

**FISCAL NOTE**  
**Requested by Legislative Council**  
**02/03/2017**

Bill/Resolution No.: SB 2241

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2015-2017 Biennium		2017-2019 Biennium		2019-2021 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
<b>Revenues</b>						
<b>Expenditures</b>			\$64,149		\$52,683	
<b>Appropriations</b>			\$64,149		\$52,683	

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2015-2017 Biennium	2017-2019 Biennium	2019-2021 Biennium
<b>Counties</b>			
<b>Cities</b>			
<b>School Districts</b>			
<b>Townships</b>			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

The Bill amends NDCC relating to the Autism Spectrum Disorder Database. It requires that the database be searchable and to allow reporters to update or amend previously reported cases. It also allows for assessment of a civil fee for providers who violate this subsection.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

The bill will result in additional costs in order for users to access the system, additional ITD server costs, security configuration costs (e.g., user account set-up for an autism reporter group through Conduet (our current vendor), and increased staff time to assist users as they will now have access to the system and be able to update and modify data requiring assistance that was not needed previously.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

Although section 23-01-41 4.c states that a provider who violates this subsection may be subject to a civil fee, not to exceed one hundred dollars per occurrence, the ND Department of Health is unable to determine the number of violations that might occur. For this reason, we are unable to estimate an amount that will be collected.

- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

2017 – 2019:

Expenditures are estimated to be \$64,149 and are comprised of the following:

- ITD user costs to access MAVEN - \$1.35 fee x 912 users x 24 = \$29,549
- ITD server costs – 1 additional server at \$400/month x 24 months = \$9,600
- Security configuration costs (estimate from Conduet) – 100 per hour service contract at \$130/hour = \$13,000

- Temporary salary to handle “help-desk” like functions for new MAVEN users - \$25/hour x 20 hours/month x 24 months = \$12,000

2019 – 2021:

Expenditures are estimated to be \$52,683 and are comprised of a 3% inflationary increase to the ITD user costs, the server costs and temporary salary.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation or a part of the appropriation is included in the executive budget or relates to a continuing appropriation.*

The amount is not reflected in the DoH's appropriation. Therefore, an appropriation would be necessary.

**Name:** Brenda M Weisz

**Agency:** DoH

**Telephone:** 3228-4542

**Date Prepared:** 02/07/2017

**2017 SENATE HUMAN SERVICES**

**SB 2241**

# 2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee  
Red River Room, State Capitol

SB 2241  
2/8/2017  
Job Number 28038

- Subcommittee  
 Conference Committee

Committee Clerk Signature

*Jane Williams for Mame Johnson*

## Explanation or reason for introduction of bill/resolution:

A bill relating to autism spectrum disorder database.

## Minutes:

9 attachments.

**Chair J. Lee:** All members were present. Opened the public hearing on SB 2241.

**(1:30-7:55) Bonnie Staiger, Executive Director, North Dakota Psychological Association (NDPA):** Introduced the bill, please see attachment #1 and #1A.

**Senator Anderson:** What are problems that need correcting? What are we trying to fix?

**Bonnie Staiger:** Its ethically and confidentiality issues and the following testifiers will answer in much more detail.

**Chair J. Lee:** There is a fiscal note if this change is made within the current system and that would be for IT changes.

**Senator Anderson:** One of the reasons the database was established was to capture the population so that going forward and long term, ideology studies could be done to determine if a service being provided to these people was helping. The database was trying to tie them through, so that researchers could look at that, not to publish individual name, starting point. So 30 years from now, we can say, this is that same individual, and determine what was effective and what was not. Hope someone can answer that questions for me if we remove that information from the database.

**Bonnie Staiger:** You are correct, in the intent, the implementation of it, is a violation of code of ethics. It's a violation of confidentiality and it is a deterrent to seeking and following through with treatment. The replacement of the current registry with the proposal using the CDC data, within the DSM would negate the fiscal note.

**Chair J. Lee:** Would it give us the same outcome, allowing follow-up to see if treatments have been useful?

**Bonnie Staiger:** We feel the replacement language would be more effective because it would not be a deterrent to seek treatment. Once they realize the registry is a mandated reporting and their personal info is being collected, in many cases, refusing treatment.

**(12:05-17:20) Dr. Angela Cavett, President-elect NDPA:** testified in favor, please see attachment #2.

**Senator Anderson:** Those of us that are health care providers are trying to do the best for the patients and we need to know info about the patents to take proper care of them. Been a long time campaign against confidential mental illness, that's a disservice to those people, as the next person taking care of them doesn't know. If we make this optional, practitioners

won't do it, resulting in an incomplete database. How are we going to provide services to an individual if we don't know they have the diagnosis? When we have a professional code, that's always subject to local and fed laws, follow fed laws even if it isn't in best interest of patient. This is a confidential database, nobody put people taking care of the patients have access without a real study and release from all people involved.

**Dr. Angela Cavett:** Prevalence rates, we can calculate from the population, not all people diagnosed will need services, skewing the numbers. Diagnosis and misdiagnosis will be discussed later, for example, the school can't diagnose, but will give a child education autism. After a clinical diagnosis, the child might have something else. Our database numbers aren't going to be accurate

**Senator Anderson:** The school isn't authorized to make the diagnosis and enter into the database.

**Dr. Angela Cavett:** In terms of gathering info, along the lines of research when we have that population group as participants, 5 years from now people are contacting them. We realized the law does contradict our ethics. The law says we can give the information, but we're concerned about the welfare of patients. For example, a 30-year-old man who comes in for marital therapy and he has an autism diagnosis, we would have to report him to the database the way it is written. When he is contacted, we feel like that is hurting the relationship with psychologists in terms of confidentiality. Then you go back to that person and they feel violated.

