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December 29, 2015

The Honorable Nikki R. Haley
Governor, State of South Carolina
Post Office Box 12267
Columbia, South Carolina 29211

The Honorable Hugh K. Leatherman, Sr.
State Senator
Chairman, Senate Finance Committee
111 Gressette Building
Columbia, South Carolina 29201

The Honorable W. Brian White
State Representative
Chairman, House Ways and Means Committee
525 Blatt Building
Columbia, South Carolina 29201

Dear Governor Haley, Chairman Leatherman, and Chairman White:

Pursuant to PART IB, SECTION 36-J16 – Department of Disabilities and Special Needs, 36.8 (DDSN: Pervasive Developmental Disorder) of the 2015-2016 General Appropriations Act, the SC Department of Disabilities and Special Needs is reporting on the Pervasive Developmental Disorder Program. This report was also provided to legislative subcommittees and Governor's staff during fall budget presentations.

Please contact us if you require additional information.

Sincerely,

A handwritten signature in black ink that reads "Beverly A. H. Buscemi Ph.D." with a stylized flourish at the end.

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

BAHB/dg

CC: Angie Willis

Ryan Burnaugh

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South Carolina Department of Disabilities and Special Needs

Pervasive Developmental Disorder (PDD) Program

October 2015

Number of Children

- Almost 2,350 children have received PDD services since the program's inception.
- 974 children are currently participating in the PDD Program. (698 enrolled in the waiver and 276 in state-funded slots).
- 1616 children are on the waiting list; 51% (818) are age five (5) and younger; 13% (195) are age two (2) and younger.
- Approximately 81% of all participants are male and 19% are female.
- Approximately 42% of participants are ages 3-5; 44% are ages 6-8; 14% are ages 9-10.

Summary of USC's Research Analysis 2014

- The results of this evaluation corroborate the findings of the 2011 evaluation.
- Results suggest that children made statistically significant gains across all measures of adaptive behaviors (i.e., communication, daily living skills, social and motor skills).
- There is some evidence that age at enrollment makes a difference in second year gains. Children who are younger at enrollment make greater gains.
- Children who participate in the PDD Program achieve significant improvements in their adaptive behaviors and language skills. These improvements were most significant during the first year of participation.
- Children who receive more treatment hours from Line Therapist and Lead Therapist were more likely to demonstrate reliable improvements.

Summary of USC's Research Analysis 2011

- Children enrolled in the PDD Program show improvement across all measure of functioning.
- Within specific domains, including Communication, Social, and Adaptive Behavior Composite (ABC), approximately 70 percent of children achieve reliable change.

- Within the domains of Daily Life Skills, Receptive Language and Expressive Language over 55 percent of children achieve reliable change.
- Both younger and older children show improvement.
- There is some evidence that the highest-performing children at baseline show less improvement through time.

These findings were promising and suggest that the PDD Program is increasing the skills and adaptive functioning of children in South Carolina.

Utilization of Services/Resources

- The proviso caps expenditures for each individual child at \$50,000 per year.
- The average budget DDSN authorized for each child based on the individual assessment and service plan is \$30,893 per year (as of June 2015).
- The number of qualified providers is 28 companies with over 70 consultants; an increase of ten (10) consultants from October 2014. The Program began with three (3) companies and five (5) consultants.
- Increased the number of children transitioning from BabyNet to the PDD Program. This prevents disruption of services. 588 children have transitioned since October 2012.
- Approximately 72% of children are Medicaid eligible.

Funding

\$6.975M	Current appropriated base
\$6.006M	Actual expenditures for FY2012
	Note: DDSN had requested Medicaid's approval of a rate increase for direct line therapists in FY2011. It was anticipated this would be approved and expended in FY2012.
\$7.232M	Actual expenditures for FY2013
	Note: Includes base and carry forward spending.
\$8.945M	Actual expenditures for FY2014
	Note: Includes \$500,000 payment to Greenwood Genetic Center per proviso.
\$8.578M	Actual expenditures for FY2015 as of 06/30/2015.

Services

Children accepted in the Pervasive Developmental Disorder (PDD) Program receive two (2) types of services:

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

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

Program Improvements

1. Award state-funded slots to children prior to Medicaid eligibility determination. This allows the family to complete paperwork, the child to be assessed, the plan developed and the start of therapy before completion of Medicaid eligibility process. If the child is determined Medicaid eligible, funding is shifted from 100 percent state to PDD waiver.
2. Allow children younger than three (3) years of age to apply for PDD services. Children are not enrolled in the Program until after they turn three (3), but the ability to apply prevents time delay.
3. Implemented new process to increase utilization of authorized budget by families. This includes better education of families about the program and family responsibility. By working with families at the beginning, it can more realistically be determined how much time the family can commit to a therapy schedule.
4. More frequently monitor family utilization of services and adjust hours and corresponding budget up or down accordingly. This method is still responsive to the needs of the individual child, but also prevents over-authorization of state funds.
5. Changed timing of provider payment to improve timeliness of service delivery. Previously DDSN paid provider once the assessment and service plan were completed. Now full payment is withheld until the provider completes these and trains direct-line therapists, decreasing time delay before actual services begin.
6. Began providing learning supplies and tools for families receiving EIBI to enhance their children's outcomes.
7. Collaborate with the SC Autism Society and the Developmental Disabilities Council to ensure that parents of children on the PDD waiting list have a clear understanding of what the PDD Program provides, how it works, and the family's commitment.
8. Through its contract with the University of South Carolina, DDSN graduated its third set of students in May 2014 whereby 21 professionals completed the five graduate-level courses approved by the National Board of Applied Behavior Analysis to prepare them

for Board Certification. The second set graduated previously in December 2011. These increase the capacity of approved providers of DDSN's PDD program. A fourth set of students began the course sequence in 2014 and will complete course work in summer 2016.

9. Developed and began a quality assurance review of EIBI providers to ensure high quality of services.
10. Finalized contract language in partnership with DHHS for EIBI providers that focus on the provider delivering a minimum level of the authorized intervention hours. This helps DDSN ensure budgets are closer to utilization.
11. DDSN collaborates with USC's Department of Psychology. At no charge, the Department assists DDSN and its network of EIBI providers to identify the direct-line therapists who do the majority of the in-home interventions with children and their families.
12. DDSN collaborated with USC's College of Social Work. At no charge, the College conducted an evaluation of DDSN's PDD program focusing on results, parent satisfaction, and family indicators that lead to better outcomes. This research and final report were completed.
13. Recruited qualified Board-Certified Behavior Analysts (BCBA) attended the National Association of Behavioral Analysts annual meeting June 2011.
14. Coordinated policy efforts with First Steps. DDSN created a smooth transition for children diagnosed with a Pervasive Developmental Disorder (PDD) receiving Early Intensive Behavioral Intervention (EIBI) services through the BabyNet program to move seamlessly into the PDD Program. As these children age out of BabyNet services at age three (3), individualized EIBI services through the PDD Program continue essential interventions which improve children's skills. The result eliminated a gap in services and improved the children's outcome measures.
15. Developed and distributed the PDD Parent Handbook which is available online and hard copy in both English and Spanish. This new handbook informs parents about the Pervasive Developmental Disorder Program. It describes the specialized services and options parents have to manage and maximize their child's services, including their role in assuring the best possible outcomes are achieved. The result is increased consumer information, increased involvement of parents in their children's treatment, and increased consumer control over who provides the services.
16. Submitted a formal request to DHHS for approval of a rate increase in 2011 for direct-line therapists (not provider overhead) to meet the need to recruit and retain the necessary number of individuals who work directly with the children. At least one (1) direct-line therapist is needed for each child/family. This rate increase went into effect January 1, 2013.

17. An additional PDD Program evaluation was completed in spring 2014 (see findings on page 1). In December 2012, DDSN requested that USC conduct another, more comprehensive study of the PDD program to determine if children participating in the program continue to show improvement across all measures of functioning [areas of adaptive functioning (eating, bathing, dressing, toileting), expressive and receptive communication (speaking, understanding what others are saying to them, and learning), socialization (playing with peers, being able to grocery shop with mom) and cognitive functioning (learning, staying on par with peers.)]
18. Due to the richness of available data, DDSN is uniquely positioned to advance knowledge regarding the predictors of positive outcomes associated with this program. These results provide important additional insights for the delivery of treatment services at DDSN and for the broader understanding of treatment policy for children with Autism Spectrum Disorder.

This study included about 500 more children and families and:

- a. Evaluated the impact of PDD services on child outcomes (cognitive functioning, adaptive functioning and verbal ability)
- b. Assessed the child-specific factors associated with differences in outcomes (attributes of children who are most likely to experience positive outcomes)
- c. Explored the relationship between the changes in adaptive behaviors through time and the actual treatment hours received (how differences in treatment hours contribute to the positive outcomes)

New Initiatives

Developed and issued a third RFP for graduate level training courses to increase the number of Board Certified Behavior Analysts specifically for children participating in the Pervasive Developmental Disorder (PDD) Program and people participating in the Intellectual Disabilities/Related Disabilities Waiver and the Traumatic Brain Injury and Spinal Cord Injury Waiver. One result is a more cost-effective approach to training a core group of students than the typical university enrollment process and fees. Another result is students who complete the training commit to providing services for a minimum of two (2) years in exchange for tuition costs. DDSN had 21 students to successfully complete the course requirements in May 2014. A new class of 25 students began in fall 2014 with completion expected in summer 2016.

