



DEPARTMENT OF HEALTH AND HUMAN SERVICES  
OFFICE OF DIRECTOR

ACTION REFERRAL

|                |        |
|----------------|--------|
| TO             | DATE   |
| Liggett / Mary | 3-4-13 |

| DIRECTOR'S USE ONLY   | ACTION REQUESTED  |
|---|---|
| 1. LOG NUMBER<br>000268   | <input type="checkbox"/> Prepare reply for the Director's signature<br>DATE DUE _____   |
| 2. DATE SIGNED BY DIRECTOR<br>cc: Mr. Keck, COS, Walden<br>Cleared 3/22/13, letter attached | <input checked="" type="checkbox"/> Prepare reply for appropriate signature<br>DATE DUE 3-13-13<br><input type="checkbox"/> FOIA<br>DATE DUE _____<br><input type="checkbox"/> Necessary Action |

| APPROVALS<br>(Only when prepared for director's signature) | APPROVE  | * DISAPPROVE<br>(Note reason for disapproval and return to preparer.) | COMMENT |
|--|--|---|---------|
| 1. Liggett   |  |   |         |
| 2. Mary  | <br>3/14/13 |   |         |
| 3. Attwood   | <br>3-14-13 |   |         |
| 4.   |  |   |         |

RECEIVED

MAR 06 2013

Bureau of Long Term Care Services  
SC Department of Health and  
Human Services

M. Kim Nelson  
2604 Live Oak Circle  
Beaufort, SC 29902

Cell: 843-592-7536, Home: 843-524-0478  
[nelsonmk@email.sc.edu](mailto:nelsonmk@email.sc.edu)

Department of Health & Human Services  
OFFICE OF THE DIRECTOR

FEB 28 2013

RECEIVED

February 15, 2013

Division of Appeals and Hearings  
SC Department of Health and Human Services  
ATTN: Mr. Anthony Keck  
PO Box 8206  
Columbia, SC 29202-8206

Dear Mr. Keck,

My name is Kim Nelson. I am advocating for my daughter Suzie Nelson with autism. I am writing to request you grant my daughter an extension of her PDD Waiver to cover Applied Behavior Analysis at least until at least the end of this year (2013) to compensate for the services that were not delivered by her provider and to provide her with a second chance to become an independent individual in society.

I am asking you grant this request for the following reasons:

1. DDSN did not have sufficient built in accountability regarding the PDD Waiver for any authorized agency receiving PDD Waiver funding, so they will not abuse the public trust by not delivering quality ABA services. The following are a few of many reasons why I believe Suzie needs compensatory services:
  - a. The Coordinator did not have regular monthly visits to monitor progress, implement the program to meet evolving needs, and to train the lead and line therapists regularly.
  - b. Everything has been extremely time consuming for my husband and I with three children to keep trying to make coordinators and lead therapists to responsive to Suzie's program, as they were regularly ignoring our emails and phone calls, so we have been keep trying to get their responses. Even as simple as to schedule Suzie's coordinator or lead therapists, who frequently ignores our emails, we had to spend great deal to keep sending emails to get their responses. Yet, they still missed many of their required visits.
  - c. Frequently, the Coordinator did not implement the necessary findings from assessments in a timely manner. For example, Suzie's coordinator had an assessment of Suzie in May 2012, and I had to send multiple emails to request where were the findings and implementation for the findings, without success of her responses. Finally, after a half year, when the parents received the report, a large portion of assessments was missing. In addition, the parents rarely received a report of



coordinator or lead therapists' observation of Suzie or any ideas implemented during a basketball practice before she entered Kindergarten April 2011. We had to spend great deal of time sending emails to remind the coordinator to implement appropriate programs for the findings, so she would add these findings in her reports. But, we never received the report. I had to beg the coordinator for months for the implementation of these programs; however, this left us with concerns about how many findings from assessments not properly implemented over the years.

Another example is when Suzie began engaging in maladaptive behaviors that were significantly affecting her social life as peers started saying, "Suzie, you are weird," since last December 2012. Lines have been charting frequencies and intensity (these behaviors occurred before any charting) of maladaptive behaviors, yet as of today, nothing is being implemented to correct Suzie's maladaptive behaviors. If lines spend great deal of time recording the data, there should be something implemented, especially if these behaviors are new, keep escalating, and affect her social life.

- d. One lead named, Lisa Pace filed a claim for the service that was not rendered. Suzie was gone out of state in the first part of August in 2011. Lisa Pace worked with Suzie over two years, and along these months, she only stayed onsite for 4 hours while she was billing for 6 hours. She rarely responded to our emails or line's emails, so I was not sure why she had to get paid for 2 hours of offsite.

Please note here that I was not able to check all the itemized bills, so I would not know how much EAP overbilled over the years; however, certain days such as the above case, I do know since it was not our regular visit. During her visits and other visits from leads', those days seem to be filled with little or no training that was documented on any forms.

- e. Suzie's second lead caused Suzie to be asked to leave a private pre-school because of the manner she disciplined Suzie in the classroom, which concerned the teacher and school. Suzie had nowhere to go for some time. She later lost lines due to the actions of this coordinator moving those lines to another family, leaving Suzie without line therapists, so my husband desperately had to locate other lines at our own expense.
- f. The Coordinator never provided any continuity of the program to new leads each time we had lead changes. One former lead named, Catherine Carbon implemented wrong programs that were already tried and removed by Suzie's previous lead, Lisa Pace, and the coordinator, for reasons they were not appropriate for Suzie. Catherine Carbone also cut Suzie's programs to minimize her work, as claimed Suzie mastered even when not so. Furthermore, due to the lack of sharing information between the coordinator and the leads, wrong programs were implemented against parents' resistance, which eventually proved to Catherine Carbone why those programs were already taken out previously costing Suzie valuable time with the PDD Waiver.
- g. Catherine Carbone always had many excuses for not showing up, leaving early, placing wrong programs, never training lines, etc.