**Chair J. Lee:** Who is contacting that man? Especially since his name isn't supposed to be there.

**Dr. Angela Cavett:** When we contacted Kodi Pinks and asked her what the information would be used for. In her response to us, the North Dakota Psych Association, she said "yes we may or may not contact them", that is a possibility,

**Chair J. Lee:** If your risk is with the code of ethics, protection from liability would fix that, wouldn't it? If other states protect psychologist from liability, why wouldn't that resolve the problem? What our goal is; to learn, if everyone was to opt out, we'd have no idea where the people are, or what their needs might be. The whole purpose is to find out if they're high functioning or high need. We have no picture of what's going on without mandatory report.

**Dr. Angela Cavett:** We do have prevalence rates, we feel that we do have a good estimate of the people who are in and knowing how many people would be diagnosed is not an accurate assessment of how many people would need treatment.

**Senator Heckaman:** In the database, it was done specifically for legislators to do planning for programing, for funding, and so how many people across the state of North Dakota over the age of 50 have autism.

**Dr. Angela Cavett:** Dr. Garaas will talk about prevalence rates, we went to the population and calculated it for people under 18 and the population in general. But we could easily go into the population over 50 and calculate the prevalence from the DSM gives us 1% and CDC gives us 1.5%. We calculated them for children, and we were interested in the data. There are 756,927 people in North Dakota 23% under 18. If you calculate by the CDC there are about 2,560 children. If you calculate by the DSM, about 1,740 people. And we could get that info for you for the population of people over 50.

**Chair J. Lee:** I don't understand why an estimate nationally of a percentage is actually more accurate than a mandated reporting. I'm sure somebody will tell me why I'm wrong.

**(26:30-32:40) Catherine Yeager:** testified in favor of SB 2241, please see attachment #3

**Senator Anderson:** I agree that you should be able to access records and make adjust. You can't do that if you de-identify them. When we originally did the database, we tried to

restrict those who could make the diagnosis, and other practitioner should be able to attach addendum. When information is de-identified, you make it moot. Explain why you think we ought to be able to change it, but you can't identify the individual and how they work together.

**Catherine Yeager:** If the purpose is tracking these people to see over time, the reality is DD case management and autism waiver in state, apply to get waivers in case management services. So we have numbers for people disabled enough of those seeking treatment. They are being followed and monitored by case managers. There may be other ways to do this, without us breaking confidentiality. In terms of the registry, a lot of cases we don't really know if it is truly autism or how many with autism actually need services. Qualified people make this diagnosis because there is a public panic over autism, it's not just specialists who are making these diagnoses. People are being called on more and more to assess this using a checklist and getting diagnoses like that. Being made not just by people we would think as being underqualified, also pediatricians and psychologists who technically are defined as trained. They would be able to make it, it would go into the registry, doesn't mean it's accurate. Right now, the most frequent referral question. 9 out of 10 people coming in do not have autism. A good chunk of them have been told they do not.

**Senator Anderson:** It is true. There is a pretty advanced, robust health network. If everybody is using that we could glean diagnoses from the health information network. We wouldn't need to maintain a separate database. We have a fairly robust opt out. About .6% of people opt out. That would be right there and would have to ask patient to override one of the options. However, that doesn't fix misdiagnosis, all diagnosis going into database and search all records, and could find out about an autism diagnosis by somebody else.

**Catherine Yeager:** One of the problems, is if this registry is used exactly as it's supposed to be, and end up with 1 in 41 kids, and 1 in 28 boys. I don't know what we do with that. Whether they have true autism, I don't know how the database sorts that out, I don't know how we figure out how to fund that. Department of Health and the DD case management system, already has that in place. This has puzzled us, families who need help get referred to DD case management, apply, determine level disability and then goes into the case management system or autism waiver support system, and they are tracked and followed through there. Doubling up, people who don't apply are higher functioning. We have denied applications, who are receiving those services, that information is already there, I think will inflate the count of people who need services.

**Chair J. Lee:** I think significant increase in the number of people who are on the spectrum, is because the definition of autism has been wildly expanded. It isn't fair to say that because of having a registry. I resist the idea that schools are diagnosing. Lots of places in state that don't have people like you, who can go forward with this work. So if the local pediatrician is trying to help a family and there may be a potential for a need for services. I don't have problem with that screening being done so we can find out if that individual needs. I also understand that someone who is diagnosed at an early age, often could outgrow it. The whole goal for everyone here is to be able to provide services to individuals who need the services. The concept that a percentage by a national office is going to determine how many people in North Dakota need services, just isn't working for me.

**Senator Clemens:** Autism Speaks report shows an increase of 600% increase national

**Catherine Yeager:** Yes. Schools don't diagnose, they categorize.

**Senator Heckaman:** Are you telling us that the mandatory reporters that we have are not qualified to diagnose.

**Catherine Yeager:** In the group that was captured, we have a lot of people worried about autism and want to get in for quicker methods of diagnosis. Even people who are otherwise

qualified to do a lengthier evaluation, not necessarily trained. Quick visit vs a full evaluation. Sometimes it is fairly obvious. It's those murky on the boarder cases, people strapped for time, end up with misdiagnoses.

