

2015 SENATE HUMAN SERVICES

SB 2176

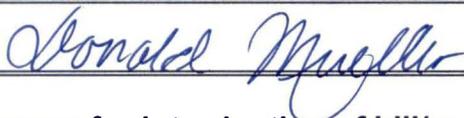
2015 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2176
1/21/2015
22263

- Subcommittee
 Conference Committee

Donald Mueller



Explanation or reason for introduction of bill/resolution:

A bill relating to the autism spectrum disorder database; and to declare an emergency

Minutes:

Attach #1: Testimony by Senator Joan Heckaman
Attach #2: Testimony written by Barbara Stanton
Attach #3: Testimony by Tamara Gallup Leim
Attach #4: ND Autism Spectrum Disorder Form

Senator Joan Heckaman provided overview and spoke IN FAVOR of SB 2176. (attach #1) (testimony ends 4:35)

Written testimony by **Barbara Stanton**, Prairie St. John's in Fargo, (attach #2) supports IN FAVOR of SB 2176 (Senator Heckaman read her testimony - ends 8:15).

Chairman Judy Lee stated that she doesn't have a problem with the record of the physical examination not being there, but have a problem that there is any suggestion that they wouldn't have a physical examination at the time the assessment is going to be done because part of the reason we did that in the first place is because there maybe something else that shows up in the physical examination that may contribute to the behavior situation is. Is it your understanding that this would be optional?

Senator Heckaman indicated that in their discussions on this, this pertains more to individuals coming from out of state. Physicians are seeing people coming in with diagnosis, and then finding there was no examination. As far as reporting this to the database, they would have to indicate this as no physical. The Doctors that were present that day indicated they do perform a physical. All the physicians and diagnosticians in the state do require this. This information would be more for those who are coming in, and if we wait for them to get a physical and they don't get it, then maybe they won't come back and get services. That is one of the reasons the checkbox is on the form. As far as requiring it, Senator Heckaman referred to Kodi Pinks.

Chairman Judy Lee indicated that it needs to be done here then.

Tamara Gallup Leim, Director of the Division of Children's Special Health Services for the North Dakota Department of Health, spoke IN FAVOR of SB 2176 (attach #3) (9:48-17:05)

Chairman Judy Lee feels strongly that at some point in the beginning process that the physical is done. If the box is checked no, then we may look that a physical should be done in 30 days. As stated earlier, there are times when the physical hasn't been done and we certainly want the reporting done, but Chairman Judy Lee thinks the physical exam is critical for the report, as it could be evident of situations and behaviors. It needs to be practical but ensures the physicals will be done.

Ms. Lelm asked if looking at the report form might be helpful. (attach #4).

Chairman Judy Lee asked how they work with Patricia Paige, the coordinator in the Department of Human Services.

Ms. Lelm indicated that they do work with her, most closely when we participate in the State Autism Task Force, and also in the autism conference.

Senator Dever asked if they have begun gathering data for the database.

Ms. Lelm indicated not yet. It has not been fully implemented. We do have a model, developed on the Maven System, but we are still fine tuning before we roll out. Want to make sure administrative rules are consistent with the desires of the legislature.

Senator Dever indicated that other bills want to define who is a qualified mental health professional.

Chairman Judy Lee discussed history of this committee having discussions on who is included as a qualified mental health professional.

V. Chairman Oley Larsen this database - we are working on another database. Will this talk with that one or is this a stand-alone database?

Ms. Lelm indicated it is part of the overall disease surveillance system, but it is its own separate module. Designated people have access to the database, but part of a larger system.

Chairman Judy Lee stated that the health information hub, this is one of the entries, it will be a repository for the information, but will only be available and accessible to the appropriate people.

V. Chairman Oley Larsen stated looking at the application, the DSM-4 is now updated with DSM-5.

Ms. Lelm recognizes this, although there may be some folks who may have used the criteria for DSM-4, and we don't have any age groups outlined in this, so we are trying to cover past and future and combine. This was a recommendation of the panel of experts.

Senator Warner understands that this will be an online form. Is that correct?

Ms. LeIm indicated the form will be both paper and web-based online.

Senator Warner asked if paper form comes in, will it be digitized.

Ms. LeIm answered yes, that is correct

Kodi Pinks, the Autism database administrator for Department of Health in the Children's Special Health Services Division. This form was created after researching eight different states and also expert panel in October 2014. The physical is identified on page 3. The doctors thought it was important to have a physical evaluation as part of the diagnostic process. It previously stated "complete physical", so they liked adding the part about having a hearing test, if other organic causes were excluded, and also allowed room on the report form to add additional details as needed.

Chairman Judy Lee said you think the form will tell the people who check no in the box, that they still need to submit the information in a timely manner on the other stuff.

Ms. Pinks indicated that timeliness requirements would be put in the administrative rules, but the form can still be changed. One concern that many expert panel members had is that if a physical examination wasn't done, or if it was an out of state diagnosis, that they couldn't report the individual. This is something the group thought should be a requirement so it can be done. The report form, if they say no, then we have the option to make it a requirement that it can be done.

Chairman Judy Lee indicated that she would like it to be a requirement.

Opposed
No testimony

Neutral
None

Closed Public Hearing.

2015 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2176
1/21/2015
22262

- Subcommittee
 Conference Committee

Donald Mueller



Explanation or reason for introduction of bill/resolution:

A bill relating to the autism spectrum disorder database; and to declare an emergency

Minutes:

"Click to enter attachment information."

These are minutes from committee work on January 21, 2015.

Chairman Judy Lee discussed the requirement to have physical. The whole idea of having someone skilled in this diagnosis was a critical issue. When we talked about this last time, we want to make sure people who knew what they were doing were doing it. We didn't want family practice doctors who didn't have any special training in this, we wanted them to refer them to experts in this area. We wanted to make sure the right people were doing the assessment with the right training and expertise. There might be some physical circumstances that might occur. There are also cases where there could be an intellectual disability in which the behaviors would mirror some of the same things we see with autism spectrum disorder, so the goal is to have the correct diagnosis in the first place. We were restrictive on who could do this work.

V. Chairman Oley Larsen asked if this bill is expanding it further.

Chairman Judy Lee indicated that it will allow them to make sure the box is checked, and they will make sure it will be done, and the recording can be done by someone other than the physician or whoever the professional is themselves.

Senator Howard Anderson, Jr. indicated that under B on page 2, we could add a sentence, "whether a completed physical examination was performed by a licensed independent practitioner as part of the diagnostic process for autism spectrum disorder, or has been arranged within the next xx days". We could make it clear that they have to do the physical. What is a licensed independent practitioner - is it mean they have to work for someone different than the person who is making the autism diagnosis?

Chairman Judy Lee read from the bill, physician or psychologist or any other licensed or certified health care professional who is qualified by training and by licensure or certification to make the diagnosis, as stated on the bottom of page 1.

