

# Senate Medical Affairs Committee

## Summary Report on the Department of Disabilities and Special Needs

### November 2017

---



The Department of Disabilities and Special Needs (DDSN) is the state agency tasked with authority over all of the state's services and programs for the treatment and training of persons with intellectual disability, related disabilities, head and spinal cord injuries. This agency is governed by a seven member Commission appointed by the Governor with the advice and consent of the Senate. The agency should transition from the current band payment to some variation of direct billing and implement a defined policy for allocating funds other than Medicaid reimbursements. DDSN should also strengthen the monitoring function by implementing person centered monitoring and unannounced inspections, greater controls on consumer finances through the use of a debit card system and a more automated inventory control process. The agency would benefit from changes to the governing model which include some form of authority controlling the interaction between DDSN and the state's Medicaid agency. The current ad hoc system of consumer advocacy should be replaced with a statutory Consumer Advisory Committee.

### *Agency at a Glance*

Established in 1963, the stated mission of the SC Department of Disabilities and Special Needs (DDSN) is to assist people with disabilities and their families through choice in meeting needs, pursuing possibilities and achieving life goals; and minimize the occurrence and reduce the severity of disabilities through prevention. DDSN is governed by a seven member commission appointed by the Governor with the advice and consent of the Senate and has approximately 1,700 state employees and 200 temporary employees. With a General Fund budget of approximately \$249 million and a total budget of \$748 million, the agency is heavily reliant on Medicaid funding to fund both the agency's internal operations and to reimburse local providers for services to consumers. DDSN utilizes local Disabilities and Special Needs (DSN) boards, private providers and agency staff and facilities to provide services to consumers with DSN boards paid through the band system and private providers paid primarily through retrospective reimbursement for services.

### *Issues*

#### *Reorganization*

The agency's reliance on Medicaid funding means that it must work cooperatively with the SC Department of Health and Human Services which is the state Medicaid agency. A lack of a single governing authority for these two entities means that if the agencies are unable to cooperate effectively there is no designated entity to mediate and disagreements regarding policy, funding or the respective roles of the two agencies.

### **Legislative Recommendations**

The SC General Assembly may wish to clarify the roles and authority of the Department of Health and Human Services and that of the Department of Disabilities and Special Needs in providing services to consumers of DDSN services and in the development and implementation of the state waivers administered by DDSN through statute and/or proviso.

The SC General Assembly may wish to establish a governing authority to mediate disputes between DHHS and DDSN on Medicaid funded programs for individuals with disabilities. This could involve transferring DDSN to the Governor's cabinet, establishing a joint legislative committee or creating an appointed independent entity to arbitrate these disputes and make recommendations to the General Assembly.

### *Commission Operations*

The Commission does not have an agreed upon coherent vision regarding the direction of the agency and the manner of governance. They also lack policies for communicating with staff and the media. The agency has pursued legislative changes without Commission input. The Commission does not utilize objective criteria in evaluating the performance of providers. Some Commissioners do not believe that they have adequate knowledge of the operations of the agency.

### **Agency Recommendations**

The agency should notify the Governor's Office in a timely manner when a Commissioner's term is expiring and inform the Governor if the Commissioner is willing to serve a subsequent term.

The Commission should debate and adopt policies that establish a governance model and adhere more closely to parliamentary procedure to facilitate debate during Commission meetings.

The Commission should adopt a policy regarding who may represent the views of the Commission and the agency when speaking to the media and formalize how individual Commissioners communicate with agency staff.

The agency should provide the opportunity for training for the Commission members.

The Commission should evaluate providers based upon compliance with agency policies and directives when assessing provider performance and measure this against a specified minimum threshold.

In addition to the existing two committees, Policy and Finance/Auditing, the Commission should establish a Legislative committee to coordinate the agency's legislative agenda and ensure that the Commission's position on all relevant legislation is accurately conveyed to the General Assembly.

### *Allocation of Resources*

The band system is unnecessarily complex and has proven to be divisive in the provider community. It is poorly understood by providers, advocates, clients and other interested parties including the state's Medicaid agency and has resulted in overpayments to local DSN boards. The agency's grant process is vaguely defined and allows for the impression of capriciousness in the practice of allocating state resources.

### **Agency Recommendations**

DDSN should adopt a process of provider reimbursement that is essentially a fee for service model or direct reimbursement which pays local DSN Boards and private providers in the same manner. This would allow the agency to concentrate on ensuring that the services being purchased are provided in compliance with agency policies and Medicaid rules. While DHHS could eventually make the actual payment for services for providers, DDSN should take the primary role in establishing reimbursement rates.

The agency should clearly articulate the process for allocating other funding. In lieu of the current process of awarding a single grant, it might be possible to establish a time limited additional reimbursement rate for consumers at new facilities to help defray the cost of building or buying a new house, supported work site etc.

## *Consumer Advocacy*

Consumers' interests are often represented by an unsystematic self-appointed ad hoc group of individuals. Many of these advocates have expressed the perception that their input has been routinely ignored by the agency.

### **Legislative Recommendation**

The General Assembly may wish to establish a Disabilities and Special Needs Consumer Advisory Committee with requirements that the members represent the various communities that DDSN serves and specify the role of this committee in formally providing input into shaping the agency's policies.

## *Agency Directives*

Many of the directives issued by the agency to the providers do not impact all programs. The titles of directives do not always reflect all of the areas impacted by a directive. Therefore, it is possible for a private provider offering a limited array of services to assume that a particular directive does not apply. This can result in the entities unintentionally failing to comply with DDSN directives.

### **Agency Recommendation**

At the beginning of directives, the agency should enumerate those programs impacted by the directive. This would allow private providers to readily determine which directives apply to their programs and reduce the possibility of these providers ignoring pertinent information.

## *Consumer Finance*

The prevalence of the use of actual cash used by consumers and managed by direct care providers significantly increases the risk of mistakes and malfeasance. Additionally, cash is more difficult to effectively monitor since it requires paper receipts for even minor expenditures.

### **Agency Recommendation**

The agency should explore adopting a policy requiring providers to utilize a specialized debit card system designed for individuals with disabilities.

## *Inventory Control*

Providers are required to use a system of inventory control that requires a narrative description of an individual's personal belongings. These descriptions can be incomplete and the accuracy varies between providers and between staff performing the inventory. Also, this system is laborious and requires monitoring of paper records.

### **Agency Recommendation**

DDSN should investigate establishing a standardized inventory system that utilizes available technology and digital pictures of the belongings that would allow electronic monitoring of consumer property inventories.

## *Financial Audits*

The agency has a policy of requiring financial audits from all providers receiving over \$250,000 in revenue from the agency regardless of the services provided. In the case of private providers that do not provide residential services, these audits are not useful to the agency and are costly to the providers.

### **Agency Recommendations**

The Commission should consider revising the current policy to exclude providers that do not provide residential services from the requirement to furnish an annual financial audit. Instead, a less expensive and onerous accountant's Report on Applying Agreed-Upon Procedures (RoAAP) should be required.

## *Conflict Free Case Management*

Case managers are often employees of the same local DSN board providing services to the consumers referred by the case manager. The Centers for Medicare and Medicaid Services has determined that this creates a conflict of interest.

### **Agency Recommendations**

DDSN should work cooperatively with DHHS to phase in a system of conflict free case management that meets the federal requirements and provides minimal disruption to consumers while maximizing consumer options.

## *Technology*

DDSN's Therap system has not been fully implemented. The information currently available through the Provider Dashboard is not easily understood and is not adequate in prescreening a local provider.

### **Agency Recommendations**

DDSN should ensure that Therap can be customized to meet the changing needs of the agency and the provider community and proceed with full implementation. The agency should continue to utilize input from the provider community, consumer groups and other stakeholders to revise the Provider Dashboard in subsequent phases to make it more useful to consumers and their families.

## *Waiting List*

Although the number of individuals and the wait times have been reduced, there is still a significant waiting list for the ID/RD and CS waivers. Due to federal requirements, the numbers reported on the waivers may not give an accurate depiction of the actual number of eligible consumers waiting for services. Providers and the agency argue that local providers should not be compelled to accept consumers that they are not able to safely serve. However, this is a unique perspective for providing state/federally funded services. Most state and local government agencies cannot turn away individuals due to an inability to provide services. Instead, they must develop the capacity to serve the person or find an alternative. This applies to public schools, prisons, and even private hospitals.

### **Legislative Recommendation**

The General Assembly may wish to change the law to require local DSN boards to specifically justify not taking a consumer needing the services they provide when funding is available.

## **Agency Recommendations**

DDSN should develop a voluntary questionnaire requesting consumers and their families to provide information about their circumstances upon entry in a waiting status.

Although the agency voiced concern about compliance with federal laws mandating that consumers be treated in the least restrictive environment, the agency should explore using excess capacity at the regional centers to temporarily provide services to some consumers on the waiting list.

## *DDSN Owned Community Properties*

To increase residential capacity in the local community, DDSN has purchased buildings or partially financed buildings for local providers. Most of these are operated by the local providers but some are operated with DDSN staff. Also, DDSN provides grants to local providers for facilities and then retains a financial interest in these facilities.

## **Agency Recommendation**

DDSN should seek to divest itself of properties within the communities by transitioning current properties to local providers. To encourage local providers to expand capacity, the agency should incentivize expansion by developing a temporary add-on reimbursement for new facilities that ties the funding to the consumers using that facility. The reverter clauses in the grant agreements should phase out over time.