While Suzie was gone to overseas in July, 2012, Catherine Carbone insisted the family have her visit, otherwise, Suzie's program might be cancelled. She worked less than 2 hours in these weeks. She knew the program would not be cancelled as long as there was a service within 30-day period, but she insisted to come. In the fear of retaliation, my husband let her come to the house during Suzie's trip to overseas.

h. EAP never helped us to locate lines. We spent hundreds of dollars to advertise for lines; however, once lines were situated in our home, the agency placed them in somebody else's house. EAP would even solicit the lines we had working for Suzie to work with other families, in other locations or even lead positions when we did not have any other lines and needed lines to fill Suzie's authorized ABA hours.

i. Due to the lack of line therapists' availability, Suzie could not get to fully utilize her authorized hours (37 hours per week).

j. We were retaliated if we shared our concerns, such as our emails went unanswered, no return phone calls, the coordinator cancelled visits or lines were placed in somebody else's house, etc.

k. When lead was on vacation, the coordinator brought in-clinic regional lead therapist named Erica Painter, BCaBA, to drive the coordinator. I have not seen one single word coming out of her mouth to train lines during any of those visits/ days. She just sat as a lead and watched the coordinator, yet she billed her hours as a lead visit. I would rather not have her to save my tax dollars on the days when she drove the coordinator down to bill for her lead hours.

Our current fill-in coordinator named Jaime White mentioned that she would love to be Erica Painter whose job description was to go get coffees for other coordinators, drive around Suzie's coordinator named Angie Keith to different places, run errands and receive a good salary. I do believe in some accountability need for this portion also.

l. The Coordinator and lead inflate and manipulate the data as if there were true progress. Lines affirmed that the current lead was collecting only selective data. The former leads probably did the same thing, but back then, neither of us were not trained enough to know how much they had been inflating the data. I am a fulltime student at College of Social Work in USC, so I know better now.

2. Research supports that prevention intervention is much more cost effective than crisis intervention. The most recent tragedy at Sandy Hook was a good example of how Adam Lanzas might be a victim of lack of early intervention. I do understand that it was beyond one simple causation for this unspeakable tragedy; however, if Adam was taught to choose more adaptive behaviors to deal with whatever he was feeling, Sandy Hook tragedy might have been avoided.

Suzie is extremely intelligent but continues to struggle with social and pragmatic deficits.

As parents, we support her fully to prepare her to become a productive individual in social. It would be much more cost effective for South Carolina to grant Suzie with extended ABA services to prepare her than let her miss that opportunity. If services by the EAP were delivered as intended fully, Suzie would have met her full potential more than where she is at right now.

Please read the attached appeal letter to DDSN also to supplement these claims.

Sincerely,

A handwritten signature in cursive script, appearing to read "Kim Nelson".

Kim Nelson

**FW: Suzie Nelson/itemized bills**

M Kim [mkn\_550@naver.com]

Sent: Friday, February 15, 2013 9:39 PM

To: NELSON, MYUNGHEE

Attachments: EIBI EAP.pdf (662 KB)

A copy of email that I sent to Mr.  
Daniel Davis @ DDSN.

-----Original Message-----

From: "M Kim"<mkn\_550@naver.com>

To: "Davis Daniel"<DDavis@ddsn.sc.gov>;

Cc:

Sent: 2013-02-13 (ㄴ) 11:05:30

Subject: Suzie Nelson/itemized bills

2-12-13

Hi, Mr. Davis,

Pursuant to your conversations with Ron this afternoon that it would be difficult to check the EAP's billing if they overbilled, I am going to explain how I knew they were billing me more.

Before the Waiver kicked in, I applied and received some grants to pay toward Suzie's deductibles and copayments toward her ABA that were provided by EAP. In order for the grantor

to pay, the EAP had to provide itemized bills such as the attached bill. I only received \$3k, so every single dollar was very important for me, so I compared itemized bills with timesheets

that were submitted. Sure enough, I noticed many false claims that were not rendered. I asked EAP to reimburse me, and it tooks months for them to honor. I spent so much time with them

to get my money back. Even after the Waiver kicked in, they were keep charging my credit cards without my authorization. Kate from Bright Start and you helped me to get our money

back from the EAP. (Thank you!)

I began making copies of all time sheets, after noticing how much EAP overbilled. Unfortunately, EAP would not provide me with any more itemized bills since there was no grantor who