Senator Howard Anderson, Jr. asked about the word "Independent"

Chairman Judy Lee indicated that a primary care provider, such as a nurse practitioner could do the physical, but not the autism evaluation. If the physician assistant is not an independent practitioner, for example, we are really only talking about medical doctors and APRN's. They all work for the doctor. The Health Department understands that we think the physical is important and they can do this through administrative rules.

(Note - Chairman Judy Lee waited for further action until Senator Dever returned (8:27)

Senator Howard Anderson, Jr. updated Senator Dever that if Chairman Judy Lee was concerned about the issue of physical exam, we could add line. We still want the reporting.

Chairman Judy Lee indicated that she is comfortable so don't need to change on her account.

Senator Howard Anderson, Jr. made a motion that the Senate Human Services Committee recommend a DO PASS on SB 2176. The motion was seconded by **V. Chairman Oley Larsen.**

No discussion.

Roll Call Vote
6 Yes, 0 No, 0 Absent

Chairman Judy Lee will carry the bill.

**2015 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. SB2176**

Senate Human Services Committee

Subcommittee

Amendment LC# or Description: _____

Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
 Other Actions: Reconsider _____

Motion Made By Anderson Seconded By Larson

| Senators | Yes | No | Senators | Yes | No |
|---------------------------------|-----|----|------------------------|-----|----|
| Senator Judy Lee (Chairman) | ✓ | | Senator Tyler Axness | ✓ | |
| Senator Oley Larson (V-Chair) | ✓ | | Senator John M. Warner | ✓ | |
| Senator Howard C. Anderson, Jr. | ✓ | | | | |
| Senator Dick Dever | ✓ | | | | |
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Total (Yes) 6 No 0

Absent 0

Floor Assignment Lee

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2176: Human Services Committee (Sen. J. Lee, Chairman) recommends DO PASS
(6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2176 was placed on the
Eleventh order on the calendar.

2015 HOUSE HUMAN SERVICES

SB 2176

2015 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

SB 2176
3/24/2015
Job # 25319

- Subcommittee
 Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

Relating to the autism spectrum disorder data base and declare an emergency

Minutes:

Attachments 4

Chairman Weisz opened the hearing on SB 2176.

Sen. Joan Heckaman: From New Rockford, District 23 introduced and supported the bill. (See Testimony #1 and Testimony #2, testimony of Dr. Barbara Stanton handed out and read by Sen. Heckaman)

8:19

Rep. Fehr: I'm looking at your subsection 2, page 1. It looks like the change went from trying to make sure we have a doctoral level person to make sure the diagnosis is accurate to saying lets be more inclusive to be sure we get the people counted. With the statement, "other licensed or certified health care professionals". If somebodies a counselor and they've taken a class or two, and they say I've got one in front of me. They would indicate or self-identify that they must be a reporter then?

Sen. Heckaman: Looking at individuals at the doctorate level we excluded a lot of people who are, on page 20, qualified by training, licensure and certification. Some of those individuals as counselors are not qualified by training or licensure or certification to do that diagnosis and they would not be allowed to do that. This has to do with scope of practice. In North Dakota, others are able to diagnose for autism. That's why we wanted to make sure we have all those people who are qualified are included.

Chairman Weisz: Who are we leaving out?

Sen. Heckaman: I think it's some of the other practitioners. Maybe Miss Pinks can answer that better.

Chairman Weisz: Why did we have to specifically mention physician or psychologist, aren't they a certified health care professional?

Sen. Heckaman: I can't answer that.

11:55

Kodi Pinks: Autism Database Administrator for the ND Dept. of Health testified in support of the bill. (See Testimony #3)

16:13

Chairman Weisz: Who is currently being left behind?

Pinks: I spoke to ND Board of Examiners licensed independent clinical social workers, licensed professional clinical counselors, nurse practitioners, and clinical nurse specialists are within their scope of practice able to diagnose autism.

Chairman Weisz: Don't they all have doctorates?

Pinks: Not always.

Chairman Weisz: Nurse practitioners?

Pinks: Some have master's degrees and they're changing the program to doctoral level.

Chairman Weisz: Why did you have to specifically include physician and psychologists when it would seem like they are licensed and certified health care professionals?

Pinks: Some of this language is used from other states that have autism registries. That is the common language that they use. They wouldn't have to be separated.

Chairman Weisz: Currently you can diagnose someone as having ASB (Autism Spectrum Disorder), and yet they've never had a complete physical examination for other issues. That's the way we're doing it?

Pinks: I'll give you my reporting form so you can see what we're requiring? (See Handout #4) On page 3, at the top on the right hand side is the part that asks about the physical evaluation. According to my expert panel, most of the time there is always a physical evaluation that is part of the diagnostic process. Our concern is for the people who have been diagnosed out of state or previously diagnosed. We didn't want to exclude those just because they had not had a physical evaluation.

Rep. Mooney: Who is on the expert panel?

Pinks: Twenty-eight people, would you like me to list all of them?

Rep. Mooney: You can e-mail the list. It's nice to know who the experts are.

Pinks: There were State agency staff, psychologists, pediatricians, the representative that runs the New Jersey registry, Special Education, and Blue Cross Blue Shield on the panel.

Rep. Fehr: If a counselor suspected some kind of autism disorder on a child, does he have to report it?

Pinks: That would be correct. We want to try to ensure accuracy with the data base. We hope that individuals such as that be referred to the right professional that can do a diagnostic process. What we also hope to find out who is diagnosing in North Dakota. We need to know what's going on in North Dakota; who is diagnosing, who is being diagnosed and how many are being diagnosed. From there we can determine what we need to do.

Rep. Fehr: Is your understanding consistent with what Senator Hechaman had said that the changes to go from trying to be real accurate to trying to have a broader scope, which may not be as accurate with exact diagnosis, but is more likely to get the numbers in?

Pinks: I talked to a psychologist who was very concerned that we brought in the qualifications of the reporter. He felt it might result in inaccurate diagnoses of those being reported. I believe and the psychologist concurred that my report form will help ensure accuracy of diagnosis.

Chairman Weisz: Clinical impressions are one of your tools?

Pinks: Yes, but there are additional requirements for diagnosis.

NO OPPOSITION

Chairman Weisz closed the hearing on SB 2176.

2015 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

SB 2176
3/31/2015
Job # 25645

- Subcommittee
 Conference Committee

Committee Clerk Signature 

Minutes:

Attachments 0

Chairman Weisz: Let's take up 2176.

Rep. Fehr: I motion a Do Pass on SB 2176

Rep. Hofstad: Second.

Vote: Yes 13, No 0, Absent 0

Rep.Fehr: Carrier.

Chairman Weisz closes discussion.

