

North Dakota SYMPOSIUM ON AUTISM

Executive Summary & Report

By *Cathy Haarstad, MS*

March 17, 2008

Overview

The North Dakota Symposium on Autism was held on March 17, 2008 at Minot State University. The one-day event was sponsored by the North Dakota Center for Persons with Disabilities (NDCPD). NDCPD is a University Center for Excellence in Developmental Disabilities Education, Research, & Service at Minot State University (MSU).

Planning Committee

Bryce Fifield, Executive Director
Brent Askvig, Associate Director
Susie Mack, Administrative Assistant
Marcia Johnson, Accounts Manager

Terri Aufforth, Assistant
Vickie Brabandt, Secretary
Cathy Haarstad, Consumer Affairs
Wendy Thomas, Autism Specialist

Presenters:

Thomas Higbee Utah State University ASSERT Program Director
Sally Burton Hoyle, PhD. Eastern Michigan University, Special Education
Teresa Edison, sibling, Magic City High School student

Panel Participants:

Thomas Higbee (Early Intervention) **Missy Brademeyer** (Parent)
Sally Burton-Hoyle (Higher Education) **Vicki Peterson** (Parent)
Dion Darveaux (School Psychologist) **Michelle Well** (Educator)

Special Thanks To:

Leon Perzinski, Student Center Manager
Amy Woodbeck, Center for Extended Learning
Lisa Johnson, Town Hall Facilitator
Darren Seifert, Technology Support

Outcomes

Conference planners identified the following outcomes for this conference.

1. Launch the Great Plains Autism Spectrum Disorder Treatment Program (GPAST).
2. Recruit at least 100 parents, advocates and educators as participants from across North Dakota (ND).
3. Identify participant perspective on key service issues in Autism for our state.
4. Provide participants with evidence-based information on service models.
5. Obtain participant recommendations for future training and GPAST development.

Outcome 1 - Showcase

Senator Byron Dorgan announced (video) that NDCPD recently received federal earmark dollars for one year to fund the GPAST. Letters of support from Senator Kent Conrad and Representative Earl Pomeroy were also available for participants.

The GPAST will provide training, research, diagnostic and treatment services for ND children and youth diagnosed with autism spectrum disorders. The program will assemble an interdisciplinary team of medical and allied health professionals, educators and specialists who have expertise in diagnosing and treating this complex disability. The focus of service delivery will be to families and schools in rural communities.

NDCPD has already begun to leverage additional funding for the outreach services by partnering with the Anne Carlson Center for Children. This partnership is not designed to increase the child enrollment in center-based programs but rather to deliver in-home and community-based services throughout ND.

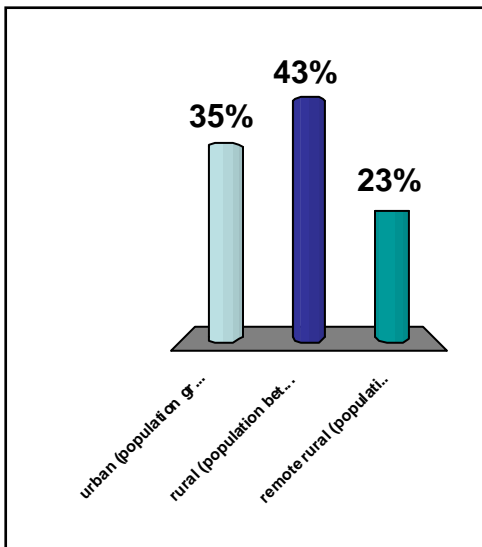
Participants seeking services from GPAST should contact the program director:

Wendy Thomas, MS
Program Director
500 University Avenue W., Minot, ND 58707
1-800-233-1737 or 701-858-4367
wendy.thomas@minotstateu.edu

Outcome 2 – Recruitment

Attendance at the symposium exceeded expectations. A total of 300 people registered for the conference and 284 attended. An additional 20 students from MSU stopped by in the afternoon for about one hour. It was difficult to turn people away. A number of latecomers were unable to participate because the attendance exceeded room capacity.