**Senator Heckaman:** If you say people that are mandatory reporters and are qualified; we wouldn't have anybody else reporting anyhow. They wouldn't be able to access the database, and not reporting.

**Catherine Yeager:** A physician or psychologist within that large group of qualified individuals, there's only a small subset, truly qualified to diagnose. For a pediatrician who sees someone for a short visit, that's a tough order for them to make that diagnosis in that time.

**Senator Anderson:** When we created this database in first place, the people with autism and the people with children with autism, they were the ones who wanted it, your group is saying you don't want it anymore. We need to resolve that difference.

**Catherine Yeager:** I can tell you the reaction of my patients, especially the newly diagnosed ones hasn't been positive. Families with older kids with autism who have had the chance to absorb that and get used to it, those families much more open.

**(45:40-49:30) Dr. Jennifer Garaas:** Testified in favor, please see attachment #4.

**Chair J. Lee:** You don't see advantage to a database that records a number who may or may not need the services?

**Dr. Jennifer Garaas:** I don't think we're going to be able to collect that data. I know people won't seek services, they don't want that label, who will know. I've seen patients who stopped seeing another provider because they are concerned about confidentiality.

**(51:00-51:51) Courtney Koebele:** Testified in favor, please see attachment #5.

**(52:20-56:55) Gabriella Balf:** Testified in favor, please see attachment #6.

**Chair J. Lee:** Can you tell me what the four organizations that are involved with your registry?

**Gabriella Balf:** The ones that have implemented already are Shepard-Pratt, MGH and their associate hospitals. It was offered to us to implement at no cost, and the reason why people sign up, is because there's no time burden. I have attached a registry and frequent questions because they answer a lot of the specific aspects. Data is de-identified and taken away from the EMR directly, so there is no direct provider work. It is also stored securely.

**Chair J. Lee:** If this is designed for psychiatrists to enter information, the psychologist are they then welcome to enter information into the same system? Who else would be able to input into that registry and why have you not come forward and said it's available.

**Gabriella Balf:** Any medical organization can sign up with this. Usually takes place at the large healthcare facilities. Once we sign up, all 6 major hospitals and all the 26 clinics will get the data, de-identified, without additional burden to the providers. Smaller facilities that are inundated with patients, they can sign up too and it's free for them. Right now, they should hire someone to do all this work.

**Senator Piepkorn:** How is the stigma of autism realized and observed?

**Gabriella Balf:** Even your doctor will have reticence to treat the child differently. We have sensitivity training to address prejudices we may have.

**Senator Anderson:** I'd like to point out, none of the people finding out the child has autism from the autism database. They're finding it out on their own by observations or a family member who talks about it. I'm not sure how removing the database resolves that issue.

**Gabriella Balf:** Extremely concerned about rush diagnoses, carry stigma, come back to haunt families. ADHD, any doctor can make diagnosis, proper diagnosis takes half a day. And there are a lot of people involved.

**Chair J. Lee:** We received written testimony in support, please see attachment # 7.

**(1:04:08-1:09:30) Kodi Pinks, Autism Database Administrator:** Testified neutral please see attachment #8.

**Senator Anderson:** Are we making any productive use of this info currently?

**Kodi Pinks:** I believe so, I have put together a report that I have shared at conferences, the report is available online. It breaks down what we're seeing across the state. It lets us know who is reporting, what tools there using to make the diagnosis.

**Chair J. Lee:** Closed the hearing on SB 2241.

**Received testimony #9 via email after the hearing was closed.**

# 2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee  
Red River Room, State Capitol

SB 2241  
2/13/2017  
Job Number 28248

- Subcommittee  
 Conference Committee

Committee Clerk Signature

*Jan Bellamy for Maura Johnson*

## Explanation or reason for introduction of bill/resolution:

A bill relating to the autism spectrum disorder database.

## Minutes:

1 Attachment

**Chair J. Lee:** All members were present. Began committee work on SB 2241.

**Chair J. Lee:** Is the information that is currently provided, is it all mandatory or if there are blanks left empty, is there a problem?

**Kodi Pinks, Health Department:** At this time, there are no required fields on the report. Has received reports with some filled in and some with blanks fields. There are some issues, some things are a little hard to find, when we looked at reviewing the report form with the autism database advisory group that convenes in March. Will look at again, what's always missing and what's really relevant to the database.

**Chair J. Lee:** So nobody's report is returned if its incomplete.

**Kodi Pinks:** No.

**Chair J. Lee:** During discussions held, people have indicated there have been many discussions that have resulted in changes.

**Kodi Pinks:** The expert panel, which was required under the initial House Bill 1038. The group consisted of 28 people including 3 psychologists, a psychiatrist was invited but unable to attend, 3 pediatricians, as well as others. The group went through it in detail and after the database went live concerns were brought forth by providers. The hope was to address some of the issues with the advisory group, making it not as time consuming and to gather relevant information.

**Chair J. Lee:** Was there a reasonable consensus from the expert panel on the final outcome?

**Kodi Pinks:** Yes, when we went through it thoroughly, there was great discussion, and the end, the finalized form is the one everyone agreed on.

**Senator Anderson:** What would be the process, heard lots about the misdiagnosis or incorrect is there a process or put in own paperwork.