## *Agency Relationship with Providers*

DDSN exhibits a paternalistic relationship towards providers generally and local DSN boards in particular. The agency tends to treat the providers as clients rather than vendors from whom they are purchasing services for the client population.

## **Agency Recommendation**

The agency should treat all providers as contractors from whom they are purchasing services rather than extensions of DDSN that have to be managed to ensure the success of the provider. This could allow the agency to concentrate on ensuring that the purchased services are being provided adequately in the manner required by the Commission's policies.

## *Monitoring/Licensing*

DDSN has contracted out most of the monitoring and licensing functions. The monitoring/inspections primarily looks at documents including consumer's records, employee's records and facilities and are scheduled in advance. Although the monitoring and inspection visits include some interaction with the consumers this emphasis has increased in FY18 as direct observation has become a separate component of monitoring and unannounced visits are implemented.

## **Agency Recommendation**

DDSN should continue to emphasize and implement a system of person centered monitoring that includes interviews and observation of the actual consumers as well as reviewing files. DDSN should also proceed with plans to conduct unscheduled visits to observe staff interaction with consumers to ensure best practices are being implemented and assess the impact of these policy changes.

## *Abuse, Neglect & Exploitation Reporting*

Law enforcement defines reports as closed regardless of what transpired if there is no prosecution. These definitions are used in the overall reporting on provider performance.

### **Agency Recommendation**

DDSN should work with law enforcement to more accurately classify the results of abuse, neglect and exploitation reports and improve the way that these are used for informing consumers and the public and make recommendations to the General Assembly for statutory changes if needed.

## *Agency Roles/Responsibilities*

Because DDSN is primarily funded through federal Medicaid funding combined with state Medicaid matching funds, it is necessary that they work cooperatively with the state's Medicaid agency. At times, this relationship has been contentious. Failure to work cooperatively on some issues has led to inefficiency in utilizing resources.

### **Legislative Recommendation**

The General Assembly may wish to adopt in statute language that clearly differentiates the responsibilities of DHHS and DDSN for the disabilities programs operated by DDSN. The General Assembly may also wish to establish an authority to mediate disputes between these agencies regarding Medicaid funded programs.

## *Responsibility/Public Perception*

An absence of specific policies and performance measures has created an atmosphere throughout the disabilities and special needs system in which the agency and the local providers pay more attention to media reporting and negative public perception than actual policy considerations. Too often the Commission, DDSN and the local providers point out that they are separate entities and portray the other bodies as having sole responsibility for systemic problems. The diffusion of responsibility can frustrate consumers and advocates and has led to the perception that the agency is not properly protecting the individuals under the care of the DDSN provider network.

### **Agency Recommendations**

DDSN should recognize when the system fails and hold the responsible entity and/or individual accountable for the failure.

After an appropriate investigation, the Commission and agency should defend the system when policies are followed and deemed adequate.

The agency should ensure that all providers are treated similarly and consumers all have equal access to appropriate services/resources as determined by their treatment team.

# Senate Medical Affairs

Senator Harvey S. Peeler Jr., Chairman



## Report on the Department of Disabilities and Special Needs

November 2017

The Department of Disabilities and Special Needs (DDSN) is the state agency tasked with authority over all of the state's services and programs for the treatment and training of persons with intellectual disability, related disabilities, head injuries, and spinal cord injuries. This agency is governed by a seven member Commission appointed by the Governor with the advice and consent of the Senate. The agency should transition from the current band system of reimbursement for services to some variation of direct billing to reimburse providers and implement a defined objective policy for allocating funds other than Medicaid reimbursements. DDSN should also strengthen the monitoring function by implementing person centered monitoring and unannounced inspections as well as greater controls on consumer finances through the use of a debit card system and a more automated inventory control process. The agency would benefit from changes to the governing model which include some form of authority controlling the interaction between DDSN and the state's Medicaid agency. The current ad hoc system of consumer advocacy could be replaced with a statutory Consumer Advisory Committee. The agency should focus on ensuring that policies are implemented and assess compliance by providers.

## ***I. Agency at a Glance***

### *Mission*

The stated mission of the SC Department of Disabilities and Special Needs (DDSN) is to assist people with disabilities and their families through choice in meeting needs, pursuing possibilities and achieving life goals; and minimize the occurrence and reduce the severity of disabilities through prevention. In practice, this mission includes a wide array of services including housing, medical care, employment assistance, supervision and assistance in daily activities that meet the level of need without infringing upon the individual autonomy of the consumer. The agency's enabling legislation specifically gives DDSN "authority over all of the state's services and programs for the treatment and training of persons with intellectual disability, related disabilities, head injuries, and spinal cord injuries". (Section 44-20-240 of the SC Code of Laws)

### *History*

Beginning in 1916, South Carolina conducted a survey of people who were considered "feeble-minded" leading to the construction of the SC State Training School for the Feeble-minded in Clinton under direction of the Board of Regents at the State Hospital. Later, the Board of Regents became the South Carolina Mental Health Commission and the school was renamed Whitten Village. Another facility, named Pineland State Training School and Hospital, was constructed near Columbia as an institution for African American people with mental retardation operated by the Mental Health Commission. The state Department of Education began operating programs for children who were considered to be "educable mentally retarded." In 1963, a third institution was constructed in Ladson. With the acquisition of a facility from the Department of Youth Services in Florence in 1973, and the purchase of a nursing home in Hartsville a final state institution (the Pee Dee Center/Saleeby Center) was created. These would become the four regional centers still operating today. That same year, Act 1127 was passed establishing the County Disability and Special Needs Boards to serve as the provider network throughout the state. The SC Department of Mental Retardation (DMR) was established in 1963 and renamed the SC Department of Disabilities and Special Needs (DDSN) in 1993 as part of restructuring in Act 181. This Act combined several programs under the newly named agency. These programs were Autism programs, formerly Head and Spinal Cord Injury Information System and the former Department of Mental Retardation. In 2002,



private for-profit and non-profit entities were given the opportunity to provide services to the DDSN client population.

## Governance

The SC Department of Disabilities and Special Needs is governed by a seven member commission appointed by the Governor with the advice and consent of the Senate. Members of the Commission must reside in each of the seven Congressional districts. Commissioners serve for a term of four years or until their successor assumes office. All of the current Commissioners were appointed by previous Governors and four members' terms have expired, however, the current Governor has submitted the name of a replacement for the Commissioner from the 2<sup>nd</sup> district whose term has expired. This candidate will not assume office until the Senate confirms the nomination. Therefore, it is anticipated that the current Commissioner will serve until the replacement is confirmed. This means that the new Commissioner will only serve a partial term until the expiration of their initial term. Several Commissioners are currently serving partial terms due to delays in the nomination and process. The statutory role of the Commission is to determine the policy and promulgate regulations governing the operation of the department and the employment of professional staff and personnel, appoint and in its discretion remove a South Carolina Director of Disabilities and Special Needs, appoint advisory committees, educate the public and state and local officials as to the need for the funding, development, and coordination of services for persons with intellectual disability, related disabilities, head injuries, and spinal cord injuries and promote their best interest. This role is described in Section 44-20-240 of the SC Code of Laws. The current composition of the Commission is as follows:

Members					
Representing	Position Title	Current Members	Appointed By	Appointed Date	Expiration Date
1st Congressional District	Chairman	Ravenel, Eva	Governor Nikki R. Haley	8/31/2012	6/30/2016
2 <sup>nd</sup> Congressional District	Member	Danielson, William O.	Governor Nikki R. Haley	6/5/2014	6/30/2016
3rd Congressional District	Member	Thompson, Vicki A	Governor Nikki R. Haley	5/19/2015	6/30/2017
4th Congressional District	Member	Fayssoux, Catherine O	Governor Nikki R. Haley	4/7/2016	6/30/2017
5th Congressional District	Vice-Chair	Lemel, Gary C.	Governor Nikki R. Haley	5/19/2015	6/30/2018
6th Congressional District	Secretary	Barnwell, Mary Ellen	Governor Nikki R. Haley	6/18/2015	6/30/2018
7th Congressional District	Member	Broughton, Samuel F. Jr.	Governor Nikki R. Haley	4/7/2016	6/30/2018

*Note:* Governor McMaster has appointed Lorri Shealy Unumb to replace the Commissioner for the second congressional district whose term has expired. The new appointee's term is from June 2016 to June 2020. This appointee is currently awaiting Senate confirmation.

## *Consumers*

Individuals that utilize the services of DDSN having severe, lifelong Intellectual Disability and/or Related Disabilities (ID/RD), Autism Spectrum Disorder, Traumatic Brain Injury (TBI), and/or Spinal Cord injury are referred to as consumers. This generic term belies the diversity of the population that is served as well as the vast range of their needs and abilities. Some consumers of DDSN services exhibit high levels of independence and self-sufficiency which, in some instances, may include living alone, working at a job in the community and having an independent social life. While at the other extreme, some consumers have limited cognition coupled with physical impairments and require significant medical care and assistance with the most basic tasks of daily living. These extremes do not capture the vast range and individuality of the consumers served by the agency.

