



**Prepared for the SC House of Representatives
Ways and Means Committee**

Healthcare Subcommittee

**Representative G. Murrell Smith, Jr.
Chairman**

January 27, 2015

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January 27, 2015

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The Honorable J. Derham Cole, Jr.
The Honorable William "Bill" Clyburn

Ways and Means Healthcare Subcommittee
South Carolina House of Representatives

Dear Mr. Chairman and Subcommittee Members:

The S. C. Department of Disabilities and Special Needs' budget request is hereby submitted for your consideration.

The department is requesting \$21,865,000 in recurring funds for FY 2015 – 2016. Each priority relates directly to the agency's core mission and to the safety of individuals and provision of quality services. Funding this request will enable DDSN to comply with federal requirements and initiatives, prevent crisis situations, address the needs of elderly caregivers and individuals on waiting lists, and support people at home and in community settings.

DDSN's request focuses on the components of CMS' recent Final Rule. Funding these items will better position the agency to meet these new obligations. There are no capital or proviso requests. There are no requests for new FTEs.

Thank you for your support of the agency's efforts to serve individuals with severe lifelong disabilities and their families. Your actions allow the department to provide essential services to many individuals in great need and to significantly expand services to people who were waiting for new services.

Thank you for your leadership and service to our state. Please let me know if you have any questions or require additional information about DDSN's request or services. We are glad to help.

Sincerely,

Beverly A. H. Buscemi, Ph.D.
State Director

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SC Department of Disabilities and Special Needs

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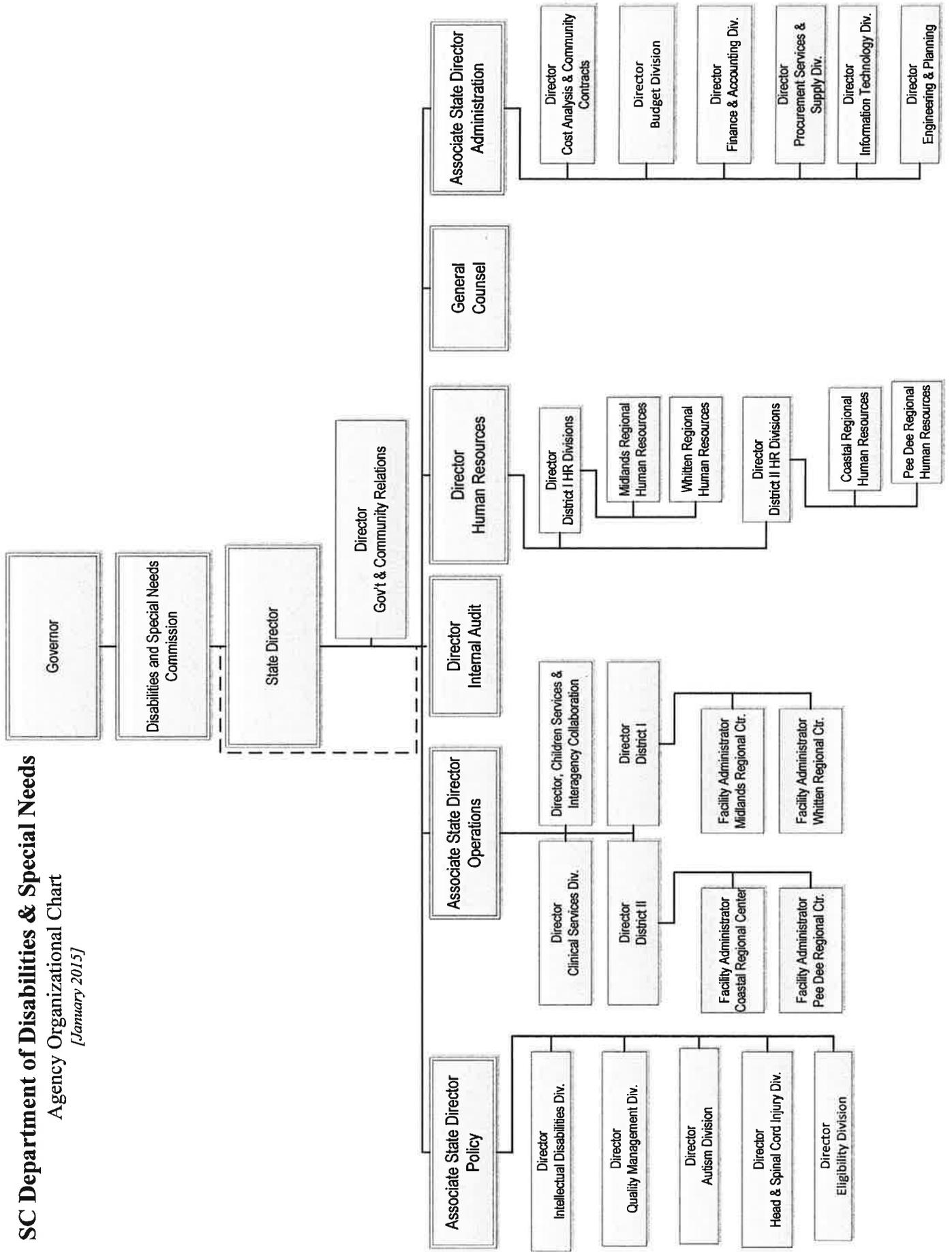
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SC Department of Disabilities & Special Needs

Agency Organizational Chart

[January 2015]



Summary of the FY 2013-2014 Accountability Report

- **South Carolina ranked 6th nationally in the United Cerebral Palsy 2014 Case for Inclusion report.** UCP annually evaluates all state disability and related Medicaid systems across the country to rank the degree of community inclusion offered to citizens with disabilities. South Carolina has ranked the highest among the southeastern states six out of the past nine years and in two of the remaining three years, ranked second.
- **Ensuring the needs of eligible individuals in crisis situations were met was the highest priority of the agency.** An effective system is in place to respond quickly to consumers whose situations jeopardize their health, safety and welfare. Examples include the unexpected death or major health concern of a primary caregiver, harm/abuse to a consumer or family, or extreme deterioration of the consumer's home.
- **Serving individuals in the least restrictive environment and offering services to support individuals in their own home/their family's home continued to be a focal point for service delivery.** This philosophy is operationalized through serving consumers in their family homes rather than state funded residential settings. This approach affords a better quality of life for the consumer, is preferred by families, and is also a more cost effective model of service delivery for taxpayers. Of the approximately 34,550 people eligible for DDSN services, including all disability groups, 86 percent live at home with family or in their own home.
- **Preparing for significant system changes was a major focus this year.** In January 2014, the Centers for Medicare/Medicaid Services (CMS) issued the new Final Rule for Home and Community Based Settings which more clearly defines the definition of community inclusion. This rule, which went into effect in March 2014, requires states to transform their service delivery systems to be more community inclusive and rely less on segregated service settings. CMS is requiring states to come into full compliance with the New Final Rule within five years.
- **Substantially moving waiting lists remained a high priority again this year.** Once the agency's funding stabilized with new recurring state funds, service dollars were again redirected to the next person on the waiting list when someone left that service. This allowed over 1,200 individuals to receive new services during the FY 2014 and almost 2,000 people received new services over the past two years.
- **Employing people with disabilities got a boost this year with the development of a new employment pilot.** Consumers transitioning from school to adult life are more likely to desire and anticipate having a career yet these transition-age consumers are less likely to have access to needed supports. DDSN developed a pilot to 1) expand access to individual Employment Services, 2) incentivize providers to offer that service by establishing an outcomes-based payment structure that allows for higher potential reimbursement rates for high quality services and 3) create a new "Career Support" service aimed at providing less intensive and less expensive, long-term supports needed to maintain employment and achieve career objectives. Expansion of this pilot is important and will help the agency with the overall effort to bring services into full compliance with the CMS Final Rule.

Summary of the FY 2013-2014 Accountability Report

- **Increasing and improving opportunities for stakeholders to offer input in decision-making continued as a high priority.** There are numerous systems in place to ensure that stakeholders participate in discussion and decision making processes. Regularly scheduled meetings occur with consumers, family members, advocates and provider representatives.
- **Increasing consumer and family choice and control of services continues to be an important goal.** During FY 2014, DDSN worked to change the process through which residential services are offered to eligible individuals. Now, once an individual is approved for residential services, the individual can choose any qualified provider in the DDSN statewide system to serve their residential needs. Individuals in the DDSN system have long since been able to move from provider to provider based on their choice, and the money to serve them moves with them. But sometimes if a person wanted to move to another county, they would have to wait for a vacancy to become available. Now a provider can work with the family to develop the placement.
- **Redirecting Regional Center service funds for individuals on the waiting list and those choosing to move to community services continued in FY 2014.** Approximately \$1.7 million was redirected to local community services from regional centers during FY 2014.
- **Implementing the agency's plan to prevent and limit unnecessary institutional placement is consistent with the US Olmstead ruling.** The critical case review process is a primary method utilized to prevent unnecessary institutionalization. A concerted effort was also made to provide a more family like setting for children with the most complex needs requiring out of home placements. DDSN started a new service pilot focusing on those consumers who desire to live and function with more independence in homes or apartments of their choice, with roommates of their choice.
- **Ongoing collaborative prevention activities reduce the incidence and severity of disabilities.** Primary prevention efforts produce the greatest return on investment of time and dollars. DDSN continues its efforts to reduce the rate of infants born with neural tube defects (NTDs) in partnership with the Greenwood Genetic Center. The prevention of 69 infants born each year with an NTD results in a \$24 – \$34.5 million savings in lifetime medical care costs. The Metabolic Treatment Program consistently has 75-100 children age birth to 7 years on curative treatment to prevent severe lifelong developmental disabilities. This treatment saves about \$40 million per year in medical costs which would be necessary if the newborns were not identified and successfully treated.
- **DDSN maintained its Regional Center per diems below national averages.** DDSN's current administrative cost remained below two percent of the overall budget. Resources are shifted from administration to service priorities whenever possible.
- **Strengthening the agency's information/data security posture was a priority.** DDSN was one of 15 state agencies chosen to participate in the statewide agency security assessment and audit.
- **Responding to all external audits and ensuring necessary changes were made for federal and state compliance and improvement was achieved while maintaining fiscal responsibility.**

**SC Department of Disabilities and Special Needs
Appropriation/Authorization and Expenditures**

Funding Source	FY 2011-2012		FY 2012-2013		FY 2013-2014		FY 2014-2015
	Appropriation / Authorization	Expenditures	Appropriation / Authorization	Expenditures	Appropriation / Authorization	Expenditures	Appropriation / Authorization
State Appropriation - Recurring	\$ 169,938,223	\$ 167,447,992	\$ 184,817,241	\$ 182,584,290	\$ 190,190,563	\$ 189,368,561	\$ 207,708,871
State Appropriation - Non-Recurring	\$ -	\$ -	\$ 250,000	\$ 250,000	\$ -	\$ -	\$ 1,750,000
Federal Authorization	\$ 340,000	\$ 252,474	\$ 340,000	\$ 209,783	\$ 340,000	\$ 234,395	\$ 340,000
Other Authorization	\$ 407,685,908	\$ 301,189,709	\$ 393,705,617	\$ 297,572,248	\$ 393,705,617	\$ 343,908,421	\$ 430,209,269
Total	\$ 577,964,131	\$ 468,890,175	\$ 579,112,858	\$ 480,616,321	\$ 584,236,180	\$ 533,511,377	\$ 640,008,140

SC Department of Disabilities and Special Needs
Major Program Areas

1. Prevention

Primary prevention of the occurrence of developmental disabilities, traumatic brain and spinal cord injuries. Provide early identification and timely intervention aimed at reducing the duration of the disability and/or minimizing its consequences. Study the prevalence and incidence of various disabling conditions in South Carolina and study public policies affecting implementation of effective prevention initiatives. Develop and promote continuing educational materials for professionals and make the public aware of risk factors and appropriate interventions to reduce the incidence of disabilities.