Date: 3-31-15
 Roll Call Vote #: 1

**2015 HOUSE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. 2176**

House Human Services Committee

Subcommittee

Amendment LC# or Description: _____

- Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
 Other Actions: Reconsider _____

Motion Made By Rep. Fehr Seconded By Rep. Hofstad

| Representatives | Yes | No | Representatives | Yes | No |
|---------------------|-----|----|-----------------|-----|----|
| Chairman Weisz | ✓ | / | Rep. Mooney | ✓ | / |
| Vice-Chair Hofstad | ✓ | / | Rep. Muscha | ✓ | / |
| Rep. Bert Anderson | ✓ | / | Rep. Oversen | | |
| Rep. Dick Anderson | ✓ | / | | | |
| Rep. Rich S. Becker | ✓ | / | | | |
| Rep. Damschen | ✓ | / | | | |
| Rep. Fehr | ✓ | / | | | |
| Rep. Kiefert | ✓ | / | | | |
| Rep. Porter | ✓ | / | | | |
| Rep. Seibel | ✓ | / | | | |
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Total (Yes) 13 No 0

Absent 0

Floor Assignment Rep. Fehr

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2176: Human Services Committee (Rep. Weisz, Chairman) recommends **DO PASS** (13 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2176 was placed on the Fourteenth order on the calendar.

2015 TESTIMONY

SB 2176

Chairman Lee and Members of the Senate Human Services Committee:

I am Senator **Joan Heckaman** from New Rockford and I serve District 23. I am here to introduce SB 2176 to you.

This bill is an old friend from last session. This bill established an autism spectrum disorder database and several criteria for the data base were detailed in this section of code. Following the employment of a database coordinator, that coordinator began the process of developing the form that the reporters would provide to the Department of Health to process into the database. In the development phase of this document, the coordinator worked closely with New Jersey's coordinator to ensure that all items submitted were purposeful and covered all of the pertinent information needed. Following that development, the coordinator convened a panel of experts from across the state, around 25 individuals who had a background in the area of autism. That panel spent time closely inspecting each entry and found that the current law passed last session leaves out several individuals who are actually licensed and certified to diagnose autism and report. As a result of that, the coordinator could not go forward with the rule making process because the database would not be a workable nor have useful information as a number of reporters would be omitted.

It was the determination of the expert panel to have a bill presented to correct that information and add additional reporters who by training, licensure, or certification diagnose autism.

Additionally, the panel also felt that having the Department of Health store the complete physical evaluation records of individuals who have been diagnosed would be cumbersome. On page 2, line 4 you will find that the change recommended will provide an indication of whether a complete physical evaluation was completed as part of the diagnosis. This was a concern of one of the physicians that individuals are coming into the state with an autism diagnosis and there is no indication of whether they have had a physical. This would allow the current service provider to check the "No" box to indicate they believe no physical was completed. This information is important in the fact that all diagnosticians present reported they "do" complete a physical here in North Dakota. And if they find an individual has not had one, they can certainly complete that as part of their evaluation.

An emergency clause is also attached so the Health Department may begin their Administrative Rules process as soon as this bill passes both chambers and is signed by the Governor. The current rules being drafted will address the changes the department and the expert panel believe are crucial to the implementation of the data base.

Chairman Lee and members of the committee, that completes my testimony and I would be available to answer questions. But I want to let you know that Kodi Pink~~s~~, data base

coordinator, is here to present further testimony and I believe she will be more able to answer any questions you may have.

Thank you for your consideration of SB 2176.

Senator Joan Heckaman

SB2176
Attach #2
01/21/15
J# 22263

Testimony for:

SB 2176: Senate Human Services Committee

January 21, 2015

Madame Chairman Lee and members of the Senate Human Service Committee,

I am **Dr. Barbara Stanton**. I am employed at Prairie St. John's as an outpatient therapist specializing in autism spectrum disorders (ASDs). I conduct diagnostic assessments, do individual and family therapy and provide consultation, collaboration and case management services. I am also the program director of our newly opened ASD partial hospitalization program. In the past 14 years I have worked with nearly 1,500 individuals on the autism spectrum and their families. I was also a member of the expert panel convened by the North Dakota Department of Health to address the ASD Database.

This testimony is in support of the SB 2176 which is an amendment to Section 23-01-41 of the North Dakota Century Code regarding the Autism Spectrum Disorder Database.

Section 1 (2): We need to open the database to all qualified mental health professionals who are, by education and licensure, able to make diagnoses using the most recent Diagnostic and Statistical Manual. These professionals are making diagnoses and need access to the database. If we limit their access to the database we will limit the accuracy of the data and/or access to diagnosticians by families. This was discussed and agreed to by the expert panel convened by the ND Department of Health.

There is no question that this is a complicated diagnosis to make and additional training opportunities would be helpful for all disciplines. The ASD Database Report Form has a section for information regarding how the diagnosis was made, whether through instruments and/or clinical impressions. This

will provide valuable information about the process by which autism spectrum disorders are being identified and will assist in making any changes needed.

Section 1 (3b): The language about a physical was changed from requiring a physical examination to asking about whether or not the child has had a physical examination as a part of the diagnostic process. Especially in rural North Dakota, requiring a physical at the time of the assessment could delay or keep families from undergoing an ASD assessment. It is standard to encourage caregivers to have regular physicals for children. If there is a question about symptoms that could be explained by medical problems, such as a speech delay related to a hearing loss, then a referral should be made to a qualified medical professional as a matter of best practice.

Section 4: Adding the "designee" as an option to report to the database is critical to expedite the process. Physicians, in particular, do not have the time to complete the ASD Database form which is lengthy (3 pages covering a variety of pertinent data). The other health registries allow for designees to provide the report information.

I have averaged 3 autism spectrum disorder assessments with children and adults per week. Myself and other staff at Prairie St. John's will be frequent reporters to the Autism Spectrum Disorder Database. These changes are critical in order to make the database efficient and effective.

I strongly urge you pass SB 2176 an amendment to the North Dakota Autism Spectrum Disorder Database.

Attach #3
SB 2176
01/21/15
J# 22263

Testimony
Senate Bill 2176
Senate Human Services Committee
Wednesday, January 21, 2015; 9:00 a.m.
North Dakota Department of Health

Good morning, Chairman Lee and members of the Senate Human Services Committee. My name is Tamara Gallup Lelm and I am Director of the Division of Children's Special Health Services (CSHS) for the North Dakota Department of Health (NDDoH). I am here to provide testimony in support of SB 2176.

During the last legislative session, the NDDoH was given the responsibility of establishing and administering an autism spectrum disorder (ASD) database through the establishment of NDCC chapter 23-01-41.

The department has made significant progress towards development of the ASD database.