## *Independence/Risk*

An issue that is intrinsically related to the diversity of the consumer population concerns the level of individual autonomy that consumers can and choose to assert and the personal risk associated with that freedom. This is often referred to as the *dignity of risk*. One of the stated goals of DDSN is to provide consumers as much freedom to live independently and make their own choices as is feasible. This is also required under federal and state law (Section 44-26-140 of the SC Code of Laws for 2009). Once an appropriate setting has been selected and reasonable protections established appropriate to an individual's needs, consumers have the right to make both good and bad decisions and enjoy or suffer the consequences of these decisions. This tension between personal freedom and providing adequate protection can be a source of contention between DDSN and consumer advocates and generate negative press for the agency influencing the general public's view of both DDSN and the provider community. Concern about public perception was expressed consistently by Commissioners, agency staff and the provider community. Unfortunately, this has in some instances led to a reluctance by providers to serve individuals who are deemed to represent a risk to the provider's reputation thereby creating greater obstacles to placing these people in settings where they can receive appropriate services. The agency and Commission frequently respond to articles in the media and use negative outcomes as a measure of performance rather than using objective data to determine if a provider's actions have complied with the policies of the agency. At a minimum, it is undeniable that all of the individuals served by DDSN will age, suffer the infirmities accompanying age and ultimately die like the general population. Due to the medical situation of many of these people, they will often suffer adverse health conditions more frequently and at younger ages than their cohort in the general population.

## *Waivers*

Initially, South Carolina's disability and special needs services began as an institutional program supported through state funds. However, as the federal government made Medicaid funds available, the program evolved into a primarily Medicaid funded program for eligible consumers. Later, in response to changing community values, preferences of consumers/family members, and the U.S. Supreme Court's decision in the Olmstead case, more consumers were treated at home and in the community and afforded greater choice in their treatment options.

The Olmstead decision, or Olmstead v. LC, is a significant court decision impacting the civil rights of people with disabilities and guides much of the policy concerning placement and care of individuals with disabilities. This 1999 United States Supreme Court decision was based on the Americans with Disabilities Act. The U.S. Supreme Court held that people with disabilities have a qualified right to receive state funded supports and services in the community rather than institutions when the following three part test is met:

1. the person's treatment professionals determine that community supports are appropriate;
2. the person does not object to living in the community; and

3. the provision of services in the community would be a reasonable accommodation when balanced with other similarly situated individuals with disabilities.

Prior to 1981, Medicaid funding for long term care was only allowable for those being treated in an institutional setting. In amending the Social Security Act in 1981, states were provided the option of waiving the requirement to treat people in institutional settings with Medicaid funding. States are allowed to develop programs under the waivers which determine what services will be offered and defining the funds that will be paid for the services provided. Although the SC Department of Health and Human Services is the fiscal agent for all Medicaid funds including the waivers, DDSN is the agency charged with the programmatic administration of four waiver programs targeting specific groups of consumers with disabilities and offering varying services. Each waiver has its specific objectives, list of allowable services and eligibility requirements. The services actually received vary based upon the needs of the individual as determined by that person's case manager in consultation with the consumer and family members.

- 1) Intellectual Disability and Related Disabilities (ID/RD)

The ID/RD waiver is intended to allow individuals who would otherwise have been treated in an institutional setting to receive services in the community either in a residential setting or while living with their families. Once a person has been added to the ID/RD waiting list it can take several years before they begin receiving services. Although efforts have been made to shorten the time on the waiting list it currently takes approximately 3.4 years before a person obtains a waiver slot and begins receiving services.

To be eligible for services based upon Intellectual Disability and Related Disabilities, a person must have significantly below-average intellectual functioning (a valid IQ of approximately 70 or below as determined by IQ tests for children and adults and a clinical judgment for infants) and/or concurrent deficits in adaptive functioning, meaning how well an individual copes with common life demands. The onset of these conditions must have occurred before 22 years of age. The person must also be financially eligible to receive Medicaid funding and meet the Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID) level of care requirements.

- 2) Community Supports (CS)

The Community Supports waiver seeks to provide a level of assistance that will allow individuals to remain in their own homes. This waiver essentially targets the same individuals as the ID/RD waiver but has a far more limited range of available services. However, while this waiver also has a waiting list, the average time before receiving services is less than one year. This means that for those needing fewer services than those available via the ID/RD waiver, the CS waiver can provide the needed supports to function in the community without the greater levels of care that are available via the ID/RD waiver. Receiving CS waiver services can also act as a bridge until an ID/RD slot becomes available.

- 3) Head and Spinal Cord Injury (HASCI)

Once again, as a Home and Community Based waiver program, the objective of the HASCI waiver is to provide services to people suffering from serious Head and Spinal Cord Injuries at home or in the community. To receive services related to head and spinal cord injuries, a consumer must meet all four of the following criteria:

- The condition is attributed to a traumatic brain injury, spinal cord injury or both, regardless of age of onset.

- It is anticipated to continue indefinitely without intervention, and results in substantial functional limitations in at least two areas of life activities such as self-care, receptive and expressive communication, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.
- The need exists for special interdisciplinary or generic care/treatment or other services which are lifelong or of extended duration and are individually planned or coordinated.
- Also, the condition is not associated with the process of a progressive degenerative illness or dementia, or a neurological disorder related to aging.

4) Pervasive Developmental Disorder (PDD)

This waiver seeks to treat children with Autism Spectrum Disorder as early after diagnosis as is feasible to mitigate the effects of this disorder. Children ages 3-10 qualify for services under this waiver if they have been diagnosed by a licensed diagnostician by age eight. As with other waivers, the child must meet Medicaid financial eligibility requirements and the intermediate care facility level of medical care criteria. However, the Center for Medicare and Medicaid Services (CMS) has indicated that this waiver will be terminated and beginning in FY 2018, services previously provided under this waiver will become part of the Medicaid state plan for Autism Spectrum Disorder (ASD) Services program. DHHS and DDSN had been engaged in negotiations to have DDSN continue providing the administration for the programmatic side of this service array. The DDSN Commission voted not to enter into the proposed contract until additional details were addressed to their satisfaction. At this time, it appears that DHHS has decided to pursue another avenue for continued operation of the program once the waiver has been discontinued.

### Allowable Waiver Services

Intellectual Disabilities & Related Disabilities (ID/RD) Waiver	Community Supports Waiver	Head & Spinal Cord Injuries (HASCI Waiver)	Pervasive Developmental Disorder (PDD) Waiver
Personal Care I	Personal Care I	Prevocational Services	Case Management
Personal Care II	Personal Care II	Day Habilitation	Early Intensive Behavioral Intervention
Residential Habilitation	Adult Day Health Care (ADHC)	Supported Employment	
Environmental Modifications	ADHC Nursing	Attendant Care	
Private Vehicle Modifications	ADHC Transportation	Health Education for Consumer Directed Care	
DME/Assistive Technology	Respite Care	Peer Guidance for Consumer Directed Care	
Prescription Drugs	Environmental Modifications	Residential Habilitation	
Respite Care	Specialized Medical Equipment, Supplies, Assistive Technology & Appliances	Medical Supplies, Equipment & Assistive Technology	
Audiology Services	Incontinence Supplies	Prescription Drugs	
Adult Companion Services	Private Vehicle Modifications	Respite Care	
Nursing Services	Behavior Support Services	Personal Emergency Response System (PERS)	
Adult Dental	Day Activity Services	Physical Therapy	
Adult Vision	Career Preparation Services	Occupational Therapy	
Adult Day Health Care (ADHC)	Community Services	Psychological Services	
ADHC Nursing	Employment Services	Behavior Support Services	
ADHC Transportation	Support Center Services	Nursing Services	
Adult Attendant Care	In-Home Support	Speech, Hearing & Language Services	
Behavior Support Services	Personal Emergency Response System (PERS)	Private Vehicle Modifications	
Career Preparation		Environmental Modifications	
Employment Services			
Day Activity			
Community Services			
Support Center Services			
Personal Emergency Response System (PERS)			
Pest Control			

In addition to the optional waiver services, there are numerous services available under the state plan that are available to all Medicaid eligible individuals and apply across all of the waivers. These include services such as physician services, prescribed drugs, and targeted case management. All covered Medicaid waiver services are optional and Medicaid beneficiaries cannot be compelled to accept a Medicaid covered service. States are not allowed to compel Medicaid beneficiaries to accept a service like targeted case management in order to access other services or programs such as HCBS Waivers.

*Provider Network*

The provider Network is comprised of three distinct types of providers. These are the state operated Regional Centers, the Disabilities and Special Needs (DSN) Boards and the private non-profit and for profit providers on the Qualified Provider List often referred to as QPLs.

A) Regional Centers:

Regional centers are state operated institutions staffed by DDSN employees. These were once the primary location for consumers needing residential care. With the impetus to treat consumers at home and/or in the community, the use of the regional center has declined to a total of 672 residents state-wide. Some of the buildings located on the properties are no longer in use with others still serviceable but set aside for periodic habitation as needed. The primary mission of the regional centers now is to care for consumers too medically fragile to receive treatment in a community setting or those with behavioral problems of a nature that their families and the local providers are unable to provide services. In some cases, these individuals have behavioral issues that might render them a danger to the community as well as their caregivers. Despite the assertion that these centers are intended to house only those unable to reside in the community, there are still some residents that could live in a Community Training Home or other center within the community. Often they are still living at the regional center because their family members prefer the perceived security of this setting. The regional centers are located on large tracts of land and segregated from the surrounding community. For some residents, this can actually provide more freedom since they can move around the campus without being exposed to potential dangers of the community outside the gates of the regional center.