Primary prevention and timely intervention services avoid the onset of a disability, reduce the duration of the disability, or minimize the consequences of the disability. These services foster independence, enhance quality of living and avoid the State's need to provide millions of dollars of services throughout the person's lifetime.

2. In-home Individual and Family Support

Individual and family support services A) allow an individual to live independently or with family members; B) prevent costly out-of-home placement; C) promote family unity and responsibility; D) provide flexible supports to enable families to cope with caring member with a disability.

This program represents DDSN's ongoing effort to promote individual and family independence and responsibility by supporting families who are providing 85% of the informal caregiving rather than replacing families. On average individual and family support services such as personal care aids, employment, or respite services cost less than one-half the least expensive out-of-home placement options. Often these services are the difference between helping the family with supports versus replacing the family with a more expensive out-of-home placement. Supports strengthen the family and allow family caregivers to remain employed. Supports also allow people with disabilities to maximize their abilities, to earn money and often persons with physical disabilities can live independently or with limited assistance.

3. Community Residential

Locally operated, cost efficient, family-like out-of-home placements in the community which provide 24-hour care only for those individuals with disabilities whose needs cannot be met with in-home family supports.

Federal requirements, state statute, and best practice all drive services for individuals with disabilities to be provided in the least restrictive environment. Utilization of small, family-like community settings based on individual/family choice is consistent with these requirements.

4. Regional Center Services

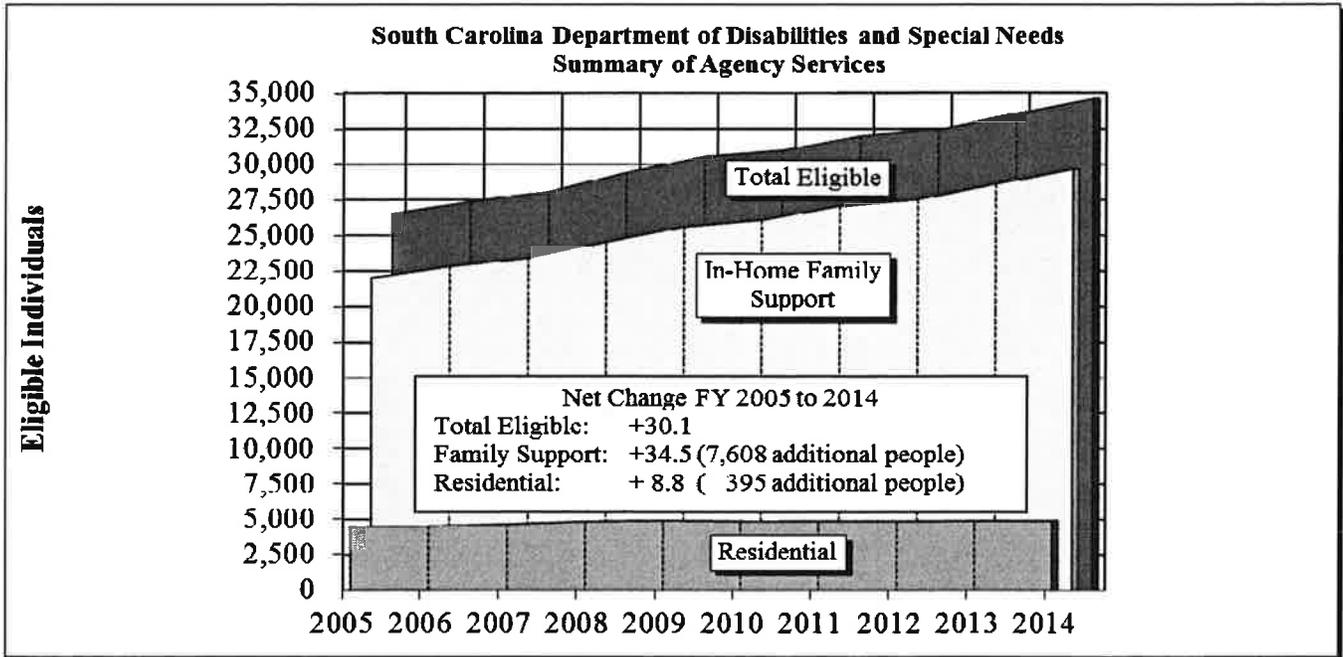
Regional Centers provide 24-hour care and supervision in state operated, specialized facilities only for those individuals unable to live in community residences due to the severity of their disabilities, complicated medical needs or most challenging behaviors.

The preferred setting for serving individuals with disabilities and special needs is at home, with their families, with necessary supports being provided. When these arrangements are not possible, smaller home-like residential services in the community are utilized. Regional Center services are reserved to ensure the State's ability to meet the essential needs of individuals with the most severely disabling conditions, complex medical needs and/or extremely challenging behaviors.

5. Administration

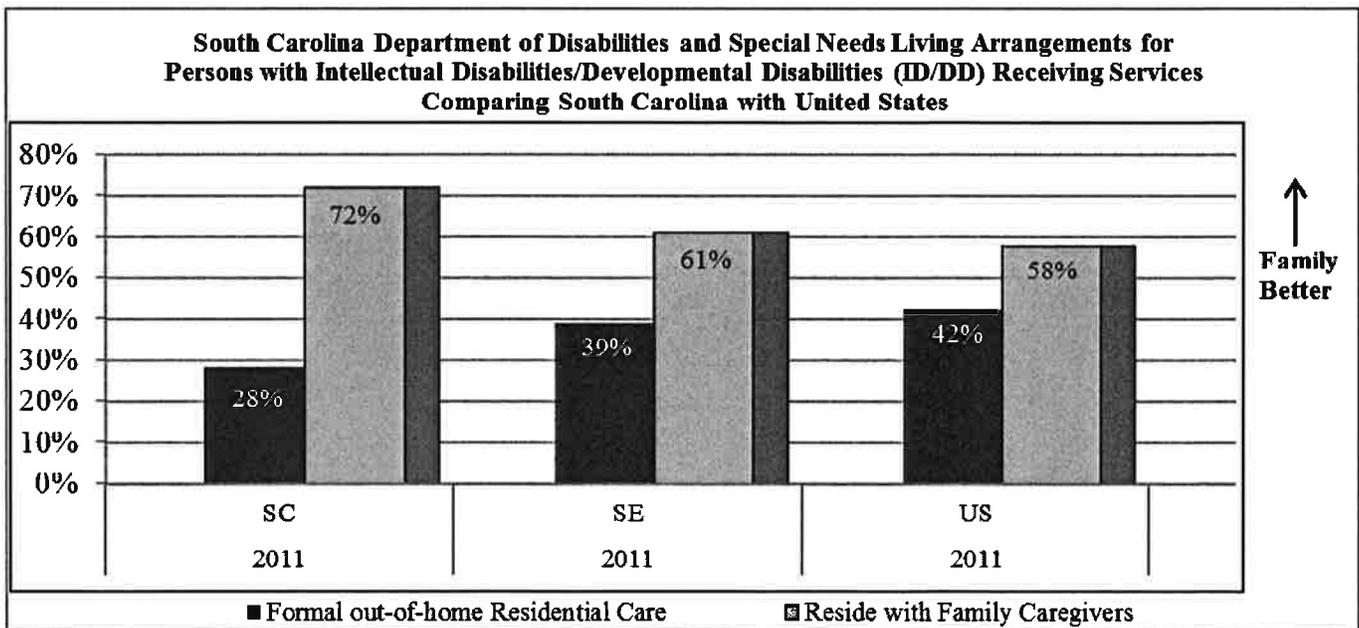
Leadership and overall direction for the agency including policy, fiscal, legal, and other support services.

KEY RESULT AREAS



DDSN policies reflect federal and state laws by supporting people in the least restrictive setting possible. In the ten year period shown, there has been a 34% growth in the use of cost-efficient family support services compared to only 8% growth in residential services, which are more expensive.

Of the approximately 34,550 individuals eligible or receiving DDSN services, 86% live at home with their families or in their own home. Of the thousands of persons with intellectual disabilities/related disabilities and autism receiving services from DDSN, 72% live with family caregivers, compared to 58% nationally. DDSN is doing a better job of helping individuals live in a family setting utilizing day services, respite, personal care, and other needed supports. Serving people with severe lifelong disabilities in their homes with family is best for the person, preferred by families and is the most cost-efficient service alternative for taxpayers.