**Kodi Pinks:** Database isn't able to delineate between accurate or inaccurate diagnosis, there is a place to update the form.

**Senator Anderson:** Do you go into the original form and put in an addendum?

**Kodi Pinks:** As it's currently set up, I can make an amendment to the original form.

**Chair J. Lee:** If one child is being seen by 2-3 different people, you could add an amendment for each provider so that the information that is available would include all the comments.

**Kodi Pinks:** Correct,

**Chair J. Lee:** Have you had any comments about the issue of the violation of the code of ethics and immunity?

**Kodi Pinks:** After the database went live, and the concerns came out. It was taken to the health department leadership team who then said we should consult with Claire Ness who represented the health department in the Attorney General's office. She met with attorneys for the boards, together, her opinion way was that the way the law works allowed for mandatory reporting and suggested meeting with the board, I attended those meetings, Afterwards, the boards were not going to agree or disagree with the law. They would just have their licensees go to those regulations and if help was needed interpreting the regulations to seek private legal counsel. The health department said to go ahead and report

**Senator Anderson:** I agree with the Attorney General's interpretation. When it says mandatory reporting in the law, that trumps what is in your own practice act. We have many people that are required to do mandatory reporting, all of them are subject to confidentiality issues.

**Kodi Pinks:** I brought the new report (please see attachment #1), I'm hoping with March meeting to get collaborate work together happy medium, feel comfortable. 2 concepts for the report form, and an additional way of changing the way Maven is setup, they enter minimal info, survey in. That was a third option.

**Chair J. Lee:** I don't want a FN, recognize IT costs and changes with Maven,

**Kodi Pinks:** I don't think the survey would create costs, expanded user access would generate costs.

**Chair J. Lee:** There are some providers who just want to get rid of the registry?

**Kodi Pinks:** I have heard the opposite, as well, it depends on presentation, I tell people to contact me.

**Mike Krumwiede, Representative, NDPA:** Where we see the changes helping everyone, in the bill put forward, it protects the psychologists and those who are providing the information. It also protects those who are getting information reported. We found out through

this process, that there is a new reporting agency Interactive Autism Network, it's nationally known, was just started in 2016. One of the things, we feel there's other ways to get information, way we're proposing this bill would help everyone along the lines of confidentiality, reported for fines since it's a misdemeanor to not report.

**Chair J. Lee:** The family has that option, why wouldn't it be a good idea to recommend that someone who had a concern, that had a family member visit with the Health Department to see benefit. How do we know what we need to do if we don't know who needs it, where they are, and the level of service needed?

**Mike Krumwiede:** Psychologists believe in data, use nationally known and use other reports to come up with the numbers of how they see people. They don't feel the need to mandatory report everyone, if they have to they will. The biggest issue is with contacting the Department of Health, over the last year asked the questions and it took 6 months for a response. It's a slow moving process, our people are wondering what to do. Tough space which isn't intention

**Senator Heckaman:** Interactive autism network national?

**Mike Krumwiede:** It's so new, is a voluntarily and free that any provider who sees an autistic person, they can voluntarily join the network, report information that way.

**Senator Heckaman:** I would almost think there would be less security than with the state autism reporting mechanism. This has a couple basis put into place at first, the legislature needs to know how many individuals are in certain age groups, how many have other conditions with them, how many are being served, how many need to be served. I would think we had more information locally that nationally, especially if it isn't mandated. I'd be more concerned about the security level at the national level than the state level.

**Mike Krumwiede:** I can see the concern with that. We're looking at the national one at this point has some of the things that we'd put in this bill. We're going to report this information, then it becomes anonymous or a number, or something along those lines.

**Chair J. Lee:** It is now; it isn't personally identifiable information in the registry now. Kodi, is this correct?

**Kodi Pinks:** The report form is full contact information.

**Chair J. Lee:** From the provider in, but nobody else has access to it. There is no privacy issue for the families, because the information isn't going anywhere. Other providers don't have access to this.

**Kodi Pinks:** Correct.

**Chair J. Lee:** Thank you for clarifying, that we weren't throwing people's names out.

**Chair J. Lee:** The name goes in, but it doesn't go anywhere. Our health information network, we've got to incorporate this I would like to see that be an option, learning about the national one. My thought is that not doing anything different would allow us to know more about both what we can do with the North Dakota health information network and the possibility of

incorporating something in there so it isn't duplicated, but also with this national registry has value.

**Senator Heckaman:** We just heard from Ms. Pinks, they're going to be convening a task force. Kodi, when you convene this work group or task force will you make recommendations on changes or what are you hoping to find out from that.

**Kodi Pinks:** Because of all the issues as we move forward, we want to get a majority of those fixed as best we can. If that means changing how or what we collect.

**Senator Heckaman:** Can you make those changes without us writing something in to code.

**Kodi Pinks:** With the report form, yes.

**Senator Clemens:** When people are submitting these reports, are you seeing quite a bit of uneasiness amongst the people who have patients?

**Kodi Pinks:** With certain parts of the form, the one we have right now is 4 pages, we really curtailed our form to look like others, we may not work the same, we have a lot of provider shortages. We knew that it would evolve, but had to have a start to have input to make appropriate changes. What's on that form mostly what CDC considers risk factors for autism.

