

10.28.2011

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Regarding Autism Priorities in the State of ND

Greetings Representative Wieland:

My name is Vicki Peterson and I presented testimony to the Human Service Interim Committee regarding Autism Spectrum Disorder study on October 25th, 2011. We had spoke briefly after session and you requested I send a list of priorities needed regarding autism in the state of ND. I have briefly listed 4 main priorities, per request.

- The first priority I would like to discuss is Access and Awareness. These two key ingredients are essential for the families whom have children with autism in the state. In my opinion awareness is growing, but must be vigilant to do more, especially to reach rural communities and the tribal nations. Access goes right along with awareness.

Access to services for children, youth and adults whom have an Autism Spectrum Disorder is quite limited compared to many other states in the US. Again, one key component to this is our rural state. Medicaid and private insurance are needed to support these families in accessing services including diagnosis, therapies, respite and general healthcare. Many with ASD have an additional secondary diagnosis, which makes coverage vital for families. Ensuring these programs will continue and developing alternatives that work for families is needed.

Respite is a resource that families need to receive a specialized care giver in their home designed to give opportunities for families to receive a "break" or to attend "support groups", or other areas where the child with needs may not be able to attend. Also respite provides a way for families to involve their child into the community. The pure fact of having a rural state, staff and training, and no coordinated effort or dollars to put forth to expanding this program, many cannot access respite. Some of the children with autism may not have the cognitive impairments that would provide them access to respite services. So while some may qualify for respite through the various waivers, others who also need this do not have access.

Many of those living with autism have needs for mental health services that need to be addressed and dollars are needed to expand these programs not diminish to transition those affected by autism into a world where they are accepted and understood.

Many treatments for autism are not covered by health insurance or other public or private programs and families are filing bankruptcy, paying enormous co-pays, and even divorcing just to get by, this is a fact in the US and in ND. I have attached a study that was done in 2006, with 2003 dollars from Harvard University on cost per capita to raise a child with autism. Though there may be conflicting figures, and onto where you live but the idea of a large amount of cost is clear.

AGE	DIRECT MEDICAL	DIRECT NON-MEDICAL	INDIRECT	TOTAL PER CAPITA COST
3-7	35,370	10,805	43,066	446,203
8-12	6,013	15,708	41,138	314,297
13-17	5,014	13,550	38,453	285,082
18-22	2,879	10,720	36,090	248,446
23-27	1,574	27,539	51,740	404,260
28-32	1,454	23,755	35,757	304,828
33-37	1,389	20,492	30,852	263,662
38-42	1,283	17,676	29,132	240,457
43-47	1,440	15,248	26,600	216,439
48-52	1,447	13,152	24,531	195,650
53-57	1,290	11,292	17,776	151,790
58-62	1,218	9,489	0	53,535
63-66	1,027	7,908	0	35,738
Totals	305,956	978,761	1,875,667	3,160,384

Age-Specific and Lifetime per Capita Incremental Societal Costs of Autism / Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3 percent. Life expectancy for men is age 66 years and for women is age 65 years. Source: 2006 Harvard study

- Next priority would be looking at different ways of delivery method of therapies and services. As in most of the testimonies from the families, it was clear that Tele-Health practices may be a solution for some, along with a medical home model. The American Academy of Pediatrics developed the medical home model for delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective. Medical Home is a best practice model of care for children with special healthcare needs. The core of a Medical Home is knowledgeable, loving health professionals, chosen by the family to take care of their child's health care needs, accessible twenty four hours a day, and seven days a week.

When a child has a Medical Home, the family is confident that a known, respected expert is always there to provide quality health services and care coordination. Currently medical home is practiced in a few clinics across the state. Expansion of medical home would help greatly.

