



NORTH DAKOTA
DEPARTMENT of HEALTH

Children's Special Health Services
ASD Expert Panel Meeting
October 23, 2014

Attendance:		
Expert Panel Members	Barb Stanton-Ph.D., Connie Lillejord-OT, Craig DeGree-Ph.D., Darren Dobrinski-Ph.D., Gerry Teevens-Special Education Director, Jacquelyn Walsh-VP Clinical Excellence and Quality at BCBS, Joan Heckaman-State Senator, Kelli Ellenbaum-SLP, Kris Wallman-Family Advocate, Lori Garnes-Ph.D., Leona Koch-State Health Council Member, Lynn Davis-Tribal Representative, Diana Read-Injury/Violence Prevention Program Director, Paul Kolstoe-Ph.D., Myra Quanrud-MD, Richelle Bautista-Azores-MD, Sandy Smith-Executive Director of ND Autism Center, Inc., Thomas Carver-DO, Tracy Miller-Ph.D., Vicki Peterson-Family Voices of ND	
Technical Consultant	Sandra Howell-Ph.D.	
CSHS Division Staff	Kodi Berg-Autism Database Administrator, Tamara Gallup-Millner-Director of CSHS, Kim Hrubby-CSHS Program Administrator, Carrie Tate-CSHS Administrative Assistant	
Welcome/Introductions/ Announcements	<p>Tammy Gallup-Millner, Children's Special Health Services Division Director, provided a warm welcome to the expert panel participants and thanked them for their assistance.</p> <p>Special appreciation was given to:</p> <ul style="list-style-type: none"> • Dr. Sandra Howell, from New Jersey, for offering technical assistance. • Dr. Tracy Miller, ND State Epidemiologist, was acknowledged for being a great partner and resource for CSHS during the development of the ASD database. <p>Introductions were made and the agenda reviewed.</p>	<u>Conclusion/Action Taken</u> Informative-no action taken
Overview of New Jersey's Autism Registry – Dr. Sandra Howell	<p>Kodi re-introduced Dr. Sandra Howell to the expert panel members and acknowledged all of her guidance and support for ND's ASD database.</p> <p>Dr. Sandra Howell gave an account of New Jersey's long history of reportable conditions that are entered into registries (e.g., birth defects registry started in 1928, etc.). The primary function of the registries is to help connect families to services by linking them to county case management.</p> <ul style="list-style-type: none"> • New Jersey has 21 counties where New Jersey Department of Health provides 	Informative-no action taken

funding for case management.

- The data collected by the registries is used to create brochures and educational materials.

Through the CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) study, in 2007, there were 1 in 94 cases of ASD in New Jersey. The study was based on data collected from health and special education records of eight year old children.

- Currently, the ASD rate in New Jersey is 1 in 45.
- Some kids meet the criteria under ADDM Network but may not have a diagnosis of ASD in the state. Diagnosed children are probably closer to 1 in 55 which indicates that New Jersey has high ASD rates.
 - School records are beneficial; states that do not use school records and only use medical records have lower rates of ASD.

Dr. Sandra Howell proceeded to describe New Jersey's ASD registry which has been active for five years. The ASD registry is a mandatory public health surveillance system, although the legislature gave parents the right to refuse identifiable information. The providers can report the child to the registry either electronically or by hard copy. There are approximately 14,000 individuals in the ASD registry.

- When discussing the registry with families, New Jersey expressed the importance of gathering ASD related data in order to understand the need for services.
 - Families generally had positive outlooks on the registry.
 - The input and support of families helped with the development and implementation of the ASD registry.
- New Jersey Department of Health sends out a letter notifying families of the ASD registry after diagnosis.
- New Jersey Department of Health staff attends parent and provider meetings as often as possible to secure feedback about the registry.
- In New Jersey, those aged 18-21 have the option to opt-out of the ASD registry.
- The registry is voluntary to those over the age of 21. New Jersey cannot compel adults to register.

New Jersey's Administrative Code:

New Jersey's Administrative Code took 14 months to get posted. It received a total of 14 comments with three or four being positive.