Early Autism Project, Inc. BILLING-1

8164

Federal ID #14-1859573  
2580 Lin-Da Court  
Sumter, SC 29150

| Date     | Invoice # |
|----------|-----------|
| 1/8/2010 | 010310    |

Bill To  
Myrtales & Rod Nelson  
2604 Live Oak Circle  
Beaufort, SC 29902

| Patient Co -Insurance Due |                      | Diagnosis      | Client ID    | Terms          |
|---------------------------|----------------------|----------------|--------------|----------------|
| 185.80                    |                      | 299.00         | Suzie Nelson | Due on receipt |
| Date of Service           | Clinical Services... | Description    | Units        | Amount         |
| 1/13/2010                 | Filed to Primary     | BCBS PPO - CBA |              |                |
| 12/29/2009                | LT-Vicki Elmore      | G0177          | 4            | 132.00         |
| 12/29/2009                | ADMIN TIME           |                | 2            | 66.00          |
| 12/21/2009                | LIT-Kimberly Do...   | H0046          | 3            | 51.00          |
| 12/22/2009                | LIT-Darlene Canga    | H0046          | 6            | 102.00         |
| 12/22/2009                | LIT-Nina Babalo...   | H0046          | 1            | 17.00          |
| 12/22/2009                | LIT-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/23/2009                | LIT-Darlene Canga    | H0046          | 5            | 85.00          |
| 12/23/2009                | LIT-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/24/2009                | LIT-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/27/2009                | LIT-Kimberly Do...   | H0046          | 1            | 17.00          |
| 12/28/2009                | LIT-Kimberly Do...   | H0046          | 6            | 102.00         |
| 12/29/2009                | LIT-Shannon Kay      | H0046          | 4            | 68.00          |
| 12/29/2009                | LIT-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/30/2009                | LIT-Kimberly Do...   | H0046          | 4            | 68.00          |
| 12/31/2009                | LIT-Kimberly Do...   | H0046          | 5            | 85.00          |
| Payments/Credits          |                      | Total          |              |                |
| \$0.00                    |                      | \$929.00       |              |                |

This statement lists charges that may be pending processing with your insurance carrier. Thank You.



Beverly A. H. Buscemi, Ph.D.

State Director

David A. Goodell

Associate State Director

Operations

Kathi K. Lacy, Ph.D.

Associate State Director

Policy

Thomas R. Waring

Associate State Director

Administration

COMMISSION

Fred Lynn

Chairman

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Christine Sharp

Secretary

Katherine W. Davis

Harvey E. Shiver

Katherine Llamas Finley

Eva R. Ravenel

3440 Harden Street Ext (29203)  
PO Box 4706, Columbia, South Carolina 29240

803/898-9600

Toll Free: 888/DSN-INPO

Website: [www.ddsn.sc.gov](http://www.ddsn.sc.gov)

January 23, 2013

Ms. Kim Nelson

2604 Live Oak Circle  
Beaufort, South Carolina 29902

Re: Request for reconsideration for Suzie Nelson

Dear Ms. Nelson:

The South Carolina Department of Disabilities and Special Needs (SCDDSN) received your letter requesting the reconsideration of the termination of Pervasive Developmental Disorder (PDD) Program services for your daughter, Suzie. I am pleased to hear that she has benefited from services through the PDD Program.

The 2006 - 2007 General Appropriations Act that created the PDD Program stipulated that participants could receive PDD Waiver services for a maximum of three years. In addition, the Centers for Medicaid and Medicare Services who approved South Carolina's PDD Waiver established the same participant criteria.

The start of Medicaid PDD Waiver services is based on a participant's enrollment date; in Suzie's case, her enrollment date was January 5, 2010. This means her three-year period began on January 5, 2010 and was scheduled to end on January 4, 2013. We realize some participants experienced difficulties in locating a provider and this lead to the passage of several weeks before services actually began. In an effort to address this, a process was developed that could extend a child's participation in the PDD Program after their initial three year period ended. The length of the extension is based on the number of days between the participant's enrollment date and their Initial Assessment; the first therapy service according to the approved Medicaid document. Per our records, Suzie's Initial Assessment was completed on May 15, 2010. This means Suzie's PDD services have been extended 130 days beyond the January 4, 2013 date and she will receive PDD State Funded services through May 14, 2013. While I understand your concern for the hours of service lost, the PDD Program does not allow EIBI therapy hours to be carried forward from week to week. Unfortunately, I am not able to grant your request to receive "compensatory Applied Behavior Analysis" services beyond the May 14, 2013 date.

If you are not satisfied with the SCDDSN decision in this matter, you have the right to appeal directly to the Medicaid agency (South Carolina Department of Health and Human Services). The appeals process is attached for your review.

Sincerely,

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

Cc: Anita Atwood, SCDHHS

DISTRICT I

P.O. Box 239  
Clinton, SC 29325-5328  
Phone: (864) 938-3497

Midlands Center - Phone: 803/935-7500  
Whitten Center - Phone: 864/833-2733

9995 Miles Jamison Road  
Summerville, SC 29485  
Phone: 843/832-5576

DISTRICT II

Coastal Center - Phone: 843/873-5750  
Pec Dee Center - Phone: 843/664-2600  
Saleeby Center - Phone: 843/332-4104



# PDD WAIVER ACCOUNTABILITY WORKSHOP

By Chris Landrum

## INTRODUCTION

*did not meet  
these requirements!*

### What is Accountability?

- **Measurable**  
A child's progress (or lack thereof) is documented, observed, and analyzed.
- **Answerable**  
Service providers are answerable for the quality and quantity of the services they provide or fail to provide.
- **Accessible**  
Parents have access to the PDD Waiver guidelines, financial records, assessments, and therapy documents.
- **Adaptable**  
Services are adapted to the child's needs.
- **Specific**  
Progress, records, data, and information is specific and action-oriented.

### What Are The Benefits Of Accountability?

- **Child Makes Maximum Progress**  
A child has the opportunity to make maximum progress when their EIBI services are measurable, adaptable, answerable, and specific.
- **Parents Feel Excited And Hopeful**  
When their children's quality of lives improve, parents feel excited and hopeful for the future.
- **EIBI Providers Feel Appreciated**  
As a result of parents feeling excited and hopeful, EIBI providers will feel like they are making a difference.
- **State Officials Improve The System**  
State officials get the feedback they need to improve the program.
- **Legislators Maintain Or Expand Funding**  
Legislators receive the justification of why they should fund the PDD Waiver instead of another worthwhile cause.