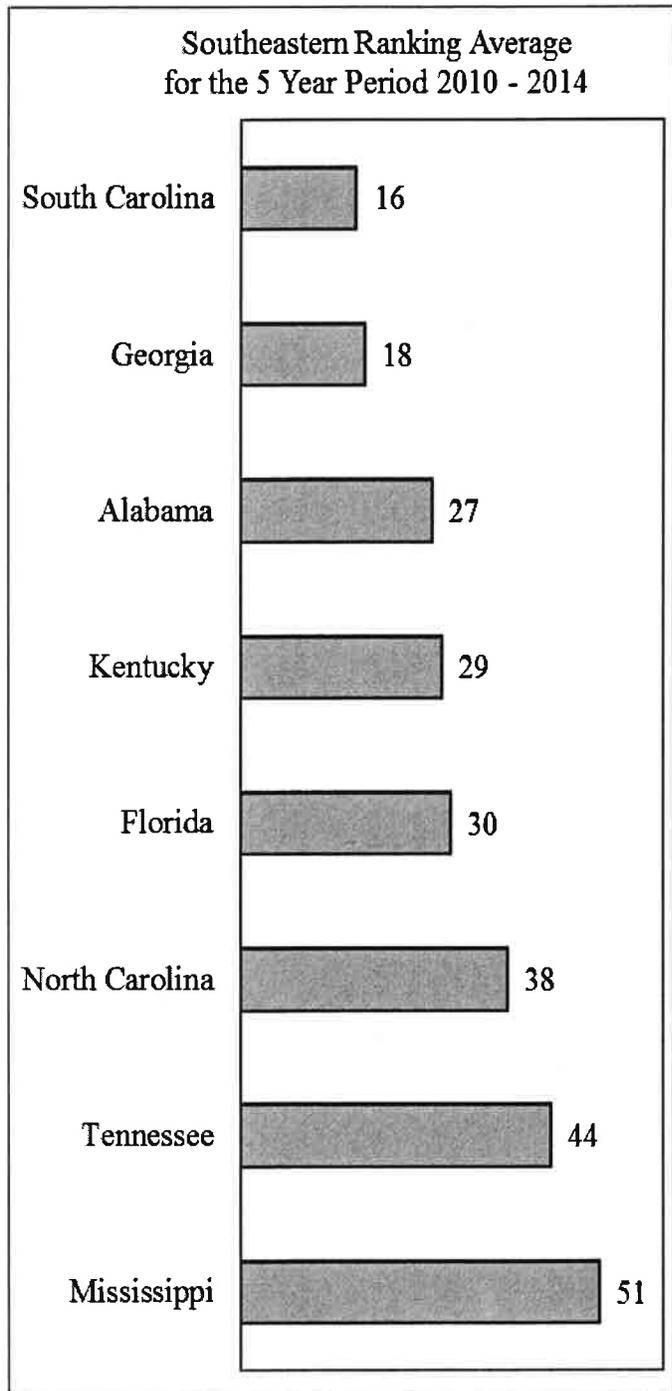
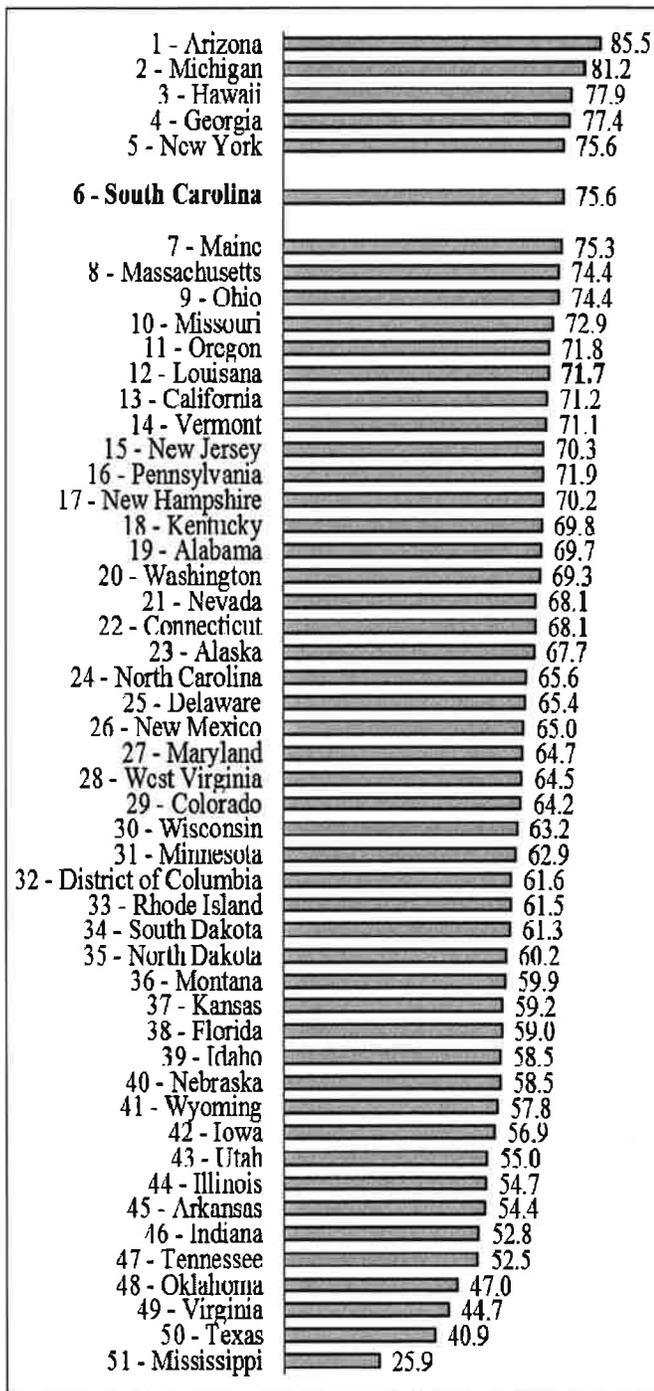
Data Source:

Chart A - Agency data provided by DDSN

National data provided by: Residential Services for Persons with Developmental Disabilities: Status and Trends through 2011 published by The University of Minnesota

Chart B - Residential Services for Persons with Developmental Disabilities: Status and Trends through 2011 published by The University of Minnesota

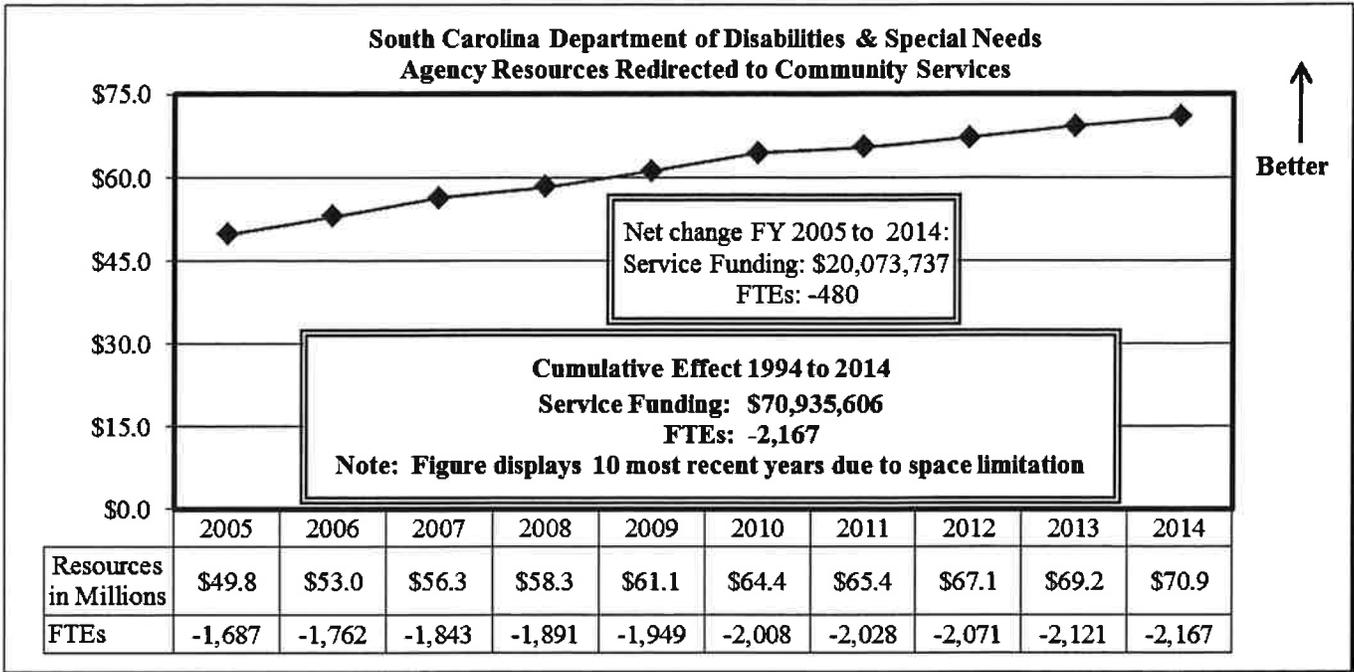
**South Carolina Department of Disabilities and Special Needs
UCP's 2014 Ranking of States' Ability to Create Community – Inclusive Lives for
Americans with Intellectual Disabilities/Related Disabilities (ID/RD)**



United Cerebral Palsy is one of the nation's leading organizations serving and advocating for 55.7 million Americans with disabilities. Their ranking is based on the states' ability to create quality, meaningful and community-inclusive lives for Americans with intellectual and developmental disabilities. South Carolina ranked 6 nationally in 2014 and ranks highly in comparison to Southeastern states and across the nation.

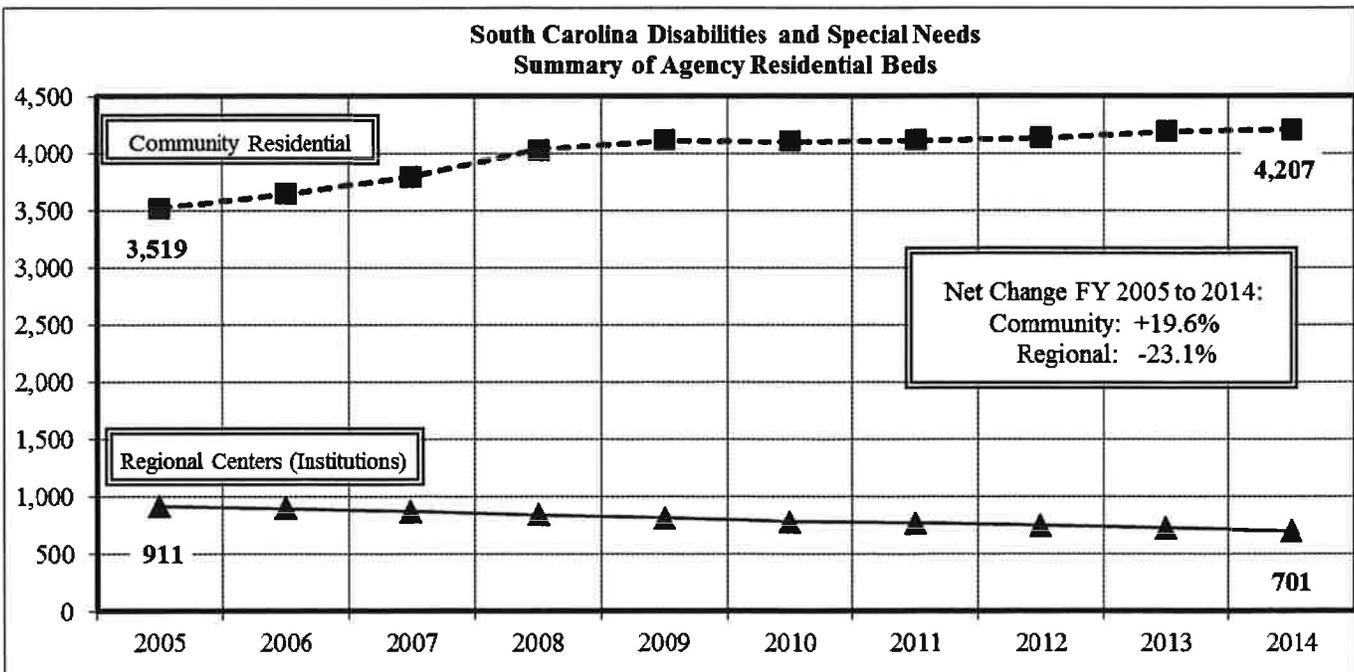
Data Source:

The Case for Inclusion - An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities: 2010, 2011, 2012, 2013 and 2014 published by United Cerebral Palsy



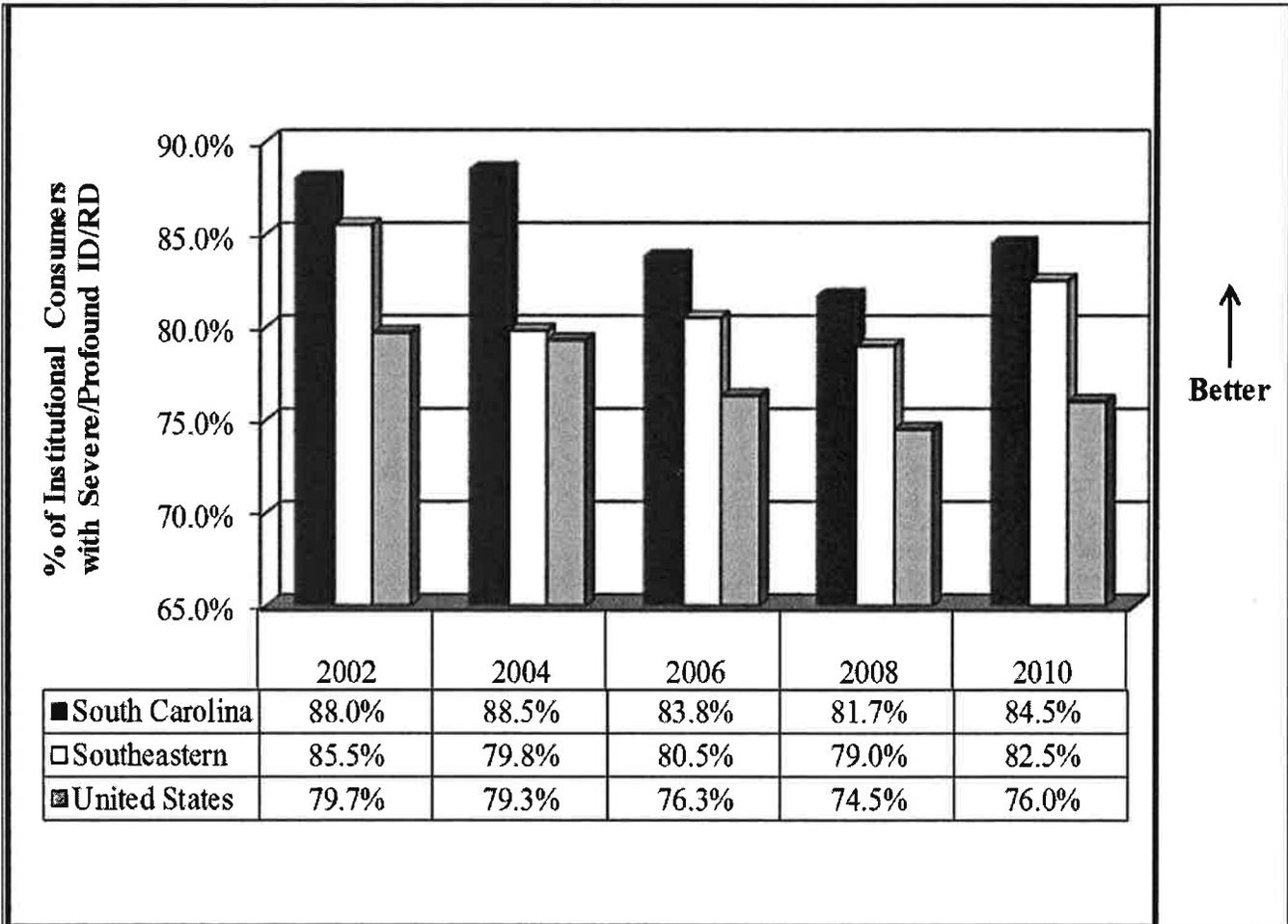
Consistent with consumer choice people move from the regional centers to community settings. When individuals choose to move, their service funding is redirected. Since implementing the “money follows the individual” (MFI) formula in fiscal year 1994, more than \$70 million has been redirected to local community services. Another significant result is the reduction of DDSN permanent workforce positions (FTEs).

While South Carolina has a twenty year history of utilizing its MFI formula, the National MFI initiative by the federal government only began in 2006 when states were given grants to help with this effort. South Carolina’s MFI effort is achieved without federal aid.



Data Source:
Agency data provided by DDSN

**South Carolina Department of Disabilities & Special Needs
 Level of Intellectual Disability of Consumers
 Residing in Regional Centers (Institutions)
 Comparing South Carolina with Southeastern and United States**

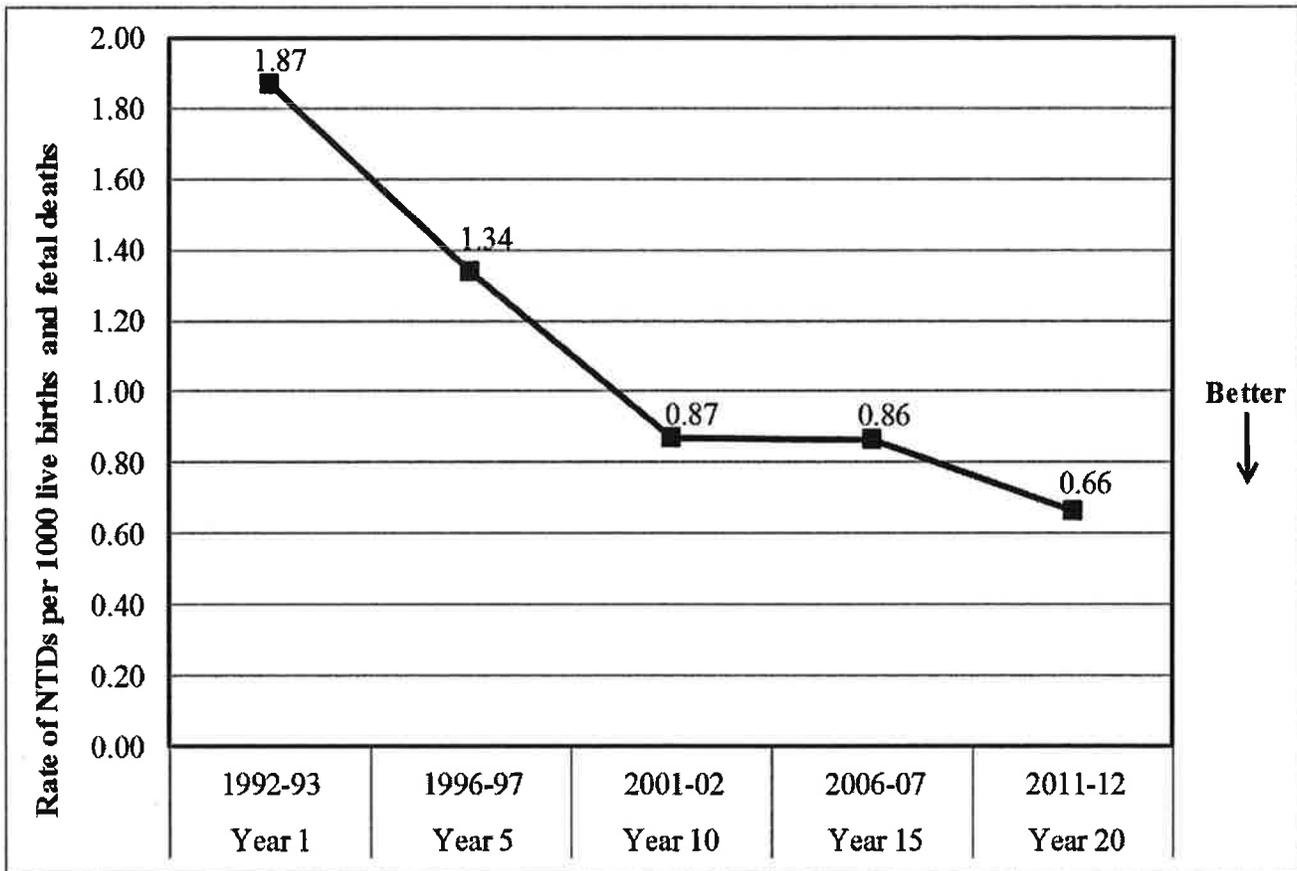


This chart compares the percentage of individuals with the most extensive disabilities who are served in DDSN's regional centers to the National and Southeastern averages. The needs of the individuals served in South Carolina's regional centers (institutions) are consistently higher than the National and Southeastern averages. DDSN uses its institutions more effectively, reserving beds only for those with the most severe levels of functioning.

