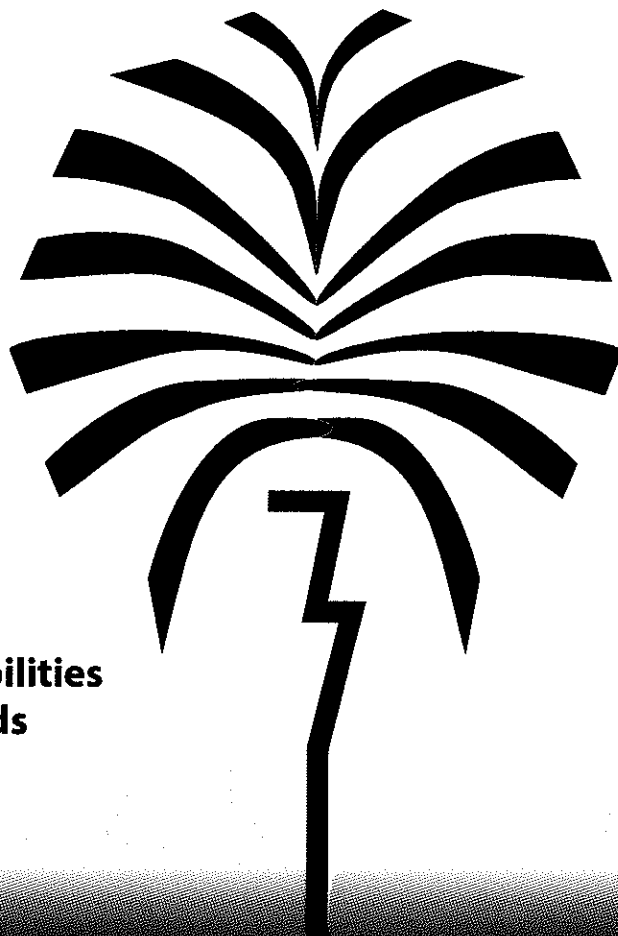
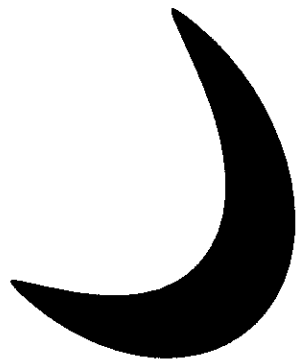


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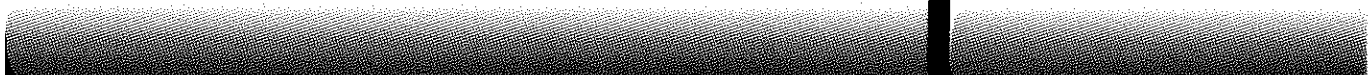
Parent Handbook

***“The Parent’s Guide to the
Pervasive Developmental Disorder
Waiver/State Funded Program”***



**South Carolina
Department of Disabilities
and Special Needs**

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What's in this Booklet?

What is PDD?.....	3
What is ABA Therapy and How Can It Help My Child?	3
What is the South Carolina PDD Program?.....	4
Is This the Right Program for My Child?	7
Application for Services.....	8
Waiting List	8
Choosing the Right Provider	9
Once My Child Receives a Slot	10
My Role as a Parent With a Child in the PDD Program	11
Center / Clinic Based Services	13
How to Handle Questions or Concerns	14
End of Program.....	14



What Is PDD?

(PERVASIVE DEVELOPMENTAL DISORDER)

Pervasive Developmental Disorders as described in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM- IV) “are characterized by severe and pervasive impairments in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior interests, and activities. The qualitative impairments that define these conditions are distinctively deviant relative to the individual’s developmental level or mental age.” Disorders included under PDD are Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified.

In more relatable terms Autism is a neurobiological disorder which affects the way information is perceived and processed. It interferes with an individual’s ability to effectively communicate and use language. It affects an individual’s ability to understand and respond to various environmental and sensory-based stimuli and alters an individual’s ability to learn and think in the same way as “age equivalent peers”. It can range from mild to severe and often results in confusion, frustration, and anxiety which can be exhibited through various behavioral responses.

To date, there is no known cause, and as such is classified as a syndrome, meaning it has multiple possible causes. It is seen in both males and females and has been documented globally.

What Is ABA Therapy And How Can It Help My Child?

ABA known as Applied Behavior Analysis is the study of behavior and how it is affected by the environment.



ABA techniques are utilized to teach skills to children with PDD and their families to increase their overall quality of life. Although there are many different ABA strategies used to affect behavioral change, children with Autism are usually taught through 1 to 1 repetitive instructional sessions that reinforce skills through principles of reinforcement; meaning that children are rewarded for successfully demonstrating the skills taught and other pro-social skills. ABA also employs strategies to decrease behaviors noted as "interfering", "maladaptive", and/or "challenging" and to increase behaviors that are considered "pro-social"; meaning socially appropriate and generally accepted.