NDCPD relied on email blasts, word of mouth, phone invitations and limited media to make families and professionals aware of the conference. These techniques were highly successful. Breakout figures for attendance are:



Students	32
Staff	33
Family members	35
Professionals	195

Attendance at the conference was broadly representative with the majority of participants coming from rural communities in the central areas in the state (see chart) The list below combines some cities and surrounding locations. For example – Fargo and West Fargo; Minot/MAFB are combined.

Bismarck/Mandan	46	Minot	110
Dickinson	6	Williston	2
Fargo	8	Other small rural towns	60
Grand Forks	10	Out of state	3
Jamestown	10		

Towns Represented - Aberdeen, Barton, Beulah, Bismarck, Carrington, Center, Devil's Lake, Dickinson, Edgeley, Emerado, Ft. Ransom, Ft. Totten, Fargo, Garrison, Glenburn, Grafton, Grand Forks, Harvey, Hazen, Jamestown, Kenmare, Lake Metagoshe, Lankin, Larimore, Linton, Makoti, Mandan, Manville, Minot, MAFB, Minto, Moball, Morehead, Mylo, New Rockford, Page, Park River, Plaza, Rolla, Rugby, Sawyer, Sherwood, Stanley, Towner, Upham, Valley City, Wahpeton, West Fargo, Williston, Willow City and Wing.

Outcome 3 – Perspective

Input from the participants was obtained through three different venues.

Panel Discussion
Town Hall Meeting
Networking Sessions

Panel Discussion

Panel participants discussed the need for early diagnosis and treatment and concerns about limited services in all communities but especially in many rural communities. Some common sense should be applied to this challenge. There is sometimes a perceived difference in access to services between the eastern and western side of the state. The panel also discussed the importance of access to an array of services and the need to understand that behavioral intervention is not limited to discrete trial training. Finally the panel discussed the importance of having a systematic training program in place at both the pre-service and in-service level so that families need not rely on the luck of the draw in finding a teacher with expertise in autism.

Town Hall Meeting

The Town Hall Meeting was one of the more exciting features of the conference. This survey was not intended to be a scientific study. It was used to give both the presenters and participants a general awareness of some of the issues and challenges facing ND and to get people thinking. Prior to hearing the speakers, participants were asked a series of questions and then indicated their response using individual remote devices. The results were then collectively and instantaneously displayed on a screen for all participants to consider. Remote devices did not always work well from the back of the large room.

Participants were asked to respond to questions about diagnosis, access, finance, treatment, training, family support and system change. Data showed that the majority (about 30%) of the audience believed children in ND are not diagnosed until after their second birthday. They also indicated that those services which are available in the state and in local communities are typically provided and financed by the public school system. Forty two percent of the audience indicated that they did not know if services for families of children with autism were available or did not have services in *their* community.

Early intervention was identified as the most important service needed by children with autism. Professionals showed the highest interest in learning more about social stories, screening and diagnosis and positive behavioral supports for children with ASD. Training for families on social stories and screening and diagnosis were also rated highest by participants. However, a potentially troubling trend was shown when the option of “don’t know” about training for families was selected as the third highest option.