Data Sources:

Residential Services for Persons with Developmental Disabilities: Status and Trends through 2000, 2002, 2004, 2006, 2008 and 2010 published by The University of Minnesota

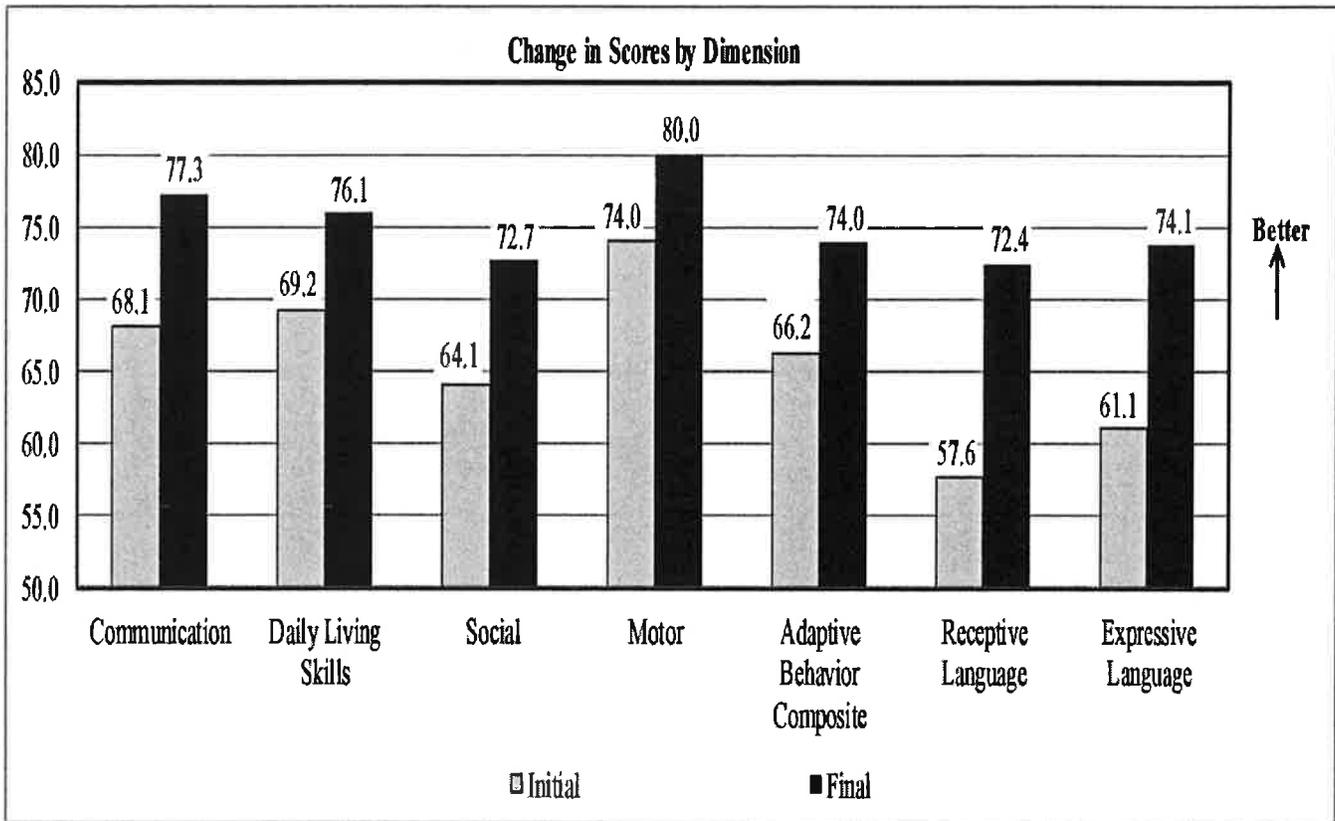
**South Carolina Department of Disabilities & Special Needs
Primary Prevention
Neural Tube Defects (NTDs) in South Carolina**



Primary prevention efforts produce the greatest return on investment of time and dollars. An example of one effort is reducing the rate of infants born with neural tube defects (NTDs) through DDSN's partnership with the Greenwood Genetic Center. The rate of NTDs per 1,000 live births in South Carolina has steadily declined over the last 20 years. The result is the prevention of 70 infants born each year with an NTD, avoiding over \$210 million in medical and disability service costs over the lifetime of these children. Twenty years ago, South Carolina's rate of NTDs was twice the National average; it is now in line with the National average.

Data Source:
Greenwood Genetic Center

**South Carolina Department of Disabilities & Special Needs
Pervasive Developmental Disorders Program**



The Pervasive Developmental Disorders program provides evidence-based individualized treatment interventions for children with autism. The program is positively changing the lives of the children and their families. DDSN requested an independent analysis from University of South Carolina (USC) to determine the outcomes of children who participate in the program. The results of the USC evaluation show children demonstrate statistically significant improvement in all seven primary measures affecting children with autism: communication, expressive and receptive language, social, adaptive behavior, daily living skills and motor skills.

Data Source:
University of South Carolina College of Social Work 2011

SC Department of Disabilities and Special Needs

Centers for Medicare/Medicaid
Services (CMS)
Home and Community Based
Services Final Rule

Dr. Beverly Buscemi, State Director

To whom does the new Final Rule apply?

- ▶ Applies across multiple populations:
 - Intellectually Disability/Related Disability (ID/RD)
 - Autism Spectrum
 - Mentally Ill
 - Elderly
 - Physically Disabled

To whom does the new Final Rule apply ?

- ▶ The ID/RD and Autism Spectrum populations are at the heart of the new rule.
- ▶ These populations will likely be the focus of follow up action from Centers for Medicaid/Medicare Services (CMS) and the Department of Justice (DOJ).

Continued Enforcement of Community Inclusion:

- ▶ Department of Justice will continue to push states through litigation towards more community inclusive systems.
- ▶ DOJ will use:
 - The Americans with Disabilities Act
 - The Olmstead Supreme Court Decision
 - New CMS HCBS Final rule

DOJ Enforcement

- ▶ In April 2014 new Rhode Island Settlement sets Employment Precedent
 - Resolves violations of the ADA for people with ID/DD/RD
 - Found that Rhode Island overly relied on segregated services to the exclusion of integrated alternatives in violation of the ADA
 - Requires Rhode Island to increase individualized supported employment and provide integrated non-work activities for time when not working

Taken from www.cms.gov

What has changed with the New Rule:

- ▶ The new rule changes the definition of community inclusive services for all Medicaid waiver services.
- ▶ Previously the rule focused on residential settings, where the person lived. Are they integrated into the community?
- ▶ The new rule looks at not only where a person lives, but where, how, and with whom they spend their day.

What does the new rule do?

- ▶ Focuses on the nature and quality of individuals' experiences
- ▶ Focuses on outcomes for a person's life
- ▶ Maximizes opportunities for individuals to have access to the benefits of community living
- ▶ Maximizes the opportunity to receive services in the most integrated setting

Taken from www.cms.gov

What does the new rule do?

- ▶ Provides some mandatory requirements for the qualities of home and community-based settings
- ▶ Defines settings presumed not to be home and community-based
- ▶ Establishes state compliance and transition requirements

Taken from www.cms.gov

How does the rule define Home and Community Settings?

- ▶ Integrated in and supports access to the greater community
- ▶ Provides opportunities to:
 - seek employment
 - work in competitive integrated settings
 - engage in community life
 - control personal resources

Taken from www.cms.gov

Examples given by CMS:

- ▶ Settings presumed NOT TO BE home and community based:
 - Institution for mental diseases (IMD)
 - Intermediate care facility for individuals with intellectual disabilities (ICF/IID)
 - Nursing facility
 - Hospital

Taken from www.cms.gov

Examples given by CMS:

- ▶ Settings presumed NOT TO BE home and community based (continued):
 - Settings in a publicly or privately-owned facility providing inpatient treatment
 - Settings on grounds of, or adjacent to, a public institution
 - Settings with the effect of isolating individuals from the broader community of individuals not receiving Medicaid HCBS

Taken from www.cms.gov

Residential settings that need to be evaluated:

- ▶ Clusters of homes in close proximity
- ▶ Homes located on the same campus or directly beside a day program or other large facility
- ▶ Supported apartment settings where the apartments are clustered together and not interspersed within a larger complex of apartments.

What about South Carolina?

- ▶ The Day Program structure that currently exists in the SC DDSN system is given by CMS as an example of a service setting that may not be considered community inclusive.

Why is the current day program structure not as community inclusive as CMS's new expectations?

- The fact that individuals go to a building to spend their entire day with other people who have a similar diagnosis as themselves.
- People do almost the same thing everyday with little choice in what they do.
- During the day, individuals rarely see people without disabilities who are not paid support staff.

What does CMS want the States to do?

- ▶ Demonstrate that individuals lead individual lives
- ▶ Individualize programming options
- ▶ Increase employment opportunities

What does this mean for the future here in SC?

- ▶ We are going to have to determine how to provide day supports in a different way than is done currently.
- ▶ We need to increase emphasis on employment opportunities for people.
- ▶ We will focus on more individualized support options for people who are not employed or only employed part time.

This DOES NOT mean that all the current day programs are closing.

- The day programs provide an essential service to families. They allow people to work or receive needed respite from caring for their loved one.
- Day programs and supports allow the individuals to socialize and engage with people outside of their families.
- SC has millions of dollars invested in the physical building structures of the community day programs that should not simply be abandoned.

This DOES mean that the way services are provided today will change.

- Services need to evolve to be more individualized and more integrated into the community.
- People need to have more say in exactly how they spend their day.
- People need to interact more with the community and not just other people with similar disabilities or paid support staff.
- More employment opportunities! By employment, we mean real jobs!
 - At least minimum wage
 - Within the greater community
 - Working along side people without disabilities
 - Greater choice, or better fit, in employment options

Opportunity is Knocking:

- ▶ This is a wonderful opportunity to improve services in South Carolina.
- ▶ The new rule is not intended to take anything away from individuals and families.
- ▶ It is intended to increase opportunities for individualized services, including “real” employment, and provide more community inclusion.

Focusing on the Mission

- ▶ DDSN will continue to focus on what is most important: meeting the needs of the people we support.
- ▶ DDSN will continue to focus on individualized supports and services and increased community participation.
- ▶ DDSN is committed to working with self-advocates, families, providers, and other stakeholders to improve services through these system changes.

SC Department of Disabilities and Special Needs

Waiting List Reduction Efforts

As of December 31, 2014

Waiting List	Number of Individuals Removed from Waiting Lists	Consumer/Family Determination		Number of Individuals Services are Pending
		Number of Individuals Enrolled in a Waiver	Number of Individuals Opted for Other Services	
Intellectual Disabilities/Related Disabilities	1,019	311	216	492
Community Supports	1,562	317	583	662
Head and Spinal Cord Injury	416	178	46	192
		806	845	
Total	2,997	1,651		1,346

Waiting List *	Number of Individuals Added Between July 1 and December 31, 2014	Number of Individuals Waiting as of December 31, 2014
Intellectual Disabilities/Related Disabilities	815	5,238
Community Supports	785	3,503
Total	1,600	8,741 **

* There is no longer a Head and Spinal Cord Injury (HASCI) waiting list.