Intensive ABA training that is started at an early age can increase skill acquisition and development in all areas of life including social, play, academic, communication, and daily living skills. Studies have shown that children who receive at least a minimum of 20 hours a week of intensive ABA training show greater improvements in skill acquisition and developmental improvement in all areas as compared to similar children who do not participate in intensive ABA training programs. Parents and families who participate in intensive ABA training programs often report less familial stress and an overall improvement in quality of life for their child and their family.

What Is The South Carolina PDD Program?

Intensive ABA based training is a well documented proven therapy for increasing skill development and affecting behavioral change for children with PDD. It is one of the most sought after treatments for children with PDD.

As such, the state of South Carolina in 2007 began offering this treatment as part of their DDSN programs.



As part of this program, children who apply may receive intensive ABA therapy for up to 3 years or until the age of 11, whichever ever comes first. In order to be eligible for services through the PDD Waiver Program, a child must:

- Be ages 3 through 10 years.
- Be diagnosed with a PDD before age eight years.
- Be eligible to receive Medicaid. This does not mean that the child must be receiving Medicaid but instead means that, once application is made, Medicaid will likely be awarded.
- Meet ICF/ID Level of Care medical criteria. The DDSN Consumer Assessment Team makes the Level of Care determination.

Children who meet the age and diagnostic criteria but do not meet ICF/ID Level of Care or are denied Medicaid eligibility may receive services outside the waiver through the PDD State Funded Program. Although these programs are funded through different sources, the services are the same.

Services that are offered as part of the PDD Program are known as Early Intensive Behavior Intervention (EIBI).

These services include:

1. **Case Management** - Each child will have a Case Manager who will assist in coordinating EIBI services; providing family support; completing required documentation; and choosing an EIBI Provider.
2. **Assessments** - Once a child has been enrolled in the PDD Program, their Case Manager will send an authorization for Assessments and services to the chosen EIBI Provider. This may be immediately done after enrollment or could take several weeks, depending on the number of EIBI Providers in your area and their availability.



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3. **Program Development and Training** - Once the initial assessments have been completed, your EIBI Provider will develop a treatment plan, individualized to your child's needs and train the Line and Lead Therapists who will be working with your child.
 4. **Plan Implementation** - Once the plan has been developed, a team will be assigned to your child to implement the treatment plan.
 5. **Lead Therapy** - Your child will have a Lead Therapist assigned to their team. This person may or may not also be a Line Therapist. The Lead Therapist makes changes to the plan as designated by the Consultant and ensures that all Line Therapists are implementing the plan with consistency. As a parent you should expect to meet with your Consultant and Lead Therapist on a regular basis.
 6. **Line Therapy** - Line Therapists are the regularly scheduled staff who will implement the treatment plan as scheduled.

EIBI services are allotted in "hours per week" which equates to a total number of hours per year. EIBI services cannot be "banked" and cannot "roll over" from week to week. If your hours are not used during the week, they are forfeited.

Also, no child may receive more than 8 hours of Line Therapy service in a day.

EIBI therapy services are to be delivered in the child's relevant "natural" environment, which may include but is not limited to the child's home or community locations directly related to the child's therapeutic goals. Delivery of these services may be deemed appropriate by the child's team based on the child's strengths and challenges. **However, at no time can a child receive EIBI services in any "educational setting" (e.g. public school, private school, home school or other**



educational setting) where educational services are being simultaneously provided to the child during “identified” school hours. The Consultant may speak with the child’s teacher to ensure continuity between the child’s plan at school and at home; however, the Consultant may not visit, observe, interact or otherwise be on school property during school hours, without the explicit authorization and approval of the local school district and relevant authorities.

Is This The Right Program For My Child?

Deciding if this is the right program for your family and your child is not always easy. Intensive ABA programs are most often run in the home. This allows for skills to be acquired and naturalized in the child’s most familiar and comfortable environment: his or her “home”. The same is true for the DDSN PDD program. Most of the teaching will occur in the home environment. Most areas of the house can easily be converted into a therapy area/room. This can be in the child’s bedroom, dining room, office area, living room, den, and even the kitchen. Your child’s Consultant will assist in setting up an appropriate learning environment, dependent on the programmatic needs of your child.

Also, key to promoting your child’s success is having you as the parent involved. This service is not a respite service, but a “therapy” service. As a parent, you will participate in team meetings with your child’s therapy providers. Your Provider will train you on how to implement various techniques and strategies and reward your child for success. They will also implement plans to address “challenging” behaviors and will train you on how to follow through with the behavior program, so that you can manage challenging behaviors consistently and



teach skills outside of therapy. The more you know, the better the outcome for your child will be. This may be time consuming, but as you see your child succeed, you will soon find it was well worth the added effort.