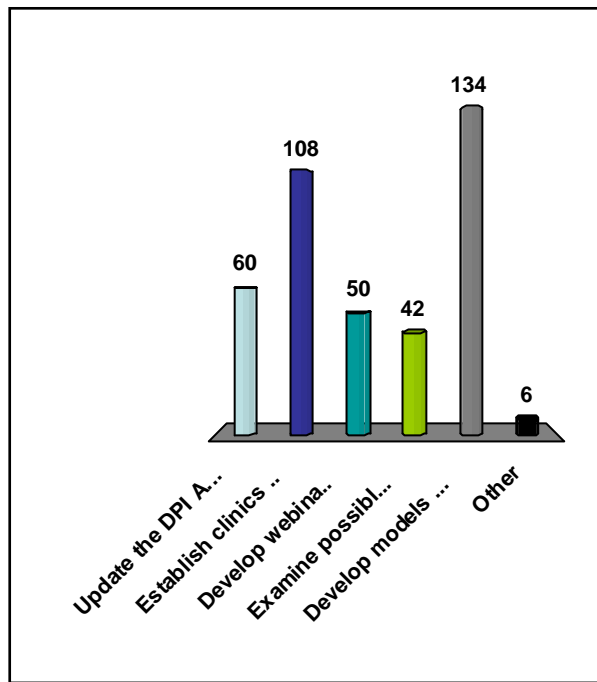


Table Two: Ideas for System Change

Intensive in-home behavioral support was selected at the highest level (42%) as the most important support for families. This was followed by financial support and trained respite providers at 23 and 22 % respectively. Participants were asked to select 3 changes for North Dakota that they believed should be addressed in the next year. The responses selected are displayed in Table Two. Of the options presented, a) Update the DPI Autism guidelines, b) Establish clinics to diagnose and treat Children and Youth with Autism (CYWA), c) Develop webinars and modules, d) Examine possible underlying causes for ASD, e) Develop models for early intervention and treatment and f) Other; item e, develop models for early intervention received the strongest rating by the group.

A detailed handout showing all of the results are available upon request or can be viewed at www.ndcpd.org/Autism.

Networking Sessions

Participants were invited to organize themselves into networking sessions by topic. The size of the group and space accommodations really made this activity difficult to carry out as planned. The networking topics suggested included *early intervention, education, transition, treatments, family support and health*. Comments by participants were highly individualized and a set of notes obtained from each group is included below. Planning committee members and NDCPD staff noted that participants networked extensively throughout the conference and that this is probably the preferred method of connecting among people who knew each other well or who felt confident about approaching relative strangers. Comments

from the networking sessions are a mixture of participant perceptions on the status of services and recommendations from individual group members.

Transition

Moving into adult hood many students fall into the cracks if they do not clearly fit into services. (DD services, aftercare, etc.)

We need information about supporting 18-21 year old students with autism

We need to inform parents about adult services/supports for youth with autism

Set up transition timelines. Let youth and parents know what to expect.

Evaluate how regions are serving YWA in transition steering committees

Develop strategies for transitioning students from home to public schools

Inform general educators about the unique neurology of YWA so they know what to expect and what not to focus on

Focus on many diverse transitions (e.g. doctor's office, dentist, public settings)

Research transition and employment for YWA

If older students moving into adulthood do not like school or get bored with school because they repeat classes because of their, the school's agenda, the student often drops out and when out of school funding drops.

Often schools say they are creative but the parents are not seeing creativity.

One school is preparing a student that will be moving into adult services and teaching counting change, job skills, and other related skills in his last year of school vs. teaching the same old thing because they have a set pattern.

There is also some fear of transition where some students are reliant on their school system and environment to the point where they will not want to leave school.

IEP teams at times inexperienced as to what to do with the students.

As a parent I feel like I am pushing schools and then looked on as overpowering and hard to work with.

Not one school person from our school came and we are only 20 miles away.

Find one person in the school to work with and get them to be your voice in meetings and help advocate in IEP's and other meetings.

Smaller communities seem to have fewer supports and the perception is that the big cities have the lion's share of services.

Respite care is a big missing link. Day care is not available. Families do not have the time/support to get services for their children.

Kids need another resource when transitioning into adult hood. Repeating lessons over and over is not enough. Maybe some advanced adult prep classes.

You need to get to your law makers and get their ear with your story.

Forcing families to jump through hoops to get IEP goals followed through with is counter productive and just not up to parents to find ways to get these things met it should be the entire team working toward these goals.