There are four regional Centers geographically dispersed throughout the state. These are:

<u>Center</u>	<u>Location</u>	<u>Residents</u>	<u>Acreage</u>
1) Coastal Center	Summerville	152	142
2) Pee Dee/Saleeby Center	Florence/Hartsville	188	95/6
3) Midlands Center	Columbia	138	215
4) Whitten Center	Clinton	194	1,560

B) Disabilities and Special Needs Boards:

These entities established by state statute are governed by a board of directors that is appointed by the Governor based upon a recommendation from either the county council or the legislative delegation. There are forty DSN Boards located throughout the state including four entities that are treated as DSN boards despite not having a governing board appointed in the same manner as the other DSN Boards. While most DSN boards are considered

quasi-governmental institutions, there are four entities (Babcock Center, Berkeley Citizens, Charles Lea Center & Tri-Development Center) that are private non-profits that were grandfathered into the DSN Board System. Serving approximately 14,327 individuals, the DSN boards often function as the initial point of entry to the system and provide services to the largest number of consumers throughout the state. The board provider network offers the largest array of services as well. Although not all boards offer all services, virtually every home and community based service available to DDSN clients is offered by some of the boards. In parts of the state, the local DSN board may be the only option available for consumers to receive a specific service.

#### C) Private Providers on the Qualified Provider List (QPL):

South Carolina does not have a particularly robust system of private providers compared to some states that rely more on the private sector for service delivery. The vast majority of the consumers served by the private providers are receiving Early Intervention (EI) Services with 35 private providers offering solely EI services. Only sixteen (16) private providers offer residential services and eleven of these provide services to less than twenty-five individuals with one serving only 2 people. The remaining five serve populations between 44 and 189. The largest of these is SC Mentor which currently has their number of consumers restricted to the current population and cannot accept any additional consumers. In some cases, private providers help to serve a niche population. SC Mentor has accepted many consumers with behavioral issues that would be difficult to place in the community through the local DSN boards or other private providers.

### *Provider Payment System*

#### Band Payment System

Introduced in 1998, the Band Payment System generally applies only to DSN boards and is the primary mechanism for funding services provided by the local boards. These payments are distributed prospectively in anticipation of services being rendered to consumers. A capitated rate is established by DDSN based upon the setting in which a consumer receives services which averages the cost of the services for which clients in this particular setting might qualify. In certain circumstances, a larger “outlier” rate can be approved if it is determined that the cost of serving a particular consumer due to unusual circumstances exceeds a predetermined threshold amount. DDSN uses state appropriated funds to pay the DSN boards in advance and then uses the service unit reports provided by the boards to submit claims to DHHS for Medicaid reimbursement of the specific services actually rendered. Some advantages of the band payment system include the prospective nature of the payments, flexibility and predictability. A DSN board can anticipate that they will receive a set level of funding in advance based upon the assigned band of the consumers they are serving and can then provide services as appropriate. The amount spent on individual consumers does not correspond to the average payment. Instead, services are provided as needed to comply with the individual’s plan of care. This creates a disconnect between services provided and the funding received by the local DSN boards.

Many providers indicate that they do not understand the manner in which the bands are set and some believe that the Medicaid funding provided by the bands is significantly less than what would be available through a direct billing system. Although the band payment funds the provision of services, these payments cannot be directly tied to payments for services. The former director of DHHS also expressed concerns about the impenetrability of this system of reimbursement. Providers have also complained that some bands have inadequate rates discouraging providers from offering these services because the costs exceed the reimbursement. Because the band system does not apply to private providers or to some services, it creates a two tiered system of reimbursement which further differentiates between the local boards and private providers. In cases where a private provider is serving a consumer for a service that has been included in the band reimbursement, they must then invoice the DSN board for the service since they have already received the funding for this service as part of

the band payment. Having the boards act as fiscal agents for services they are not providing can create confusion within the reimbursement system.

### Band Reimbursement Rates

<u>Band</u>	<u>Service</u>	<u>Annual Rate</u>
Band A	State funded Community Supports	\$14,222
Band B	At Home - IDR Waiver	\$12,990
Band C	Supported Residential - SLP II	\$31,666
Band D	Supported Residential - SLP I	\$19,568
Band E	Supported Residential - CTH I	\$24,297
Band F	Supported Residential - Enhanced CTH I	\$38,104
Band G	Residential Low Needs	\$61,563
Band H	Residential High Needs	\$82,398
Band I	At Home - Community Supports Waiver	\$13,612
Band R	Residential Placement from Regional Centers	\$90,529

### Direct Reimbursement for Services

Private providers are generally reimbursed based upon the units of service delivered. This is similar to the methodology utilized by DHHS in paying for other Medicaid services. However, DDSN utilizes a system referred to as the Band Payment System to pay for services provided by DSN boards.

### Special Grants

These grants are awarded to provide funding to providers for a variety of purposes. Most of the funds are used for Americans with Disabilities Act (ADA) compliance, consumer safety, expansion of infrastructure capacity and to repair or replace existing facilities. Sometimes these are awarded to other entities to fund specific programs such as Autism Spectrum Disorder research at Greenwood Genetics Center etc. In awarding grants for expansion or facility repair/replacement, DDSN staff report that, when funds are available, they make a determination about statewide need and promulgate an agency solicitation inviting providers to submit an application for these funds. The agency must then rely on the providers electing to expand capacity to provide the services sought by the agency.

### *Major Programs/Activities*

Although the breadth of the activities undertaken by DDSN and the provider network to provide services is too vast to completely record within this report, some of the major activities are described below.

### *Medicaid Targeted Case Management*

Targeted Case Management is considered a linchpin in the process of matching eligible consumers with appropriate medical, social, educational, and other services. This service is provided by the local provider network. Case managers perform the following four activities:

- 1) Perform an Assessment to determine what eligible services would benefit the consumer and which of these services they desire.

- 2) Prepare a Case Management Plan to coordinate these services into an actionable plan to meet the consumer's needs.
- 3) Refer the consumers to organizations that can provide the services and assist the consumer in making the linkages between these entities and the consumer.
- 4) Monitor and follow-up to determine if the consumer is receiving the recommended services and that the services provided are meeting that consumer's needs.

### *Intake*

Intake is the process of compiling the necessary information to determine if an individual is eligible for DDSN services. Intake services are provided by DSN boards and private providers. Once the documentation has been compiled, DDSN staff make the actual determination of eligibility. Historically, this function was performed by the local DSN boards. Although, DDSN briefly assumed this role, it was recently returned to the local DSN providers.

### *Residential Settings*

Residential Care is provided to qualifying individuals who are unable to continue to reside alone or with their family in a variety of settings. The goal is to place consumers in the least restrictive environment that allows them to have their social, educational, work and physical/medical needs met. Below are the various settings for residential care.

**Regional Residential Centers** provide 24-hour care, supervision and treatment to DDSN's most fragile consumers with the greatest need for support. Regional Center care is generally recommended only when all other appropriate community services are not available. Increasingly, treatment in a Regional Center is reserved for consumers with medical conditions that cannot be treated in a community setting or behavioral issues that preclude placement in the community.

**Community Intermediate Care Facilities (ICF)** offer a community living option to those people who need maximum support for their high levels of need. Twenty-four-hour care, supervision, training, recreation and other activities are provided in this structured environment.

#### **Community Residential Care Facilities (CRCF)**

This model, like the Community Training Home-II Model, offers the opportunity to live in the community in a homelike environment under the supervision of qualified, trained caregivers. However, these facilities which can be equated to an assisted living facility, normally house more than the maximum of four residents allowed in a Community Training Home. Care and supervision are provided according to identified needs as reflected in the service plan.

**Community Training Homes (CTH I & II)** provide consumers the opportunity to live in a home like environment with no more than 4 to a home with personalized care, supervision and individualized training as needed. There are two levels of CTHs.

In a CTH-I setting, the caregivers are trained private citizens administering care in their own homes with a maximum of two consumers residing with them. The idea being that the "host family" is essentially adopting the consumer into their family.



A CTH-II is staffed by employees from the provider organization which also owns the premises. Care, supervision and skills training are provided according to individualized needs as reflected in the service plan. A maximum of four people live in each residence. These homes can be one and two family dwellings, as well as townhouses and are usually owned by the provider. While an attempt is made to provide continuity of staff so that they and the consumer can become familiar with one another turnover rates can be high.

**Supervised Living Programs (SLP I & II)** provide adults with the support needed to live in apartments, duplexes or other (single family) housing. Supervision and support services are tailored to the person's needs.

#### SLP II - Supervised Living Program II

This model is for people who need intermittent supervision and supports. They can handle most daily activities independently but may need periodic advice, support and supervision. It is typically offered in an apartment setting that has staff available on-site or in a location from which they may get to the site within 15 minutes of being called, 24 hours daily. SLP-II homes are located in one and two family dwellings, as well as townhouses,

#### SLP I - Supervised Living Program I

This model is similar to the Supervised Living II model; however, people generally require only occasional support. It is offered in an apartment setting and staff are available 24 hours a day by phone.

**Community Inclusive Residential Supports (CIRS)** This model was created to promote personal development and independence in people with disabilities by creating a customized transition from 24-hour supervised living to a semi-independent living arrangement. Participants are responsible for selecting support providers, house mates and housing. A lease support agreement connects participants with landlords and provides an extra level of support which might be needed to facilitate a positive landlord/tenant relationship.

### *Technology*

DDSN began piloting the Therap system of electronic health care records in 2012 at the Saleeby Center. The contract for state-wide implementation was awarded in 2014. Therap is a system that is specifically intended to provide electronic records and documentation in long-term care services for people with Intellectual or Developmental Disabilities. This web-based application suite should facilitate transitioning the agency's reimbursement system since it allows for electronic documentation, reporting, communication and billing by the providers. Therap data can also be used for some of the agency's administrative monitoring functions. However, full integration and implementation of Therap with all providers reporting is still in progress.