- The auditing of providers was part of the ASD registry’s Administrative Code. It gave the New Jersey Department of Health access to inspect medical records.
 - They do not fine providers for non-compliance but they can turn them over for licensure if they don’t comply, although this is rarely done.

New Jersey’s Reporters:

A physician, psychologist, and any other health care professional licensed pursuant to Title 45 of the Revised Statutes who is qualified by training to make the diagnosis and who then makes the diagnosis that a child is affected with ASD shall report this diagnosis to the Department of Health and Senior Services in a form and manner prescribed by the Commissioner of Health and Senior Services. These roles are further defined in New Jersey’s Administrative Code.

- Dr. Sandra Howell commented that if the physician is the diagnostician, the reporter could be someone in the office filling out the information on the form.
 - Sometimes families will fill out the demographic portion of the form and the diagnostician or designee will fill out the remainder of the form.
- The reporter becomes the state’s contact person for the registry. In New Jersey’s experience, staff has to contact the reporters often since they usually retrieve the necessary information from medical records.
- New Jersey has very few doctoral-level reporters and instead use masters-level health care professionals which include:
 - Nurse practitioners, master level social workers, etc.
 - If a team approach is used for ASD diagnoses, someone on that team could be the designated reporter.
- The health care professional usually puts a note in the child’s medical records that the child has been reported into the ASD registry. A copy of the report form does not need to be included in the child’s medical file.
 - Health care professionals can also call New Jersey Department of Health to see if a child has been registered.
 - It is not the job of the state to validate an ASD diagnosis.

New Jersey’s Current Progress:

New Jersey is currently working on updating the ASD registration form. New Jersey Department of Health will convene stakeholder meetings across the state to discuss changes to the form.

	<ul style="list-style-type: none"> • The registration form is being transitioned from DSM-IV to DSM-5. • Some potential additions to the new ASD registration form include: <ul style="list-style-type: none"> ○ Co-morbidities (e.g., ADHD, seizures, mental health, etc.). ○ Changing “date of first diagnosis” to “age at first diagnosis”. ○ Functional assessments (e.g., verbal vs. non-verbal and independent vs. non-independent). ○ Medication use (e.g., psychotropic drugs, etc.). ○ Collection of clinical observations. • New Jersey may change the way sibling information is collected on the ASD registration form. They have been receiving information about half-siblings and step-siblings and they aren’t doing anything with this information. • Conversation has been made about providing a postcard to families that are willing to be contacted by New Jersey Department of Health about potential research opportunities. • There has been discussion about the possibility of letting providers have access to the ASD registry in the future. The providers would be able to do a soft search with a name and date of birth to see if the child’s been registered. <p><u>Case Management Role:</u> Dr. Sandra Howell is one of two people who administers New Jersey’s ASD registry.</p> <ul style="list-style-type: none"> • Dr. Sandra Howell’s epidemiology role includes: <ul style="list-style-type: none"> ○ Educating the public and providers about the ASD registry. ○ Finding missing data by auditing providers. ○ Running reports about ASD in New Jersey. ○ Updating diagnostic information in the registry. 	
<p>History and Progress to Date for North Dakota’s ASD Database</p>	<p>Tammy discussed the legislative history of autism that started with four bills. These four bills were eventually consolidated into one comprehensive bill known as House Bill 1038 during the 2013 legislative session.</p> <p>Kodi went over the progress of the ASD database:</p> <ul style="list-style-type: none"> • Purchased MAVEN from Consilience Software. • Drafted the ND ASD database report form. • Designed the ASD database with the assistance of Dr. Tracy Miller. • Co-presented with Dr. Sandra Howell at the ND ASD Conference on October 22, 2014. 	<p>Informative-no action taken</p>
<p>Criteria for Qualified Reporters</p>	<p><u>Who is qualified to report into the database?</u> ND law requires that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of ASD, including intellectual</p>	<p>The expert panel recognized the value of requiring a doctoral-level professional who is experienced</p>