**Chair J. Lee:** You didn't dream this up without input, run it up the flag pole, and see if it has had input.

**Senator Heckaman:** I sat on the expert panel and there was good conversation, a consensus was reached.

**Senator Piepkorn:** Does this bill, in anyway cut anybody out or is it going to limit access to treatment?

**Chair J. Lee:** It isn't going to limit treatment; they'll find a provider. If they chose not to have provider for a family member, they should find out just what the registry does.

**Senator Piepkorn:** The reason they would do that is because of the registry?

**Chair J. Lee:** Honestly, nobody knows the name is in there. We need to know the numbers, because this is a moving target, who are the individuals, are they high risk or not. If we don't know, how do we serve the state.

**Senator Piepkorn:** People not seeking help because of this bill.

**Senator Heckaman:** I guess I can't speak for families, I can go back to my time in special education, where I needed permission and wouldn't give it for variety of reasons. They were fearful the federal government was going to get after them for something. People have different opinions for different authority that they give. I would imagine there are going to be people out there who are going to stay, no, I'm not going to bring my child in for this. I would gather, in my 40 years of teaching, it was one family. I think, that all the other good work that was done, outweighs the fact that someone can complain about this. How many children are we looking at?

**Kodi Pinks:** At this time; I have 310 in the database. The Department of Public Instruction is the only one with real numbers and they're well over 1000.

**Senator Heckaman:** If we look at 1000 from there, plus others that aren't in the DPI system. There's a large number of families and there's a couple that might not agree to it. But that's their choice, the reason it's going to come around better is Kodi's willing to work with a group that's willing to adjust.

**Senator Anderson:** There are always a few individuals who are afraid of a diagnosis. Once the information is known by individuals, that the database is confidential, and once they know that nobody else is seeing their child's information, that will alleviate their fears. It will help with the gathering of the information we need to take care of the people better.

**Senator Piepkorn:** No one's going to be denied access to treatment, it's personal choice?

**Chair J. Lee:** No. The psychologists wouldn't do that.

**Senator Heckaman:** I move **Do Not Pass on SB 2241.**

**Senator Kreun:** Second

A roll call vote was taken. 6-1-0.

**Senator Heckaman will carry.**

Date: 2/13 2017

Roll Call Vote #: 1

2017 SENATE STANDING COMMITTEE  
ROLL CALL VOTES

BILL/RESOLUTION NO. 2241

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 Sen. Heckaman Seconded By Sen. Kreun

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee (Chairman)	X		Senator Joan Heckaman	X	
Senator Oley Larsen (Vice-Chair)		X	Senator Merrill Piepkorn	X	
Senator Howard C. Anderson, Jr.	X				
Senator David A. Clemens	X				
Senator Curt Kreun	X				

Total (Yes) 6 No 1

Absent 0

Floor Assignment Sen. Heckaman

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

**REPORT OF STANDING COMMITTEE**

**SB 2241: Human Services Committee (Sen. J. Lee, Chairman) recommends DO NOT PASS (6 YEAS, 1 NAYS, 0 ABSENT AND NOT VOTING). SB 2241 was placed on the Eleventh order on the calendar.**

2017 TESTIMONY

SB 2241

SB 2241  
Attache #1  
2/8



Chairman Lee and Members of the Senate Human Services Committee:

For the record, my name is Bonnie Staiger, Executive Director of the North Dakota Psychological Association. (Lobbyist registration 171). I'm here to introduce this bill which arose from the many issues resulting from the implementation of the autism database/registry (HB 1038 in 2013 Session and the corresponding administrative code effective Jan 1, 2016).

First, let me thank you, Sen. Lee for bringing an overarching awareness of autism to the legislature. In that regard, you have been its champion. In the 2013 session, this bill did not raise any red flags for psychologists who treat these patients, including our member, former Representative Alan Fehr, a psychologist, who served on the Human Services Committee hearing the bill and ultimately the conference committee resolving the 2 chamber's differences.

A couple of early amendments in the House outlined the specifics of data to be collected. On the floor, the bill carrier, Rep. Alon Wieland, reassured the assembly that the database/registry would not contain the name or address of the child. We took that to mean any identifying information.

Along its way, the bill was hog-housed to merge 4 bills (HBs 1037, 1038, 1039 and SB2193) together dealing with what seemed to be of greatest emphasis and goal: a pilot project, funding—including federal funds, training, vouchers, waivers and an FTE to manage it all. The ultimate impact to the general fund: just north of 2 million dollars. As a casualty of that important re-focusing and the last day of the 2013 session, the language codifying the narrow parameters of the database/registry slipped through the cracks—perhaps inadvertently. I think it important that you see the lost language:

*A physician, psychologist, or any other licensed provider who is qualified by training to make the diagnosis and who then makes the diagnosis that a child is affected with autism spectrum disorder shall report each new case of this diagnosis to the department in a form and manner prescribed by the state health officer. The report must include the child's birth date, gender, zip code at birth residence, and the specific diagnosis of the child diagnosed as having autism spectrum disorder. The report may not include the name or address of the child. Nothing in this section may be construed to compel a child who has been reported as affected with autism spectrum disorder to submit to medical or health examination or supervision by the department.*

Since then, the database/registry implementation took on a life of its own—becoming something beyond legislative intent. NDPA members, alarmed by what they felt is unethical, invasive and unnecessary data collection, sent the Health Department specific questions in that regard at the

end of March, 2016 and finally received responses in the attached document on Oct 5, 2016—6 months later. At the time we received the responses, the Dept of Health also informed NDPA they were establishing an Autism Spectrum Disorder (ASD) Database Advisory Group to provide guidance on the ASD Database. NDPA was asked to appoint a licensed psychologist to serve on it and we appointed Dr. Catherine Yeager. As of today, the Department has yet to convene the group—another lapse of 4 months.