- In April 2014, an Autism Database Administrator was hired in CSHS
- The ASD module, which is an addition to the infectious disease surveillance system called MAVEN, was obtained
- Data collection fields were researched and defined for the ASD module
- In October 2014, an ASD expert panel meeting was held in conjunction with a technical assistance visit from autism registry staff from New Jersey, ND's mentor state for the ASD database (consultation with experts to establish reporting criteria is required in NDCC 23-01-41)
- The ASD database report form was drafted and is being finalized
- The department is in process of drafting Administrative Rules for the ASD database; final content of the rules is dependent on the outcome of the proposed SB 2176

The ASD expert panel that was convened in October raised concerns that language in NDCC 23-01-41 was potentially too restrictive and might hinder reporting into the ASD database. The panel recommended that the following areas be addressed during the 2015 legislative session before the ASD database was fully implemented.

Section 1, Part 2 – This section addresses criteria for qualified reporters. Rather than a doctoral level professional who is licensed, credentialed, and experienced in the field of ASD, including intellectual testing and other formal, evidenced-based assessments for ASD, the expert panel recommended the qualifications of reporters

be changed to include physicians, psychologists and other masters-level diagnosticians who are trained, licensed, and credentialed to diagnose ASD. Expert panel members had concerns about a reporter's ability to address both the physical evaluation/exam and intellectual testing or other assessments required for the ASD diagnosis to be reported. For example, psychologists on the panel might not be able to report on the complete physical evaluation and pediatricians might not be able to report on intellectual testing. Although the expert panel determined the gold standard in making an ASD diagnosis is often considered a multi-disciplinary team, the panel recognized that option is not always offered or practiced across the state.

Section 1, Part 3 - The expert panel recommended that a change be made regarding the physical evaluation. Rather than including a complete physical evaluation for ASD reporting, it was recommended that the reporter indicate whether a complete physical evaluation was performed as part of the diagnostic process for ASD. The panel recognized that, in addition to physicians, licensed independent practitioners may also perform physical evaluations. Use of this language is consistent with that used by Joint Commission and Centers for Medicare & Medicaid Services (CMS) to credential the billing of independently functioning practitioners. Including licensed independent practitioners for physical evaluations as part of the diagnostic process for ASD supports reporting in rural parts of ND and physician shortage areas.

Section 1, Part 4 - The expert panel recognized that the person reporting into the database could be different from the diagnostician; therefore, members recommended that a reporter's designee also be allowed to fill out the report form for the database.

Senate Bill 2176, if passed, should help to ensure the success of the ASD database as it is initiated.

This concludes my testimony and I would be happy to answer any questions you may have regarding these proposed changes.

J#22263

01/21/15

Attach#4 SB2176

North Dakota Autism Spectrum Disorder
 Database Report Form
 Children's Special Health Services
 ND Department of Health
 600 E. Boulevard Ave., Dept. 301
 Bismarck, ND 58505-0200
 701.328.4832 or 1.800.755.2714
 SFN xxxxxx (1/20/15)



REGISTRATION INFORMATION

New Update

INSURANCE INFORMATION

None Private Medicaid Medicare
 Tricare Other Unknown

INDIVIDUAL'S INFORMATION

NAME OF INDIVIDUAL (AS APPEARS ON BIRTH CERTIFICATE)

Last Name Suffix

First Name Middle Name

ALSO KNOWN AS

Last Name Suffix

First Name Middle Name

INDIVIDUAL'S CURRENT ADDRESS

Street Address

PO Box City State

Zip code Country Country

Social Security Number (Optional) Telephone Number ()

HOSPITAL/PLACE OF BIRTH

Clinic/Doctor's Office Freestanding Birthing Center Homebirth
 Hospital Other, Specify: _____

Name of Hospital/Place of Birth

Street Address of Homebirth

City State Country

BIRTH MOTHER'S ADDRESS AT TIME OF INDIVIDUAL'S BIRTH

If mother was institutionalized (e.g., nursing home, prison, state hospital, etc.) at time of birth, enter mother's home address before she was institutionalized
 Unknown Same as individual's current address

Street Address

PO Box City State

Zip code County Country

PRIMARY CARE PROVIDER

Provider Name (Last, First) Unknown None

Practice Name

City State Zip code

Telephone Number ()

BIRTH INFORMATION

Date of Birth / / Sex Female Male Indeterminate

Birth Weight _____ Grams -OR- _____ Lbs., _____ Oz. -OR- Unknown

Weeks of Pregnancy Preterm (<37 Wks.) Post Term (≥42 Wks.) Term (37-41 Wks.) Unknown Birth Order

Plurality Single Other Multiple Twin Unknown Father's age at time of delivery _____ Mother's age at time of delivery _____

ETHNICITY INFORMATION

Hispanic/Latino Yes No Unknown

Primary Language Spoken in Home English Spanish Other, Specify: _____

Race (Check ALL that apply) White Black/African American American Indian/Native Alaskan Asian Indian Chinese Filipino Korean Vietnamese Other Asian Native Hawaiian Guamanian Samoan Other Pacific Islander Other, Specify: _____ Refused/Unknown

PARENT/GUARDIAN INFORMATION (A)

Parent Adoptive Parent Foster Parent Legal Guardian

Vital Status Alive Dead Unknown

Sex Female Male Biologically Related to Individual Yes No Unknown

PARENT/ GUARDIAN NAME

Last Name Suffix

First Name Middle Name

Maiden Name

MAILING ADDRESS

Same as individual's current residence address

Street Address

PARENT/GUARDIAN INFORMATION (A), CONTINUED

| | | |
|----------------------|-------------------------|---------|
| PO Box | City | State |
| Zip code | County | Country |
| Date of Birth / / | Telephone Number () | |

ETHNICITY INFORMATION

Hispanic/Latino Yes No Unknown

Race (Check ALL that apply)

| | |
|---|---|
| <input type="checkbox"/> White | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Black/African American | <input type="checkbox"/> Other Asian |
| <input type="checkbox"/> American Indian/Native Alaskan | <input type="checkbox"/> Native Hawaiian |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Guamanian |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Samoan |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Other Pacific Islander |
| <input type="checkbox"/> Korean | <input type="checkbox"/> Other, Specify: _____ |
| | <input type="checkbox"/> Refused/Unknown |

PARENT/GUARDIAN INFORMATION (B)

Parent Adoptive Parent Foster Parent Legal Guardian

Vital Status
 Alive Dead Unknown

Sex Female Male

Biologically Related to Individual
 Yes No Unknown

PARENT/ GUARDIAN NAME

Last Name _____ Suffix _____

First Name _____ Middle Name _____

Maiden Name _____

MAILING ADDRESS

Same as individual's current residence address

Street Address _____

| | | |
|----------------------|-------------------------|---------|
| PO Box | City | State |
| Zip code | County | Country |
| Date of Birth / / | Telephone Number () | |

ETHNICITY INFORMATION

Hispanic/Latino Yes No Unknown

Race (Check ALL that apply)

| | |
|---|---|
| <input type="checkbox"/> White | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Black/African American | <input type="checkbox"/> Other Asian |
| <input type="checkbox"/> American Indian/Native Alaskan | <input type="checkbox"/> Native Hawaiian |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Guamanian |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Samoan |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Other Pacific Islander |
| <input type="checkbox"/> Korean | <input type="checkbox"/> Other, Specify: _____ |
| | <input type="checkbox"/> Refused/Unknown |

DIAGNOSTICIAN INFORMATION

Name of Individual Making Diagnosis (Last, First) _____

Degree (select one):

M.D. D.O. Psy.D. Ph.D. N.P. P.A.