Application For Services

Once you have determined that this service is indeed the right program for you and your child, you will need to apply for services. If your child is already a DDSN consumer, your Case Manager will assist you in completing all the necessary paperwork and submitting the appropriate documentation.

If you are new to the area or your child is not currently served by DDSN, you will need to call the PDD Intake and Referral number (1-888-576-4658) and leave your name and phone number. Your call will be returned by a screener within 48 hours. All calls are processed and returned in the order received. If the screener finds that your child is appropriate for a referral, then the screener will assist you through the intake process.

Waiting List

Once it is determined that your child meets the criteria to receive PDD services and all documentation has been submitted, your child's name will be added to the current waiting list. This waiting list contains the names of all children who meet the criteria for participation in the PDD program. Once your child's name has been added to the waiting list, you will receive written notice confirming that their name has been added and where they rank on the list. If you do not receive this letter within two weeks of submitting your child's application, please contact your Case Manager.



Due to the high demand for this program, there is a waiting period prior to a slot being awarded to your child. The wait time can vary and is affected by the number of children eligible for services and the length of the wait list.

Choosing The Right Provider

While on the waiting list, you as a parent should begin researching EIBI Provider agencies in your area. Your Case Manager can assist with this. You will want to speak with potential EIBI Providers before deciding which to choose. There are questions you can ask your EIBI Provider to determine if they are the right choice. Asking questions such as What is your methodology?; How do you decide on what goals and objectives you will teach my child?; How much experience do you have?; Do you have difficulty finding Lead and Line Therapists?; How will you determine which Consultant will work with my child? (for larger agencies); How do you handle end of program transitions?; How will you train your staff?; What training do you provide the family?; How often do you hold team meetings?. These questions and others will help you decide which EIBI Provider to choose. The more information you have, the more empowered you will feel when it is time to choose the right EIBI Provider. Also, speaking with other families in your area and/or asking an EIBI Provider for references can give you additional feedback in your search.

The S.C. PDD Program also offers the **Responsible Party Option** to parents. The **Responsible Party Option** offers parents the opportunity to “employ” and provide “employer authority” to Line therapists providing EIBI services through the PDD program. Line therapists can often be difficult to find, especially in rural areas. This option provides many benefits in that



parents can employ individuals who they or their child are most comfortable with and who meet the criteria for employment as set forth under the PDD Program “Qualification Checklist for Line Therapists”. With the guidance of your child’s consultant, a parent choosing the “Responsible Party” option will be able to hire and supervise your child’s Line therapists. Parents choosing this option, will develop work schedules; verify time sheets; evaluate performance and if needed terminate. DDSN has contracted with a third party entity that will perform the necessary financial transactions on behalf of the PDD participant. If you are interested in becoming a **Responsible Party** or finding out more about the benefits of choosing the **Responsible Party Option**, please see your child’s Case Manager. Your child’s Case Manager can assist with completing the necessary paperwork and providing you with more detail about the program. Choosing this option can look intimidating and overwhelming at first, but we have many supports in place to walk you through each and every step. Many parents who have chosen this option have found it to be an asset to their child’s program.

Once My Child Receives A Slot

You will be notified when your child is to be awarded a slot. At this time, your child’s Case Manager will set up a time to meet with you to complete a plan and all necessary pre-assessment documentation. The Case Manager will then work with you to contact the EIBI Providers you selected to determine their availability. If there is an EIBI Provider immediately available, an authorization for services will be sent to that EIBI Provider. When the EIBI Provider receives the authorization, they will set up a time to administer all assessments. After assessments have been completed and a treatment plan has been developed, the EIBI Provider you selected will work with you to set up and begin therapy services.



We know that locating an EIBI Provider with immediate availability is a concern for some. In the event the EIBI Provider you selected is not immediately available, your Case Manager will work with you to find another EIBI Provider. If your Case Manager is unable to “**authorize**” service immediately upon enrollment due to Provider unavailability, your child will **not** lose time from their program. There are procedures currently in place to allow for compensation of time in the event that an EIBI Provider cannot accept your child immediately once the child is enrolled. EIBI Providers are not allowed to accept new children for EIBI services unless the Provider has the ability to complete assessments and begin therapy within the designated time frame set forth by DDSN. Once an authorization has been sent to a Provider, any time lost will not be compensated for.