Not having paid professionals that are willing to stay here due to lack of resources to keep them in the state.

Education

Provide resources and strategies for funding ABA

Training options available online

Make options available statewide not just in a few areas

Coordination between home, school and child care

Focus on transitions as they are often the greatest behavioral challenges

Strengthen teacher ability to accept recommendations from consultants/families.

Improve assessment processes and access to assessment tools

Change how the law defines autism. Some people would like to see a change in the ND guidelines from Autism exclusively category to an ASD

Disparity for children with autism treatment options in rural versus “urban” settings. Limitations in rural settings were addressed. One parent sees the benefits of rural schools.

Lack of training for teachers and everybody. Autistic children don’t get the training they need unless parents push the issue.

Paraprofessional training: Lack of paraprofessional training. Lack of preparations for paraprofessionals was discussed. Understanding the rules of training needs to be discussed and followed up on in schools as well.

Family Support

Provide information on the types of family support available in each region

Train speech therapists in principles of ABA

Provide information on the different support groups in the state

Educate physicians so they can do more than refer to someone else

Create an Autism hot-line working with the 211 staff

Build on strengths – infant development programs

Work with families to keep kids in the home as much as possible

Health Care

Provide Services in the context of medical home

Develop resources so that we can actually refer families to appropriate services

Compare a team versus a individual physician model of care

Educate physicians on how to provide health support to CYWA and families

Get to families prior to age 3

Train child care providers to observe the red flags of autism and to know what to say to parents

Inform physicians and families about alternate vaccination schedules

Provide nutritional consultation for families from nutritionists who specialize in the issues of autism.

Treatments

Diagnosis is a fight. But now only have a diagnosis.
Exchange information on alternate therapies. Research doesn't necessarily dictate validity of treatments in the mind of parents because what works is valid for them.
Need for early intervention and recognizing of symptoms
Integration with high support levels and visual symbols
Support for in-home ABA so parents don't burn out
Research on which items work best and when to expect change
Strategies on how to put together diverse financing resources (self, school, insurance, volunteers, etc.)
Families struggle with bowel training. A reward system seems to work but takes longer. A lot of children are facing fear in this.
Central clearing house of information on Autism
Make services easier for the family – child's behavior is already difficult
Teach parents how to interrupt routines of CWA
Teach parents how to incorporate treatment into daily life
Provide information on videography, Social Skills training, Social Stories and Biomedical treatments
Show families how to keep some data on what works and when and how to decide if it is working and what to do next.
As CYUWA get older options are institutionalize or to home-school.

Early Intervention

Provide services so families get an early diagnosis and referral.
Make sure parents know how to obtain MA funding for out of state referrals
Physicians often don't know where to refer.
Keep up-to-date on current literature.
Let families know where to go for support, especially families living in the country.
Work with physicians on early intervention and not waiting until the child is older (2-3).
Help physicians work as part of a diagnostic team so families benefit.
Make sure families get correct information and support to make educated decisions.
Single biggest issue is Respite Care. Devastating to family. Crisis state in rural areas especially. Lack of caregivers is the issue
Design models for children under age three. These models should not require a child to sit for a long period.
Develop a current directory with referral information. This would be for families, professionals, physicians. On the web-site show the last time it was updated. Check resources for accuracy.
Get information to physicians, link with them. Keep them updated.
Educate physicians, seeking their support.

Provide training/education/support for child care providers.
Provide basic training/strategies to try when working with kids.
There is a concern about how Anne Carlson operated in the past. Don't want to return to residential placements. ACC is now doing outreach services
More research from OTs to show effectiveness of sensory motor integration.
Demonstration sites in public schools needed. It's important for parents to be able to see strategies in action.
How do we keep up with evidence based practices/information is coming out so fast. Need to work with university programs to get research accomplished on strategies.