** Approximately 30 percent of 8,741 are duplicated names.

**South Carolina Department of Disabilities and Special Needs
 FY 2015 – 2016 Budget Request In Priority Order
 Approved by Commission on September 25, 2014**

	Program Need	Budget Request for FY 2015-2016	New Services By Individual Based on FY 2016 Request
1	<p>Service funding rates must be sufficient to cover the actual cost of care as a maintenance of effort to the providers of services. If not funded, local community providers will not be able to continue to provide the same level of service or maintain quality as there are no automatic increases to cover increased operational expenses. Over the past years the costs of gasoline, food, electricity, medical professionals and other goods and services have increased significantly.</p>	\$5,000,000	Statewide
2	<p>Provide individuals with severe disabilities on waiting lists with in-home supports and services necessary to keep them at home with family and prevent unnecessary and expensive out-of-home placements. This request will provide approximately 1,650 children and adults with severe disabilities on waiting lists with in-home supports and services necessary to maximize their skill development, help them live at home with family and prevent unnecessary and expensive out-of-home placements. Supports improve developmental achievement, strengthen the family and allow family caregivers to remain employed. Provide necessary residential supports and services for 125 individuals living with aging caregivers. As of June 30, 2014, there were over 1,200 individuals with severe disabilities living with parents/caregivers age 70 and over. More than 450 of these caregivers are at least 80 years old. The requested funds will provide residential and day supports and services for 125 individuals.</p>	\$10,500,000	<p align="center">1,650 In-Home Supports 125 Out-of Home Residential</p>
3	<p>Employment initiative that represents the state's need to develop school to work transition for individuals aging out of the public school system and the need to establish job recruitment, job coach and job retention for adults with disabilities currently receiving day supports or on the waiting list. A two-prong approach, \$600,000 of this new funding will provide employment services for approximately 75 adults with an intellectual disability, autism, traumatic brain injury or spinal cord injury and \$500,000 of this funding will allow approximately 50 younger individuals to transition from public school to employment.</p>	\$1,100,000	125
4	<p>Increase and improve access to respite services critical to helping parents and other family caregivers cope with the stress of providing daily care and supervision to their loved one. DDSN needs to increase the hourly rate that is paid to respite caregivers. The hourly rate that DDSN pays for this service has been increased only once during the last twelve years, a \$1.00 increase two years ago. DDSN is requesting new state funds to further increase the hourly rate by an additional \$2.00, for a total hourly rate of \$11.30. This increase will provide better access to this valuable service by identifying more caregivers as well as attracting more providers on a statewide basis who will qualify to provide this important service.</p>	\$1,000,000	Statewide
5	<p>Provide for the increased cost of providing care and addressing nursing and supervision needs of consumers. Address workforce issues to recruit and retain quality staff that provide essential 24/7 nursing care and direct supervision and care of consumers. Quality cannot be reduced and staffing ratios must meet compliance standards and be maintained. Wage compression exists where longtime quality employees make the same wage as new hires. Loss of longtime quality employees due to wage levels not keeping up with industry benchmarks increases turnover, affects the quality of consumer care, results in higher contract cost and increases the cost of training new staff to perform these vital services.</p>	\$1,000,000	Statewide

**South Carolina Department of Disabilities and Special Needs
 FY 2015 – 2016 Budget Request in Priority Order
 Approved by Commission on September 25, 2014**

	Program Need	Budget Request for FY 2015-2016	New Services By Individual Based on FY 2016 Request
6	Boost the continued transition of individuals with very complex needs from institutional (ICF/ID) settings to less restrictive community settings, while maintaining quality care. DDSN has managed this movement within its own resources for 19 years. With increasing cost of care for those individuals leaving the regional centers, new state funds are necessary to allow individuals with the most complex medical and behavioral challenging needs to move without jeopardizing their health and safety. This request also maintains the provision of quality care at the regional centers as required. Funds requested will allow 40 individuals to move to community settings.	\$1,200,000	40
7	Increase access to post-acute rehabilitation that is specialized for traumatic brain or spinal cord injuries. This request will fund specialized rehabilitation for 8 to 10 individuals who are uninsured or underinsured.	\$500,000	8 – 10
8	Maintain and expand statewide access to genetic services provided by Greenwood Genetic Center. New state funds are required to replace resources no longer available to maintain current service levels. New funds will also be used to expand the metabolic treatment and genetic counseling services.	\$565,000	Statewide
9	Improve IT/Data Security statewide, replace obsolete systems, create a bridge to address BabyNet requirements and make system modifications related to Medicaid requirements to include data security and HIPAA compliance. The intended impact is to protect personal and healthcare data, to create efficiencies in DDSN's statewide network and to meet new demands required by external entities.	\$1,000,000	Statewide
TOTAL		\$21,865,000	

Pending Issues with Fiscal Impact for FY 2015 - 2016:

- Change in Interpretation of DDSN Eligibility for Individuals Determined Incompetent to Stand Trial
- Change to Administrative Cost as it relates to Medicaid
- Changes and Implementation of Waiver Case Management

ABLE Act Becomes Law

The US Senate voted 76 to 16 to approve the Stephen Beck, Jr. Achieving a Better Life Experience (ABLE) Act as part of a package of tax measures on December 16, 2014. The legislation, first introduced in 2006, passed the House the week before and has been signed by President Obama. Stephen Beck, Jr. was a longtime proponent of the legislation who died on the eve of its passage; Congress added his name to the bill to recognize his dedicated advocacy.

The ABLE Act would allow people with disabilities to establish special accounts where they could save money to pay for education, health care, transportation, housing and other expenses. Individuals could deposit up to \$14,000 annually under current gift-tax limitations and accrue as much as \$100,000 without risking eligibility for Social Security, Medicaid, and other government programs. Each person may only have one ABLE account and to qualify a person must have a condition that occurred before the age of 26.

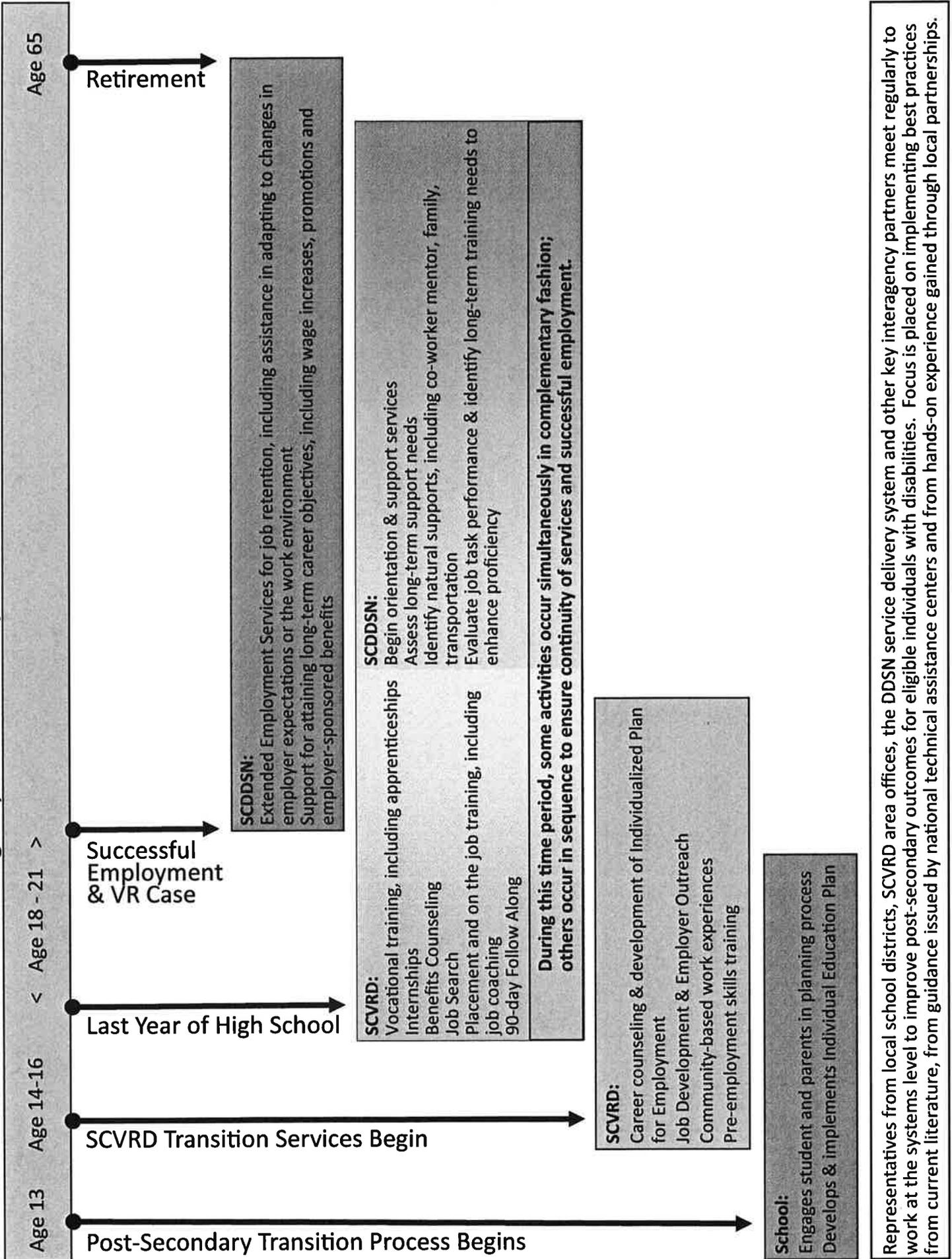
ABLE accounts follow all the requirements and regulations of a traditional 529 qualified tuition program. ABLE account funds can be spent on "Qualified Disability Expenses," which include:

- Education - including tuition for preschool thru post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education services.
- Housing - Expenses for a primary residence, including rent, purchase of a primary residence or an interest in a primary residence, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- Transportation - Expenses for transportation, including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- Employment Support - Expenses related to obtaining and maintaining employment, including job related training, assistive technology, and personal assistance supports.
- Health Prevention and Wellness: Expenses for health and wellness, including premiums for health insurance, mental health, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, nutritional management, communication services and devices, adaptive equipment, assistive technology, and personal assistance.
- Other Approved Expenses - Any other expenses which are approved by the Secretary under regulations and consistent with the purposes of this section.
- Assistive Technology and Personal Support - Expenses for assistive technology and personal support.
- Miscellaneous Expenses - Financial management and administrative services, legal fees, expenses for oversight, monitoring, or funeral and burial

SCDDSN
 Summary Of Individuals Living With Aging Caregivers
 By Residing County - As Of December 31, 2014

