

Twenty Years After the Mickelson Autism Bills

by Gail C. Eichstadt

"It's tough being green." - Kermit the Frog.

We laugh at this statement because we know frogs cannot talk and we perceive it cannot be tough being a green frog. It can be tough, however, if being green means you are different, like having a physical or cognitive impairment. Many South Dakotans remember a time when children with cognitive disabilities were not allowed in public schools and were instead sent to the South Dakota Developmental Center in Redfield. I remember a young man with braces and arm crutches at my three-story community school. Throughout each day, he left class early with a friend who carried his books. They slowly climbed or descended the stairs to get to their next class.

In 1975, President Gerald Ford signed the Education for all Handicapped Children Act (EAHCA), which was also commonly referred to as Public Law 94-142 (with later amendments, the name was changed to the Education of the Handicapped Act (EHA), the Individuals with Disabilities Education Act (IDEA), and most recently, the Individuals with Disabilities Education Improvement Act (IDEIA, but still referred to as IDEA in practice)). Congress passed this legislation to "...insure that all handicapped children have a free and appropriate public education which includes special education and related services to meet their unique needs."

The categories of disabilities in P.L. 94-142 included mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, other health impairments, and specific learning disabilities. Autism was not a listed disability. In 1975, South Dakota was one of two States that did not identify a child who needed special education by specific category. Massachusetts was the other "non-categorical" State. A child with autism could be included under the category of other health impaired or mental retardation as appropriate for a given child.

Some districts in South Dakota recognized that children with autism were eligible for and were provided special education services. Other districts took the position autism was a medical condition that was not the district's responsibility and refused to provide special education to a child with autism.

If a child with autism received special education services, his teachers had little, if any, preparation to teach the child. A survey conducted for the Learning Disabilities Task Force in 1986 reported that 71% of elementary teachers trained in South Dakota colleges and universities felt they were inadequately prepared to recognize a child with autism (let alone teach the child).

Parents of children with autism in South Dakota formed the South Dakota Autism Society. Cathy Maynard and Julie Wratz were co-presidents. They and other parents recognized their children needed the free appropriate public education guaranteed to other children with disabilities by P.L. 94-142.

In 1987, the Summer Legislative Education Committee formed an Autism Task Force to study the unmet needs of children with autism. Task Force members were Representative

Roger Porch, Ron Goldsmith, Curt Keiser, Deb Barnett, Cathy Maynard, Julie Wratz, and Sachi Spiegle. In January 1989, the Task Force issued a report detailing the difficulties parents faced in locating professionals who were able to recognize signs of autism and diagnose it. Most families traveled to other States for a diagnosis. It also detailed abusive and aversive treatment some children received under the guise of behavior modification, including: restraint in a chair used for children with spinal injuries (Kinder Chairs); forced toe-touches; isolation for child tapping chin; forced tooth brushing with Listerine for spitting; applying Bite-X to front and back of hand to prevent putting hands in mouth; withholding water; strait-jacket style physical restraint for 20 minutes; isolation room without light for a preschooler; and using a locked time-out room for a day with no restroom breaks.

After identifying problems, the Autism Task Force Report set out recommendations to improve the education of children with autism. These included: Establishing an independent autism center for evaluation and diagnosis, training, dissemination, technical assistance, and research; pre-service and in-service training for teachers; a definition of autism; early diagnosis; parent/family support services; protective measures; autism representation on boards/councils; and appropriate education.

All the recommendations were introduced in the 1989 legislative session as House Bill 1239 - "An Act to appropriate money for the operation of an autism training center." Representative Roger Porch of Wanblee and Senator Mary Wagner from Brookings spoke in favor of the bill before the House Appropriations Committee on February 3, 1989. Five parents and two professionals testified in favor of the bill. A motion to defer the bill prevailed on a voice vote of committee members. The Committee took testimony again on February 15 and witnesses reviewed what work had been done in the State. The members took no action on the bill.

The Appropriations Committee considered HB 1239 again on February 25, 1989. The Committee tabled HB 1239. Unfortunately, no parents were able to be present at the hearing. This action killed the bill for that session. [See House Committee on Appropriations minutes for 64th legislative session.]

Concerned parents continued working for change to help their children. The Task Force recommendations were divided into six separate bills for the 1990 legislative session. Senator Mary Wagner championed the cause for children with autism as the prime sponsor for:

1. Senate Bill 203: Required tracking of autism in surveys, child counts, and tracking systems of several State departments;
2. SB 204: Required the State Board of Education to adopt certification requirements for teachers of those with autism;
3. SB 205: Provided rule-making authority for autism diagnosis procedures and standards;

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4. SB 206: Prohibited abusive treatment of those with developmental disabilities; and

5. SB 207: Defined autism in the SD Codified Laws.

Furthermore, Representative Jan Nicolay sponsored House Bill 1325, which provided funding for an independent autism center at the University of South Dakota.