	<p>testing and other formal evidenced-based assessments for ASD.</p> <ul style="list-style-type: none"> • The intent of the bill was to safe guard accurate reporting of ASD. <p>The expert panel recognized that the gold standard for diagnosing ASD would be using a multi-disciplinary team approach.</p> <ul style="list-style-type: none"> • Many rural areas in ND do not have doctoral-level professionals available and instead use other health care professionals such as nurse practitioners and physician assistants. • There were recommendations to include trained, credentialed, and licensed masters-level health care professionals as reporters such as: <ul style="list-style-type: none"> ○ Physician assistants, nurse practitioners, and masters-level psychologists, etc. <p>There was a lot of discussion about the difference between a diagnostician and a reporter.</p> <ul style="list-style-type: none"> • The expert panel agreed that the reporter could be different from the diagnostician. <ul style="list-style-type: none"> ○ The diagnostician could assign a designee from the same facility to fill out the report form and submit it to the ND Department of Health. <p>There were concerns about the reporter being experienced in the field of ASD, including intellectual testing and other formal evidenced-based assessments for ASD.</p> <ul style="list-style-type: none"> • Different specialties aren't qualified to conduct intellectual testing and other formal evidenced-based assessments as part of the diagnostic process for ASD. • The form required that the diagnostician verify whether or not the diagnostician was experienced in the field of ASD, including intellectual testing and other formal evidenced-based assessments for ASD. The expert panel determined that the "Yes" or "No" statement on the reporting form was too literal. It could potentially inhibit reporters from reporting into the ASD database. <p>Dr. Tracy Miller suggested that language concerning qualified reporters could be adapted from North Dakota Century Code – Chapter 23-07, regarding reportable diseases which states:</p> <p><u>Who is to report reportable diseases:</u></p>	<p>in the field of ASD, including intellectual testing and other formal evidenced-based assessments for accurate ASD diagnoses. The expert panel had concerns about a reporter's ability to address both the complete physical evaluation and intellectual testing or other evidenced-based assessments required for the ASD diagnosis to be reported. It was also determined that the gold standard for ASD diagnoses would be a multi-disciplinary team approach; however, that option is not always offered or practiced across the state.</p> <ul style="list-style-type: none"> • It was the expert panel's recommendation to include physicians, psychologists, and other masters-level diagnosticians who are trained, licensed and credentialed to diagnose ASD. • The expert panel recognized that the person reporting into the database could be different from the diagnostician; therefore, the expert panel recommended that a reporter's designee also be allowed to fill out the report form.
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	<p><i>Except as otherwise provided by section 23-07-02.1, the following persons or their designees shall report to the State Department of Health any reportable disease coming to their knowledge:</i></p> <ul style="list-style-type: none"> <i>All health care providers, including physicians, physician assistants, nurse practitioners, nurses, dentists, medical examiners, or coroners, pharmacists, emergency medical service providers, and local health officers.</i> <i>If the person reporting is the attending physician or the physician's designee, the physician or the physician's designee shall report not less than twice a week, in the form and manner directed by the State Department of Health, the condition of the person afflicted and the state of the disease. A person making a report in good faith is immune from liability for any damages which may be caused by that act.</i> 	
<p>North Dakota Autism Database Report Form</p>	<p>Kodi discussed the ASD database report form with the expert panel by breaking it down into sections according to the major headings.</p> <p><u>Registration Information:</u> Do the options of “New” and “Update” work?</p> <ul style="list-style-type: none"> Expert panel members agreed that no changes were needed. <p><u>Insurance Information:</u> Insurance information was added as a possible linkage for services.</p> <ul style="list-style-type: none"> Expert panel members agreed that this was beneficial. The list should be expanded to include Tricare and Medicare. <p><u>Individual's Information:</u> There were some concerns over the purpose of requesting an individual's Social Security Number. The purpose behind collecting Social Security Numbers is to eliminate multiple entries and to potentially link to other registries in the future.</p> <ul style="list-style-type: none"> The expert panel advises that the Social Security Number should be listed as optional. <p><u>Individual's Current Address:</u> The unit description and unit number are meant to signify apartment buildings and the correlating apartment number.</p> <ul style="list-style-type: none"> It was recommended that unit description and unit number should be reworded or removed. <p><u>Hospital/Place of Birth:</u></p>	<p>The ASD report form has been revised with the recommendations given by the expert panel. It was also updated to have the demographics coincide with ND's birth registry.</p>