To further outline issues with the reporting, we have 3 psychologists here to testify. While members of NDPA, they are here to offer their own perspective as practitioners whose practice includes much work with autism patients.

In order of their testimony:

- Dr. Angela Cavett, from Beacon Behavioral Health Services and Training Center in West Fargo, will speak to the issues of confidentiality
- Dr. Catherine Yeager, from Assessment and Therapy Associates in Grand Forks, will speak to the issue of diagnosis and misdiagnosis
- Dr. Jennifer Garaas, also of Beacon Behavioral Health in West Fargo will speak to prevalence rates and how using the CDC and DSM population data would likely be much more accurate than a database and does not have any cost or the downside of this registry

Madam Chair, we thank you for taking the time to visit with us early in the session about the ramifications of the database/registry and being willing to be prime sponsor of this bill to bring them to light and to Sen. Heckaman for also being a cosponsor.

If this bill passes, it will go a long way to correct the more egregious issues. However, we suggest you further amend it to restrict the reporting to nothing more than *the child's birth date, gender, zipcode at birth residence, and the specific diagnosis of the child diagnosed as having autism spectrum disorder. The report may not include the name or address of the child.* Even better, we hope you will conclude that it can be replaced with a more ethical, accurate and defensible data collection alternative as will be suggested by Dr. Garaas.

**North Dakota Department of Health (NDDoH) Response to Questions from  
the North Dakota Psychological Association  
October 2016**

1.1. Why is the registry mandated instead of a voluntary registry?

The legislature determined that the Autism Spectrum Disorder (ASD) Database be mandatory.

1.2. Do parents of the children being registered or individuals being registered need to be told they are being placed on the registry?

No, North Dakota Century Code (NDCC) 23-01-41 and North Dakota Administrative Code (NDAC) do not require mandated reporters to inform individuals about reports that are submitted into the ASD database. However, the NDDoH encourages reporters to discuss the reporting requirements for the database with the reported individual or the parents/guardians of the individual.

1.3. What is the specific reason the database needs to include names and other identifying information if the main purpose is to "count" the number of individuals with autism in ND? By collecting even a birth date and initials the statistical likelihood of overlap is extremely low and any possible overlapping data could be easily cleared up by contacting the clinician.

Names and other identifying information is collected to reduce duplication and increase accuracy of the database. NDCC and NDAC do not state that the main purpose of the database is to "count" the number of individuals with ASD in ND. The law does state that the purpose of the database is to conduct epidemiologic studies, research and analysis, and to provide services for individuals with ASD.

1.4. Other states with registries do not collect names or other personal information. For example, New Hampshire only collects the first initial of the patient's last name and the last four digits of the SSN. Why did we choose to go the more invasive route?

Prior to implementation, the NDDoH researched several other autism registries. NDDoH opted to model North Dakota's database on New Jersey's Autism Registry because of its successful track record. The ASD report form developed by the NDDoH was based on New Jersey's report form, which included names and personal information which are necessary to meet the intent of the law. The information collected on ND's ASD report form was reviewed and approved by an ASD Expert Panel convened by the NDDoH in October, 2014. Additional input was solicited from various entities (e.g., ASD Task Force, Children's Special Health Services Medical Advisory Council, ND Autism Spectrum Disorder Advocacy Coalition, etc.).

1.5. Why do you need patient phone numbers, addresses, etc.? Will patients be contacted at any time?

Addresses and phone numbers are collected to reduce duplication and increase accuracy of the database. NDCC indicates the purpose of the database includes providing services to individuals with ASD. Names and other information would be necessary to meet that purpose. NDCC and

NDAC do not specify whether or not people reported into the database can be contacted. The NDDoH staff have not contacted any individuals that have been reported into the database. At this point in time, the NDDoH has not determined what role, if any, the Autism Database Administrator will have in linking individuals to direct services.

1.6. Who decided what information went on the form and what are the reasons for the questions? Specifically, NDCC 21-01-41 (1): "The database must include... Any other information determined relevant and appropriate by the department."

Prior to implementation, the NDDoH researched several other autism registries. NDDoH opted to model North Dakota's database on New Jersey's Autism Registry because of its successful track record. The ASD report form developed by the NDDoH and approved by an ASD Expert Panel reflects the information that was determined relevant and appropriate. Additional input was solicited from various entities (e.g., ASD Task Force, Children's Special Health Services Medical Advisory Council, ND Autism Spectrum Disorder Advocacy Coalition, etc.).

1.7. Why is hospital/Place of birth relevant?

In public health surveillance, the occurrence of disease by place provides insight into the extent of ASD and its geographic variation. Characterization by place refers not only to place of residence but to any geographic location relevant to disease occurrence. Such locations include place of diagnosis or report, birthplace, site of employment, school district, hospital, or recent travel destinations.

1.8. Why is birth mother's address at time of birth relevant?

The birth mother's address at time of birth is relevant because it gives the option to assess environmental exposures, which can be potential triggers for those with underlying genomic issues.