In an effort to assist consumers and their families in selecting a provider, the agency has recently begun the implementation of a Provider Dashboard. This initiative provides additional information to families that is not available in most states. The initial implementation of this web based tool relies on aggregate data collected from providers to give families data to compare providers based upon their relative scores on the metrics used. The agency offers the disclaimer that this should only be used as a tool to begin searching for a provider and should be followed-up with in person visits during which the family obtains more information. The agency has a list of suggested questions for families to pose to a prospective provider. Below is an example of the information provided on the dashboard.

<b>Residential Services</b> ★★★★★ i	
i Residential Services/Habilitation Average	98.5
i Res Licensing 3 Year Avg	89.7%
i Residential Observation Average	100.0
i Administrative Indicators Average	97.3
i Timely Initial Abuse, Neglect & Exploitation Reporting	100.0
i Timely Final Abuse, Neglect & Exploitation Reporting	100.0
i Timely Initial Critical Incident Reporting	93.0
i Timely Final Critical Incident Reporting	86.0
i Plans of Correction for Citations noted in Contract Compliance	100.0
i Plans of Correction for Citations noted in Licensing	100.0
i Provider Size	Medium
i 18 Month Cycle	Yes
i Special Certifications/Accreditation	N/A
i Compliance Enforcement Action	No
Annual reports and audits are available upon request from the provider agency	

A brief explanation of the title is provided when a user clicks on the i icon.

### *Monitoring*

Provider monitoring can be divided into three categories. These include facility licensing, quality assurance and what DDSN terms internal audit.

Facility Licensing is primarily concerned with assessing such factors as: qualifications of staff, staff ratios, fire safety, medication management, facility size and construction, storage of hazardous liquids and health maintenance. DHEC inspects and licenses all ICFs (including the regional centers), and CRCFs. For all other residential facilities operated by local providers of four beds or less, DDSN utilizes an independent contractor to carry out the inspections. The entity that has currently been awarded this contract is Alliant. DDSN contracts for these services to avoid the potential conflict of having the funding entity licensing the facilities that it funds. Beginning July of 2017, Alliant began conducting unannounced inspections as part of the licensing process.

Quality Assurance is primarily concerned with issues of contract compliance and abuse, neglect and critical incidence reporting. This function is also contracted out to Alliant. Alliant is one of the federally certified providers for this monitoring. Using a provider certified by CMS allows the agency to charge Medicaid at the 70/30 rate that is allowed for most direct services. In the past, most of the activities undertaken to demonstrate contract compliance involved collecting and evaluating data indicators. The monitoring entity does this through a process of reviewing records and announced provider inspections. Although quality assurance included residential observation this will be a separate review component beginning in FY 2018. The contracted monitoring review team will be required to physically observe twenty-five percent of a provider's residential locations and all of the day service locations annually. Unannounced visits also began July of 2017.

Internal Audit is responsible for monitoring consumer finances and consumer property inventory for all providers as well as conducting operational audits of the DSN boards.

### *Consumer Finances/Property*

Many DDSN consumers have private funds available from one or more sources. These sources include income from employment, Supplemental Social Security Income and funds provided by family members, etc. The degree of control consumers are able to exercise over their finances varies widely from one individual to the next. For those in a community residential setting, a significant portion of the individual's private money goes to the provider for the person's room and board costs. The balance of the funds (often in cash) are available for purchasing clothing and other discretionary spending such as entertainment or purchase of personal items including furniture. Since many consumers in community residential setting require assistance in managing their finances and this task usually devolves to the direct care staff there is a significant risk for abuse in this system. The policy of limiting the available cash on hand to a maximum for an individual consumer is intended to reduce the risk of misuse or malfeasance. This maximum was recently increased from \$50 to \$100. The Internal Audit Division monitors how consumer finances are managed by the providers to determine if the applicable policies have been followed. This includes checking the inventory of personal items such as furniture, electronics and appliances to ensure that they are properly accounted for and are present for the consumer's personal use. Because they only monitor a percentage of providers in any given year, providers are required to reconcile consumer finances within 30 days to increase the rate of compliance. Recently, the Commission voted to impose financial penalties on providers if they fail to implement corrective actions in a timely manner for findings related to health and safety.

The operational audits of DSN boards assess how the boards are being managed to ensure that these providers remain fiscally sound. As the primary providers for the largest number of consumers, their continued operation is considered essential. Should a DSN board or large private provider become financially unstable it might be impossible to relocate the large number of residential consumers to suitable living situations. Without emergency financial aid from the state, this could result in a crisis situation for many of these consumers.

### *Physical Facilities*

DDSN owns over 200 buildings. Approximately 55 are community residential facilities while the rest are on state property at the Regional Centers. The agency also has a financial interest in many other properties owned by local providers that DDSN provided a grant to partially fund. Should the provider dispose of these properties, a pro rata portion of the funds generated from the sale must be remitted to DDSN. Some of the properties owned by DDSN are in need of repair. Some of the buildings located at the regional centers are no longer useable and need to either be refurbished or demolished. The necessary repair and maintenance costs for buildings requires the commitment of a significant portion of the agency's limited non-Medicaid related funding. The agency has indicated a desire to divest itself of some of the community based properties but has been unable to transition them to the local providers.

### *Employment*

An important component in enabling consumers to realize a fulfilling life and being integrated into the community is the opportunity for gainful employment. DDSN advocates an "Employment First" philosophy which states that employment should be the preferred day service option for adults with disabilities. To this end, providers are expected to offer employment training, and assist consumers who desire employment with opportunities to obtain jobs commensurate with their abilities and preferences. The degree to which states' disabilities agencies encourage and provide this opportunity is one of the key measures used to gauge the effectiveness of disability

programs in a state. Some consumers are able to work independently at jobs in the community and some employers are increasingly seeing the value in hiring these individuals. Other consumers are employed on site at provider run day centers and others are transported by the provider as a group to job sites employing several consumers. The U.S. Department of Labor allows individuals with disabilities to work for sub minimum wage based upon that person's productivity compared to the average productivity of someone without a disability. In theory, this provides an incentive for a business to employ individuals with disabilities. A 2017 report by Protection and Advocacy for People with Disabilities was critical of the state's use of segregated work environments and sub-minimum wages. While DDSN had voiced agreement with the findings in the report, there are substantial barriers to placing all consumers in jobs integrated within the community. Some of these barriers include transportation, costs associated with making employment economically viable to the employer and limitations on some consumer's abilities and desire for employment.

### *Early Intervention*

Early Intervention is a family-focused, in-home service for children from birth to 6 years of age. An Early Interventionist helps families understand their child's development and gives specific training to assist the family in addressing these areas of delay. Family Training and Service Coordination are provided in accordance with an Individualized Family Service Plan (IFSP) for children birth to 3 or a Family Service Plan (FSP) for children 3 to 6 years of age. The birth to age 3 component is administered by BabyNet with DDSN transferring the funding from the agency's state appropriations for this activity. BabyNet has been transferred to the Department of Health and Human Services making them the lead agency for this program.

Children under 36 months of age whose genetic, medical or environmental history indicates that they are at a substantially greater risk than the general population for a developmental disability are eligible for services from DDSN. Eligibility may be limited to a specific period of time until a comprehensive assessment can be made regarding the presence or absence of a qualifying disability.

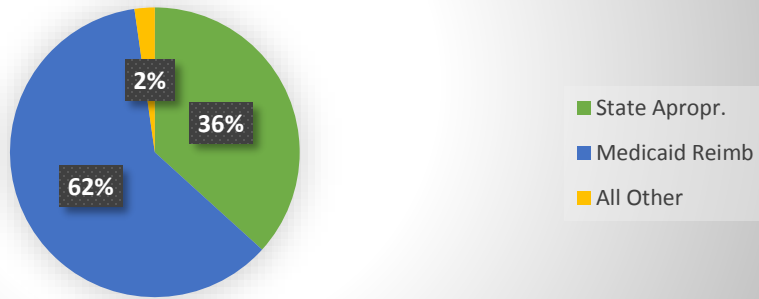
At the conclusion of the specified time period, DDSN will re-evaluate the child's eligibility status. If the diagnosis remains unclear beyond 36 months of age and the child has developmental delays greater than 20% in three or more areas of development, the child will be considered "at-risk" and will be eligible only for service coordination and family training (Early Intervention Services).

### ***Finance:***

#### *Revenues*

Of DDSN's total revenues, 62% is derived from federal Medicaid funding (\$403.4 M). Of the state appropriations to DDSN, 84% (\$204 M) is used as Medicaid matching funds. This demonstrates that the agency is heavily reliant on Medicaid to fund operations and services. This reliance on Medicaid funding brings with it many requirements to conform to CMS directives that determine many of the agency's policies.

## DDSN FY2017 Revenues



### *Expenditures*

For FY 2017, DDSN expended \$652.6 million in the following categories:

#### Community Contract Services

DDSN Board Band System Payments	\$350.5 M
Reimbursements to Private Providers	\$96.7 M
State Matching Funds Transferred to DHHS	\$86 M
Special Grants to Providers	\$6.2 M
<b>Total</b>	<b>\$539.4 M</b>

#### State Provided Services

Regional Centers	\$91.3
Regional Autism	\$3 M
<b>Total</b>	<b>\$94.3 M</b>

#### State Level Administration & Support Services

Administration	\$8.6 M
District Offices	\$1.4 M
Program Services	\$5.2 M
<b>Total</b>	<b>\$15.2 M</b>

Capital Expenditures	\$3.7 M
----------------------	---------

Community Contract Services equates to 84% of the total expenditures in 2017 with administration and support services accounting for 2% of total expenditures. At only 1% of expenditures, funding for capital expenditures relies on either a specific appropriation from the General Fund and/or non-recurring funds carried forward from other programs.