Region	County	Ages 55+	Ages 65+	Ages 72+	Ages 75+	Ages 80+
Coastal	Allendale	33	12	6	6	4
	Bamberg	37	23	12	10	6
	Barnwell	56	28	20	15	11
	Beaufort	132	72	39	30	14
	Berkeley	207	103	41	35	12
	Charleston	321	167	81	66	36
	Colleton	70	41	19	17	7
	Dorchester	143	62	33	23	9
	Hampton	37	19	9	9	6
	Jasper	38	21	10	10	5
	Orangeburg	263	141	86	70	47
		1,337	689	356	291	157
Midlands	Aiken	152	80	45	29	13
	Calhoun	40	26	14	12	6
	Chester	29	17	10	9	6
	Fairfield	47	21	14	9	5
	Kershaw	55	23	10	7	4
	Lancaster	59	31	21	18	9
	Lexington	156	78	47	35	21
	Newberry	59	23	12	9	3
	Richland	346	212	118	98	56
	York	123	56	26	20	11
		1,066	567	317	246	134
Pee Dee	Chesterfield	48	23	7	6	3
	Clarendon	38	26	14	11	8
	Darlington	73	23	12	8	5
	Dillon	49	19	5	3	2
	Florence	111	62	35	31	22
	Georgetown	87	48	26	18	8
	Horry	175	93	56	42	22
	Lee	17	6	2	0	0
	Marion	48	12	7	6	2
	Marlboro	64	36	17	10	2
	Sumter	111	52	25	20	11
	Williamsburg	73	38	22	17	8
			894	438	228	172
Piedmont	Abbeville	22	15	11	9	6
	Anderson	151	89	44	32	16
	Cherokee	58	29	19	15	10
	Edgefield	21	14	6	6	5
	Greenville	392	151	86	71	40
	Greenwood	91	48	21	17	9
	Laurens	103	59	29	21	9
	McCormick	16	10	9	8	4
	Oconee	82	46	22	14	7
	Pickens	112	55	35	26	14
	Saluda	28	18	10	7	3
	Spartanburg	274	141	67	52	27
	Union	55	29	17	12	10
			1,405	704	376	290
		4,702	2,398	1,277	999	544

Interagency Post-Secondary Transition Process in SC



Proposal for Augmentation of State Funding for Genetic Prevention Services through the South Carolina Department of Disabilities and Special Needs

Since its founding in 1974, the Greenwood Genetic Center has had a close relationship with the SC Department of Disabilities and Special Needs. The Center has established a statewide presence to assure that genetic evaluation and testing are available for families served by DDSN. The collaboration with DDSN has been essential in every major treatment and prevention initiative at the Greenwood Genetic Center. Families statewide have benefited from the close collaboration between GGC and DDSN.

Two examples will suffice. DDSN and GGC established the SC Birth Defects Surveillance and Prevention Program in 1992 to prevent severe birth defects of the brain and spine. This very successful program has reduced and maintained the rate of these defects by over 60% with annual savings in medical costs of over \$20 million. DDSN and GGC established the SC Metabolic Disease Treatment Program in 2002 to assure that all babies found on newborn screening to have a genetic metabolic disease receive prompt curative therapy. This very effective program has over 100 children on active treatment protocols and is estimated to save over \$40 million in medical costs annually.

In order to further enhance the genetic services for disabilities in South Carolina, we request an increase in state funding of \$1.765 million dollars for the following uses:

1. Metabolic Treatment and Genetic Counseling Programs - \$600,000. With this funding
 - a) A third metabolic treatment team (Clinical Biochemical Geneticist, dietician, neuropsychologist, clinic coordinator) will be formed and located in the GGC's Columbia office. Due to the success of the Metabolic Treatment Program, referrals have increased and resulted in insufficient time available for the two current treatment teams to manage these complex medical conditions. The number of children in the Program today far exceeds the original estimate when the program was created.
 - b) A Clinical Geneticist, genetic counselor, and clinic assistant will be placed in the Florence office which is currently served only by traveling genetic teams. This region has been underserved for years. In 2013, 437 patients from this 13 county region were served in comparison to 3,476 patients from the 16 county Upstate region and 911 patients from the 10 county Midlands region.

[We anticipate that the \$600,000 will be matchable – for some activities at 2:1 and for others at 3:1 ratio.]

2. Replacement of Autism Proviso - \$600,000. The Greenwood Genetic Center has benefited over the past 2 years from an Autism Proviso (\$500,000 each year) to further the development of a blood test for autism. This blood test based on blood cells utilization of the amino acid tryptophan for energy has been developed, is relatively inexpensive to perform, and has >90% sensitivity in young children with autism aged 1 - 10 years. The test is now being challenged with 300 additional samples from children with autism and age matched controls. As this progress in effect converts the biology of autism into a biochemical pathway, we need now to direct our energies to putting in place the strategy and infrastructure for treatment by manipulation this pathway with drugs or diet in much the same way we treat other metabolic diseases. It is anticipated that moving into the treatment phase will require an additional \$100,000 in expenses annually. With the knowledge that the current Proviso mechanism of funding cannot last, we request replacement of this funding with a state appropriation.

3. Replacement of Greenwood County Funds - \$265,000. During the past decade, Greenwood County has provided \$265,000 per year to compensate for the shortfall in state funds available for the delivery of genetic services statewide. This funding has now come to an end and we request state funding in order to maintain the genetic services that will benefit families with disabilities throughout the state.

[We anticipate that the \$265,000 in state funds to be matchable at 3:1 for the provision of services.]

4. Scientific Equipment and Instruments - \$300,000. The Greenwood Genetic Center is responsible for providing genetic services statewide for persons with disabilities. Laboratory testing is essential in providing these services. It has become critical that the laboratory equipment and instruments utilized in the genetics field be upgraded continuously in order to stay current with the latest diagnostic technology that can have a life altering effect on the children involved.

[We anticipate the \$300,000 in state funds to be matchable at 3:1 for this purpose.]

**South Carolina Department of Disabilities and Special Needs
Head and Spinal Cord Injury (HASCI) Division**

Funding for Specialized TBI/SCI Post-Acute Rehabilitation

WHAT:

SCDDSN has limited state funding to pay for medical rehabilitation for uninsured or underinsured people with traumatic brain injury (TBI) and/or spinal cord injury (SCI) in CARF accredited inpatient/outpatient TBI/SCI Rehabilitation Programs. These funds may be used subsequent to, but cannot supplant or subsidize, any other funding.

WHO:

Applicants must be legal residents of South Carolina and must be uninsured or unable to access sufficient post-acute rehabilitation through private health insurance, Medicare, Medicaid, Worker's Compensation, Veterans Administration, or any other payers. If receiving or eligible for Medicaid, applicants must be 21 years of age or older.

Applicants must have traumatic brain injury and/or spinal cord injury caused by external physical trauma and resulting in hospitalization or treatment in an emergency department or by a physician and not congenital or due to a chronic, degenerative, or progressive medical condition. (*TBI does not include anoxic or hypoxic brain damage, aneurysm, stroke, or dementia. Traumatic SCI does not include spinal column fracture, disc injury, spinal stenosis, or demyelinating disease.*)

Applicants must meet medical necessity and clinical level of care criteria. Applicants must no longer require acute care, be able to actively participate in and benefit from intensive rehabilitation, and be reasonably expected to achieve neurological recovery and/or improved functioning. Patients in coma, persistent vegetative state, or minimally responsive state are not eligible. Applicants must have viable and productive post-rehabilitation options.

WHEN:

The intent is for specialized TBI/SCI post-acute rehabilitation to begin when acute care is no longer needed and upon discharge from a hospital or after diagnosis by a physician.

WHERE:

SCDDSN currently contracts with four entities to provide specialized rehabilitation:

- Roger C. Peace Rehabilitation Hospital (Greenville, South Carolina)
Telephone: 1-800-868-8871 *TBI and SCI, Inpatient and Outpatient*
- Roper Rehabilitation Hospital (Charleston, South Carolina) *Contract Pending*
Telephone: 1-843-724-2842 *TBI Inpatient; SCI Inpatient and Outpatient*
- Carolinas Rehabilitation (Charlotte, North Carolina)
Telephone: 1-704-355-5869 *TBI and SCI, Inpatient and Outpatient*
- Rehab Without Walls (Augusta, Georgia) *Treatment teams in most of South Carolina*
Telephone: 1-866-734-2296 *TBI Home-based Outpatient*

HOW:

Trauma centers, acute care hospitals, and physicians may refer patients to the entities above. Potential applicants or their representatives may also contact these entities for information.

If interested in contracting with SCDDSN as a provider for this funding, other entities with CARF-accredited TBI/SCI Rehabilitation Programs may contact the Head and Spinal Cord Injury Division at 803/898-9789.

TBI/SCI Post-Acute Rehabilitation Funding

FY-2015: 7/1/2014 - 12/31/2014

Total Funding Authorized: **\$1,531,907** \$1,527,690 Rehabilitation; \$4,217 Equipment

Carolinas Rehab	<u>\$551,140</u>
• <i>SCI Inpatient</i>	\$273,390
• <i>SCI Outpatient</i>	\$0
• <i>SCI Equipment</i>	\$0
• <i>TBI Inpatient</i>	\$240,000
• <i>TBI Outpatient</i>	\$37,750
• <i>TBI Equipment</i>	\$0

Roger C. Peace Rehab	<u>\$897,316</u>	\$893,500 Rehabilitation; \$3,816 Equipment
• <i>SCI Inpatient</i>	\$451,200	
• <i>SCI Outpatient</i>	\$24,000	
• <i>SCI Equipment</i>	\$2,250	
• <i>TBI Inpatient</i>	\$268,800	
• <i>TBI Outpatient</i>	\$149,500	
• <i>TBI Equipment</i>	\$1,567	

Rehab Without Walls	<u>\$83,450</u>	\$83,050 Rehabilitation; \$400 Equipment
• <i>TBI Outpatient</i>	\$83,050	
• <i>TBI Equipment</i>	\$400	

Total Individuals Funded: **35** (22 TBI; 13 SCI) 100% of applications approved

Carolinas Rehab	12 (8 TBI; 4 SCI)	100% of applications approved
Roger C. Peace Rehab	20 (11 TBI; 9 SCI)	100% of applications approved
Rehab Without Walls	4 (4 TBI)	100% of applications approved

The total number of individuals funded is 1 more than the sum of individuals funded at each location as 1 individual (TBI) received inpatient at one location and outpatient at a different location.