Outcomes

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

To date, DDSN has provided EIBI programs to more than 1,740 children ages three (3) through ten (10) years old. The outcomes of these individualized programs are remarkable and mirror the research conducted on programs just like DDSN's program. The majority of children in the PDD program experience statistically significant gains in all areas for which children with autism have severe deficits: expressive communication, receptive communication, adaptive living and use of appropriate social skills.

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

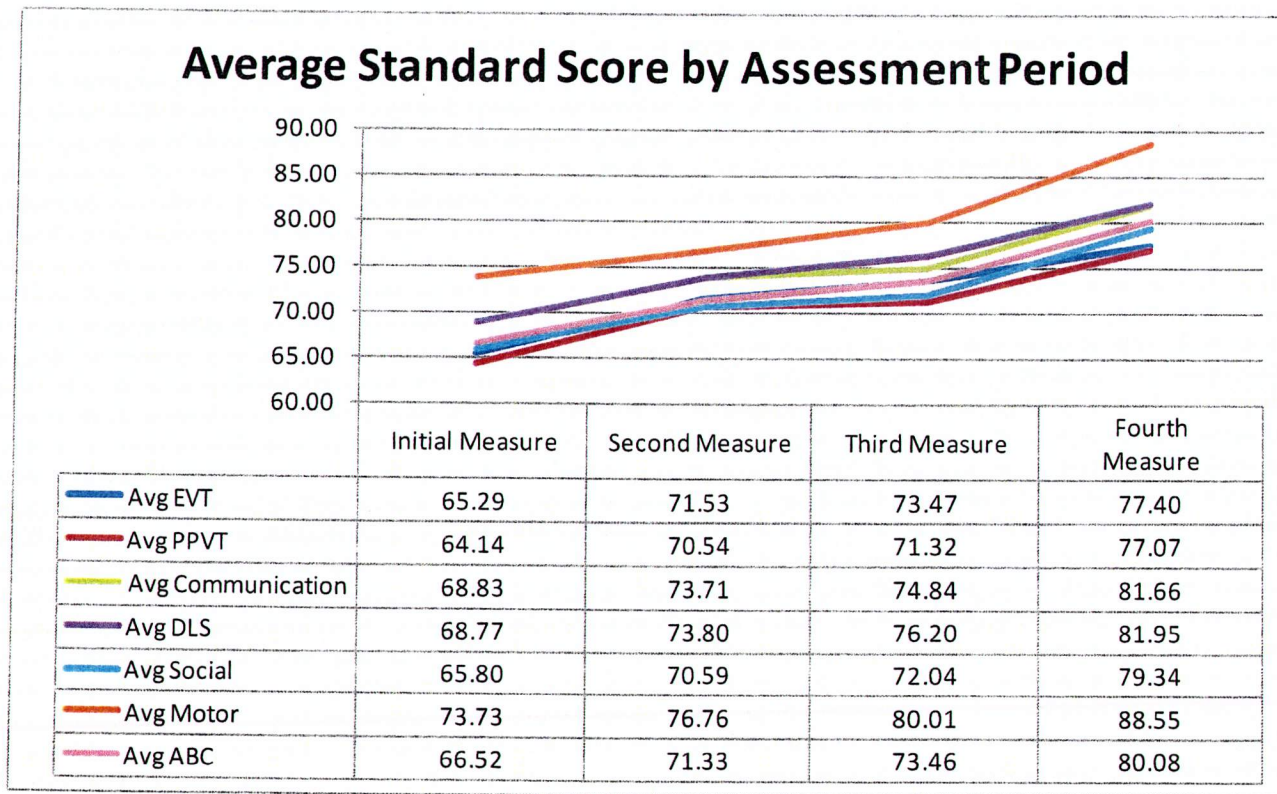
Receptive communication is a child's ability to understand, process, and react or respond to the verbal and nonverbal language of others. Growth in this area affects one's ability to follow directions, answer questions, and respond to commands in emergency situations. Being able to follow directions leads to the development of expressive communication skills. Children who received EIBI services for three (3) years showed an average gain of 15% in the area of Receptive Communication.

Daily living skills are being able to care for one's self by learning skills such as toileting, bathing and getting dressed and are extremely important skills for children with a PDD to develop so they can function as independently as possible. The average gain in this area for those who completed three (3) years of service was seven (7) years.

Socialization skills - Many children diagnosed with a PDD do not interact with their family members or typically developing peers in an appropriate manner. The deficiency in language and communication also make it difficult to form personal relationships and friendships. Intensive programming delivered in the child's natural environment enhances their skills and abilities in this area. Children who received three (3) years of EIBI services saw a reliable change of 72%.

2014 USC Final Evaluation Report of South Carolina Pervasive Developmental Disorders Program *Additional Analysis*

- All Measures show significant gains over baseline



Avg EVT=expressive language skills, Avg PPVT= receptive language skills, Avg Communication = communication skills, Avg DLS= daily living skills, Avg Social = social skills, Avg Motor= fine and gross motor skills, Avg ABC=Vineland Adaptive Behavior Composite



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