Tele-Therapy practices and services are evidenced-based.” The American Speech-Language- Hearing Association states TeleSpeech is a practice that is a method of delivering services that overcome barriers of distance, unavailability of specialists and impaired mobility.” This would mean a family living in rural western ND, where no therapist may be located, would not have to drive 200 miles to locate the nearest therapist. The transportation costs alone to ND families is exuberant amount just to get the help they need for their child to learn to speak, or cope with sensory issues and any other service that may not be available in their area but is located in ND. It is needed that private health insurance and Medicaid programs accept this method for reimbursement. A fundamental concept underlying this advocacy is clarifying that tele-practice is not a different service; it is simply a different method of service delivery. Assuring that the quality of the service is comparable to traditional face-to-face services is essential to acceptance by payers, providers, and clients.

- Training and cross-training need to be happening. As I am a parent living in west central ND, and work with many families across the state, there is a definite dividing line of what type of services are offered. This may of course be in part to the geography of our state, though I think it will benefit everyone, including stakeholders, to be together, on the same page of how programs need to be implemented, and services delivered. This will be a great task but one I am confident can be achieved.

One of the barriers I know is that a diagnosis of autism seems to look different with each individual and the professionals giving a diagnosis. There needs to be a more standard definition across the state, which I feel may be a daunting task, as much as it is federally as well.

Cross- training of professionals and families I think will be a good step forward. Having more of a central location for resources in our state instead of divided by location. Family Voices of ND is a State Affiliate of the National Family Voices Organization, offering tools to build partnerships and link families to resources, offering families support in navigating systems, applying for services...but with this takes funding. Family Voices of ND is designated as the Health Information and Education Network for families of children with special health care needs and disabilities, as well as the professionals who assist families. Demands on staff time are increasing of which while we don't and won't turn a family away...the increasing needs that families face is placing strain on the infrastructure.

Additionally, Family Voices hosts the parent to parent program which matches families on a 1:1 basis for emotional support. There has been a huge increase in the number of families with autism that we provide support to.

Family Voices of ND is not the only parent organization in the state. While it is the only **health information and education center and parent to parent program** we partner with our other 2 sister organizations a) Pathfinder Family Center (which main focus is education and the special education process) and b) Federation for Children's Mental Health (assisting families with mental health and behavioral issues).

All three organizations assist families of children with autism and many other diagnoses. Each of the three organizations receive state and federal grants. It is important that these 3 organizations continue to provide consistent emotional and informational support services to families. None of the three have a legislative line item in any state budget. All three are very worried with the cuts at the federal level that they will not be able to maintain existing services if those funds are lost. It is felt that in order to keep moving forward and to continue to do the good work that we do, that somehow we pursue some funding from our legislative body. For many families these 3 organizations are the only avenue of receiving family support. There exists such a variety of support organizations across the state with many different approaches and focus. All of the family organizations work and partner with existing support groups, I believe that they could aid in constant ongoing feedback to the legislative body.

Other training and cross-training opportunities need to be done in a collaborative method in our education system. The education system needs to be utilizing new technology that is available and embracing inclusion. There is a lack of trained aides whom can assist in the child's educational environment. IDEA is still not fully funded. There is no clear number of how many students in ND that have a diagnosis of autism. Not all students diagnosed with an Autism Spectrum Disorder are on IEP's or 504 Educational plans, which means they may not be receiving services they need in school to have a beneficial education.

- The last priority I want to list is looking ahead. We are all asking what will the future hold for our children. Serious planning needs to be going on at the tables now. Stakeholders need to be looking at the adult services we have in place now for Autism Spectrum Disorders and other Developmental Disorders and improving and expanding our knowledge about them. Family-Centered Care needs to be the continuum across the lifespan. Higher Education needs to be involved to develop new programs, continue to educate professionals. Additionally efforts need to be increased and invest in opportunities, especially looking at job coaching, housing, and independence, creating new jobs for North Dakotans. Autism is across the lifespan and we need to develop programs that include the above to help meet the needs as your children transition into adulthood. .

I want to thank you for giving me the opportunity to inform you of some areas of priority for all those persons with autism and the families and caregivers. I hope that as policy-makers solutions will arise and the well-being of our children, youth and adults with Special Healthcare Needs including Autism, hold a bright future.

Sincerely;

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