

TESTIMONY

Senate Bill 2155—Senate Human Services Committee

Senator Lee, Chairperson

February 14, 2011

Chairperson Lee, members of the Senate Human Services Committee, I am Dr Kenneth Fischer, a physician who specializes in Pediatric Psychiatry.

I have had the privilege of working with Autistic Spectrum Disorders (ASD) afflicted children and their families for over a decade now, in multiple settings (inpatient, outpatient, community, schools, etc). I am also the newly appointed Medical Director for Behavioral Health, at Blue Cross Blue Shield of North Dakota.

I am familiar with the findings of the North Dakota Autism Spectrum Disorder Task Force Initial State Plan-2010 and the published North Dakota *Guidelines: Identifying, Serving and Educating Children and Youth with Autism*. For me SB2155 is personal.

The cornerstone of good professional practice remains, even in our own time, *Primum Non Nocerum: First Do No Harm*. By helping to define uniform standards, content and criteria for the licensure and registration of “Applied Behavior Analysts”, “Registered applied behavior analysts” or “registrants”, **SB2155** helps to maintain that cornerstone. So I want to share my support of **SB2155**, and in particular the amendments prepared by the legislative council in **11.0017.01001**, with some slight modifications outlined in the following three brief points:

(1), I am glad that both sets of **amendments --11.0017.01001 and 11.0017.01002**—when referring to **un-amended SB2155, Page 1, line 14, after “2”**, include the insertion of a definition of an Autism Spectrum disorder.

Indeed, like diabetes or cerebral palsy for that matter, ASD is a chronic **neurobiological medical condition**. I agree with the language of both amendments exactly as written.

(2), I worry about some troubling ambiguity in the language on **page 5 of amendments 11.0017.01001**, which refers to **un-amended SB2155, page 3, line 23** where after the word **“member”**, the amended language would insert **“or as a paid or volunteer caregiver implementing procedures established by the family or by the individual served in any setting, if the caregiver does not represent as a registrant or applied behavior analyst”**

I would simply request that three additional words be inserted after the second use of the word **“caregiver”** to read: **“Implementing applied behavior analysis services to an immediate family member or as a paid or volunteer caregiver implementing procedures established by the family or by**

the individual served in any setting, if the caregiver or family member does not represent as a registrant or an applied behavior analyst.”

In some states that lack of clarity has allowed that a parent or parents then be eligible for reimbursement as a services provider without the oversight provided by licensure and registration. There is, in my measured professional opinion, an inherent contradiction in any legal definition that might define a parent as their son or daughter’s therapist, not to mention the obvious classic conflict of interest.

(3), I am also worried about the proposed language in the exemptions section on **page 6 of 11.0017.01001**, which refers to un-amended SB2155: **page 5, after line 7, insert** under “6 c. **Registration as an applied behavior analyst if the applicant has a bachelor’s degree; provides a board-approved plan of supervision from a licensed psychologist or applied behavior analyst; and is employed as a behavior analyst as verified in writing by the applicant’s employer. Acceptable work titles for an applicant under this subdivision include behavior analyst, behavior interventionist, and behavior modification specialist.”**

The titles *behavior analyst*, *behavior interventionist*, and *behavior modification specialist* are not uniformly defined titles in the bill, or in the world of clinical practice. They are not, by definition, interchangeable with ABA based on the true intent of this bill. Their presence in the bill, as written, essentially tie the hands of the Psychology Board from any meaningful credentialing, quality control and oversight.

I would propose that immediately following the words “**Acceptable work titles**”, the words “**for an applicant under this subdivision include behavior analyst, behavior interventionist, and behavior modification specialist**” be deleted.

In their place, insert: “shall be determined by the board.” In my opinion, such determination should unequivocally be done by the board of psychologists via administrative rule or some other equivalent procedure.

Consider that we have an obligation to these children, as **SB2155** sets out to do, to ensure that there are uniform standards, content and criteria included in the definition of “**Applied Behavior Analyst**”, “**Registered applied behavior analyst**” or “**registrant**” that: clearly meet the legal standards established through state, federal and case law, identify “best practice” and ethical standards of the behavior analysis profession, and develop eligibility standards to certify or recertify that professional.

(See **amendment 11.0017.01001, page 5**, referring to **un-amended bill Page 4, line 16**, replace...” **which may not be less than...**” Please recall, Senators, that the amended language then goes on to cite professionally agreed upon the *minimum* ABA standards that should be required to treat these vulnerable, medically complicated and unique children).

In addition to the specific three points noted above, I agree with SB2155's obvious intent to ensure high quality standards for these children by licensing and registering Applied Behavior Analysts without endorsing Applied Behavioral Analysis (ABA) above other forms of therapies. To have done so would have the net result of moving the care of ASD afflicted individuals out of the setting where best practice guidelines and an emerging expert consensus believe they should stay: the school.