Other, Specify: _____

Specialty:

| | | |
|--|--|--|
| <input type="checkbox"/> Family Practice | <input type="checkbox"/> Nurse Practitioner | <input type="checkbox"/> Psychology |
| <input type="checkbox"/> Geneticist | <input type="checkbox"/> Physician Assistant | <input type="checkbox"/> Other, Specify: _____ |
| <input type="checkbox"/> Internist | <input type="checkbox"/> Pediatrics | |
| <input type="checkbox"/> Neurology | <input type="checkbox"/> Psychiatry | |

PRACTICE/FACILITY WHERE DIAGNOSIS MADE

Practice/Facility Name _____

Department/Unit _____

Street Address _____

| | | |
|--------|------|-------|
| PO Box | City | State |
|--------|------|-------|

| | | |
|----------|--------|---------|
| Zip code | County | Country |
|----------|--------|---------|

Telephone Number
()

INFORMATION ON PERSON SUBMITTING REPORT

Relationship to Person Being Registered

Diagnostician Other Health Care Provider

Diagnostician's Designee Other, Specify: _____

Title
 Dr. Mr. Ms.

Name (Last, First) _____

CONTACT INFORMATION (IF DIFFERENT FROM DIAGNOSTICIAN)

Practice/Facility Name _____

Department/Unit _____

Street Address _____

| | | |
|--------|------|-------|
| PO Box | City | State |
|--------|------|-------|

| | | |
|----------|--------|---------|
| Zip code | County | Country |
|----------|--------|---------|

Telephone Number
()

DIAGNOSIS INFORMATION FOR REGISTRATION

AUTISM SPECTRUM DISORDER HISTORY

| | |
|------------------|--|
| Age at Diagnosis | Age Symptoms First Noted by Anyone ____ Yrs. ____ Mos. <input type="checkbox"/> Unknown |
|------------------|--|

Diagnose using **DSM-IV** (choose one)

Autism Spectrum Disorders:

- Asperger's Disorder
- Pervasive Developmental Disorder NOS
- Autistic Disorder
- Rett Syndrome
- Childhood Disintegrative Disorder

Diagnose using **DSM-5: Autism Spectrum Disorder (ASD)**

Restricted, Repetitive Behavior Severity Levels:

- (choose one)
- Level 3: "Requiring very substantial support"
 - Level 2: "Requiring substantial support"
 - Level 1: "Requiring support"

Social Communication Severity Levels:

- (choose one)
- Level 3: "Requiring very substantial support"
 - Level 2: "Requiring substantial support"
 - Level 1: "Requiring support"

Instruments/References Used (check all that apply)

- Autism Behavior Checklist ABC
- Autism Diagnostic Interview-Revised ADI-R
- Autism Diagnostic Observation Schedules ADOS
- Autism Spectrum Rating Scale ASRS
- Childhood Autism Rating Scale CARS
- Intellectual/ Cognitive Testing
- Clinical Impressions
- Diagnostic and Statistical Manual 4th Ed., Revised DSM-IV-R
- Diagnostic and Statistical Manual 5th Ed. DSM-5
- Gilliam Aspergers Disorder Scale GADS
- Gilliam Autism Rating Scale GARS-2
- Modified Checklist for Autism in Toddlers M-CHAT
- Pervasive Developmental Disorder Screening Test-II PDDST-II
- Social Communications Questionnaire SCQ
- Screening Tool for Autism in Two Year Olds STAT
- Social Responsiveness Scale SRS
- Other, Specify: _____

CLINICAL IMPRESSIONS

PERSISTENT DEFICITS IN SOCIAL COMMUNICATION AND SOCIAL INTERACTION ACROSS MULTIPLE CONTEXTS

- Deficits in social-emotional reciprocity (e.g., reduced sharing of interests, emotions, or affect)
- Deficits in nonverbal communication behaviors used for social interaction (e.g., abnormalities in eye contact and body language, poorly integrated verbal and nonverbal communication)
- Deficits in developing, maintaining, and understanding relationships (e.g., difficulties adjusting behavior to suit various social contexts, absence of interest in peers)

RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOR, INTERESTS, OR ACTIVITIES

- Hyper or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., adverse response to specific sounds or textures)
- Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects)
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., rigid thinking patterns)
- Stereotyped or repetitive motor movements, use of objects, or speech (e.g., lining up toys or flipping objects, idiosyncratic phrases)

Was a complete physical evaluation done by a licensed independent practitioner as part of the diagnostic process for autism spectrum disorder

- Physical Evaluation completed** Yes No
- Hearing Test Done Yes No
- Have Excluded Organic Causes Yes No
- Other, Specify: _____ Yes No

Co-morbidities (check all that apply):

- ADHD
- Asthma
- Depression/Bipolar/Mood
- Feeding/Eating Disorders
- Fetal Alcohol Syndrome
- Genetic Disorders
- GERD or other Gastro Conditions
- Hydrocephalus
- Intellectual disability
- Microcephaly/Macrocephaly
- Obesity
- OCD
- ODD
- Schizophrenia
- Seizures/Epilepsy
- Sleep Disorders
- Tic Disorders
- Other, Specify _____

MEDICATION(S) USE

| | Current | Former |
|--|--------------------------|--------------------------|
| Alpha Agonist (e.g., Catapres, Doxazosin, Prazosin) | <input type="checkbox"/> | <input type="checkbox"/> |
| Anticonvulsants (e.g., Depakote, Lamictal) | <input type="checkbox"/> | <input type="checkbox"/> |
| Antidepressants (e.g., Lexapro, Prozac, Zoloft) | <input type="checkbox"/> | <input type="checkbox"/> |
| Anxiolytics (e.g., Ativan, Buspar) | <input type="checkbox"/> | <input type="checkbox"/> |
| CAMs (e.g., acupuncture, massage therapy, yoga) | <input type="checkbox"/> | <input type="checkbox"/> |
| Neuroleptics (e.g., Abilify, Risperdal, Seroquel) | <input type="checkbox"/> | <input type="checkbox"/> |
| Non-stimulants (e.g., Intuniv, Strattera) | <input type="checkbox"/> | <input type="checkbox"/> |
| Nutritional Supplements (e.g., herbs, minerals, vitamins) | <input type="checkbox"/> | <input type="checkbox"/> |
| Sleep Aid (e.g., Ambien, Lunesta) | <input type="checkbox"/> | <input type="checkbox"/> |
| Stimulants (e.g., Adderall, Ritalin, Dexedrine) | <input type="checkbox"/> | <input type="checkbox"/> |
| Other, Specify: _____ | <input type="checkbox"/> | <input type="checkbox"/> |