My son, Carl, was diagnosed with mild-to-moderate autism in 1988 when he was three years old. It was my concern for him that led me to leave my job as a home day-care provider and ask South Dakota legislators to pass laws to improve the lives of children with autism. Under Senator Wagner's direction, I asked legislators to co-sponsor the bills. Two other parents (Helen Beckwith and Alan Kingsley) and I actively lobbied legislators to explain the bills and why passage of all the bills was needed for our children with autism. Armed wearing buttons with a picture of our child, we approached legislators, introduced ourselves as parents of a child with autism, and urged passage of bills. Our sincerity and honesty could not be doubted. We were volunteer lobbyists and were experts in the area of autism.

Before each bill was scheduled for hearing, we spoke with members of the committee and testified in committee in favor of the bills. Lorena Overweg, Stan Arnold, Margie Martens, and Kit Ludens traveled to Pierre to testify for several of the bills. Vennie Heibel monitored House and Senate sessions when the bills were considered. Professionals such as John Stengle of the Association of Retarded Citizens of South Dakota and Robert J. Kean of South Dakota Advocacy Services also testified in favor of the bills. Outside of the Capitol, family members and friends wrote letters, left telephone messages, and spoke with legislators urging passage of the autism bills. I telephoned Cathy Maynard daily to keep her informed of our efforts.

There was opposition to the bills. On February 2, 1990, James Hansen, Secretary of the Department of Education and Cultural Affairs, testified as an opponent to SB 207 - "An Act to define autism" - in the Senate Health and Welfare Committee. Senator Austad from Sioux Falls made a motion to defer the bill to the 36th day. This motion would kill the bill because there were only 35 days in that legislative session. The motion failed for lack of a second. The bill passed out of committee on a 5-2 vote. When the House Health and Welfare Committee considered the bill, there were no opponents.

The House Health and Welfare Committee considered SB 206 - "An Act to prohibit abusive treatment of persons with developmental disabilities" - on February 14, 1990. John Stengle, Helen Beckwith, Gail Eichstadt, and Verle Rogers, Superintendent of the South Dakota Developmental Center, testified as proponents of the bill. All members present voted in favor of the bill and then voted to put the bill on the consent calendar in the House. The "consent calendar" is a listing of bills that require a vote of the particular House of the Legislature to become law, but that are considered (by the committee assigned to the bill) to be non-controversial. Rather than debating and voting on each bill on the consent calendar, the House (or Senate) votes on the consent calendar in a single vote without debate each day before considering other bills individually.

The House Education Committee considered HB 1325 - "An Act to appropriate money to operate an autism and related developmental disabilities center." Parents, as well as James Hansen, Secretary of the Department of Education and Cultural Affairs, and Sam Tidball, lobbyist for the Association of School Boards, testified in favor of the bill. It passed out of committee and passed unanimously in the House of Representatives on February 20, 1990.

SB 206 - "An Act to prohibit aversive and other abusive treatment to persons with developmental disabilities," was specifically amended on January 31, 1990, by the Senate Health and Welfare Committee to include schools. This and other changes made that day were codified as follows in 1990:

27B-1-10. "Legislative findings on aversive or abusive treatment of disabled persons. The Legislature hereby finds that:

- (1) Research does not support the long-term efficacy of aversive behavioral intervention;
- (2) The use of aversive or abusive treatment raises disturbing legal and ethical issues, and may well deprive the recipient of constitutional or statutory rights and be outside the ethical guidelines imposed upon the treatment professional;
- (3) Severely disabled persons have the same right to be treated with dignity and respect as all other citizens; and
- (4) The use of aversive and abusive treatments on persons with disabilities diminishes the dignity and humanity of the treatment professional and the disabled person."

27B-1-11. "Prohibited practices in serving developmentally disabled persons. Any agency, facility, school, or person who provides services to persons with developmental disabilities shall be prohibited from using the following practices:

- (1) Corporal punishment--physical or verbal abuse, such as shaking, screaming, swearing, name calling, or any other activity that would be damaging to a person's physical well-being or self-respect;
- (2) Seclusion--placement of an individual alone in a room or other area from which egress is prevented;
- (3) Denial of food--preventing an individual from having access to a nutritionally adequate diet as a means of modifying behavior. Persons enrolled in residential programs or living units are expected to partake in meals at a predetermined scheduled time.
- (4) An individual served disciplining other individuals enrolled; and
- (5) Medication shall not be used as punishment, for the convenience of staff, as a substitute for a program, or in quantities that interfere with an individual's developmental program."

27B-1-12. "Review of treatment procedures. All agencies providing treatment to persons with developmental disabilities shall review their treatment procedures to ensure compliance with §§ 27B-1-10 and 27B-1-11."

27B-1-13. "Enforcement of treatment requirements. This legislation shall be enforced by the appropriate state department

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by assuring adequate monitoring of, staffing of, and technical assistance to all agencies, schools or persons providing services to those with developmental disabilities.”