*Suzie was not challenged  
to make maximum  
progress due  
to lack of  
EAP's  
commitment  
to  
Suzie's  
program*

## How Should Parents Be Held Accountable?

- Educate Yourself On EIBI Services  
Learn the basic principles of Applied Behavior Analysis (ABA) so you can hold the quality of your provider's services accountable.
- Improve Your Communication
- Advocate For Your Child
- Participate in the PDD Responsible Party Program
- Educate Other Parents About Issues Concerning The PDD Waiver

## OBSTACLES

### What Are The Obstacles? Parents/Guardians

- ✓ Misinformation  
It is my understanding the PDD Waiver guidelines are vague, ambiguous, and open to interpretation. Parents find it difficult to get access to the information. As a result, it is difficult to fact check what others tell you. It takes time and effort to contact the limited few who can answer your questions.
- ✓ Lack of Information  
Parents fail to have a concept of what is possible (the best possible program) because they find it difficult to get access to the PDD Waiver guidelines, have limited knowledge of ABA, and are conditioned to trust and comply with authority figures.
- ✓ Fear of Retaliation  
Parents feel if they ask questions or complain, the providers might reduce therapy time, take away therapists, provide a less knowledgeable Coordinator, deny services, or abuse their child.

### What Are The Obstacles? EIBI Providers

- ✓ Lack of Staff  
Providers have an insufficient number of qualified and trained staff to perform EIBI services.
- ✓ Finding a Needle in a Haystack  
Finding motivated and interested people to become Line Therapists expends time, effort, and money.
- ✓ Less Profit  
To attract more potential Coordinators, Lead Therapists, and Line Therapists, providers may be forced to accept less profit per hour billed.
- ✓ Resistance To Change  
Some providers may resist change because they are complacent with their current business practices.

Even if parents know, it is very difficult to make providers provide what one necessary for their children or would face retaliation.

## Your Plan For Accountability

### Step #1: Gather Information

- ✓ **Initial Evaluations**  
Evaluations performed by the EIBI Consultant/Coordinator before your child was authorized to receive PDD Waiver services.
- ✓ **SCDDSN Authorization Paperwork**  
Paperwork that tells how many units (or hours) of Plan Implementation, Lead Therapy, and Line Therapy a child is authorized to receive through the PDD Waiver.
- ✓ **EIBI Records**  
Supervision notes, skills trading (probe) sheets, manding sheets, program sheets, behavior sheets, communication logs, and graphs.
- ✓ **Financial Records**  
An itemized printout of what the EIBI provider has billed for through the PDD Waiver.

## Your Plan For Accountability

### Step #1: Gather Information

- ✓ **PDD Waiver Guidelines**  
The policies and procedures that govern the PDD Waiver.
- ✓ **Correspondence Logs**  
All correspondence with the providers, service coordinator, state officials, legislators, organizations, other parents, etc.
- ✓ **Contact Information**  
The contact information for the provider, service coordinator, coordinator, lead therapist, and line therapists

## Your Plan For Accountability

### Step #2: Know The Rules

- ✓ Know Your Child
- ✓ Know Your Rights and Responsibilities
- ✓ Know The People
- ✓ Know The System

## Your Plan For Accountability

### Step #3: Get Informed

- ✓ Analyze The Data
- ✓ Reverse Engineer The Perfect Program
- ✓ Organize Any Questions and Concerns



## PROBLEMS/CONCERNS

### Who Do You Contact With Concerns And Problems?

- **Service Coordinator**  
If you have any questions or concerns about the quality or quantity of services your child received or didn't receive from your EIBI provider, contact your PDD Waiver Service Coordinator.
- **SCDDSN (Autism Division)**  
Contact Daniel Davis, Director of the S.C. Department of Disabilities and Special Needs (SCDDSN) Autism Division, about any questions, concerns, or suggestions you may have concerning your child's PDD Waiver services. You can reach him at 803-898-9639 or [ddavis@ddsn.sc.gov](mailto:ddavis@ddsn.sc.gov)
- **EIBI Provider**  
Contact your child's EIBI provider with any questions, concerns, or suggestions. Send the provider any written responses from your Service Coordinator or Daniel Davis.



### Who Do You Contact With Concerns And Problems?

- **Parent Support Groups**  
Join a parent support or advocacy group and learn from other parents who have dealt with the same or similar issues.
- **Parent Training/Advocacy Organizations**  
Contact a parent training or advocacy organization to get more information on your issue, referrals to the right contacts, or



### How Do You Make A Formal Complaint Against A Provider?

- **Does Your Child Receive PDD Waiver Services Through Medicaid?**  
Contact the S.C. Department of Health and Human Services Fraud & Abuse Hotline at 1-888-364-3224 or [fraudfse@scdhhs.gov](mailto:fraudfse@scdhhs.gov) (If fraudulent activity is suspected, the Division of Program Integrity will turn the case over to the Medicaid Fraud Control Unit in the State Attorney General's office.)
- **Does Your Child Receive PDD Waiver Services Through State Funds?**  
Contact Daniel Davis, Director of the S.C. Department of Disabilities and Special Needs (SCDDSN) Autism Division, at 803-898-9639 or [ddavis@ddsn.sc.gov](mailto:ddavis@ddsn.sc.gov)



## How Do We Persuade Legislators To Maintain Or Expand Funding?

- Enlighten Them About Autism and the PDD Waiver
- Present Evidence Of Progress
  - Show video evidence and proof to legislators (a DVD or CD compilation of parents and children).
- Build Relationships
  - Establish a relationship with legislators by contacting them throughout the year (not just when we need funding).
- Visit The State House In Groups and Take Your Children With Therapists

March 22, 2013

Mrs. Kim Nelson  
2604 Live Oak Circle  
Beaufort, South Carolina 29902

Dear Mrs. Nelson:


The South Carolina Department of Health and Human Services has received your letter concerning your daughter, Suzie Nelson. Based on your concerns and dissatisfaction with the service providers and their unprofessional behaviors we will forward your information to our Quality Assurance and Program Integrity staff for appropriate follow up.

