

SPECTRUM UPDATES

July-September 2012

The End of the Spectrum: Helping Families Find Solutions to their Autism Housing Needs.

Dear Friends,

This past quarter has again seen our work focused on legislation, this time in the form of follow up and shepherding of our two housing bills which passed last spring. There has been ongoing difficulty in communication with DHS and the unbiased research required regarding our campus housing bill. After meeting with Gov. Dayton recently, and with the support of his office, things seem to be moving forward in a positive direction. Life in politics is really a different world. As families and children suffer, government churns slowly working to uphold the process rather than advocating for the individual, in this case our children. My frustration can run high at times, but I hold a vision of the finished product, a rural campus with horses, gardens and a pool, trained caretakers and healthy food, green and quiet, with the children thriving. The process may be slow, but we are progressing towards our goal.

Hope everyone is enjoying the fall,

Sheryl Grassie / Executive Director

Understanding Severe Autism

Recently, my son Seth fell at his group home and smashed his chin. No one saw it happen, but the injury was serious and warranted surgery. That first night when the anesthesia wore off he woke up and pulled out all of his stiches. This necessitated a second surgery with the stiches done internally. Now, some weeks later, he is recovering nicely.

Why is this story important? It exemplifies the need for a better understanding of severe autism. Someone educated in this population could have warned the surgeon about exposed stiches and prevented the need for a second surgery. Had I been there I would have intervened. You can't simply say, "Don't pull out those stiches, Seth." He has very little understanding and almost no impulse control.

The issue of trained staff in residential settings looms as another issue to be taken up in legislation.



Seth, who lives in a group home four hours north of his family home in Minneapolis, was back for a one day visit in September.

The word autism derives from the Greek word autos, referring to self. Autism or "self-ism" was a term first published in 1911.

Legislative Update



The study mandated by our Campus Housing Bill (HF 2252 / SF1882) has been delegated to *The Institute on Community Integration* at the U of M. We have been asked to consult on aspects of the research design. This will include site visits to out-of-state autism centers.

The Disabled in Society

Incorporating individuals with disabilities as full members of society moved from a social notion to active legislation in the 1970's with the passing of *The Individuals with Disabilities Education Act* (IDEA, 1975). This act began a trend that eventually forced care for children with disabilities to be executed in the Least Restrictive Environment (LRE), (*Olmstead vs. L.C.*, 1999). It essentially required children with disabilities to be kept at home. Although the early precedent for this legislation grew out of the civil rights movement and the goal of insuring a child's right to grow up in their family of origin, it has created a significant backlash forcing care for children with severe disabilities to take place in less than adequate environments, with untrained familial caretakers, and limiting both the funding and the options for alternate, and more appropriate care.

Documentary with Twin Cities Public Television

We at Spectrum continue to grant write and fundraise in the hopes of generating enough funding to co-produce a documentary with TPT about the children we are working to support.

If you have leads on funding sources, or can donate to this project, your support is greatly appreciated.

A special thanks to Paul and Destini Molitor for their generous donation in support of this project and to Bob Jewett, from St. Paul Academy for all the donated pottery for our sale.

[Thank You to everyone who supports work with autism in Minnesota!](#)