	<ul style="list-style-type: none"> • Expert panel members suggested adding home births and midwives to this section. <p><u>Primary Care Provider:</u> The primary care provider may not be the ASD diagnostician.</p> <ul style="list-style-type: none"> • Expert panel members agreed that no changes were needed. <p><u>Birth Information:</u> Kodi asked for any input on whether the term “indeterminate” is appropriate for sex determination. It is the term used in ND’s birth defects registry.</p> <ul style="list-style-type: none"> • Expert panel members agreed that the term is accurate. <p><u>Ethnicity Information:</u></p> <ul style="list-style-type: none"> • Expert panel members suggested that Other/Unknown should be added to the list of races. <p><u>Birth Mother’s Residence at Time of Individual’s Birth:</u></p> <ul style="list-style-type: none"> • The heading of this section should be reworded to minimize confusion. • The word “institutionalized” should be defined or replaced by a different term. • Expert panel members agreed that state and country is all that is needed for the mother’s residence at the time of delivery. The street address should be removed from the form. <p><u>Parent/Guardian Information (A)/(B):</u> Discussion was made on whether (A)/ (B) or mother/father would be better to identify the parent’s/guardian’s information. The form was set up as (A)/ (B) in order to prepare for same-sex couples where the use of mother/father wouldn’t be applicable.</p> <ul style="list-style-type: none"> • The expert panel members agreed that using (A)/ (B) would work the best. <p><u>Diagnostician Information:</u> The expert panel discussed adding to the specialty list on the form to include masters-level health care professionals such as:</p> <ul style="list-style-type: none"> • Physician assistants, nurse practitioners, and psychologists, etc. <p>The part on the form that asked for verification of experience in the field of ASD including intellectual testing and other formal evidenced-based assessments had many members of the expert panel concerned and unwilling to confirm “yes” or “no” on the</p>	<p>It was determined by the expert panel that the qualifications for the reporter be changed to include physicians, psychologists, and other masters-level diagnosticians who are trained, licensed and credentialed to diagnose ASD.</p>
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form.

- Consensus was that this needs to be changed to encourage reporting and not deter it.

Practice/Facility Where Diagnosis was Made:

- Expert panel members agreed that no changes were needed.

Information on Person Submitting Report:

- Expert panel members agreed that no changes were needed.

Diagnosis Information for this Registration Form:

Both DSM-IV and DSM-5 diagnosis information was included on the form in order to collect as many individuals diagnosed with ASD as possible in the state.

- The expert panel wants to keep DSM-IV information on the form to include individuals that have been previously diagnosed or for those diagnosed out of state.
- The expert panel recommended adding adaptive tests and intellectual tools to the list of instruments/references used for diagnosis.
- Noted: social communication severity levels are missing under DSM-5 diagnosis and in the tools/references box DSM-5 needs to be added to the list.

Autism History:

- The heading of this section should be switched to “Autism Spectrum Disorder History” per the expert panel.
- “Date of Diagnosis” was changed to “Age of Diagnosis”

Sibling Information:

There was discussion about adding genetic information about the siblings into the form.

- The expert panel decided that the number of siblings diagnosed with ASD would suffice.

Clinical Observations:

The necessity of collecting clinical observations was discussed and it was decided that clinical observations could be beneficial for research and analysis.

- It was determined that the heading of “Clinical Observations” needed to be changed to “Clinical Impressions” or “Observations & History”.