Total Not Approved:	0 (0 TBI; 0 SCI)	0% of applications not approved
Carolinas Rehab	0 (0 TBI; 0 SCI)	0% of applications not approved
Roger C. Peace Rehab	0 (0 TBI; 0 SCI)	0% of applications not approved
Rehab Without Walls	0 (0 TBI)	0% of applications not approved

South Carolina Department of Disabilities and Special Needs Pervasive Developmental Disorder (PDD) Program September 2014

Number of Children

- Almost 1640 children have received PDD services since the program's inception
- 932 children are currently participating in the PDD Program (655 enrolled in the waiver and 277 in state-funded slots)
- 1352 children are on the waiting list; 56% are age 5 and younger; 10% (134) are age 2 and younger
- Approximately 80% of all participants are male and 20% are female
- Approximately 47% of participants are ages 3-5; 41% are ages 6-8; 12% are ages 9-10

Summary of USC's Research Analysis 2011

- Children enrolled in the PDD Program show improvement across all measure of functioning.
- Within specific domains, including Communication, Social, and Adaptive Behavior Composite (ABC), approximately 70 percent of children achieve reliable change.
- Within the domains of Daily Life Skills, Receptive Language and Expressive Language over 55 percent of children achieve reliable change.
- Both younger and older children show improvement.
- There is some evidence that the highest-performing children at baseline show less improvement through time.

These findings were promising and suggest that the PDD Program is increasing the skills and adaptive functioning of children in South Carolina. A subsequent analysis by USC is expected to be published in 2014.

Utilization of Services/Resources

- The proviso caps expenditures for each individual child at \$50,000 per year.

- The average budget DDSN authorized for each child based on the individual assessment and service plan is \$32,899 per year.
- The number of qualified providers is 19 companies with over 60 consultants; an increase of 15 consultants from last year. In addition, 4 more are awaiting Medicaid enrollment. The Program began with three companies and five consultants.
- Increased the number of children transitioning from BabyNet to the PDD Program. This prevents disruption of services. 357 children have transitioned since October 2012.
- 82% of children are Medicaid eligible

Funding

\$7.5M	Original appropriated amount
\$6.975M	Current appropriated base
\$6.006M	Actual expenditures for FY2012
	Note: DDSN had requested Medicaid’s approval of a rate increase for direct line therapists in FY2011. It was anticipated this would be approved and expended in FY2012.
\$7.232M	Actual expenditures for FY2013
	Note: Includes base and carry forward spending.
\$8.945M	Actual expenditures for FY2014
	Note: Includes \$500,000 payment to Greenwood Genetic Center per proviso.

Services

Children accepted in the Pervasive Developmental Disorder (PDD) Program receive two types of services:

- 1) Early Intensive Behavioral Intervention (EIBI) and
- 2) Case Management

EIBI services seek to develop skills of children in the areas of cognition, behavior, communication and social interaction. Case management services assist children and their families in gaining access to needed waiver and other State Medicaid plan services, as well as medical, social, educational and other services.

Program Improvements

1. Award state-funded slots to children prior to Medicaid eligibility determination. This allows the family to complete paperwork, the child to be assessed, the plan developed and the start of therapy before completion of Medicaid eligibility process. If the child is determined Medicaid eligible, funding is shifted from 100 percent state to PDD waiver.

2. Allow children younger than three years of age to apply for PDD services. Children are not enrolled in the Program until after they turn three but the ability to apply prevents time delay.
3. Implemented new process to increase utilization of authorized budget by families. This includes better education of families about the program and family responsibility. By working with families at the beginning, it can be more realistically determined how much time the family can commit to a therapy schedule.
4. More frequently monitor family utilization of services and adjust hours and corresponding budget up or down accordingly. This method is still responsive to the needs of the individual child but also prevents over-authorization of state funds.
5. Changed timing of provider payment to improve timeliness of service delivery. Previously DDSN paid provider once the assessment and service plan were completed. Now full payment is withheld until the provider completes these and trains direct-line therapists, decreasing time delay before actual services begin.
6. Began providing learning supplies and tools for families receiving EIBI to enhance their children's outcomes.
7. Collaborate with the SC Autism Society and the Developmental Disabilities Council to ensure that parents of children on the PDD waiting list have a clear understanding of what the PDD Program provides, how it works, and the family's commitment.
8. Through its contract with the University of South Carolina, DDSN graduated its third set of students in May 2014 whereby 21 professionals completed the five graduate-level courses approved by the National Board of Applied Behavior Analysis to prepare them for Board Certification. The second set graduated previously in December 2011. These increase the capacity of approved providers of DDSN's PDD program.
9. Developed and began a quality assurance review of EIBI providers to ensure high quality of services.
10. Finalized contract language in partnership with DHHS for EIBI providers that focus on the provider delivering a minimum level of the authorized intervention hours. This helps DDSN ensure budgets are closer to utilization.
11. DDSN collaborates with USC's Department of Psychology. At no charge, the Department assists DDSN and its network of EIBI providers to identify the direct-line therapists who do the majority of the in-home interventions with children and their families. DDSN is now targeting Winthrop, Francis Marion and Coastal Carolina universities to replicate USC's model.
12. DDSN collaborated with USC's College of Social Work. At no charge, the College conducted an evaluation of DDSN's PDD program focusing on results, parent

satisfaction, and family indicators that lead to better outcomes. This research and final report were completed.

13. Recruited qualified Board-Certified Behavior Analysts (BCBA) attending the National Association of Behavioral Analysts annual meeting June 2011.
14. Coordinated policy efforts with First Steps. DDSN created a smooth transition for children diagnosed with a Pervasive Developmental Disorder (PDD) receiving Early Intensive Behavioral Intervention (EIBI) services through the BabyNet program to move seamlessly into the PDD Program. As these children age out of BabyNet services at age 3, individualized EIBI services through the PDD Program continue essential interventions which improve children's skills. The result eliminated a gap in services and improved the children's outcome measures.
15. Developed and distributed the PDD Parent Handbook which is available online and hard copy in both English and Spanish. This new handbook informs parents about the Pervasive Developmental Disorder Program. It describes the specialized services and options parents have to manage and maximize their child's services, including their role in assuring the best possible outcomes are achieved. The result is increased consumer information, increased involvement of parents in their children's treatment, and increased consumer control over who provides the services.

New Initiatives

1. Submitted a formal request to DHHS for approval of a rate increase in 2011 for direct-line therapists (not provider overhead) to meet the need to recruit and retain the necessary number of individuals who work directly with the children. At least one direct-line therapist is needed for each child/family. This rate increase went into effect January 1, 2013.
2. Continue to contract with a professional recruiting company to recruit, screen, and conduct background checks on potentially qualified line therapists; the line therapists are the people who spend the most time with the child and family implementing the plan prepared by the BCBA. 480 hired since November 2011.
3. Developed and issued a third RFP for graduate level training courses to increase the number of Board Certified Behavior Analysts specifically for children participating in the Pervasive Developmental Disorder (PDD) Program and people participating in the Intellectual Disabilities/Related Disabilities Waiver and the Traumatic Brain Injury and Spinal Cord Injury Waiver. One result is a more cost-effective approach to training a core group of students than the typical university enrollment process and fees. Another result is students who complete the training commit to providing services for a minimum of two years in exchange for tuition costs. DDSN had 21 students to successfully complete the course requirements in May 2014.

4. In December 2012, DDSN requested that USC conduct another, more comprehensive study of the PDD program to determine if children participating in the program continue to show improvement across all measures of functioning [areas of adaptive functioning (eating, bathing, dressing, toileting), expressive and receptive communication (speaking, understanding what others are saying to them, and learning), socialization (playing with peers, being able to grocery shop with mom) and cognitive functioning (learning, staying on par with peers.)]

Due to the richness of available data, DDSN is uniquely positioned to advance knowledge regarding the predictors of positive outcomes associated with this program. These results will provide important additional insights for the delivery of treatment services at DDSN and for the broader understanding of treatment policy for children with Autism Spectrum Disorder.

This new study will include about 500 more children and families and will specifically aim to:

1. Evaluate the impact of PDD services on child outcomes (cognitive functioning, adaptive functioning and verbal ability)
2. Assess the child-specific factors associated with differences in outcomes (attributes of children who are most likely to experience positive outcomes)
3. Explore the relationship between the changes in adaptive behaviors through time and the actual treatment hours received (how differences in treatment hours contribute to the positive outcomes)

This study was completed in the spring 2014 and is expected to be published by the end of the year.

Outcomes

DDSN operates an evidence-based program for children with a Pervasive Developmental Disorder (PDD). The interventions are based on Early Intensive Behavior Intervention (EIBI) and focus on enhancing cognition, communication, adaptive behavior and social skills, all of which are significant issues for children with autism spectrum disorders. DDSN's model is a home-based treatment program that requires parental involvement to ensure the interventions are carried out throughout the child's day.

To date, DDSN has provided EIBI programs to more than 1,640 children ages 3 through 10 years old. The outcomes of these individualized programs are remarkable and mirror the research conducted on programs just like DDSN's program. The majority of children in the PDD program experience statistically significant gains in all areas for which children with autism have severe deficits: expressive communication, receptive communication, adaptive living and use of appropriate social skills.

Expressive communication is what children can say with words or sign language. Many children came into the program unable to speak or used very few meaningful words. Now, the majority of children uses words, sign language or picture exchange systems to communicate with peers, teachers and parents. Quotes from a survey of parents of children in the program include, "He is a different child. I would never have imagined that he would respond to a question or initiate conversation with his family or schoolmates." "Please do not take this program away from my child. She is talking! She has made so much progress, and I can't thank you enough for giving my daughter a chance to be like other children." To be able to ask for what one wants or needs or to let a parent or teacher know that they are in pain is a huge milestone for these children. By enhancing Expressive Communication, behavior challenges can be markedly decreased, allowing socially significant behaviors to improve.

Receptive communication is a child's ability to understand, process, and react or respond to the verbal and nonverbal language of others. Growth in this area affects one's ability to follow directions, answer questions, and respond to commands in emergency situations. Being able to follow directions leads to the development of expressive communication skills. Children who received EIBI services for three years showed an average gain of 15% in the area of Receptive Communication.

Daily living skills are being able to care for one's self by learning skills such as toileting, bathing and getting dressed and are extremely important skills for children with a PDD to develop so they can function as independently as possible. The average gain in this area for those who completed three years of service was seven years.

Socialization skills - Many children diagnosed with a PDD do not interact with their family members or typically developing peers in an appropriate manner. The deficiency in language and communication also make it difficult to form personal relationships and friendships. Intensive programming delivered in the child's natural environment enhances their skills and abilities in this area. Children who received three years of EIBI services saw a reliable change of 72%.