## *Staffing*

The agency has 2,122.90 FTEs authorized. Of this total, 1,462.85 are state funded FTEs. The agency averages approximately 1,700 filled FTE's and 200 temporary employees. These employees work in the regional centers, in administration at the central office in Columbia and at the two district offices. In addition to the administrative staff, some employees work directly with consumers while others provide services to the provider community. The largest single cohort of employees fall under the job title of Human Services Assistant/Specialist. These account for nearly half of the entire number of authorized and filled FTEs. These employees provide the direct care services to consumers. The agency has reported significant turnover in direct care staff both for the agency and in the provider network. Although local provider employees are not state employees, DDSN requested and received funding to increase the minimum wage (from \$10.11 to \$11.00 per hour) for direct care staff at the agency and local providers to help recruit and retain employees in these positions. The agency also removed the requirement for a high school diploma to qualify for employment as a direct care employee.

## *National Rankings*

As an independent measurement of performance, the state rankings of the United Cerebral Palsy's (UCP) Case for Inclusion provides some objective data for comparing performance between states. The data utilized is intended to measure how states are performing in the categories of:

- 1) Promoting Independence
- 2) Promoting Productivity
- 3) Keeping Families Together
- 4) Reaching Those in Need
- 5) Tracking Health, Safety & Quality of Life

In the 2016 report (which primarily utilized 2014 data) South Carolina had an overall ranking of 14. The next highest ranking among states in the Southeast was Kentucky with a rank of 19. South Carolina's neighboring states of Georgia and North Carolina ranked 23 and 38 respectively.

## ***II. Issues***

### ***A) Reorganization***

During the previous two legislative sessions, several bills were introduced to reorganize the Department of Disabilities and Special Needs. Two of these would have established the Department as a cabinet agency with the director appointed by and reporting to the Governor and devolving the current Commission into an advisory council. A third iteration would have made the Department a division within the SC Department of Health and Human Services, (a cabinet agency). (S768, S180, S600)

The various models for locating DDSN within the structure of state government have various advantages and disadvantages. In the current structure, with DDSN as an independent agency reporting to an appointed commission, DDSN has greater autonomy in deciding how best to meet the needs of the consumers it is tasked with serving. Also, with seven Commissioners from each of the Congressional districts, there is an opportunity to derive value from the diversity of experience provided by the Commissioners and to ensure that the various regions of the state are adequately represented in the agency's decision making process. However, other than geographic, there are no statutory requirements for diversity on the Commission that would lead to representation of specific interest groups including race, ethnicity or specific disabilities. Also, as appointees, the Commissioners are not directly responsible to the residents/voters in their districts. Despite being appointed by the Governor, most of the Commissioners indicated that they have had no interaction with the Governor or Executive staff subsequent to their nomination to serve on the Commission. Should DDSN become a department in the Governor's cabinet, this will allow for more responsiveness to the electorate and place a single authority over both DDSN and DHHS.

Since most of DDSN's programs are funded with Medicaid funds, DHHS has a significant role in shaping the programs administered by DDSN. In the last few years, this has become more pronounced despite DDSN's statutory "authority over all of the state's services and programs for the treatment and training of persons with intellectual disability, related disabilities, head injuries, and spinal cord injuries" (Section 44-20-240 of the SC Code of Laws) as DHHS has asserted more control over Medicaid funded programs. In the case of the DDSN waiver programs, DHHS has taken a greater role in preparing the Medicaid waiver renewal request, commissioned studies and offered critiques of the band payment system, and met separately with DDSN provider groups. This blurring of the authority between the two agencies has led to some difficulties. One result of DHHS meeting with disability provider groups has been to magnify fissures in the relationships between these entities and in some cases between the providers and DDSN. The limited input allowed of DDSN in developing the waiver renewal may have played a role in the delays in getting the renewal authorized by the Center for Medicare and Medicaid (CMS) and certainly led to the failure to designate the administering agency (DDSN) as an Organized Health Care Delivery System (OHCDS) which could potentially jeopardize funding for the programs covered by the ID/RD waiver. Discrepancies over roles has led both agencies to expend resources in contracting with outside consulting groups to bolster their positions on issues related to funding. The two agencies were unable to reach an agreement to facilitate the transition of the PDD services from a waiver to a direct Medicaid program with DDSN continuing to administer the programmatic portions.

- **Legislative Recommendations**

The General Assembly may wish to clarify the roles and authority of the Department of Health and Human Services and that of the Department of Disabilities and Special Needs in providing services to consumers of DDSN services and in the development and implementation of the state waivers administered by DDSN through statute and/or proviso.

The General Assembly may wish to establish a governing authority to mediate disputes between DHHS and DDSN on Medicaid funded programs for individuals with disabilities. This could involve transferring DDSN to the Governor's cabinet, establishing a joint legislative committee or creating an appointed independent entity to arbitrate these disputes and make recommendations to the General Assembly.

## *B) Commission Operations*

Several of the Commissioners expressed concern about their lack of knowledge of the subject matter and parliamentary procedure for participating in the Commission meetings. This can be attributed to a lack of experience in the field of disabilities and special needs and in the case of newer members the brevity of their tenure on the Commission. In some cases, Commissioners report that this has been exacerbated by truncated terms due to delays in replacing their predecessors. Commissioners without a background in managing disability programs expressed hesitancy in making decisions contradicting agency staff recommendations. This can be seen in the magnitude of staff involvement in Commission meetings and has resulted in division among the Commissioners based upon the level of governance individual Commissioners wish to exercise. The Commission does not have an agreed upon coherent vision regarding the direction of the agency and the manner of governance.

Individual Commissioners are frequently quoted expressing their views directly to the media. It is unclear if their statements reflect the views of the Commission/agency. The Commission has no policy defining who may speak publicly for the Commission and/or the agency. In interviews, Commissioners expressed the concern that voting to adopt policies regarding interactions with the press would be represented in the media as an attempt to silence critics of the agency.

The statute clearly anticipates that Commissioners will be advocates for the agency, "to...educate the public and state and local officials as to the need for the funding, development, and coordination of services..." However, some Commissioners have adopted the role of critics of the agency and service delivery model that they govern rather than accepting responsibility for the performance of the agency.

The lack of a policy regarding the manner in which Commissioners and agency staff interact results in numerous individual requests to staff that are not coordinated through either the Chairperson or the agency Director. The failure to follow parliamentary procedures has led to Commission meetings devolving into debates between staff and Commissioners with the staff becoming defensive of the agency's position. The failure to have a coordinated method of communication between the Commission and staff has often created an adversarial relationship between Commissioners and staff in which the staff defend current agency policies and resist Commissioners' attempts to institute change. In the absence of specific direction, DDSN staff have pursued legislative initiatives without the Commission's input.

When assessing incidents that occur at the provider level, the Commission debate focuses on the occurrence of specific events rather than policy compliance. Since some negative outcomes will inevitably occur despite policy compliance, this leads to using subjective criteria, general impressions and media reporting in evaluating the actions of providers.

- **Agency Recommendations**

To help prevent truncated terms, the agency should notify the Governor's Office in a timely manner when a Commissioner's term is expiring and inform the Governor if the Commissioner is willing to serve a subsequent term.



The Commission should debate and adopt policies that establish a governance model and adhere more closely to parliamentary procedure to facilitate debate during Commission meetings.

The Commission should adopt a policy regarding who may represent the views of the Commission and the agency when speaking to the media. This could be the Chairperson or someone else designated by the members when speaking for the Commission. This could be the Director or their designee when speaking for the agency. If other Commissioners are authorized to speak to the media independently, they should either adhere to the positions adopted by the Commission or be required to indicate that they are speaking as private citizens and expressing their personal views.

The Commission should debate and adopt policies formalizing how individual Commissioners communicate with agency staff.

The agency should solicit input from the Commission to determine what subject matter training would benefit the members and provide the opportunity for the members to avail themselves of training provided by the agency on a schedule established by the Commission.

The Commission should evaluate providers based upon compliance with agency policies and directives when assessing provider performance in the case of negative events concerning consumers. If the provider followed established procedures, then the Commission should determine if the policies in place are reasonable and adequate. Should the Commission determine that policies are insufficient to address the situation then the policies should be revised to ensure that policy compliance will serve to appropriately protect consumers. This evaluation practice should be applied uniformly to both local DSN boards and private providers. The policies should also establish thresholds for adequate compliance and the ramifications of failure to meet these minimum thresholds.

In addition to the existing two committees, Policy and Finance/Auditing, the Commission should establish a Legislative committee to coordinate the agency's legislative agenda and ensure that the Commission's position on all relevant legislation is accurately conveyed to the General Assembly.