1.9. Why is guardian's ethnicity relevant (since ethnicity is requested for the one diagnosed with ASD)?

Since ethnicity is collected for the individual diagnosed with ASD, it may not be necessary to collect it for either parent or guardian.

1.10. Why does the web page state to parents that form is collecting "demographic" information when in fact much more specific information related to diagnoses and comorbid conditions are actually being collected? Is this seen as being fully honest with parents about what you are collecting? Were parents involved in the development of this law told that more than "demographics" would be collected?

The website and brochures indicate the following information is collected in the database:

- Demographics such as individual's date of birth, gender, race
- Contact information of the individual and the parents/guardians
- Information about the diagnostician and the person submitting the form
- Information about the tools that were used to make the diagnosis

As the brochures were being developed, input was obtained from families, family advocacy groups, providers, and public information officers. The brochures were printed in May 2015 but the ASD report form was not finalized until September 2015. In the interim, changes were made

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that included specific information related to diagnoses and co-morbidities. The appropriate content additions have been made on the ASD website. The brochures will be revised after a more thorough review is conducted by the ASD Database Advisory Group that is being established.

1.11. Are we mandated to report adults?

Adults must be reported. According to NDCC, the database must include a record of all reported cases of ASD in the state.

1.12. Do college students who are temporary residents of ND need to be reported?

College students who are temporary residents of ND would not need to be reported. NDAC states that a reporter or the reporter's designee shall report to the department any individual diagnosed with ASD who is the reporter's patient or client, provided the individual or at least one of the individual's parents or guardians is a resident of North Dakota. Although not specifically defined in NDCC or NDAC for the ASD database, the NDDoH's interpretation of a resident would be individuals with a fixed and permanent ND address that is not transitory in nature.

1.13. Are clinicians working in university/college counseling centers required to submit the reporting form for every one of those students seen who reports a prior diagnosis of ASD? And if so, would this include existing clients we have already been seeing, who are not aware of this new law—or would it only include new clients we see from here on in?

NDCC and NDAC do not differentiate between the various places of employment for mandatory reporters (e.g., educational setting, clinical setting, etc.). NDCC and NDAC indicate who is a mandated reporter and is required to report cases of ASD into the database. Mandatory reporters include physicians, psychologists, nurse practitioners, clinical nurse specialists, licensed independent clinical social workers, or licensed professional clinical counselors.

Under NDAC, a reporter or the reporter's designee shall report newly diagnosed individuals to the NDDoH within 30 days of the diagnosis. A reporter or the reporter's designee shall report a previously diagnosed individual to the NDDoH within 30 days of the individual's first patient or client encounter with the reporter, or 30 days of the effective date of these regulations, whichever is later. The effective date of NDAC was January 1, 2016.

1.14. Was the fact that higher functioning adolescents or adults would make the choice not to seek services because of this registry once it becomes public knowledge? Not all people with autism are nonverbal three year old children. Some older, higher functioning individuals will respond very badly to the idea of being "registered", if adults are to be included.

The legislature determined that the ASD Database include a record of all reported cases of ASD in the state. Functional ability is not referenced in NDCC and NDAC.

1.15. Do I have to go back in time to do this? If I saw a client with autism, who came into my clinic today and got my notice saying I had to report from my receptionist, and then decided they were going to seek services in MN instead, do I have to report them since I have not seen them since this became law? If so, how far back do I have to go? Do I have to pull old case files from last month, last year?

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Reporting is required for any patient seen by a mandatory reporter on or after January 1, 2016, which is the date Administrative Rules for the ASD Database were promulgated.

When House Bill 1038 was passed in the 2013 Legislative Session, the law for mandatory reporting of ASD went into effect August 1, 2013. The effective date of Administrative Code was January 1, 2016. In Administrative Code, a reporter or the reporter's designee shall report newly diagnosed individuals to the NDDoH within 30 days of the diagnosis. A reporter or the reporter's designee shall report a previously diagnosed individual to the NDDoH within 30 days of the individual's first patient or client encounter with the reporter or 30 days of the effective date of these regulations, whichever is later.

1.16. Why do you need to collect data on high functioning people who will never apply or qualify for state-based services? Is "finding" these people even ethical? Don't they have a right to privacy, especially if they sought psychological services for something other than an ASD? The legislature determined that the ASD Database include a record of all reported cases of ASD in the state. Functional ability is not referenced in NDCC or NDAC.

1.17. Are people mandated to report only those diagnoses they themselves make, or if I see a client who comes to me with a diagnosis of autism; am I required to report this as well? Mandatory reporters are required to report any patient or client of theirs who has a confirmed case of ASD into the database, regardless of who made the diagnosis.

Under NDCC, the database must include a record of all reported cases of ASD in the state. Under NDAC, a reporter or the reporter's designee shall report newly diagnosed individuals to the NDDoH within 30 days of the diagnosis. A reporter or the reporter's designee shall report a previously diagnosed individual to the NDDoH within 30 days of the individual's first patient or client encounter with the reporter or 30 days of the effective date of these regulations, whichever is later. The effective date of NDAC was January 1, 2016.

1.18. Over diagnosis *is* a problem in ND. Clinicians who work with kids with autism routinely see children who have been misdiagnosed, often by other clinicians with less experience with this diagnosis. If we are to report these incorrect diagnoses these individuals would be reported to the state and these children "counted" as having autism. This is not a small problem - national estimates suggest overdiagnosis rates of about 10%. Some of our experiences suggest that it is much more significant. How will this problem be dealt with if we are to report previous, potentially dubious, diagnoses?