The following is a summary of your concerns as we understand them:

- Lack of communication and coordination on scheduling appointments by the service coordinator and lead therapist with the family;
- The providers leaving early from the scheduled home visit;
- The providers missing appointments as scheduled with the family and Suzie;
- Assessment documentation by the lead therapist was not shared with the family;
- Inflating documentation by the service coordinator and lead therapist about Suzie's progress in EIBI therapy even though she was demonstrating maladaptive behaviors;
- The lead therapist inappropriately disciplining Suzie at her pre-school;
- Charging Medicaid for rendered services in July, 2012 when Suzie was out of the country and there was no child to serve.
- Overbilling for services not rendered by EIBI provider.
- Lack of line therapists in the geographical area.

Should you have any questions, please contact Anita Atwood, LMSW at (803) 898-4641.

Sincerely,

  
Pete Liggett, Ph.D.  
Deputy Director

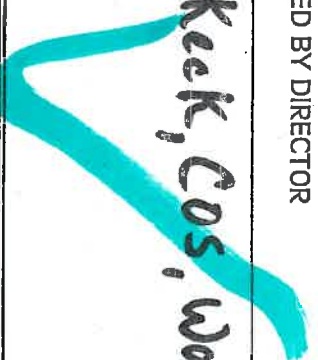
PL/mh

cc: Lenora Crum, SCDHHS  
Betty Jane Church, SCDHHS

DEPARTMENT OF HEALTH AND HUMAN SERVICES  
OFFICE OF DIRECTOR

ACTION REFERRAL

|                      |                       |
|----------------------|-----------------------|
| TO<br><i>Liggett</i> | DATE<br><i>3-4-13</i> |
|----------------------|-----------------------|

| DIRECTOR'S USE ONLY   | ACTION REQUESTED   |
|---|--|
| 1. LOG NUMBER<br><br><i>000268</i>  | <input type="checkbox"/> I Prepare reply for the Director's signature<br>DATE DUE _____  |
| 2. DATE SIGNED BY DIRECTOR<br><br><i>cc: Mr. Keck, COS, Waldrep</i><br> | <input checked="" type="checkbox"/> Prepare reply for appropriate signature<br>DATE DUE <i>3-13-13</i><br><br><input type="checkbox"/> FOIA<br>DATE DUE _____<br><br><input type="checkbox"/> Necessary Action |

| APPROVALS<br>(Only when prepared for director's signature) | APPROVE | * DISAPPROVE<br>(Note reason for disapproval and return to preparer.) | COMMENT |
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**RECEIVED**

FEB 28 2013

Department of Health & Human Services  
OFFICE OF THE DIRECTOR

M. Kim Nelson  
2604 Live Oak Circle  
Beaufort, SC 29902

Cell: 843-592-7536, Home: 843-524-0478  
[nelsonmk@email.sc.edu](mailto:nelsonmk@email.sc.edu)

February 15, 2013

Division of Appeals and Hearings  
SC Department of Health and Human Services  
ATTN: Mr. Anthony Keck  
PO Box 8206  
Columbia, SC 29202-8206

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1. DDSN did not have sufficient built in accountability regarding the PDD Waiver for any authorized agency receiving PDD Waiver funding, so they will not abuse the public trust by not delivering quality ABA services. The following are a few of many reasons why I believe Suzie needs compensatory services:
  - a. The Coordinator did not have regular monthly visits to monitor progress, implement the program to meet evolving needs, and to train the lead and line therapists regularly.
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Another example is when Suzie began engaging in maladaptive behaviors that were significantly affecting her social life as peers started saying, "Suzie, you are weird," since last December 2012. Lines have been charting frequencies and intensity (these behaviors occurred before any charting) of maladaptive behaviors, yet as of today, nothing is being implemented to correct Suzie's maladaptive behaviors. If lines spend great deal of time recording the data, there should be something implemented, especially if these behaviors are new, keep escalating, and affect her social life.

- d. One lead named, Lisa Pace filed a claim for the service that was not rendered. Suzie was gone out of state in the first part of August in 2011. Lisa Pace worked with Suzie over two years, and along these months, she only stayed onsite for 4 hours while she was billing for 6 hours. She rarely responded to our emails or line's emails, so I was not sure why she had to get paid for 2 hours of offsite.

Please note here that I was not able to check all the itemized bills, so I would not know how much EAP overbilled over the years; however, certain days such as the above case, I do know since it was not our regular visit. During her visits and other visits from leads', those days seem to be filled with little or no training that was documented on any forms.

- e. Suzie's second lead caused Suzie to be asked to leave a private pre-school because of the manner she disciplined Suzie in the classroom, which concerned the teacher and school. Suzie had nowhere to go for some time. She later lost lines due to the actions of this coordinator moving those lines to another family, leaving Suzie without line therapists, so my husband desperately had to locate other lines at our own expense.

- f. The Coordinator never provided any continuity of the program to new leads each time we had lead changes. One former lead named, Catherine Carbon implemented wrong programs that were already tried and removed by Suzie's previous lead, Lisa Pace, and the coordinator, for reasons they were not appropriate for Suzie. Catherine Carbone also cut Suzie's programs to minimize her work, as claimed Suzie mastered even when not so. Furthermore, due to the lack of sharing information between the coordinator and the leads, wrong programs were implemented against parents' resistance, which eventually proved to Catherine Carbone why those programs were already taken out previously costing Suzie valuable time with the PDD Waiver.