### *C) Allocation of Resources*

Despite some advantages, the band system is unnecessarily complex and has proven to be divisive in the provider community. It is poorly understood by providers, advocates, clients and other interested parties including the state's Medicaid agency. Also, the agency's process for allocating other resources in the form of special grants is vaguely defined and allows for the impression of capriciousness in the practice of allocating resources. Use of the band system has resulted in overpayment to providers and necessitates retracting funds from providers. This usually occurs as part of the routine system of reconciliation. However, there have been circumstances when this overpayment was done in error. Also, when a private provider furnishes a service to a consumer for which the local DSN board already received funding through the band system, they must then invoice the DSN board for payment. Some private providers report long delays in obtaining payment for services rendered from the local boards. The manner in which the funds are distributed causes the agency to continually amend the contracts with the DSN boards. The agency and Commission expend a great deal of time and effort in the process of allocating resources to providers. The agency has also spent significant sums in contracting with a consulting firm largely in an effort to defend the continuation of the band system. Also, the dual allocation process used to fund local DSN boards and private providers tends to pit these two groups' interests against each other. The methodology for distributing funds outside of the band system and direct reimbursement is even less clear. Most of these funds are distributed in the form of special grants for a variety of purposes including expansion of services by the provider.

- **Agency Recommendations**

DDSN should adopt a process of provider reimbursement that is essentially a fee for service model or direct reimbursement which pays local DSN Boards and private providers in the same manner. This would allow the agency to concentrate on ensuring that the services being purchased are provided in compliance with agency policies and Medicaid rules. While DHHS could eventually make the actual payment for services for providers, DDSN should take the primary role in establishing reimbursement rates.

The agency should clearly articulate the process for allocating other funding. In lieu of the current process of awarding a single grant, it might be possible to establish a time limited additional reimbursement rate for consumers at new facilities to help defray the cost of building or buying a new house, supported work site, etc.

*D) Consumer Advocacy*

Although DDSN frequently consults with the provider community for input and forms advisory committees comprised of representatives from the provider community, consumer representation is largely unsystematic and led by an ad hoc group of individuals that have taken on the task of broadly representing consumers but have no official standing. This has led to a system in which providers purporting to represent consumers' interest have the greatest input into the agency's decision making process.

- **Legislative Recommendation**

The General Assembly may wish to establish a Disabilities and Special Needs Consumer Advisory Committee with requirements that the members represent the various communities that DDSN serves and specify the role of this committee in formally providing input into shaping the agency's policies.

*E) Agency Directives*

In order to ensure providers are operating in accordance with the agency's policies it is necessary that DDSN promulgate numerous directives regarding the manner in which the various programs are to be operated. Due to the complexity of the programs the agency governs, many of these directives are quite long and complex. Since DSN boards typically operate virtually every program available they can be expected to carefully examine and implement all aspects of every directive promulgated. However, some of the private providers only offer a limited array of services. This means that some of the directives do not apply to these entities. Because the titles of the directives do not always reflect all of the areas impacted by a directive, it is possible for a private provider to assume that a particular directive does not apply. This can result in the entities unintentionally failing to comply with DDSN directives.

- **Agency Recommendation**

At the beginning of directives, the agency should enumerate those programs impacted by the directive. This would allow private providers to readily determine which directives apply to their programs and reduce the possibility of these providers ignoring pertinent information.

## *F) Consumer Finance*

The prevalence of the use of actual cash used by consumers and managed by direct care providers significantly increases the risk of mistakes and malfeasance. Additionally, cash is more difficult to effectively monitor since it requires paper receipts for even minor expenditures.

- **Agency Recommendation**

The agency should explore adopting a policy requiring providers to utilize a specialized debit card system designed for individuals with disabilities. Some providers already use these tools to manage consumer finances alleviating some of the risks that handling cash entails.

## *G) Inventory Control*

Providers are required to use a system of inventory control that requires a narrative description of an individual's personal belongings. These descriptions can be incomplete and the accuracy varies between providers and between staff performing the inventory. Also, this system is laborious and requires monitoring of paper records.

- **Agency Recommendation**

DDSN should investigate establishing a standardized inventory system that utilizes available technology and digital pictures of the belongings that would allow electronic monitoring of consumer property inventories.

## *H) Financial Audits*

The agency has a policy of requiring financial audits from all providers receiving over \$250,000 in revenue from the agency regardless of the services provided. In the case of private providers that do not provide residential services, these audits are not useful to the agency and are costly to the providers. Should a private provider, that does not offer residential services, cease operations the consumers could receive services from another provider with little dislocation for the consumer.

- **Agency Recommendation**

The Commission should consider revising the current policy to exclude providers that do not provide residential services from the requirement to furnish an annual financial audit. Instead, a less expensive and onerous accountant's Report on Applying Agreed-Upon Procedures (RoAAP) should be required.

## *I) Conflict Free Case Management*

It has been the custom for the provider network to also handle case management for the consumers. It was not uncommon for the provider organization to be the employer of a consumer's case manager and be the entity that provided the services recommended in the case management plan. CMS has expressed concern that this could result in a tendency on the part of case managers to direct consumers to the services offered by their employer creating an obvious conflict of interest. Should case managers exhibit a bias to refer consumers to their employer for services, the integral role of the case manager in assisting consumers can lead to reduced choices for the consumer which violates one of the primary tenets of the Medicaid program. To resolve this, CMS has insisted that states adopt a system of "conflict free case management" in which the case managers are not employed by the same organization as the service providers for an individual. Ideally, there would be separate organizations

which provided only case management services and had an array of available providers to which they had no special relationship. In South Carolina, most of the case management services are still performed by the providers and there are insufficient options currently available to offer completely conflict free case management. Some providers have divided their operation to create a separate case management organization but this division is somewhat illusory. Because of the shortage of providers, consumers may still be left with few options for case management and other direct care services. Currently, DHHS is working with CMS to determine if a person specific system of case management would meet the definition of conflict free. Person specific conflict free case management would mean that although a provider might furnish both direct services and case management, it could not provide both types of services to a specific individual. The shortage of multiple providers in parts of the state offering services may make it difficult to achieve this goal quickly. Also, conflict free case management may have the unintended side effect of reducing consumer choice if a consumer is currently receiving both forms of service from a single provider and is happy with the services. Under conflict free case management, the consumer and their family would be restricted from selecting a single provider for both services.

- **Agency Recommendation**

DDSN should work cooperatively with DHHS to phase in a system of conflict free case management that meets the federal requirements and provides minimal disruption to consumers while maximizing consumer options. Encouraging a larger cohort of private providers to offer case management services should be part of this overall strategy.

#### *J) Technology*

DDSN is currently working on some promising improvements in their use of technology. However, at this time they are not fully implemented and/or do not completely accomplish the intended goal. Despite input from parents, advocates and providers, the information currently available through phase I of the Provider Dashboard is not easily understood and is not very helpful in preselecting a provider. Most of the measurements used are minimums that a provider could be expected to meet in order to still be eligible to provide services. For example, the private provider that the Commission has restricted from accepting any additional clients has good ratings on the dashboard system. While Therap may potentially expedite and improve provider reporting, and facilitate monitoring it is not yet fully implemented.

- **Agency Recommendation**

DDSN should ensure that Therap can be customized to meet the changing needs of the agency and the provider community and proceed with full implementation.

In implementing phase II of the Provider Dashboard, the agency should utilize additional input from the provider community, consumer groups and other stakeholders to make revisions which provide a more useful tool for consumers and their families.

#### *K) Waiting List*

Once a consumer/family determines that they wish to receive services from DDSN there can be a significant delay in actually obtaining these services. Both the ID/RD waiver and the C/S waiver have a waiting list. Although the agency has made great strides in reducing the waiting lists, the average wait time for ID/RD is 3.4 years and for C/S it is one year. There are currently in excess of 8,000 people on the two waiting lists, with the majority of these awaiting ID/RD services. While the General Assembly has provided additional funding to reduce both the wait times and the numbers in a pending status, there are barriers to accomplishing this goal. The most obvious

problem is that individuals are continually being added to the list even as others are removed. Also, the agency states that CMS requires that anyone requesting services be placed on the waiting list regardless of their qualification to receive waiver services. Some of these individuals may not qualify either medically or financially for services and while attempts are made to purge the lists some may have left the state or be deceased. This means that the numbers reported on the waiting list are not entirely useful measures. Additionally, individuals can only receive services if the infrastructure is in place to provide those services. This problem is particularly significant in the case of residential services since not only is it necessary to expand the number of trained staff, supplies etc. but residences must be available to house the consumers. All of this is further complicated by the fact that neither private providers nor local DSN Boards can be compelled to expand their services or accept a particular consumer. This can result in difficulty in placing a consumer in geographic proximity to their family if a placement cannot be found anywhere. Wariness on the part of providers about having an incident which becomes public further exacerbates this problem.

- **Legislative Recommendation**

Providers and the agency argue that local providers should not be compelled to accept consumers that they are not able to safely serve. However, this is a unique perspective for providing state/federally funded services. Most state and local government agencies cannot turn away individuals due to an inability to provide services. Instead, they must develop the capacity to serve the person or find an alternative. This applies to public schools, prisons, and even private hospitals. The General Assembly may wish to change the law to require local DSN boards to specifically justify not taking a consumer needing the services they provide when funding is available.

- **Agency Recommendations**

DDSN should develop a voluntary questionnaire requesting consumers and their families to provide information about their circumstances upon entry in a waiting status. The agency could then use this information to categorize individuals on the waiting list among those that are potentially qualified for services, those not qualified at this time, those electing to not respond and the relative urgency of need among those on the waiting list. This would better illustrate the actual status of the unmet need for services in the community.

Although the agency voiced concern about compliance with federal laws mandating that consumers be treated in the least restrictive environment, the agency should explore using excess capacity at the regional centers to temporarily provide services to some consumers on the critical needs waiting list to stabilize their circumstances until a local provider can be found to accept the individual.

