

NOV - 4 2010

Assemblyman Jim Beall Jr.
State Capitol
916-319-2124 (Fax)

November 2, 2010

Dear Assemblyman Beall,

I am writing to you in response to requests for comments for the Senate and Assembly Human Services Joint Oversight Hearing of California's Regional Centers on November 4, 2010.

I am a Marine Corps wife and mother of 2 children (one with autism). My husband is currently deployed to Afghanistan in support of Operation Enduring Freedom.

As a leader in our community, I know you understand the fiduciary responsibility to our California taxpayers to make sound decisions for the good of society. Along those same lines, I know you also understand the moral obligation our community has to support and care for our military service members and their families. During this time of war with its high tempo of operations and attendant stresses, military families face an extreme set of circumstances. Add the challenges of autism and the difficulties in accessing and paying for effective treatments, and families are understandably pushed to the brink. We need your help and leadership to address the shortfalls in autism treatment services and improving the health and well being of our military children.

That being said, it is important to highlight the cost effectiveness of providing for behavior intervention services. Autism is treatable, and with treatment, children can make significant gains reducing the long term costs to society. Cost to care for an individual with autism is estimated at \$3.2 million dollars over the individual's lifetime. To a great extent, this will be funded with tax dollars with approximately 90% of costs associated with adult services (i.e. assisted living, medical, etc.). Without effective intervention, approximately 90% of individuals with autism will require lifelong care. Evidenced based behavioral early treatments, like Applied Behavior Analysis (ABA therapy) have been shown to be effective in reducing this figure to less than 50% and reducing the costs of lifelong care by two-thirds! The cost savings associated with providing early intervention services for the treatment of autism is well documented. Families need your help to ensure services through the Regional Centers are accessible and provided at appropriate amounts to families that need assistance.

I believe that my personal story highlights some of the short sided and frankly impulsive decision making the San Diego Regional Center (SDRC) is making.

In September 2009 the SDRC sent me a Notice of Proposed Action stating that "SDRC will stop funding 5 days per week ABA program as of 10/16/09, with Comprehensive Autism Center." In response I filed a Fair Hearing Request and had an informal meeting on October 13, 2009. Unfortunately, very little came of the informal meeting—not because of a lack of willingness by either party to forge an understanding or agreement—but largely because, as Mr. Plotkin admitted, the parties from SDRC had not yet even reviewed Jacob's file or the circumstances surrounding our appeal. Not surprisingly, this made discussion of Jacob's case on the merits impossible, leaving us to do our best to summarize our main concerns yet again, to someone who had little to no knowledge of the contents of Jacob's Individual Program Plan (IPP), his continued deficits and areas of need, or his "developmental potential" based on a more current evaluation of his program data, recent diagnostic information, and a more developed understanding of his cognition and prognosis for independence.

I am concerned that SDRC's approach to our son's case has had very little to do with his individual needs as they relate to his progress on identified areas of his IPP, or even current input from his service provider. Instead, it is evident there appears to be a uniform approach by SDRC toward nearly all of its military clients receiving ABA services.

Because some military dependents have access to a few hours of ABA services under TRICARE's Extended Care Health Option (ECHO - a supplement to our Tricare health insurance available for certain eligible military dependents), military clients of the SDRC received notices of termination. This appears to be SDRC's justification to cut all ABA services being provided by SDRC—instead of first doing appropriate needs assessment to determine whether they have a responsibility to continue to supplement ECHO services. It is important to note that ECHO services have always fallen far short of our son's prescribed treatment plan and that is why we (and many more military families residing in San Diego) rely on the additional services of the SDRC.

While SDRC took nearly eight months from the time of Jacob's initial referral to begin providing any services (7/15/08-3/1/09), our family was forced to pay privately--thousands of dollars each month--to supplement his ECHO services so that Jacob's program might approach a level of intensity which research shows would likely result in Jacob's ability "to enable [Jacob] to approximate the pattern of everyday living available to people without disabilities of the same age." (Welfare and Institutions Code Division 4.5 Sec. 4501)

The resolution to the Informal Meeting was set forth in a letter dated October 15, 2009 as follows: "Plan of Action: As is apparent that there is ambiguity with respect to determining Jacob's ABA needs and identifying the relative responsibility from each funding agency. It is therefore proposed that Dr. Lynn Wilson, a psychologist/BCBA vendor of the Regional Center conduct a thorough assessment of Jacob's needs and develop recommendations regarding the appropriate number of

hours of ABA services to be funded by the Regional Center. This report and recommendations would then be presented at Jacob's IPP meeting for discussion and approval." As this plan of action was what I believe should have occurred in the first place, I agreed and signed the Notification of Resolution on October 29, 2009.

We held the IPP on March 24, 2010. In accordance with the plan of action, an Intensive Behavior Intervention Review dated February 24, 2010 was conducted by Dr. A. Lynn Wilson. The recommendation of the report was "4 days per week of intensive interventions (2 hours per session) with supervision of 2 hours per week, with anticipated reductions after 6 months to one year of continued service."

We were shocked that Dr. Wilson would recommend a program that was more than a 70% reduction in the current direct hours and at a level well below that recommended by the American Academy of Pediatrics (25 hours per week of direct therapy). SDRC sent a Notice of Proposed Action on March 25, 2010 stating "SDRC has been funding 12 hours per week since 3/2009. SDRC will reduce to 6 hours (4 hours direct, 2 hours supervision) per week effective 30 days from receipt of this notice." I filed a Fair Hearing Request stating that the proposed action was a "60% reduction in direct hours. A reduction in therapy hours will severely and negatively impact Jacob."

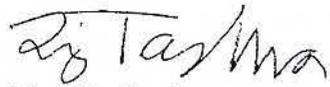
At our Fair Hearing on July 26, 2010 we presented our own assessment by Dr. Mitchel Perlman. In the Fair Hearing Decision, Judge Donald P. Cole wrote that "Dr. Perlman testified in a highly professional, straightforward, articulate manner...Dr. Wilson and Dr. Perlman were in agreement that Jacob needs 20 hours of direct ABA per week. Dr. Perlman stated that Jacob in fact needs at least 25 hours per week. Accordingly, that Jacob needs the ten hours of direct ABA services currently funded by the service agency is not in dispute. Instead, the issue presented in the case is whether the ten hours per week of direct ABA services currently funded by the service agency is available through Jacob's school district, so that pursuant to Welfare and Institution Code section 4649, subdivision (c) the service agency is no longer obligated to fund such services." Our appeal was granted and the service agency ordered to continue to fund ten hours per week of direct ABA services.

Jacob has made tremendous gains since accessing intensive, research-based ABA in the fall of 2008. We are glad that we pursued funding from SDRC even though the process was expensive and especially difficult as my husband was in Afghanistan during the Fair Hearing. We believe it was the right thing to do. I do not believe that the legislature intended that direct services be the first to be cut in order to balance the budget, and yet that seems to be exactly what SDRC has done for most of the military children with autism depending on these vital services to supplement the shortfalls of TRICARE programs. It is important to again highlight the cost effectiveness of providing for behavior intervention services.

Attached for your consideration is a copy of Assembly Joint Resolution 46 (which passed unanimously through the Assembly Health Committee, Assembly Floor, and

Senate Floor) calling on Congress to address the treatment needs of military children with autism. Until Washington can come up with the answers, our children need your help.

Sincerely,

A handwritten signature in black ink that reads "Liz Tashma". The signature is written in a cursive, flowing style.

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