Through the efforts of concerned legislators and determined family members of people with autism, five of the six bills passed and were signed into law by Governor George S. Mickelson. Only SB 204, dealing with teacher certification, was not enacted into law.

The process of getting this legislation passed appears easy on paper. In reality, it was a monumental, exhausting, and exhilarating task for parents who did not have the assistance of a contracted paid lobbyist and who had a mailing list with only 120 names of persons with autism, family members, professionals, other interested persons, and members of the South Dakota Autism Society. We were driven because the only treatment for our children with autism was education. They were entitled to a free appropriate public education.

There have been many changes in the past twenty years. The children who inspired their parents to approach the Legislature are all adults. The Department of Education tracks the number of children in each category under IDEA. Autism became one of the listed federal categories under IDEA and is now defined in administrative rule in South Dakota. The Autism Spectrum Disorders Program under the Center for Disabilities moved from the USD campus to Sioux Falls. It provides diagnostic clinics, consultation and technical assistance, and workshops for educators and parents. Children with autism are diagnosed at an earlier age. Several school districts have their own autism teams to evaluate students.

We believed children with disabilities would not receive abusive treatment or face behavior modification in locked rooms after the enactment of 27B-1-10. Unfortunately, SDAS continues to receive reports, such as locked rooms where egress is prevented and preschool children with autism (and no orthopedic impairments) being restrained in Kinder Chairs during preschool classes. There is still progress to be made.

[Sources: Materials from the notes and archives of the author; committee minutes from the 64th and 65th Legislative Sessions; and *Autism Task Force Report*.]

From the Editor: Many of the names listed in this article played roles beyond helping to get the legislation passed. Legislatively requiring schools to acknowledge autism as a disability requiring special education services was monumental, but only had the effect of finally “getting a foot in the door.” Numerous roadblocks remained in terms of getting schools to evaluate for autism, to provide trained teachers, and to provide appropriate services based on the individual needs of each child.

In 1990, there were very few options for getting a child evaluated for autism. Once the Autism Program at USD was established as a result of the legislation, South Dakota finally had a publicly-sponsored option for evaluating children for autism. About the same time, Children’s Care Hospital and School was another option. Getting schools to agree to have children evaluated for autism, however, was often a difficult task. It may well have been that many schools balked at having

children evaluated for autism because they were unprepared to educate children with autism.

While South Dakota was gradually seeing more children diagnosed with autism and placed on IEPs, very few districts had staff with sufficient training in how to teach a child with autism, and along with that the ability to determine a child’s individual needs. There were countless situations where parents, who had done the research and attended trainings, attempted to teach their respective districts what their children needed. Fortunately, the Autism Program at USD began providing week-long training twice each summer, but enrollment was limited. Teacher training issues arose frequently at IEP Team meetings. In one of those situations, the Sioux Falls School District wanted to remove existing teacher training language from an IEP and the parents filed for a due process hearing. The parents prevailed at the hearing level, as the hearing officer determined the child needed a teacher trained in autism (that was not disputed) and therefore the district had not demonstrated that the child’s needs had changed such that it would be appropriate to remove the language. The district appealed into State Circuit Court, which took exception with the language in the IEP that required a specific amount of training, and reversed. The parents appealed to the South Dakota Supreme Court. Instead of addressing the basis for the circuit court’s reversal of the hearing officer’s decision, the Court instead ruled that teacher training could not be included as a related service in an IEP, period. *Sioux Falls School District v. Koupal*, 526 N.W.2d 248 (S.D. 1994). The United States Supreme Court denied the parents’ Petition for *Certiorari* on June 19, 1995. *Koupal v. Sioux Falls School District*, 515 U.S. 1143 (1995). The South Dakota Supreme Court’s decision was widely chastised by national commentators. Curiously, when IDEA was reauthorized in 1997, the language, “supports for school personnel” (which certainly includes teacher training), was added to the required IEP contents, which effectively overturned the *Koupal* decision.

All the individuals named in this article should be proud of the legislation they played a part in getting passed. Some of these and other parents of children with autism actively became teachers/advocates for other parents. It was through those types of continuing efforts that positive changes slowly occurred in South Dakota.

SDAS assisted countless parents of children with autism both prior to and following passage of the legislation. To effectively advocate for a child with autism’s needs, as it was with school personnel, it was often these parents who became teachers/advocates for others who provided our knowledge base. For example, I recall having conversations with Helen Beckwith and Gail Eichstadt from time-to-time. The biggest driving force for children with autism in South Dakota for many years was Cathy Maynard, who was the president of the South Dakota Autism Society. She not only played a major role in drafting the legislation, but she selflessly assisted countless families by attending IEP Team meetings, drafting language to include in IEPs, and by making herself available to families for phone calls. Cathy was my mentor as we worked together to assist families to receive appropriate services from school districts for their children with autism and was of great assistance while litigating the *Koupal* case. It was through the continuing efforts of Cathy, Helen, Gail, and many others that the legislation they worked so hard to get passed began showing more and more positive results for children with autism in South Dakota. That continues today.