Outcome 4 – Information

Conference planners chose speakers whose content might challenge the audience to think about two service models. The first speaker, Dr. Thomas Higbee provided data on an early intensive behavior intervention model that includes in-home and pre-school components. The second speaker, Dr. Sally Burton-Hoyle described a more eclectic, family-centered model that views ASD as a condition that will last throughout the lifespan and calls on families and schools to form strong partnerships in addressing the needs of children with ASD. Both models are important to ND. Copies of their handouts are available at www.ndcpd.org/Autism. A brief bio-sketch for each speaker is included below.



Thomas S. Higbee, Ph.D., BCBA

Associate Professor, Department of Special Education and Rehabilitation
Director, Autism Support Services: Education, Research, & Training
(ASSERT) Program
Utah State University

Dr. Thomas S. Higbee is an Associate Professor in the Dept. of Special Education and Rehabilitation at Utah State University where he has worked since 2002. He is also Director of the Autism Support Services: Education, Research, and Training (ASSERT) program which he founded in 2003. He is a Board Certified Behavior Analyst and has published research and given presentations at state and national conferences on topics related to behavioral assessment and intervention strategies for individuals with autism and other developmental disabilities. He is on the board of editors of the *Journal of Applied Behavior Analysis* and *Behavior Analysis in Practice*. Over the past ten years, he has worked with children with developmental disabilities in home-, center-, and school-based programs. Through workshops and consultation, he has trained teachers in school districts in Utah, California, Idaho, and Wyoming. Before coming to USU, Dr. Higbee served for three years as Senior Clinician at

Spectrum Center for Educational and Behavioral Development in Berkeley, CA which is a nonprofit agency that operates non-public schools for students with severe disabilities and behavioral disorders.



Sally Burton-Hoyle Ed.D.

Assistant professor in special education: Past director of the Autism Society of Michigan.

Eastern Michigan University

Dr. Burton-Hoyle is currently an Assistant Professor of Special Education at Eastern Michigan University in Ypsilanti, Michigan. Eastern Michigan University recently approved a masters of arts in Autism Spectrum Disorders developed by Burton-Hoyle to train special education teachers, social workers and other service providers in ASD. Previously, Sally was the Executive Director of the Autism Society of Michigan from 1994-2006. She served as the Associate Director of the Idaho Center for Developmental Disabilities prior to this. She resides in Brighton, Michigan with her husband Dohn and her children, Meredith, Rob, Drew, Frazer and Price. Sally has been blessed to grow up with a brother with autism, who has taught her that you do not have to be perfect to have a good life.

Miss Teresa Edison is a high school student at Magic City Campus in Minot and has a sister with ASD. Miss Edison is planning to major in special education after completing her senior year in high school. She provided an important family-centered perspective during the noon luncheon. Her comments and perspective were warmly received. Over seventy-five percent of the evaluations made a positive comment about her presentation. Copies of her presentation are available at www.ndcpd.org/Autism.

Participant Evaluation

Overall about 83% of the participants rated their level of satisfaction with the symposium as satisfied or highly satisfied. Participants were complementary about many aspects of the conference however the crowded conditions, room arrangements, food supplies and limited opportunities for breaks received numerous negative comments. Decisions to include as many people as possible strained resources and were reflected in the comments from our participants. A detailed list of comments can be viewed at www.ndcpd.org/Autism.

Overall Satisfaction with the ND Symposium on Autism				
Highly Satisfied	Satisfied	Somewhat Satisfied	Not Satisfied	No Response
21% (n = 33)	60% (n = 93)	10% (n = 15)	3% (n = 4)	6% (n = 9)

In spite of numerous negative comments about the room arrangements and food, 81% of the participants reported being satisfied or highly satisfied with the conference. Participants who were only somewhat satisfied tended to either dislike a choice of speaker or did not feel their individual interests were adequately addressed.