SIBLING INFORMATION

Siblings with Autism Spectrum Disorder Diagnosis Yes No If so, how many: _____

EACH SIBLING WITH AUTISM SPECTRUM DISORDER DIAGNOSIS SHOULD BE REGISTERED ON A SEPARATE FORM

Chairman Weisz and Members of the House Human Services Committee:

I am Senator Joan Heckaman from New Rockford and I serve District 23. I am here to introduce SB 2176 to you.

This bill is an old friend from last session. This bill established an autism spectrum disorder database and several criteria for the data base were detailed in this section of code. Following the employment of a database coordinator, that coordinator began the process of developing the form that the reporters would provide to the Department of Health to process into the database. In the development phase of this document, the coordinator worked closely with New Jersey's coordinator to ensure that all items submitted were purposeful and covered all of the pertinent information needed. Following that development, the coordinator convened a panel of experts from across the state, around 25 individuals who had a background in the area of autism. That panel spent time closely inspecting each entry and found that the current law passed last session leaves out several individuals who are actually licensed and certified to diagnose autism and report. As a result of that, the coordinator could not go forward with the rule making process because the database would not be a workable nor have useful information as a number of reporters would be omitted.

It was the determination of the expert panel to have a bill presented to correct that information and add additional reporters who by training, licensure, or certification diagnose autism.

Additionally, the panel also felt that having the Department of Health store the complete physical evaluation records of individuals who have been diagnosed would be cumbersome. On page 2, line 4 you will find that the change recommended will provide an indication of whether a complete physical evaluation was completed as part of the diagnosis. This was a concern of one of the physicians that individuals are coming into the state with an autism diagnosis and there is no indication of whether they have had a physical. This would allow the current service provider to check the "No" box to indicate they believe no physical was completed. This information is important in the fact that all diagnosticians present reported they "do" complete a physical here in North Dakota. And if they find an individual has not had one, they can certainly complete that as part of their evaluation.

An emergency clause is also attached so the Health Department may begin their Administrative Rules process as soon as this bill passes both chambers and is signed by the Governor.

That completes my testimony and I would be available to answer questions. But I want to let you know that Kodi Pinks, data base coordinator, is here to present further testimony and I believe she will be more able to answer any questions you may have.

Thank you for your consideration of SB 2176.

Testimony for:

SB 2176: House Human Services Committee

March 24, 2015

Chairman Weisz and members of the House Human Services Committee,

I am Dr. Barbara Stanton. I am employed at Prairie St. John's as an outpatient therapist specializing in autism spectrum disorders (ASDs). I conduct diagnostic assessments, do individual and family therapy and provide consultation, collaboration and case management services. I am also the program director of our newly opened ASD partial hospitalization program. In the past 14 years I have worked with nearly 1,500 individuals on the autism spectrum and their families. I was also a member of the expert panel convened by the North Dakota Department of Health to address the ASD Database.

This testimony is in support of the SB 2176 which is an amendment to Section 23-01-41 of the North Dakota Century Code regarding the Autism Spectrum Disorder Database.

Section 1 (2): We need to open the database to all qualified mental health professionals who are, by education and licensure, able to make diagnoses using the most recent Diagnostic and Statistical Manual. These professionals are making diagnoses and need access to the database. If we limit their access to the database we will limit the accuracy of the data and/or access to diagnosticians by families. This was discussed and agreed to by the expert panel convened by the ND Department of Health.

There is no question that this is a complicated diagnosis to make and additional training opportunities would be helpful for all disciplines. The ASD Database Report Form has a section for information regarding how the diagnosis was made, whether through instruments and/or clinical impressions. This

will provide valuable information about the process by which autism spectrum disorders are being identified and will assist in making any changes needed.

Section 1 (3b): The language about a physical was changed from requiring a physical examination to asking about whether or not the child has had a physical examination as a part of the diagnostic process. Especially in rural North Dakota, requiring a physical at the time of the assessment could delay or keep families from undergoing an ASD assessment. It is standard to encourage caregivers to have regular physicals for children. If there is a question about symptoms that could be explained by medical problems, such as a speech delay related to a hearing loss, then a referral should be made to a qualified medical professional as a matter of best practice.

Section 4: Adding the "designee" as an option to report to the database is critical to expedite the process. Physicians, in particular, do not have the time to complete the ASD Database form which is lengthy (3 pages covering a variety of pertinent data). The other health registries allow for designees to provide the report information.

I have averaged 3 autism spectrum disorder assessments with children and adults per week. The clinical and medical staff at Prairie St. John's will be frequent reporters to the Autism Spectrum Disorder Database. These changes are critical in order to make the database efficient and effective.

I strongly urge you pass SB 2176 an amendment to the North Dakota Autism Spectrum Disorder Database.

Testimony
Senate Bill 2176
House Human Services Committee
Tuesday, March 24, 2015; 9:30 a.m.
North Dakota Department of Health

Good morning Chairman Weisz and members of the House Human Services Committee. My name is Kodi Pinks and I am the Autism Database Administrator for the North Dakota Department of Health (Department). I am here to provide testimony in support of SB 2176.

During the last legislative session, the Department was given the responsibility of establishing and administering an autism spectrum disorder (ASD) database through the establishment of NDCC chapter 23-01-41.

The Department has made significant progress towards development of the ASD database.

- In April 2014, an Autism Database Administrator was hired in CSHS
- The ASD module, which is an addition to the infectious disease surveillance system called MAVEN, was obtained
- Data collection fields were researched and defined for the ASD module
- In October 2014, an ASD expert panel meeting was held in conjunction with a technical assistance visit from autism registry staff from New Jersey, North Dakota's mentor state for the ASD database (consultation with experts to establish reporting criteria is required in NDCC 23-01-41)
- The ASD database report form was drafted and is being finalized
- The Department is in process of drafting Administrative Rules for the ASD database; final content of the rules is dependent on the outcome of the proposed SB 2176

The ASD expert panel that was convened in October raised concerns that language in NDCC 23-01-41 was potentially too restrictive and might hinder reporting into the ASD database. The panel recommended that the following areas be addressed during the 2015 legislative session before the ASD database is fully implemented.

