

## **South Carolina Department of Disabilities and Special Needs Pervasive Developmental Disorder Program**

### **Legislative History**

During the 2006 session of the South Carolina General Assembly, parent advocates organized a grassroots initiative seeking new legislation that would require insurance companies to provide coverage for the treatment of a Pervasive Developmental Disorder (PDD). At the time the insurance companies opposed this mandate. As a compromise to both help families and hold insurance companies harmless, \$3 million in non-recurring funds was appropriated to the Department of Disabilities and Special Needs (DDSN) by the General Assembly. These one-time funds came with specific instructions to the agency, via a budget proviso, regarding the new program to be coordinated with the Department of Health and Human Services (DHHS) to provide therapies to young children diagnosed with a PDD.

During the legislative process it was acknowledged that some children were receiving some services through the BabyNet program or through their school. It was clear that this new program and new funds were not to replace or enhance these pre-existing entitlement programs. Those are to continue. The new DDSN/DHHS initiative is not an entitlement program and is to be separate from BabyNet and education services, thus not duplicating state services.

### **Funding Issues**

Data from MUSC about the prevalence of PDD in children in South Carolina along with data from DHHS and the Department of Education indicate there are about 1,100 children who may be eligible for this new PDD Program. It was estimated that the \$3 million appropriated could serve about 140-150 of these children, some through a new Medicaid waiver and some with 100% State funds. Every effort has been made to obtain Medicaid eligibility for each child. This helps more children receive the services they need. However, a child does not have to qualify for Medicaid to get this service.

It was clear that all interested families and their children who met the required criteria for participation in the program could not be served. Therefore, in addition to requesting the one-time \$3 million appropriated be funded with recurring dollars, DDSN requested an additional \$4.5 million in its 2007-2008 budget request to serve an additional 220 children with PDD. It was estimated that a total of \$7.5 million could serve approximately 370, or about one-third of the total 1,100 children. This funding was approved by the General Assembly and the Governor for FY 2007-2008.

### **Service Development**

Children accepted in the Pervasive Developmental Disorder (PDD) Program receive two types of services: 1) early intensive behavioral intervention (EIBI) and 2) case management.

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

The initial \$3 million one-time service funds were not available to DDSN until December 2006. Over the summer and early fall of 2006, DDSN and DHHS completed a Medicaid waiver application, held a public meeting attended by over 50 interested parents, advocates and providers, and met with Centers for Medicare and Medicaid Services (CMS) officials. The final version of the application was submitted for federal review and comment on September 28, 2006, which usually takes up to 90 days. The federal government (CMS) approved South Carolina's PDD waiver effective January 1, 2007, without any changes. This was only the second waiver of this type approved in the nation.

Meanwhile, DDSN developed information and referral strategies and application procedures, including the establishment of a toll-free number. Information was shared with families and providers, sent to the media and published on the Internet. Parents or families interested in applying for services were encouraged to gather the necessary information and documentation to prevent delay of their child's application process.

### **Application Response and Process**

The initial round of applications was accepted from 8:30 A.M. Thursday, December 28, 2006, until 5:00 P.M. Friday, January 12, 2007. Applications received during this time period were considered by DDSN to be received at the same time. This was the fairest way for all families to start on a level playing field since the funding was not enough to serve every child. Using this process meant it did not matter where someone lived, if they were privately paying for the service or if they were receiving DDSN services.

On Wednesday, January 17, 2007, applications were randomly selected one at a time and numbered in the order they were drawn. This process continued until all of the applications received by 5:00 P.M. Friday, January 12, 2007, had a number. Applications received or postmarked after January 12, 2007, are added on a first-come, first-served basis.

About 390 applicants were received in the first round. DDSN expected that only about 140 to 150 children would be able to participate in the new program at this time based on available funding.

Once numbered, the applications go through the next step of the process in numerical order. This is the Intermediate Care Facility/Mental Retardation (ICF/MR) level of care determination. This process is required by Medicaid to confirm the child's diagnosis of PDD and determine whether or not the child's services can be provided through the PDD Medicaid waiver. Diagnostic evaluations for this process are only repeated if they do not meet a quality standard. DDSN took as many initial applications as possible through the ICF/MR level of care determination until all slots were filled. The remaining applicants were placed on a waiting list.

