the waitlist will need services and the extent of the services needed. These options offer sound strategies to plan to serve the waitlist over time. As North Carolina collects more information about the waitlist, it may be possible to develop more specific plans.

Cumulative Resources Needed to Meet Service Demand 2010-2022 by Two Service Utilization Patterns
($ Million)
Table 1

Utilization Pattern	Year	Additional Capacity Needed	Total Cost (HCBS Waiver) $47,191 per person	Cost in North Carolina General Revenue
212 People Served per 100k	2010-11	5,965	$281.47	$101.19
	2011-12	6,058	$285.87	$102.77
	2012-13	6,152	$290.30	$104.36
	2013-14	6,244	$294.66	$105.93
	2014-15	6,337	$299.03	$107.50
	2015-16	6,428	$303.36	$109.06
	2016-17	6,520	$307.69	$110.61
	2017-18	6,611	$311.99	$112.16
	2018-19	6,702	$316.28	$113.70
	2019-20	6,793	$320.54	$115.23
	2020-21	6,883	$324.80	$116.77
	2021-22	6,973	$329.05	$118.29
250 People Served per 100k	2010-11	9,680	$456.82	$164.23
	2011-12	9,831	$463.95	$166.79
	2012-13	9,984	$471.13	$169.37
	2013-14	10,134	$478.22	$171.92
	2014-15	10,284	$485.31	$174.47
	2015-16	10,433	$492.34	$177.00
	2016-17	10,582	$499.37	$179.52
	2017-18	10,730	$506.34	$182.03
	2018-19	10,877	$513.30	$184.53
	2019-20	11,024	$520.23	$187.02
	2020-21	11,170	$527.15	$189.51
	2021-22	11,316	$534.03	$191.98

Notes:

1. Estimated costs do not include corrections for (a) potential inflation, implementation of the current
2. 64.05% of estimated Total costs will be federally reimbursed through use of Medicaid
3. Lakin, et al. (2010)

Implementation Sequence

This *Strategic Analysis for Change* provides a complex and intertwined action agenda for system restructuring in North Carolina. Necessarily, the approach taken requires that all aspects of the adult system be taken into account and provides opportunities for DHHS and other state agencies to commit to making the changes necessary to achieve excellence in service system performance. Still, these *Action Steps* may also prompt concern about their potential impact on people with I/DD, their families, committed professionals, and other stakeholders. Such concerns may be entirely legitimate, and if not addressed can fuel resistance to change. In addition, experience shows[36] that systems managers seeking to make change can inadvertently make matters worse if systems change strategy does not:

- Articulate and communicate a clear, unambiguous vision of the future that appeals to most key stakeholders, and to take consistent policy action that advances the vision;
- Establish a strong sense of urgency around the restructuring effort that illustrates the consequences of inaction and the benefits of taking action;
- Engage stakeholders in the restructuring effort and forging a coalition backing system change;
- Remove policy, financing, or other structural barriers that may impede system restructuring;
- Plan systematically for restructuring and implementing the plan step by step, building short-term successes along the way; and
- Anchor the restructuring in organizational cultures within agencies across the state and to encourage learning communities among stakeholders to support the effort.

A successful strategy for implementing these *Action Steps* must involve purposeful action to avoid pitfalls such as these. In fact, several of the *Action Steps* presented earlier take these potential hazards into account. Steps may promote, for example, collaborative problem solving, remove policy barriers or improve systems infrastructure. Such action will inevitably improve service delivery, help build confidence in the community system, and stimulate momentum among stakeholders for additional change.

Overall, the implementation of each action step will require a considerable number of follow-up activities and more detailed planning. As a result, implementation will proceed more smoothly if it is conducted as a collaborative enterprise among constituencies that stresses full transparency and one where DHHS routinely takes action consistent with the restructuring goals.

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[36] Kotter, John (1998). *Leading change: Why transformation efforts fail*. Harvard Business Review (March-April) Reprint No. 95204.

As outlined in this report, 15 recommended *Action Steps* were developed to help DHHS and other stakeholders move the service system forward. Below is a recap of the four main action areas with their associated action steps. The accompanying graphic illustrates these steps across a 10 year implementation timeline.

Action Area A: Establish Clear Leadership for Developmental Disabilities Service System .