Participant Satisfaction with Individual Events and Speakers						
	Excellent	Above Average	Average	Below Average	Poor	No Answer
Panel & Town meeting	14% (n = 22)	34% (n = 52)	45% (n = 69)	4% (n = 6)	2% (n = 3)	1% (n = 2)
Dr. Higbee	32% (n = 49)	41% (n = 63)	25% (n = 39)	1% (n = 2)	0% (n = 0)	1% (n = 1)
Dr. Burton Hoyle	38% (n = 58)	45% (n = 70)	12% (n = 19)	2% (n = 3)	1% (n = 2)	1% (n = 2)
Networking	11% (n = 17)	27% (n = 42)	27% (n = 42)	8% (n = 13)	1% (n = 2)	25% (n = 38)

Option 6 - Recommendations

Trends among responses indicated that some participants doubted whether an applied behavior analysis model would be accepted in ND. Other participants couldn't wait to learn more about the model. A few participants expressed concerns that a representative from a private instead of a public school was chosen for the panel. Some participants were concerned that parent voice was overwhelmed by the number of professionals who attended.

Participants commented on future trainings, services, and informational resources. A complete list of comments can be provided upon request or viewed on the NDCPD website at www.ndcpd.org/Autism . Some participants are seeking basic information. They want to know what Autism is. Others are exasperated with basic information and want to know what to do and how to do it. Everyone wants their population of interest addressed and a fair and equitable system of services that is informative, practical and available in at least four quadrants of the state. A review of responses indicated that participant priorities were:

General Information

More about the Great Plains Autism Spectrum Disorders Treatment Program

More information for stakeholders about how the money will be spent
More information for the general public in ND on Autism
Publish research results specific to types of intervention
Gather information on adults with autism to inform system
Provide routine updates on GPASDT progress
Coordinate future conferences
Make sure you have a progression of topics so that the same basic information isn't presented at each one.

Resources

Create a central clearinghouse for info/resources
Pull together a list of places to get a diagnosis in ND
Put together a list of service providers
Create a list of resources available in ND

Training

Offer classes not just workshops for better quality training
Offer in-depth information on ABA on a regular schedule
Make sure trainings really teach teachers how to teach CWA
Provide specific strategies for early intervention
Provide In-depth information on screening/diagnosis
Offer in-depth information on a wide array of treatments
Hold workshops on ASD populations especially Asperger's
Provide training for parents/parent perspective/parenting skills
Provide training for respite workers and child care providers
Create or obtain video examples of children and teachers
Summer internship 2-4 weeks on ABA
Remember to offer basic training to those new to the field
Training on how to provide classroom accommodations for CWA
Training for health care professionals including nurses
Training on sunrise , floor time, TEACCH
Training on children with ED
Training for para-educators

Early Intervention

Create a check list of red-flags for early diagnosis
Support for parents in beginning stages/next steps

Family Support

Identify what supports families need
Bring together parent support groups
Initiate system change activities

Assure equal access to training

System change

Involve the primary care community

Work with ND Legislature to include early intervention (ABA) funding in Medicaid.

Consult with school districts – help them think outside the box

Tailor services for rural schools

Create models so services are available at least in 4 regions

Work collaboratively with other universities

Keep partnering to leverage funds

Treatment

Look at the multi-disciplinary clinic approach.

Include education and health care providers

Start a model program like ASSERT

Start several early intervention models and compare/give options

Visit model programs in other states and use the data.

Help provide an array of treatments so communities can individualize

Summary

The first ever ND Symposium on Autism was highly successful and well attended with some environmental problems that can be used to inform future conferences. Participant needs are diverse on a continuum from very basic to highly-sophisticated among both professionals and parents. Challenges include the cost of providing evidence based services in both rural and urban communities and providing an array of model programs and effective training formats as rapidly as possible. Participants would welcome more information about the Great Plains Autism Spectrum Disorder Treatment Program and are waiting with great interest to see how NDCPD will address the needs of people with ASD across the lifespan.



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