Section 1, Part 2 – This section addresses criteria for qualified reporters. Rather than a doctoral level professional who is licensed, credentialed, and experienced in the field of ASD, including intellectual testing and other formal, evidenced-based assessments for ASD, the expert panel recommended the qualifications of reporters be changed to include physicians, psychologists and other masters-level

diagnosticians who are trained, licensed, and credentialed to diagnose ASD. Expert panel members had concerns about a reporter's ability to address both the physical evaluation/exam and intellectual testing or other assessments required for the ASD diagnosis to be reported. For example, psychologists on the panel might not be able to report on the complete physical evaluation and pediatricians might not be able to report on intellectual testing. Although the expert panel determined the gold standard in making an ASD diagnosis is often considered a multi-disciplinary team, the panel recognized that option is not always offered or practiced across the state.

Section 1, Part 3 - The expert panel recommended that a change be made regarding the physical evaluation. Rather than including a complete physical evaluation for ASD reporting, it was recommended that the reporter indicate whether a complete physical evaluation was performed as part of the diagnostic process for ASD. The panel recognized that, in addition to physicians, licensed independent practitioners may also perform physical evaluations. Use of this language is consistent with that used by Joint Commission and Centers for Medicare & Medicaid Services (CMS) to credential the billing of independently functioning practitioners. Including licensed independent practitioners for physical evaluations as part of the diagnostic process for ASD supports reporting in rural parts of North Dakota and physician shortage areas.

Section 1, Part 4 - The expert panel recognized that the person reporting into the database could be different from the diagnostician; therefore, members recommended that a reporter's designee also be allowed to fill out the report form for the database.

Senate Bill 2176, if passed, will help ensure the success of the ASD database as it is initiated.

This concludes my testimony. I am happy to answer any questions you may have.



AUTISM SPECTRUM DISORDER REPORT FORM
 NORTH DAKOTA DEPARTMENT OF HEALTH
 CHILDREN SPECIAL HEALTH SERVICES (CSHS)
 SFN ### (3-2015)

Instructions: Please submit the completed form via mail, fax, or email to the NDDoH within 30 days of diagnosis.

SB 2174
 Mar. 24, 2015 #4 p. 1
 Children Special Health Services
 600 E. Boulevard Ave., Dept. 301
 Bismarck, ND 58505-0200
 701.328.2436 or 1.800.755.2714
 Fax: 701.328.1645
 Email: dohcshsadm@nd.gov
 Website: www.ndhealth.gov/cshs/autism.htm

| REGISTRATION INFORMATION | | |
|---|---|------------------------------------|
| <input type="checkbox"/> New | <input type="checkbox"/> Update | |
| INSURANCE INFORMATION | | |
| <input type="checkbox"/> None | <input type="checkbox"/> Private | <input type="checkbox"/> Medicaid |
| <input type="checkbox"/> Tricare | <input type="checkbox"/> Other | <input type="checkbox"/> Medicare |
| <input type="checkbox"/> | <input type="checkbox"/> Unknown | |
| INDIVIDUAL'S INFORMATION | | |
| NAME OF INDIVIDUAL (AS APPEARS ON BIRTH CERTIFICATE) | | |
| Last Name | | Suffix |
| First Name | Middle Name | |
| ALSO KNOWN AS | | |
| Last Name | | Suffix |
| First Name | Middle Name | |
| INDIVIDUAL'S CURRENT ADDRESS | | |
| Street Address | | |
| PO Box | City | State |
| Zip Code | County | Country |
| Social Security Number (Optional) | | Telephone Number () |
| HOSPITAL/PLACE OF BIRTH | | |
| <input type="checkbox"/> Clinic/Doctor's Office | <input type="checkbox"/> Freestanding Birthing Center | <input type="checkbox"/> Homebirth |
| <input type="checkbox"/> Hospital | <input type="checkbox"/> Other, Specify: _____ | |
| Name of Hospital/Place of Birth | | |
| Street Address of Homebirth | | |
| City | State | Country |
| BIRTH MOTHER'S ADDRESS AT TIME OF INDIVIDUAL'S BIRTH | | |
| If mother was institutionalized (e.g., nursing home, prison, state hospital, etc.) at time of birth, enter mother's home address before she was institutionalized | | |
| <input type="checkbox"/> Same as individual's current address <input type="checkbox"/> Unknown | | |
| Street Address | | |
| PO Box | City | State |
| Zip Code | County | Country |
| PRIMARY CARE PROVIDER | | |
| Provider Name (Last, First) | | <input type="checkbox"/> Unknown |
| | | <input type="checkbox"/> None |
| Practice/Facility Name | | |
| City | State | Country |

| Telephone Number () | |
|--|---|
| BIRTH INFORMATION | |
| Date of Birth / / | Sex <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Indeterminate |
| Birth Weight _____ Grams -OR- _____ Lbs., _____ Oz. -OR- <input type="checkbox"/> Unknown | |
| Weeks of Pregnancy <input type="checkbox"/> Early Term (Between 37 weeks 0 days and 38 weeks 6 days) <input type="checkbox"/> Full Term (Between 39 weeks and 0 days and 40 weeks 6 days) <input type="checkbox"/> Late Term (Between 41 weeks 0 days and 41 weeks 6 days) <input type="checkbox"/> Post Term (Between 42 weeks 0 days and beyond) <input type="checkbox"/> Unknown | |
| Plurality <input type="checkbox"/> Single <input type="checkbox"/> Other Multiple <input type="checkbox"/> Twin <input type="checkbox"/> Unknown | Father's age at time of delivery: _____ Mother's age at time of delivery: _____ |
| ETHNICITY INFORMATION | |
| Hispanic/Latino <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown | |
| Primary Language Spoken in Home <input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other, Specify: _____ | |
| Race (Check ALL that apply) | |
| <input type="checkbox"/> White | <input type="checkbox"/> Other Asian |
| <input type="checkbox"/> Black/African American | <input type="checkbox"/> Native Hawaiian |
| <input type="checkbox"/> American Indian/Native Alaskan | <input type="checkbox"/> Guamanian |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Samoan |
| <input checked="" type="checkbox"/> Chinese | <input type="checkbox"/> Other Pacific Islander |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Other, Specify: _____ |
| <input type="checkbox"/> Korean | <input type="checkbox"/> Refused/Unknown |
| <input type="checkbox"/> Vietnamese | |
| PARENT/GUARDIAN INFORMATION (A) | |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Foster Parent |
| <input type="checkbox"/> Adoptive Parent | <input type="checkbox"/> Legal Guardian |
| Vital Status <input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown | |
| Sex <input type="checkbox"/> Female <input type="checkbox"/> Male | Biologically Related to Individual <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown |
| PARENT/ GUARDIAN NAME | |
| Last Name Suffix | |
| First Name | Middle Name |
| Maiden Name | |
| MAILING ADDRESS | |
| <input type="checkbox"/> Same as individual's current residence address | |
| Street Address | |
| PO Box | City State |

