

North Carolina's Public System of Services and Supports for Individuals with Intellectual and Developmental Disabilities

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The goal of North Carolina's public system of services and supports for people with intellectual and developmental disabilities (I/DD) is to promote independence and self-advocacy for the people they support. To achieve these goals the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS) endeavors to provide best practice services and supports designed to enable people with I/DD to live in housing of their choice, preferably their own home or with friends or family, and to encourage, whenever possible, meaningful employment. We believe that individuals with disabilities and the community as a whole are enriched when people with I/DD live and work in inclusive settings and are contributing members of society.

Three new initiatives are currently underway to further achieve these goals: (1) statewide implementation of a best practice model for providing crisis services to people with I/DD; (2) piloting a new, nationally-recognized assessment instrument to better identify an individual's need for services and supports; and (3) developing and implementing an array of home and community-based Medicaid waivers to meet the needs of people with I/DD in a more individualized manner.

NC START

Developed in 1989 by Dr. Joan Beasley as a model for providing community-based crisis intervention and prevention services to adults with I/DD and behavioral health care needs, the Systemic, Therapeutic, Assessment, Respite, and Treatment (START) model is a best practice which, based on preliminary data, indicates positive outcomes. Data are collected regularly to evaluate the effectiveness of the program. In 2008, the North Carolina General Assembly provided funding to develop and operate six START teams, and North Carolina became the first state to implement START on a statewide basis.

Two providers and three Local Management Entities (LMEs) are involved in implementing NC START on a

regional basis across the state. RHA Health Services, Inc. operates two START teams under the management of the Western Highlands Network in the western part of the state and also operates two teams under the management of East Carolina Behavioral Health (ECBH) in the eastern region of the state. Easter Seals/UCP operates two START teams serving the central region under the management of The Durham Center. Each team is comprised of a psychologist

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and other qualified developmental disabilities professionals who work in collaboration with a psychiatrist. The teams provide direct services to individuals experiencing a crisis and provide consultation and technical assistance to other providers and families on methods to prevent and de-escalate crisis situations. An example of such a crisis

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may involve an individual who exhibits extreme behavioral disruptions including property destruction, aggression towards themselves or others and/or the inability to regulate their emotions and interactions with their environment. Each team also has access to a facility that can provide planned, short-term respite services for individuals whose behavioral needs create problems in obtaining other respite services and for emergency respite to address crisis situations.

NC START is designed to provide positive outcomes for individuals with disabilities as well as for the communities in which they live. At the individual level, NC START helps people achieve stability and remain living in the community by decreasing behavioral challenges and symptoms, thereby avoiding the use of hospitals or state facilities. For the community, NC START provides resources to increase the knowledge of how to address behavioral crises in the community and serves as a means of coordinating various community resources to meet the needs of people with I/DD and behavioral health challenges.

In April 2009, the new NC START teams began providing services. During the quarter ending June 30, 2009 they provided direct services to 158 consumers, including 316 days of respite care, and conducted 428 training events in the community.

New Assessment Tool

North Carolina is pilot testing a new tool to assess the service and support needs of individuals with I/DD. The new tool, the Supports Intensity Scale (SIS), was developed over a five-year period by a team of national experts and is endorsed by the American Association on Intellectual and Developmental Disabilities. The SIS is a multidimensional scale designed to assess support needs, determine the intensity of needed supports, monitor progress, and evaluate outcomes of adolescents and adults with I/DD. Unlike some previous assessment instruments, the SIS does not measure an individual's deficits, but rather focuses on the supports needed for the individual to fully and successfully participate

in everyday life within a home and community environment. Assessment results present a graphic representation of an individual's support needs across six life-activity domains: home living, employment, community living, health and safety, lifelong learning, and social activities. It also produces a composite score reflecting an individual's overall intensity of support needs relative to others with I/DD. These results assist the team in developing a person-centered plan that identifies individualized supports that are responsive to the needs and choices of an individual based on what is important to and for this person to be successful.

The Division of MHDDAS is piloting the use of the SIS in seven LMEs across North Carolina (see Table 1). The purpose of the pilot is to determine if the SIS provides sufficient information to accurately identify services and supports needed for individuals with I/DD across a variety of possible living arrangements—independent, family, small group home, large group home, and state-operated facilities—and to evaluate for Medicaid and state funding streams. In the pilot LMEs, licensed practitioners who have at least two years of experience working with adults and children with I/DD who are enrolled to participate in the Medicaid program conduct SIS assessments. Prior to conducting the assessments, the assessors receive 13 hours of SIS training; they must also take yearly refresher training. The pilot project began in April 2008. As the table below indicates, through December 14, 2009, 428 individuals in seven LMEs have received SIS assessments.

Based upon the assessment of these 428 individuals, the Division believes that SIS does provide information that is very useful in developing plans to serve and support individuals in a more personalized manner. The pilot shows the instrument provides valid results regardless of the individual's living arrangements or source of funding. The Division is currently working to develop strategies to address some of the challenges to statewide implementation that the pilot project has identified, including the cost of the assessment instrument itself, the limited number of

Table 1.
Supports Intensity Scale Pilot Progression

Local Management Entity	SIS Assessments Completed as of December 14, 2009	Number of CAP-MR/DD Waiver Participants Ages 16 and Older	Percentage Completed
Durham	64	216	30%
ECBH	33	354	9%
Five County	56	206	27%
Guilford	28	355	8%
Mecklenburg	117	602	19%
Sandhills	122	391	31%
Smoky Mountain	8	479	2%
Total	428	2,603	16%

licensed professionals who are qualified and willing to administer the assessments, and family resistance to the time needed to accurately conduct the assessment. The North Carolina General Assembly has required the Division to report the results and recommendations from the pilot to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services and the Appropriations subcommittee by May 1, 2010.