After a child is accepted into the program, the family chooses an Applied Behavior Analysis (ABA) Consultant from a list of DDSN qualified Consultants who are specially trained in Pervasive Developmental Disorders. The Consultant assesses the child, evaluating his/her individual needs. If the child is already receiving EIBI services, the Consultant evaluates the existing treatment plan and its effectiveness. If the child has no preexisting plan, a more detailed assessment is required.

The Consultant forwards his/her evaluations to DDSN. A treatment plan is approved authorizing the number of hours of EIBI the child will receive based on individual needs. The Consultant

then coordinates the implementation of the treatment plan. Trained individuals work with the child one-on-one in the child's home. During this year, DDSN developed a service manual for all providers to use.

### **Results**

As of June 30, 2007, a total of 140 children have been accepted in the Pervasive Developmental Disorder Program. Of these 140 children, 89 meet Medicaid eligibility criteria, 33 are pending Medicaid eligibility, and 18 (13 percent) are participating with 100 percent state funds. There are 382 children on the waiting list. The new \$4.5 million appropriated for FY 2008 will serve approximately 350 children on this waiting list.

The original estimate was to serve only 220 children from the waiting list. However, it was originally estimated that only 60 percent of the children would be Medicaid eligible versus the current rate of 87 percent. In addition, the original cost estimate was \$35,200 per child versus the current average of \$38,783. These changes in current numbers will result in more children being served.

Of the current PDD Program participants and applicants, 84% are male and 16% are female. Ninety-five percent (95%) of the children have a diagnosis of autism and 5% have other PDD diagnoses. Children ages 3 through 6 comprise 67% of participants and children age 7 through 10 comprise 33%.

The age breakdown is as follows:

<u>Age</u>	<u>Percent</u>	<u>Total</u>
3	18%	
4	21%	
5	18%	
6	10%	67%
7	13%	
8	10%	
9	7%	
10	3%	33%
		100%

The average budget per child is \$38,783. This equates to an average of 29 hours per week of applied behavior analysis therapy for these children. The number of hours provided each child is determined by the individual's initial assessment. This in-depth assessment consists of a battery of four standardized tests. The provider monitors the actual delivery of therapy performed by trained staff. After 12 months of prescribed therapy, the battery of standardized tests will be repeated to assess the progress made and the individual's new level of service need.

In the summer of 2006, DDSN set up meetings to recruit EIBI providers. This first effort generated 5 qualified providers. To date DDSN has recruited 13 qualified early intensive behavior intervention providers. The effort to recruit additional providers is ongoing, both in-state and outside of South Carolina, to offer families a choice of providers and to ensure a sufficient supply of providers to meet the service demand. To further these goals, DDSN is also developing a fiscal intermediary service for families who choose to hire and coordinate their own therapists who would work with a qualified EIBI provider.

Due to the enormous task of getting approval of a new Medicaid waiver, creating eligibility criteria, creating program and service criteria, determining and processing each child's eligibility, and recruiting and educating providers, among other activities, actual therapy services began the last quarter of the fiscal year. Therefore DDSN is unable to report on the developmental progress of program participants at this time. It is expected that results will be measurable after actual service delivery is in process for at least one year.

**FY 2008**

A total of \$7.5 million has been appropriated to DDSN for the PDD Program. In order to prepare for the next year, during the FY 2008 budget process, DDSN requested DHHS submit an amendment to the Centers for Medicare and Medicaid (CMS) to increase the cap on the number of children who can be served through the new PDD Medicaid waiver up to 550 individuals. On August 1, 2007, DHHS received notice from CMS that the amendment was approved. DDSN has made all the necessary preparations to ensure the next 110 children on the waiting list have adequate records in the file to assure timely enrollment in the PDD Program. DDSN anticipates being able to serve a total of approximately 500 children with the funds appropriated.

In addition, DDSN and the University of South Carolina (USC) have entered into a new collaborative agreement. DDSN will contract with USC to increase the capacity of qualified ABA providers. USC will offer five graduate-level courses that will prepare individuals to take the national ABA Certification exam. The first class will begin the 2007 fall semester.

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