Autism Spectrum Disorder Report Form (continued)

SFN ### (3-2015) Page 2

PARENT/GUARDIAN INFORMATION (A), CONTINUED

Zip Code County Country
Date of Birth Telephone Number

ETHNICITY INFORMATION

Hispanic/Latino Yes No Unknown
Race (Check ALL that apply) White Black/African American American Indian/Native Alaskan Asian Indian Chinese Filipino Korean Vietnamese Other Asian Native Hawaiian Guamanian Samoan Other Pacific Islander Other, Specify: Refused/Unknown

PARENT/GUARDIAN INFORMATION (B)

Parent Foster Parent Adoptive Parent Legal Guardian

Vital Status Alive Dead Unknown

Sex Biologically Related to Individual Female Male Yes No Unknown

PARENT/GUARDIAN NAME Last Name First Name Middle Name Maiden Name

MAILING ADDRESS

Same as individual's current residence address
Street Address PO Box City State Zip Code County Country Date Telephone Number

ETHNICITY INFORMATION

Hispanic/Latino Yes No Unknown
Race (Check ALL that apply) White Black/African American American Indian/Native Alaskan Asian Indian Chinese Filipino Korean Vietnamese Other Asian Native Hawaiian Guamanian Samoan Other Pacific Islander Other, Specify: Refused/Unknown

DIAGNOSTICIAN INFORMATION

Name of Individual Making Diagnosis (Last, First)

Degree (select one): D.O. M.D. Ph.D. Psy.D. Masters Other, Specify:

Specialty: Clinical Geneticist Neurology Psychology Counseling Nursing Social Work Family Practice Pediatrics Other, Specify: Internist Psychiatry

PRACTICE/FACILITY WHERE DIAGNOSIS MADE

Practice/Facility Name Department/Unit Street Address PO Box City State Zip Code County Country Telephone Number

INFORMATION ON PERSON SUBMITTING REPORT

Relationship to Person Being Registered Diagnostician Other Health Care Provider Diagnostician's Designee Other, Specify: Title Dr. Mr. Ms. Name (Last, First)

CONTACT INFORMATION (IF DIFFERENT FROM DIAGNOSTICIAN)

Practice/Facility Name Department/Unit Street Address PO Box City State Zip Code County Country Telephone Number

DIAGNOSIS INFORMATION FOR REGISTRATION

AUTISM SPECTRUM DISORDER HISTORY

Age at Diagnosis Age Symptoms First Noted by Anyone Yrs. Mos. Unknown
Diagnose using DSM-IV (choose one) Autism Spectrum Disorders: Asperger's Disorder Pervasive Developmental Disorder NOS Autistic Disorder Rett Syndrome Childhood Disintegrative Disorder

Autism Spectrum Disorder Report Form (continued)

SFN ### (3-2015) Page 3

Diagnose using DSM-5: Autism Spectrum Disorder (ASD)
Restricted, Repetitive Behavior Severity Levels:
(choose one) [] Level 3: "Requiring very substantial support"
[] Level 2: "Requiring substantial support"
[] Level 1: "Requiring support"

Social Communication Severity Levels:
(choose one) [] Level 3: "Requiring very substantial support"
[] Level 2: "Requiring substantial support"
[] Level 1: "Requiring support"

- Instruments/References Used (check all that apply)
[] Autism Behavior Checklist ABC
[] Autism Diagnostic Interview-Revised ADI-R
[] Autism Diagnostic Observation Schedules ADOS
[] Autism Spectrum Rating Scale ASRS
[] Childhood Autism Rating Scale CARS
[] Intellectual/ Cognitive Testing
[] Clinical Impressions
[] Diagnostic and Statistical Manual 4th Ed., Revised DSM-IV-R
[] Diagnostic and Statistical Manual 5th Ed. DSM-5
[] Gilliam Aspergers Disorder Scale GADS
[] Gilliam Autism Rating Scale GARS-2
[] Modified Checklist for Autism in Toddlers M-CHAT
[] Pervasive Developmental Disorder Screening Test-II PDDST-II
[] Social Communications Questionnaire SCQ
[] Screening Tool for Autism in Two Year Olds STAT
[] Social Responsiveness Scale SRS
[] Other, Specify: _____

CLINICAL IMPRESSIONS

PERSISTENT DEFICITS IN SOCIAL COMMUNICATION AND SOCIAL INTERACTION ACROSS MULTIPLE CONTEXTS

- [] Deficits in social-emotional reciprocity (e.g., reduced sharing of interests, emotions, or affect)
[] Deficits in nonverbal communication behaviors used for social interaction (e.g., abnormalities in eye contact and body language, poorly integrated verbal and nonverbal communication)
[] Deficits in developing, maintaining, and understanding relationships (e.g., difficulties adjusting behavior to suit various social contexts, absence of interest in peers)

RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOR, INTERESTS, OR ACTIVITIES

- [] Hyper or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., adverse response to specific sounds or textures)
[] Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects)
[] Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., rigid thinking patterns)
[] Stereotyped or repetitive motor movements, use of objects, or speech (e.g., lining up toys or flipping objects, idiosyncratic phrases)

Was a complete physical evaluation done by a licensed independent practitioner as part of the diagnostic process for autism spectrum disorder

Physical Evaluation completed: [] Yes [] No
Hearing Test Done [] Yes [] No
Have Excluded Organic Causes (E.g., Rett Syndrome, juvenile-onset schizophrenia, Encephalopathy, etc.) [] Yes [] No
Other, Specify: _____ [] Yes [] No

- Co-morbidities (check all that apply):
[] ADHD [] Microcephaly/Macrocephaly
[] Asthma [] Obesity
[] Depression/Bipolar/Mood [] Obsessive Compulsive Disorder
[] Feeding/Eating Disorders [] Oppositional Defiant Disorder
[] Fetal Alcohol Syndrome [] Schizophrenia
[] Genetic Disorders [] Seizures/Epilepsy
[] GERD or other Gastro Conditions [] Sleep Disorders
[] Hydrocephalus [] Tic Disorders
[] Intellectual disability [] Other, Specify _____

MEDICATION(S) USE

Table with 2 columns: Medication Name, Current, Former. Rows include Alpha Agonist, Anticonvulsants, Antidepressants, Anxiolytics, CAMs, Neuroleptics, Non-stimulants, Nutritional Supplements, Sleep Aid, Stimulants, and Other, Specify.

SIBLING INFORMATION

Siblings with Autism Spectrum Disorder Diagnosis
[] Yes [] No If so, how many: _____

EACH SIBLING WITH AUTISM SPECTRUM DISORDER DIAGNOSIS SHOULD BE REGISTERED ON A SEPARATE FORM