#### *L) DDSN Owned Community Properties*

To increase residential capacity in the local community, DDSN has purchased buildings or partially financed buildings for local providers. Most of these are operated by the local providers but some are operated with DDSN staff. Also, DDSN provides grants to local providers for facilities and then retains a financial interest in these facilities. Accessing Housing Trust Fund financing requires a state match and sponsorship by DDSN which acts as the initial recipient of funds and then makes a subsequent award to the local providers. DDSN includes a “reverter clause” in these grant agreements which prevents local providers from ever disposing of these properties or using them for another purpose without reimbursing DDSN for the total amount of the grantor funds regardless of the physical state of the property.

- **Agency Recommendations**

DDSN should seek to divest itself of properties within the communities. In the case of state operated facilities, the agency should make any needed repairs to the property and work out an agreement with the local provider to take over the operation of these properties.

Instead of making special grants to local providers to encourage them to expand capacity, the agency should incentivize expansion by developing a temporary add-on reimbursement for new facilities that ties the funding to the consumers using that facility. This would give local providers additional funding to develop additional capacity that they would own, maintain and operate.

The agency should consider limiting the length of time that a “reverter clause” remains in effect, in essence devaluing the agency’s investment. DDSN could eventually turn over properties to the local providers once a minimum utilization timeframe had been met. This would allow providers to better manage the physical assets of the entity.

*M) Agency Relationship with Providers*

Both the staff at DDSN and providers are quick to point out that they are separate entities. Some of the local DSN boards have changed their names to emphasize this distinction. However, in many ways, this distinction is misleading. DDSN requests funding in the budget request for salary increases for direct care staff that work for the providers. DDSN also limits the fund balances of local DSN boards. In numerous instances, the agency interjects itself into the management of the providers. While some of these measures are acceptable to the provider community others are resented. The Commission has adopted a paternalistic stance towards the local DSN boards as evidenced by many of their policy decisions. Commissioners voted to have the agency absorb the local DSN boards’ portion of the cost for purchasing generators, declined to allow financial penalties to offset the cost of repeated Fire Marshall inspections due to non-compliance resulting in increased costs to the agency and recently refused to allow DDSN to recapture funds incorrectly distributed to local DSN boards via the band system for self-directed care. In each of these instances, the boards were protected by the Commission from losing funding that could have been used to provide services to consumers. The Commission’s relationship with the local DSN boards may actually work to the detriment of consumers and private providers. Not surprisingly, consumers and their families have difficulty distinguishing between the local providers and the state agency. This can make it difficult to hold anyone responsible when policies that protect consumers are not followed. The limited number of providers supplying residential services puts DDSN at a disadvantage in punishing poor performance. In the case of local DSN boards and large private providers, the agency indicates that restricting these entities from serving consumers would create disruption of services and leave many consumers without alternative placement. Therefore, instead of sanctioning these providers the agency must seek to work with them to try to improve performance and avoid the need to relocate consumers.

- **Agency Recommendation**

The agency should treat all providers as contractors from whom they are purchasing services rather than extensions of DDSN that have to be managed to ensure the success of the provider. Treating all providers equally in terms of resources and other assistance may entice more private providers to enter the market place in South Carolina. In this environment, providers would compete for clients and better managed entities would have an advantage in recruiting clients and generating a profit. This could allow the agency to concentrate on ensuring that the purchased services are being provided adequately in the manner required by the Commission’s policies.

## *N) Monitoring/licensing*

DDSN has contracted out most of the monitoring and licensing functions. Part of the reason for this has been to receive a favorable Medicaid match rate to fund these services by using a Quality Improvement Organization (QIO) certified by CMS. The monitoring and inspections performed by Alliant are scheduled in advance giving providers time to prepare. One reason given for the advance notification is that it is an intrusion on the privacy of the consumer. This has been changed to unannounced visits beginning in FY 18. The monitoring/inspections primarily looks at documents including consumer's records, employee's records and facilities. Some providers report that they are able to anticipate many aspects of the inspection and monitoring visits and make minor changes in advance to prepare for the visit. The monitoring and inspection visits include some interaction with the consumers, however, this will be a separate component beginning in FY 18. The efficacy in which services are provided to consumers not only varies between providers but also varies between the facilities run by an individual provider and can even vary from one room of a facility to another. During visits, some staff were observed interacting with consumers to encourage activity while staff in other areas were observed watching television and largely ignoring the consumers in their care.

- **Agency Recommendation**

DDSN should continue to expand and implement a system of person centered monitoring that emphasizes interviews and observation of the actual consumers as well as reviewing files. This would allow for an impression of the consumers actual well-being such as nutrition, dental care, cleanliness and help ensure the veracity of the documentation in the files.

DDSN should proceed with plans to conduct unscheduled visits to observe staff interaction with consumers to ensure best practices are being implemented.

## *O) Abuse, Neglect & Exploitation Reporting*

Abuse and neglect reports are a significant measurement used to inform consumer choice and evaluate provider performance. In reported instances of abuse, neglect and exploitation, if law enforcement determines that a prosecution is not warranted, the report is defined as closed. While a report may be unfounded, in other cases, a consumer may actually have been subjected to abuse, neglect or exploitation but law enforcement was either unable or unwilling to prosecute. The commitment with which these cases are pursued varies throughout the state. One reason for categorizing reports in a more favorable manner is a reluctance to negatively portray a local provider if there is no actual incident. The current reporting system can give a misleading depiction of the safety record at a facility.

- **Agency Recommendation**

DDSN should work with law enforcement to more accurately classify the results of abuse, neglect and exploitation reports and improve the way that these are used for informing consumers and the public and make recommendations to the General Assembly for statutory changes if needed.

## *P) Agency Roles/Responsibilities*

With the majority of DDSN's funding derived from Medicaid and state Medicaid matching funds, the distinction between the roles and responsibilities of DDSN as the disabilities program administrator and DHHS as the Medicaid fiscal agent is often unclear and has created problems in managing the programs. Previously, DDSN prepared the Medicaid waiver application/renewal documents which were then submitted through DHHS to CMS

for approval. During the tenure of a previous DHHS director, that agency began to assert greater control over this and other aspects of the waiver process. This decision stems from multiple factors including the incorrect Medicaid reimbursement rate claimed for administrative costs and a distrust of the band reimbursement system by DHHS staff. This has resulted or contributed to a number of negative consequences. Some of these include delays in renewal of the ID/RD waiver, a significant error in the waiver renewal application in which DDSN was not identified as an Organized Health Care Delivery System, the failure of the two agencies to reach agreement on facilitating a transition of the PDD waiver to a state plan funding model, exacerbated division among the providers and increased distrust by the consumers/families, advocates and the public of DDSN. This problem is compounded by the lack of a mediator with authority over both agencies since one is a cabinet agency while the other is governed by a commission.

- **Legislative Recommendations**

The General Assembly may wish to adopt in statute language that clearly differentiates the responsibilities of DHHS and DDSN for the disabilities programs operated by DDSN.

Since the two agencies have no unified governing authority under the current State Government structure the General Assembly may wish to establish an authority to mediate disputes between these agencies regarding Medicaid funded programs. This entity could have direct authority or make recommendations to the General Assembly for issue resolution as needed.

#### *Q) Responsibility/Public Perception*

An absence of specific policies and performance measures has created an atmosphere throughout the disabilities and special needs system in which the agency and the local providers pay more attention to media reporting and negative public perception than actual policy considerations. Too often, DDSN Commissioners, agency staff and local providers first concern is how a specific action or policy will be reported in the news media rather than how it will impact consumers. This has led to reticence on the part of providers to extend services to some of the neediest consumers and an unwillingness by the agency and the Commission to defend the system when the policies are properly applied but an unfortunate event still occurs. This avoidance of responsibility has led to timidity throughout the system with consumers suffering the consequences. Providers recognize that if something goes wrong DDSN may not support them even if it is through no fault of the provider and the agency staff is equally aware that they may not have the support of the Commission. Conversely, when an incident occurs in which a system failure was responsible, blame is deflected by the Commission, agency and providers.

An example of the former might be when a provider hires a direct care staff person after properly reviewing their qualifications and procuring any required background checks and then gives the individual appropriate training. Subsequently, DDSN and the contracted monitoring organization verify that this person is qualified, trained and supervised appropriately. Then, despite having followed all of the protocols, this staff person mistreats a consumer at which point they are fired and law enforcement is notified. While unfortunate, this is an example of the system working to identify a problem and correct it even though an individual acted with malice. Inevitably, the media report the abuse, the Commission blames the agency and the agency blames the provider.

Instances in which a provider and/or the agency are at fault are treated similarly. This diffusion of responsibility can frustrate consumers and advocates and has led to the perception that the agency is not properly protecting the individuals under the care of the DDSN provider network.



- **Agency Recommendation**

DDSN should recognize when the system fails and hold the responsible entity and/or individual accountable for the failure. This accountability should include not just the provider but the agency if the monitoring failed to uncover the problem and the Commission if appropriate policies were not in place to prevent the incident. Steps should then be taken to correct these failures and policies adopted to address any deficiencies.

At the same time, after an appropriate investigation, the Commission and agency should defend the system when policies are followed but an unfortunate outcome occurs due to something beyond either the agency's or the providers' reasonable ability to control.

The agency should ensure that all providers are treated similarly and consumers all have equal access to appropriate services/resources as determined by their case manager. Transitioning the agency's focus from allocation of resources to ensuring service delivery complies with agency policy should resolve some of these concerns.