	<p><u>Complete Physical Evaluation:</u> Current bill language states that the database must include a complete physical evaluation of the individual performed by a licensed physician; however, in many rural areas of ND they are not available. Instead rural areas utilize other health care professionals such as nurse practitioners and physician assistants for health care needs.</p> <ul style="list-style-type: none"> • Certain specialties would have to collaborate with licensed physicians in order to have the complete physical evaluation done for reporting. • The recommendation of the expert panel was to look into broadening the types of health care professionals that can perform the complete physical evaluation to include those with master degrees such as nurse practitioners and physician assistants. <p>The form asks for either a “yes” or “no” on whether the complete physical evaluation has been completed.</p> <ul style="list-style-type: none"> • A question was asked that if a complete physical evaluation was not done, could the rest of the form be filled out and turned in. • There were concerns that the complete physical evaluation would be open to interpretation depending upon the provider. There isn’t a consistent description of what a complete physical evaluation entails. • The expert panel found the hearing test and the exclusion of organic causes on the report form appropriate. • The time frame of the complete physical evaluation for reporting will have to be addressed in Administrative Rules. <p><u>Co-morbidities:</u></p> <ul style="list-style-type: none"> • The expert panel wanted to add genetic disorders/abnormalities, feeding/eating disorders, drug/alcohol exposure, and an “other” category. <p><u>Medication(s) Current or Former Use:</u> It was determined that it would be better to list the categories of the various medications along with examples. Then boxes listed as current or former could be selected for medication use.</p> <ul style="list-style-type: none"> • Some additional medication categories given by the expert panel include Alpha Agonist, CAMs, Non-stimulants, Nutritional supplements, Sleep aid and other, specify. 	<p>The expert panel recommended that a change be made regarding the complete physical evaluation.</p> <ul style="list-style-type: none"> • It was suggested that instead of including a complete physical evaluation for ASD reporting, rather the reporter indicate whether a complete physical evaluation was performed as part of the diagnostic process for ASD. • The expert panel recognized that, in addition to physicians, masters-level health care professionals may also perform the complete physical evaluation for ASD reporting.
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<p>Additional Discussions</p>	<p>Kodi asked for input from the expert panel about the timeliness requirements for reporting into the ASD database. The discussion amongst the expert panel members was between 30 days to 90 days to report into the database.</p> <ul style="list-style-type: none"> The overall consensus was that 30 days from the time the individual was seen was considered reasonable. It gave the reporter the right amount of time to get all the resources in. <p>Kodi wanted to know whether there should be an age limit for reporting into the ASD database if the ND Department of Health has the authority to do so.</p> <ul style="list-style-type: none"> No set age limit was offered by the expert panel. The majority of the expert panel agreed that all ages should be reported as directed by House Bill 1038. <p>There was a question about whether the information can be updated in the ASD database. Families have a fear of not getting services if they do not have an accurate ASD diagnosis.</p> <p>It was recommended that the ND Department of Health works with Indian Health Services (IHS) for the ASD database. It is important that the department works with medical facilities and schools on the reservations.</p> <p>The expert panel asked about out of state diagnoses and how those individuals would be entered into the ASD database.</p> <p>Another question asked about what happens when a reported individual leaves the state for a few years; how would that affect the database?</p>	<p>The expert panel determined that 30 days is sufficient time for the reporter to report an individual to the ASD database.</p> <p>There weren't any recommendations given for an age limit on who should be reported.</p> <p>The expert panel decided that the database should be based on what the needs of the individual are at the time they are reported.</p> <p>Involving IHS in the development and implementation of the ASD database is necessary.</p> <p>These were great questions that will need to be addressed in the Administrative Rules by the ND Department of Health.</p>
<p>Next Step for the ASD database</p>	<p>Although the intent of original bill language was to ensure accurate and appropriate ASD diagnoses, it was determined by the expert panel that the language is too restrictive, therefore potentially hindering reporters from across the state from reporting to the ASD database.</p> <p>New bill language is necessary to address these parts in Section 1:</p> <ul style="list-style-type: none"> Section 1 Part 2- In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorder. 	<p>New bill language will be drafted by the ND Department of Health and sent to Senator Heckaman for the 2015 legislative session.</p>

	<ul style="list-style-type: none"> Section 1 Part 3.b. - Include a complete physical evaluation of the reported individual performed by a licensed physician. 	
Closing Remarks/Wrap-up/Adjourn	<p>Once the administrative rules are drafted and sent to the State Health Council and Legislative Council, there will be a public hearing. The public hearing will be followed by a 10-day comment period where additional comments can be submitted to the ND Department of Health.</p> <p>Kodi's case management role is still to be determined. ND doesn't have the same capacity as New Jersey to directly link individuals and families to services.</p> <p>Kodi thanked everyone for their participation and the ASD expert panel meeting was adjourned.</p>	<p>The expert panel will be notified when the administrative rules are available for public hearing and the 10-day comment period.</p> <p>Kodi's case management role still needs to be defined.</p>