- g. Catherine Carbone always had many excuses for not showing up, leaving early, placing wrong programs, never training lines, etc.

While Suzie was gone to overseas in July, 2012, Catherine Carbone insisted the family have her visit, otherwise, Suzie's program might be cancelled. She worked less than 2 hours in these weeks. She knew the program would not be cancelled as long as there was a service within 30-day period, but she insisted to come. In the fear of retaliation, my husband let her come to the house during Suzie's trip to overseas.

h. EAP never helped us to locate lines. We spent hundreds of dollars to advertise for lines; however, once lines were situated in our home, the agency placed them in somebody else's house. EAP would even solicit the lines we had working for Suzie to work with other families, in other locations or even lead positions when we did not have any other lines and needed lines to fill Suzie's authorized ABA hours.

i. Due to the lack of line therapists' availability, Suzie could not get to fully utilize her authorized hours (37 hours per week).

j. We were retaliated if we shared our concerns, such as our emails went unanswered, no return phone calls, the coordinator cancelled visits or lines were placed in somebody else's house, etc.

k. When lead was on vacation, the coordinator brought in-clinic regional lead therapist named Erica Painter, BCaBA, to drive the coordinator. I have not seen one single word coming out of her mouth to train lines during any of those visits/ days. She just sat as a lead and watched the coordinator, yet she billed her hours as a lead visit. I would rather not have her to save my tax dollars on the days when she drove the coordinator down to bill for her lead hours.

Our current fill-in coordinator named Jaime White mentioned that she would love to be Erica Painter whose job description was to go get coffees for other coordinators, drive around Suzie's coordinator named Angie Keith to different places, run errands and receive a good salary. I do believe in some accountability need for this portion also.

l. The Coordinator and lead inflate and manipulate the data as if there were true progress. Lines affirmed that the current lead was collecting only selective data. The former leads probably did the same thing, but back then, neither of us were not trained enough to know how much they had been inflating the data. I am a fulltime student at College of Social Work in USC, so I know better now.

2. Research supports that prevention intervention is much more cost effective than crisis intervention. The most recent tragedy at Sandy Hook was a good example of how Adam Lanzas might be a victim of lack of early intervention. I do understand that it was beyond one simple causation for this unspeakable tragedy; however, if Adam was taught to choose more adaptive behaviors to deal with whatever he was feeling, Sandy Hook tragedy might have been avoided.

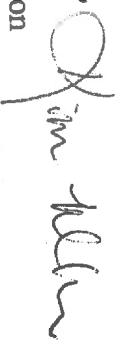
Suzie is extremely intelligent but continues to struggle with social and pragmatic deficits.

As parents, we support her fully to prepare her to become a productive individual in social. It would be much more cost effective for South Carolina to grant Suzie with extended ABA services to prepare her than let her miss that opportunity. If services by the EAP were delivered as intended fully, Suzie would have met her full potential more than where she is at right now.

Please read the attached appeal letter to DDSN also to supplement these claims.

Sincerely,

Kim Nelson

A handwritten signature in cursive script, appearing to read "Kim Nelson", written in dark ink.

**FW: Suzie Nelson/itemazied bills**

M Kim [mkn\_550@naver.com]

**Sent:** Friday, February 15, 2013 9:39 PM

**To:** NELSON, MYUNGHEE

**Attachments:** EIBI EAP.pdf (662 KB)

A copy of email that I sent to Mr.  
Daniel Davis @ DDSN.

-----Original Message-----

**From:** "M Kim"<mkn\_550@naver.com>

**To:** "Davis Daniel"<DDavis@ddsn.sc.gov>;

**Cc:**

**Sent:** 2013-02-13 (ㄴ) 11:05:30

**Subject:** Suzie Nelson/itemazied bills

2-12-13

Hi, Mr. Davis,

Pursuant to your conversations with Ron this afternoon that it would be difficult to check the EAP's billing if they overbilled, I am going to explain how I knew they were billing me more.

Before the Waiver kicked in, I applied and received some grants to pay toward Suzie's deductibles and copayments toward her ABA that were provided by EAP. In order for the grantor

to pay, the EAP had to provide itemized bills such as the attached bill. I only received \$3k, so every single dollar was very important for me, so I compared itemized bills with timesheets

that were submitted. Sure enough, I noticed many false claims that were not rendered. I asked EAP to reimburse me, and it tooks months for them to honor. I spent so much time with them

to get my money back. Even after the Waiver kicked in, they were keep charging my credit cards without my authorization. Kate from Bright Start and you helped me to get our money

back from the EAP. (Thank you!)

I began making copies of all time sheets, after noticing how much EAP overbilled. Unfortunately, EAP would not provide me with any more itemized bills since there was no grantor who