Step 1: Commit to Unified Policy Direction within DHSS

Step 2: Invest in Self-advocacy for Policy Collaboration

Action Area B: Serve People in the Most Integrated Setting

Step 3: Reduce Utilization of Developmental Centers

Step 4: Adopt Policies to Facilitate Transitions from ICFs/MR

Step 5: Evaluate Individuals Residing in Skilled Nursing Facilities

Step 6: Implement N.C. Institute of Medicine Adult Care Home Recommendations

Step 7: Utilize the Balancing Incentive Program

Action Area C: Promote Outcomes Important to Individuals and Families

Step 8: Implement a Self-directed System

Step 9: Accelerate Integrated Employment Opportunities

Step 10: Promote Mutual Support of Self-advocates and Families

Step 11: Strengthen Supports for People with Extraordinary Behavioral Challenges

Step 12: Establish Equitable Resource Allocation for Individual Budgets

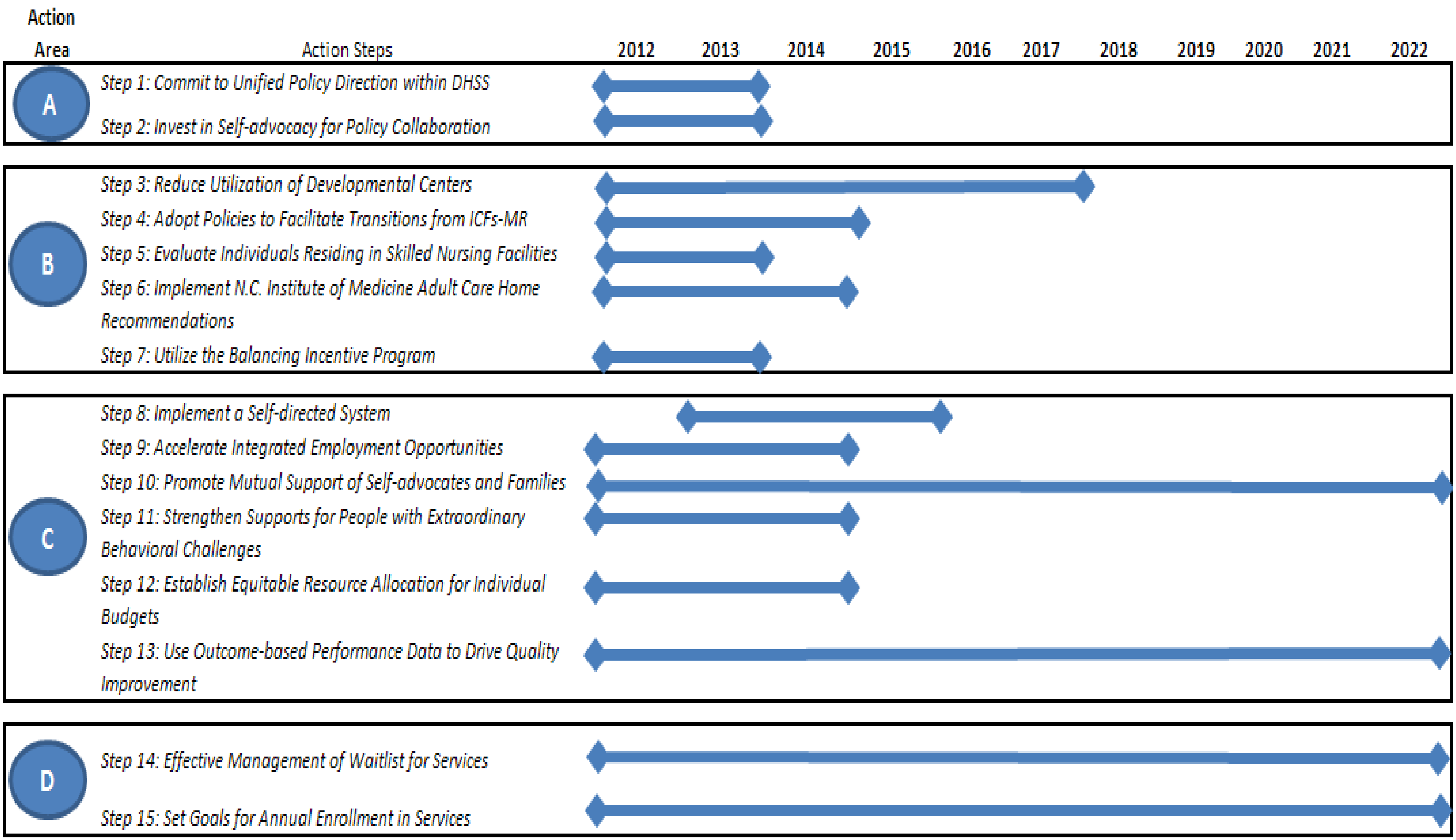
Step 13: Use Outcome-based Performance Data to Drive Quality Improvement

Action Area D: Expand Community System Capacity to Serve More Individuals.

Step 14: Effective Management of Waitlist for Services

Step 15: Set Goals for Annual Enrollment in Services

Implementing these *Action Steps* is no easy task. It will take commitment, teamwork and leadership over the next several years. The accompanying timeline offers the implementation sequence for these steps. Again, the steps are not stand alone items. There are several moving parts that will have to take place, simultaneously, to achieve the desired outcomes. The overall timeframe for the systems change is ten years (2012-2022) with several pieces being completed prior to 2022, and some steps continuing past 2022.