Tiered Home and Community-Based Waivers

The primary funding source for services and supports to people in North Carolina with I/DD is Medicaid funding provided through Home and Community Based-Services (HCBS) waivers. Medicaid regulations permit states to apply for HCBS waivers authorized under section 1915c of the Social Security Act which allows the state to deliver community-based services to individuals who would otherwise be eligible for institutional care. The regulations permit states to target waivers to specific populations, modify income and asset limitations for those authorized under the state's Medicaid plan, waive parental and spousal income and asset limits under certain circumstances, and limit the number of individuals who may participate in the waiver based upon the number approved by the federal government and the state's available funding.

In North Carolina, HCBS waivers are called Community Alternatives Programs (CAP). North Carolina has operated a CAP program for individuals with I/DD, the CAP for persons with mental retardation/developmental disabilities (CAP-MR/DD) waiver, for many years. In 2007, the General Assembly directed the Department of Health and Human Services to replace its existing CAP-MR/DD waiver with a series of "tiered" waivers designed to serve more people through this funding source by controlling growth in the cost of services. Per the direction of the General Assembly, North Carolina will eventually operate four individual CAP-MR/DD waivers, each with different benefit packages and different upper limits of services and supports available to waiver recipients.^a

On November 1, 2008, North Carolina began the implementation of a tiered approach by launching the first two waivers, the Supports Waiver that offers benefits up to \$17,500 annually, and the Comprehensive Waiver that offers services and supports costing from \$17,501 to \$135,000 on an annual basis. The array of services and supports available in the two waivers is similar, and when a service or support is included in both waivers, the service definitions and requirements for that service are the same in order to eliminate confusion for providers. For example, both waivers offer the opportunity for recipients to receive supported employment services. The supported employment service

looks identical in each waiver, but someone on the Supports Waiver would likely receive less supported employment services than someone on the Comprehensive Waiver might receive. The Supports Waiver served approximately 187 people in SFY 2009. The plan is to provide services to approximately 1,000 persons through the Supports Waiver in SFY 2010. Over 10,000 individuals currently receive services through the Comprehensive Waiver.

The Supports Waiver, also known as the Tier 1 Waiver, offers services and supports to individuals living in their own home or with family. The Supports Waiver is not appropriate for individuals living in group homes or other out-of-home living arrangements. In most cases, individuals supported through this waiver have access to significant natural supports from family members and the community and may experience less intensive needs than someone served through the Comprehensive Waiver. The Supports Waiver provides an option for individuals to participate in Self Direction. Self Direction is a national movement in the I/DD community designed to empower individuals to become active participants and managers of the services and supports they receive, as well as to become active community citizens who have valued social roles in the community. The principles of Self Direction embedded in the Supports Waiver include:

1. *Freedom* to choose services/supports and the staff that provides them;
2. *Authority* over how services and supports are delivered;
3. *Support* for organizing services/supports in a manner that may be unique to the individual;
4. *Responsibility* to manage public funds appropriately; and
5. *Confirmation* that individuals with disabilities must be a major part of the design of the service system.

The Self Direction option in the Supports Waiver will become available November 1, 2009. At this time, we do not know how many recipients will choose to elect this option.

The Comprehensive Waiver offers services and supports to individuals whose waiver needs can be met with services costing less than \$135,000 per year. It can serve people living in their own home or with family, as well as individuals living in group homes, alternative family living settings, and other out-of-home living arrangements. In most cases, individuals who receive this level of waiver funding have more intensive medical and/or behavioral needs than individuals who receive funding from the Supports Waiver.

In accordance with the General Assembly's direction to create four tiers of waivers, plans are currently underway to amend the Comprehensive Waiver to create two additional waivers. The new Tier 2 waiver will offer services and

a. Piedmont Behavioral Health, the LME serving Cabarrus, Davidson, Rowan, Stanly, and Union counties, operates its own HCBS waiver for individuals with I/DD, known as the Innovations Waiver. The direction to implement tiered waivers does not apply to the Innovations Waiver.

supports costing between \$17,501 and \$45,000 annually. This new waiver will also offer the Self Direction option. The Tier 3 waiver will provide services and supports costing between \$45,001 and \$75,000 annually, and the Comprehensive, or Tier 4 waiver, will serve individuals with the highest level of need for services and supports costing between \$75,001 and \$135,000 per year. We anticipate the two new waivers and the revised Comprehensive Waiver will be implemented sometime in 2011.

North Carolina's public system of services and supports for people with I/DD continues to advance initiatives to

promote independence and self-determination for people supported by the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. These strategies support that goal by using best practice approaches designed to support people with I/DD to live in homes of their choice, to participate in meaningful employment, and to become contributing members within their community. These fundamental tools provide the necessary structural framework to effectively provide assessment, planning, and strategic interventions that promote positive outcomes and support meaningful lives. **NCMJ**

Kathryn, MS Activist,
diagnosed with MS in 1984

I want to help shape the
policies and programs that
impact people living with MS.

move it.

MS MS Awareness Week
March 8-14, 2010

MS National
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How will you move it?
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