Early Autism Project, Inc. BILLING-1

8164

Federal ID #14-1859573  
2580 Lin-Do Court  
Sumter, SC 29150

| Date     | Invoice # |
|----------|-----------|
| 1/8/2010 | 010310    |

Bill To

Myungtee & Rod Nelson  
2604 Live Oak Circle  
Beaufort, SC 29902

| Patient Co -Insurance Due |                      | Diagnosis      | Client ID    | Terms          |
|---------------------------|----------------------|----------------|--------------|----------------|
| 185.80                    |                      | 299.00         | Suzie Nelson | Due on receipt |
| Date of Service           | Clinical Services    | Description    | Units        | Amount         |
| 1/13/2010                 | Filed To Primary ... | BCBS PRO - CBA |              |                |
| 12/29/2009                | L/T-Vikki Elmore     | G0177          | 4            | 132.00         |
| 12/29/2009                | ADMIN TIME           |                | 2            | 66.00          |
| 12/21/2009                | L/T-Kimberly Do...   | H0046          | 3            | 51.00          |
| 12/22/2009                | L/T-Darlene Casuga   | H0046          | 6            | 102.00         |
| 12/22/2009                | L/T-Nina Babanto...  | H0046          | 1            | 17.00          |
| 12/23/2009                | L/T-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/23/2009                | L/T-Darlene Casuga   | H0046          | 3            | 85.00          |
| 12/24/2009                | L/T-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/27/2009                | L/T-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/28/2009                | L/T-Kimberly Do...   | H0046          | 1            | 17.00          |
| 12/29/2009                | L/T-Shannon Ray      | H0046          | 6            | 102.00         |
| 12/29/2009                | L/T-Kimberly Do...   | H0046          | 4            | 68.00          |
| 12/30/2009                | L/T-Kimberly Do...   | H0046          | 2            | 34.00          |
| 12/31/2009                | L/T-Kimberly Do...   | H0046          | 4            | 68.00          |
| 12/31/2009                | L/T-Kimberly Do...   | H0046          | 5            | 85.00          |
| Payments/Credits          |                      | Total          |              |                |
| \$0.00                    |                      | \$929.00       |              |                |

This statement lists charges that may be pending processing with your insurance carrier. Thank You.



Beverly A. H. Buscemi, Ph.D.  
State Director  
David A. Goodell  
Associate State Director  
Operations  
Kathi K. Lacy, Ph.D.  
Associate State Director  
Policy  
Thomas R. Waring  
Associate State Director  
Administration

3440 Harden Street Ext (29203)  
PO Box 4706, Columbia, South Carolina 29240  
803/898-9600

Toll Free: 888/DSN-INFO  
Website: [www.ddsn.sc.gov](http://www.ddsn.sc.gov)

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Harvey E. Shiver  
Katherine Llamas Finley  
Eva R. Ravenel

January 23, 2013

Ms. Kim Nelson  
2604 Live Oak Circle  
Beaufort, South Carolina 29902

Re: Request for reconsideration for Suzie Nelson

Dear Ms. Nelson:

The South Carolina Department of Disabilities and Special Needs (SCDDSN) received your letter requesting the reconsideration of the termination of Pervasive Developmental Disorder (PDD) Program services for your daughter, Suzie. I am pleased to hear that she has benefited from services through the PDD Program.

The 2006 - 2007 General Appropriations Act that created the PDD Program stipulated that participants could receive PDD Waiver services for a maximum of three years. In addition, the Centers for Medicaid and Medicare Services who approved South Carolina's PDD Waiver established the same participant criteria.

The start of Medicaid PDD Waiver services is based on a participant's enrollment date; in Suzie's case, her enrollment date was January 5, 2010. This means her three-year period began on January 5, 2010 and was scheduled to end on January 4, 2013. We realize some participants experienced difficulties in locating a provider and this led to the passage of several weeks before services actually began. In an effort to address this, a process was developed that could extend a child's participation in the PDD Program after their initial three year period ended. The length of the extension is based on the number of days between the participant's enrollment date and their Initial Assessment; the first therapy service according to the approved Medicaid document. Per our records, Suzie's Initial Assessment was completed on May 15, 2010. This means Suzie's PDD services have been extended 130 days beyond the January 4, 2013 date and she will receive PDD State Funded services through May 14, 2013. While I understand your concern for the hours of service lost, the PDD Program does not allow EIBI therapy hours to be carried forward from week to week. Unfortunately, I am not able to grant your request to receive "compensatory Applied Behavior Analysis" services beyond the May 14, 2013 date.

If you are not satisfied with the SCDDSN decision in this matter you have the right to appeal directly to the Medicaid agency (South Carolina Department of Health and Human Services). The appeals process is attached for your review.

Sincerely,

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

Cc: Anita Atwood, SCDDHHS

DISTRICT I

P.O. Box 239  
Clinton, SC 29325-5328  
Phone: (864) 938-3497  
Midlands Center - Phone: 803/935-7500  
Whitten Center - Phone: 864/833-2733

DISTRICT II

9995 Miles Jamison Road  
Summerville, SC 29485  
Phone: 843/832-5576  
Coastal Center - Phone: 843/873-5750  
Pec Dee Center - Phone: 843/664-2600  
Saleeby Center - Phone: 843/332-4104

# PDD WAIVER ACCOUNTABILITY WORKSHOP

By Chris Landrum

## INTRODUCTION

*EAP did not meet these requirements!*

### What Is Accountability?

- **Measurable**  
A child's progress (or lack thereof) is documented, observed, and analyzed.
- **Answerable**  
Service providers are answerable for the quality and quantity of the services they provide or fail to provide.
- **Accessible**  
Parents have access to the PDD Waiver guidelines, financial records, assessments, and therapy documents.
- **Adaptable**  
Services are adapted to the child's needs.
- **Specific**  
Progress, records, data, and information is specific and action-oriented.

### What Are The Benefits Of Accountability?

- **Child Makes Maximum Progress**  
A child has the opportunity to make maximum progress when their EIBI services are measurable, adaptable, answerable, and specific.
- **Parents Feel Excited And Hopeful**  
When their children's quality of lives improve, parents feel excited and hopeful for the future.
- **EIBI Providers Feel Appreciated**  
As a result of parents feeling excited and hopeful, EIBI providers will feel like they are making a difference.
- **State Officials Improve The System**  
State officials get the feedback they need to improve the program.
- **Legislators Maintain Or Expand Funding**  
Legislators receive the justification of why they should fund the PDD Waiver instead of another worthwhile cause.