Immediate referral, usually by the primary care physician in the medical home, in the first few months to years of life at the moment an ASD is simply suspected, to a school based early intervention program, is critical because ASD children often have language delays and the inability to "learn how to learn" by the condition's very nature. (Hence they need an integrated multidisciplinary approach that can be realistically provided only in a school setting given the intensity of the intervention required).

Please keep in mind that prior to comprehensive treatment, a multidisciplinary assessment is essential, and includes a complete medical evaluation by a licensed physician (with particular attention to family history for an Autism Spectrum Disorder, mental retardation, fragile X Syndrome, tuberous sclerosis; seizures, brain injuries, lead and other metabolic testing, others), testing supervised and interpreted by an licensed psychiatrist or PhD psychologist including Intellectual testing, Adaptive testing, Communication testing, Autism measures, hearing testing by an Audiologist, etc.

It is essential to do all we can for autistic children. Autism Spectrum Disorders, similar to all neurodevelopmental disabilities, are not "curable" and chronic sophisticated management is required, and often best found at the local community level, in the school, and coordinated in the office of the child's physician and medical home. Educational interventions (as early as possible after proper diagnosis or even sometimes before, when ASD is only suspected) and behavioral therapies (in the child's natural school environment) and habilitative therapies (PT, SL, OT) remain the cornerstone of treatment. Though schools may differ in philosophy and relative emphasis on particular strategies, they share common goals.

The primary goals of early intervention for these children (and eventually young adults) therefore, are to minimize autism's core features (social, communication and narrow interests) and associated deficits, maximize independence and quality of life, and minister to affected families who are often in distress. We accomplish these by facilitating development and learning, promoting socialization, reducing maladaptive behaviors (usually by methods that are eclectic, incorporating some principles of operant learning theory, structured teaching, speech and language therapy with or without picture communication or related augmentive or alternative communication strategies, sensory integration therapies, head start activities, with appropriate neurological, psychological and psychiatric consultation as needed), and educating and supporting the family and school system.

Because these families are vulnerable, I often encourage them (even after proper diagnosis) to seek additional information, second opinions, and the advice of trusted family, friends, and their primary care physician, whenever they encounter claims of treatments based on simplified scientific theories, therapies that are claimed to be effective for multiple, different, unrelated conditions or symptoms (which is often the case with ASD), claims that their child will respond dramatically and that some will be

“cured to the point of being normal” (whatever “normal” means), the use of case reports or anecdote rather than carefully designed studies, etc.

By pursuing any “one size fits all” form of treatment , the opportunity costs could be high, indeed, of providing suboptimal care to these children, just because we as “expert” clinicians of all stripes don’t yet know what works best. If we accept any intervention because it “seems to work”, without solid evidence, research on alternatives often gets stifled.

We are only at the beginning, and much additional research is needed to identify those characteristics of any behavioral treatment (including ABA) for kids on the autism spectrum (content, technique, how often, when to start and when to stop) to maximize the treatment’s effectiveness.

The overall quality of the studies in the field need to be vastly improved, including a greater emphasis on randomized controlled trials when possible, larger sample sizes (number of kids enrolled), uniform outcome measures (to see if what we’re doing is making a difference), and finally, consistent treatments (by providers trained to the highest available standards) that don’t vary so much across environments.

Moreover, studies have not yet examined (or have done so woefully inadequately to date) the impact of changing from one therapeutic approach to another, (in real time) for children showing no/little progress; hence, there are no prescriptive formulas to help clinicians, parents and teachers select which types of treatment for ASD children who differ in their behavioral profiles after initial observation. Stated another way, ASD’s are associated with a tremendous range in syndrome expression; that is, symptoms change over the course of development and in relation to the degree of any associated developmental disability. An ongoing awareness of the range of syndrome expression and an appreciation of the complexities of developmental change are important, even for the most seasoned of clinicians.

Though individuals with ASD’s may present for evaluation and treatment at any point during their development, most children with ASD unfortunately will remain within the spectrum as adults, and, regardless of their intellectual functioning, continue to experience problems with independent living, employment, social relationships and mental health. That is what we know from the current state of the science, and from the clinical experience of those of us clinicians who have followed these families along their Autism Journey over time.

Each child needs a unique, comprehensive treatment and education plan from a multidisciplinary team. **SB2155** helps ensure that any newly licensed members of that team have the minimum necessary training for the immense task at hand, as they keep in mind Hippocrates’ timeless precept: First Do No Harm.

Chairperson Lee, members of the committee, I submit these remarks with gratitude for your time and consideration.

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