My Role As A Parent With A Child In The PDD Program

As a parent, you are expected to play a role in your child’s service. Although sometimes difficult, it is necessary that you stay for therapy sessions. You do not have to be in the therapy room, but should be on-site. This is not a respite program, but a therapy program. You will also need to participate in family training and team meetings coordinated by the Provider. This will allow you and your family members to carry out programs outside of therapy. Your active involvement will increase your child’s overall success.

As a therapy program, you should not request that your therapist make changes or participate in activities not listed in the treatment plan. Deviations in treatment will result in confusion and frustration for your child and could result in a loss of skills or an increase in challenging behaviors. If you have concerns about your child’s program, they should be brought to the attention of



your Consultant so that your Consultant and you can determine how to best address your concerns.

Also, you will be responsible for signing off on time logs for your Lead and Line Therapists and Consultant. Please sign these logs accordingly; however, if you have questions or concerns about the time/s documented, please communicate this with your Provider and do not sign the logs until you have resolved your concerns.

Remember, when you sign the time log, you are verifying that the time submitted on the log is the actual time worked. Once you have signed and verified their accuracy, we have little ability to dispute the accuracy of these time logs.

The PDD program requires commitment, not only of time and accessibility, but also of resources. ABA teaching involves using both verbal rewards and tangible rewards (referred to as reinforcers) to help your child acquire skills. Having an ample supply of reinforcers readily available is essential to your child's program. The program also requires "teaching" materials. Although the PDD Program covers the cost of therapy, it does not cover the cost of materials and reinforcers needed for an effective home program. Your Consultant can advise you on what materials need to be purchased or made. There are also resources available through the organizations like **Winston's Wish Foundation**, which offers "**The Teaching Toy Box**". This program helps families with children in ABA based EIBI programs have access to materials they may not otherwise have access to. Please inquire with your Case Manager or Autism Division about how to request therapy materials from **The Teaching Toy Box**.

You will want to ask questions and openly communicate with your child's treatment team. Your child's EIBI team is there to promote the success of your child. It is important to maintain a professional working relationship with your child's EIBI team. Although not recommended unless necessary, there are times



when a family needs to change Providers. You as a parent always have the “Freedom” to change Providers if it ever becomes necessary.

Center/Clinic Based Services

The Pervasive Developmental Disorder Program was funded and approved based on the concept of intensive in-home intervention and **all approved providers must offer home based EIBI services**. However, children can receive EIBI services in a Center/Clinic Based setting under the following conditions **(not an inclusive list)**:

- Any parent/legal guardian who desires center based services must write a statement of such to the EIBI Provider indicating that the parent/legal guardian has freely selected Center/Clinic Based EIBI services for their child. The Provider must maintain this documentation on file until the parent/legal guardian notifies the Provider that Center/Clinic Based services are no longer desired.
- Each child must have their own Line Therapist (i.e. the ratio must be 1:1). In addition, Consultants and Lead Therapists may not work simultaneously with more than one child.
- Under no circumstances may a child receive more than 50% of their awarded EIBI hours in a Center/ Clinic Based setting.

Parents/legal guardians are encouraged to contact DDSN to ensure that the Center / Clinic they are interested in has properly registered with DDSN and any other required entities. Parents/legal guardians may contact the Autism Division PDD Consultant at 803-898-9609 or by e-mail at PDDinfo@ddsn.sc.gov.



How To Handle Questions Or Concerns

Through the course of the program, you will find you have many questions. These questions can be answered by your Provider and Case Manager. Please openly communicate any questions you have to your Case Manager and Provider. These individuals are there to assist you. If you have concerns, you will need to express them as well so that either your Case Manager or Provider can address them. If you have questions or concerns regarding your child's program, you should notify your child's Lead Therapist as well as your Consultant. You can communicate your concerns face to face with your Lead Therapist or Consultant or e-mail, or telephone your Lead Therapist or Consultant. If you need further assistance, you can always contact the DDSN Autism Division at 803-898-9609 or e-mail your concerns to PDDinfo@ddsn.sc.gov.

End Of Program

Due to the intense nature inherent in providing Early Intensive Behavior Intervention, the PDD program for the state of South Carolina is limited to 3 years of service. EIBI programs involve a substantial amount of time from families, resources, and dedication from specialized and highly sought after service Providers. Limiting this service to 3 years provides all **eligible** children in the state of South Carolina the opportunity to receive EIBI service that might not otherwise have been available to them.

Speak with your Case Manager and Consultant at least 6 months prior to the end of the program about transition procedures. Make sure you and your Consultant and the team have a plan in place. By being prepared for the end of the program, you will



help positively affect your child's transition. Your child's Case Manager as well as Provider will assist you with preparing for the end of the PDD program. Knowing your child's program will allow you to continue implementing many of the strategies taught and utilized within the course of the program. You will be able to provide input at your child's meetings in the future to let other care takers know what strategies have been effective for your child.