## How Should Parents Be Held Accountable?

- Educate Yourself On EIBI Services  
Learn the basic principles of Applied Behavior Analysis (ABA) so you can hold the quality of your provider's services accountable.
- Improve Your Communication
- Advocate For Your Child
- Participate in the PDD Responsible Party Program
- Educate Other Parents About Issues Concerning The PDD Waiver

## OBSTACLES

### What Are The Obstacles? Parents/Guardians

- ✓ Misinformation  
It is my understanding the PDD Waiver guidelines are vague, ambiguous, and open to interpretation. Parents find it difficult to get access to the information. As a result, it is difficult to fact check what others tell you. It takes time and effort to contact the limited few who can answer your questions.
- ✓ Lack of Information  
Parents fail to have a concept of what is possible (the best possible program) because they find it difficult to get access to the PDD Waiver Guidelines, have limited knowledge of ABA, and are conditioned to trust and comply with authority figures.
- ✓ Fear of Retaliation  
Parents feel if they ask questions or complain, the providers might reduce therapy time, take away therapists, provide a less knowledgeable Coordinator, deny services, or abuse their child.

### What Are The Obstacles? EIBI Providers

- ✓ Lack of Staff  
Providers have an insufficient number of qualified and trained staff to perform EIBI services.
- ✓ Finding a Needle in a Haystack  
Finding motivated and interested people to become Line Therapists expends time, effort, and money.
- ✓ Less Profit  
To attract more potential Coordinators, Lead Therapists, and Line Therapists, providers may be forced to accept less profit per hour billed.
- ✓ Resistance To Change  
Some providers may resist change because they are complacent with their current business practices.

Then if parents know, it is very difficult to make providers' to provide necessary for children or would face retaliation



## Your Plan For Accountability

### Step #1: Gather Information

- ✓ **Initial Evaluations**  
Evaluations performed by the EIBI Consultant/Coordinator before your child was authorized to receive PDD Waiver services.
- ✓ **SCDDSN Authorization Paperwork**  
Paperwork that tells how many units (or hours) of Plan Implementation, Lead Therapy, and Line Therapy a child is authorized to receive through the PDD Waiver.
- ✓ **EIBI Records**  
Supervision notes, skills tracking (probe) sheets, manding sheets, program sheets, behavior sheets, communication logs, and graphs.
- ✓ **Financial Records**  
An itemized printout of what the EIBI provider has billed for through the PDD Waiver.

## Your Plan For Accountability

### Step #1: Gather Information

- ✓ **PDD Waiver Guidelines**  
The policies and procedures that govern the PDD Waiver.
- ✓ **Correspondence Logs**  
All correspondence with the providers, service coordinator, state officials, legislators, organizations, other parents, etc.
- ✓ **Contact Information**  
The contact information for the provider, service coordinator, coordinator, lead therapist, and line therapists

## Your Plan For Accountability

### Step #2: Know The Rules

- ✓ **Know Your Child**
- ✓ **Know Your Rights and Responsibilities**
- ✓ **Know The People**
- ✓ **Know The System**

## Your Plan For Accountability

### Step #3: Get Informed

- ✓ **Analyze The Data**
- ✓ **Reverse Engineer The Perfect Program**
- ✓ **Organize Any Questions and Concerns**



## PROBLEMS/CONCERNS

### Who Do You Contact With Concerns And Problems?

- **Service Coordinator**  
If you have any questions or concerns about the quality or quantity of services your child received or didn't receive from your EIBI provider, contact your PDD Waiver Service Coordinator.
- **SCDDSN (Autism Division)**  
Contact Daniel Davis, Director of the S.C. Department of Disabilities and Special Needs (SCDDSN) Autism Division, about any questions, concerns, or suggestions you may have concerning your child's PDD Waiver services. You can reach him at 803-898-9639 or [ddavis@ddsn.sc.gov](mailto:ddavis@ddsn.sc.gov)
- **EIBI Provider**  
Contact your child's EIBI provider with any questions, concerns, or suggestions. Send the provider any written responses from your Service Coordinator or Daniel Davis.



## Who Do You Contact With Concerns And Problems?

- **Parent Support Groups**  
Join a parent support or advocacy group and learn from other parents who have dealt with the same or similar issues.
- **Parent Training/Advocacy Organizations**  
Contact a parent training or advocacy organization to get more information on your issue, referrals to the right contacts, or



## How Do You Make A Formal Complaint Against A Provider?

- **Does Your Child Receive PDD Waiver Services Through Medicaid?**  
Contact the S.C. Department of Health and Human Services Fraud & Abuse Hotline at 1-888-364-3224 or [fraudab@scdhhs.gov](mailto:fraudab@scdhhs.gov) (if fraudulent activity is suspected, the Division of Program Integrity will turn the case over to the Medicaid Fraud Control Unit in the State Attorney General's office.)
- **Does Your Child Receive PDD Waiver Services Through State Funds?**  
Contact Daniel Davis, Director of the S.C. Department of Disabilities and Special Needs (SCDDSN) Autism Division, at 803-898-9639 or [ddavis@ddsn.sc.gov](mailto:ddavis@ddsn.sc.gov)



## **How Do We Persuade Legislators To Maintain Or Expand Funding?**

- Enlighten Them About Autism and the PDD Waiver
- Present Evidence Of Progress
  - Show video evidence and proof to legislators (a DVD or CD compilation of parents and children).
- Build Relationships
  - Establish a relationship with legislators by contacting them throughout the year (not just when we need funding).
- Visit The State House in Groups and Take Your Children With Therapists