Action Area
Action Steps
2012
2013
2014
2015
2016
2017
2018
2019
2020
2021
2022
A
Step 1: Commit to Unified Policy Direction within DHSS
Step 2: Invest in Self-advocacy for Policy Collaboration
B
Step 3: Reduce Utilization of Developmental Centers
Step 4: Adopt Policies to Facilitate Transitions from ICFs-MR
Step 5: Evaluate Individuals Residing in Skilled Nursing Facilities
Step 6: Implement N.C. Institute of Medicine Adult Care Home Recommendations
Step 7: Utilize the Balancing Incentive Program
C
Step 8: Implement a Self-directed System
Step 9: Accelerate Integrated Employment Opportunities
Step 10: Promote Mutual Support of Self-advocates and Families
Step 11: Strengthen Supports for People with Extraordinary Behavioral Challenges
Step 12: Establish Equitable Resource Allocation for Individual Budgets
Step 13: Use Outcome-based Performance Data to Drive Quality Improvement
D
Step 14: Effective Management of Waitlist for Services
Step 15: Set Goals for Annual Enrollment in Services

Conclusion

> **"When an elephant stands still, it is more bothersome for the person underfoot than for the rider on the top."**
>
> ***Indian proverb***

North Carolina faces difficult policy choices regarding the way in which it responds to the needs of its citizens with intellectual and other developmental disabilities. Such choices are made more difficult given state budget shortfalls, chronic under-funding for the I/DD system, an over reliance on developmental centers and ICFs/MR, a stressed community service system, a growing service waitlist, and changing expectations among people with I/DD and their families. Increasingly, people with I/DD and their families express a strong preference for services that promote community integration and self-determination. Unquestionably, North Carolina is at a crossroad.

To guide the way forward, in the first of two reports compiled for this effort, HSRI prepared the *Planning Context* report that compared the State's performance against five benchmarks. This analysis resulted in the finding below:

Though North Carolina has worked to offer people with I/DD the services they need, the State is ill-positioned to address the present and future needs of its citizens with I/DD due to: a lack of definitive and unified leadership, insufficient resources, inefficient use of available resources, and a lack of a cohesive and full commitment to community centered service approaches.

In response, state leaders must decide what to do. Many policy options are available, though these three stand out. The State may:

- <u>Do nothing</u>. Keeping the current investment patterns and service array in place will most likely result in more of the same -- i.e., continued inefficient use of resources, a community system that is unable to meet current and future service demand and growing waiting list for services.
- <u>Increase funding significantly, but maintain the current system of organizing and delivering services</u>. This approach would improve the service response and likely allow for additional people to be served. It would also, however, perpetuate present inefficiencies and investments in options that are inconsistent with best practice going forward.
- <u>Increase funding significantly and make necessary changes to improve inefficiencies and invest in community centered service approaches</u>. This is the most forward-looking option. It provides a pathway toward increased efficiency within the system while furnishing needed funds to strengthen the community system and address unmet service demand. Further, it would place the state on a firmer footing in developing a system that can better address present needs while developing a sustainable system.

The 15 *Action Steps* presented earlier are pinned to the third option and call for a decided commitment to:

Establish an efficient and sustainable system whereby people with intellectual and other developmental disabilities can live the life they want in the community with the supports they need.

Based on this vision, the *Action Steps* call upon DHHS and stakeholders across the state to make changes related to these four areas:

A. Establish clear leadership for developmental disabilities service system;

B. Serve people in the most integrated setting by reducing the role that developmental centers, nursing homes, and ICF/DDs play within the North Carolina service system;

C. Promote outcomes important to individuals and families, including emphasis on self-direction among people with I/DD, partnerships among service recipients, family members and community service organizations, as well as among public agencies, and strengthening infrastructure in support of the community services system; and

D. Expand system capacity so that by 2022 all people who have emergency or critical unmet needs will be served with reasonable promptness.

The actions associated with each of these areas provide state leaders with definitive direction for addressing the challenges faced by the North Carolina I/DD service system. What's more, House Bill 916, calling for a restructuring of the management, financing and delivery of services, offers an opportunity to "seize the moment" and revitalize the system consistent with these *Action Steps*.

These *Steps*, however, are inter-related and should be regarded as a unified, intertwined series of actions that build and depend on one another. And, yes, the state will need to invest more in services for people with I/DD. After all, its investment to date has been modest relative to what other states spend. As a result, success will depend on collaboration among many, but must begin with a commitment to change from chief decision makers in North Carolina inside the executive and legislative branches, as well as the Secretary of DHHS. By enacting the proposed steps North Carolina will increase system capacity, improve efficiency, and enhance the quality of life of thousands of North Carolinians with I/DD their families.

> **A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."**
>
> ***Alfred Dam***

Across the nation, people with intellectual and other developmental disabilities argue strongly for support systems that look decidedly different than the current service system in North Carolina. Two decades ago, Dirk Wasano, a long time resident of a developmental center in Hawaii who eventually was given the opportunity to relocate to the community observed that:

> *"In the 1960' s and earlier we were treated like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun.*
>
> *In the 1970s and 80s you discovered we could be taught -- we could learn -- and we were treated like pets. You taught us all types of tricks and we stood by your side.*
>
> *But now …. Here we are. We are not plants. We are not your pets.*
>
> *We are people like you and we want to be treated as real people. We want the same opportunities as anybody."*

There is no reason to believe that people with I/DD in North Carolina feel any differently. The time has come in North Carolina to push past its present circumstances and establish an action bias for change to assure that people with I/DD receive the supports they need to live in the community as other citizens do. Surely, people with I/DD will settle for nothing less.