It is not the NDDoH's responsibility to ensure the accuracy of diagnoses made by health care professionals. The NDDoH's responsibility is to record all cases of ASD diagnoses within the state. The reporter/diagnostician can re-evaluate an individual for ASD using current diagnostic tools and references. The registration information on the ASD report form can be updated.

1.19. If I do not agree with the diagnosis based on DSM-V am I still required to report? Mandatory reporters are required to report any patient or client of theirs with an ASD diagnosis into the database. The report form allows for previously diagnosed individuals to be reported into the database without the need for repeated diagnostics. Ultimately, it is up to the

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reporter/diagnostician to decide whether or not an individual needs to be re-evaluated for ASD using current diagnostic tools and references.

1.20. If a child is diagnosed with educational autism by his/her school, but the child may not meet clinical criteria for ASD, must the provider fill out a report?

A reporter would not report a child into the database with only an educational determination; the child would need a clinical diagnosis of ASD in order to be reported.

1.21. If I have not done a full evaluation, perhaps because the individual comes in for another reason, but I suspect autism, do I have to report?

Suspected cases of ASD are not reported to the database. The database is for confirmed cases only.

1.22. I have a license in MN and ND. I see a client in MN who lives in ND, who has autism. Since I hold a ND license also and the client lives in ND, am I mandated to report even though I saw the client in a state that does not require reporting?

Providers that are licensed in ND are required to report to the NDDoH any individual diagnosed with ASD who is the reporter's patient or client, provided the individual or at least one of the individual's parents or guardians is a resident of North Dakota.

1.23. If it is only required to report children; can someone have their name removed at age 18?

NDCC does not require only children to be reported, it requires *all* cases of ASD to be reported into the database so children's names will not be removed at age 18.

## 2. Security/Privacy Concerns

2.1. HIPAA states we can report to certain health organizations for "limited use", but this is 4 pages of very personal data. Who looked at this law and decided it was ok under HIPAA? Can we have a copy of their legal statement saying so and copies of the privacy and security information kept for the database (as required by HIPAA)?

NDCC related to the ASD database was reviewed by Legislative Council and Office of Attorney General staff prior to its passage into law. Questions about legal issues should be referred to the Attorney General's office at 701.328.2210 or the Legislative Council at 701.328.3615.

2.2. Who is the other person who has access to the data besides the database administrator (Kodi Pinks)? Are there multiple people (in some areas there are references to "staff" having access)?

Only those authorized by the NDDoH are able to access ASD data. Those authorized include the Autism Database Administrator, the Children's Special Health Services Division Director, and select NDDoH staff involved in the development and continuing maintenance of the ASD database.

2.3. What kind of background checks did they do on the people who have the data?

The NDDoH generally does not perform background checks on employees other than those who work with PeopleSoft or in the state laboratory. Prior to hiring, supervisors often complete a standard reference check. To help ensure privacy and confidentiality of protected health

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information, state employees receive HIPAA training annually. In addition, certain staff have been trained in the Institutional Review Board (IRB) process.

2.4. What will happen to the data when these people no longer work for the state? HIPAA and confidentiality requirements apply in this situation.

2.5. NDCC 21-01-41 (5): The department may provide these records to other state agencies as necessary to affect the purposes of this database *without regard to the confidential nature of the records.* What will be the reasons for the information to be sent to other state agencies? At this point in time, information has not been shared with other state agencies. However, information could be shared with other state agencies for public health purposes. NDDoH policy is to provide only minimum data necessary to meet the user's purposes. A data use agreement provides documentation of the user's purpose and privacy and other requirements regarding the use of the data. If identifying information is not needed, it will not be provided to the entity requesting the information. Public health surveillance data enables collaboration, capacity strengthening, and insight into public health system performance. It is also helpful in the area of program oversight, accountability, and continuous improvement. Data sharing offers a more complete picture of service provision and the effectiveness in delivery of those services. Data can be used to target better outreach, education, and training opportunities for families, professionals, providers, etc. Information can also be shared to provide case management/care coordination in order to serve this population better.

2.6. How will the people whose information is in the database be notified if information is no longer only accessible to those who originally accessed the information? How will they be informed who has the information?

NDCC and NDAC do not address notification requirements. Institutional Review Board (IRB) requirements include notification of individuals and obtaining informed consent to use information for research studies. The NDDoH follows IRB federal requirements.

2.7. How will the state ensure the confidentiality of information within the other agency?

Any agency receiving Protected Health Information (PHI) will be bound by HIPAA. The state would also ensure the confidentiality of information by having the receiving agency sign a data use agreement or a business associate agreement. A data use agreement is the means by which covered entities obtain satisfactory assurances that the recipient of the limited data set will use or disclose the PHI in the data set only for specified purposes. A HIPAA business associate agreement is a contract between a HIPAA covered entity and a HIPAA business associate that protects PHI in accordance with HIPAA guidelines.

2.8. What is the immediate plan for how the data will be used?

The database will contribute to the overall understanding of ASD in ND (e.g., prevalence, diagnostic tools/references used to make the diagnosis, average age of diagnosis, familial risk factors, co-morbidities, etc.). Over time, the database will become an invaluable tool for planning to address the future needs of the ASD population by informing policy-makers, providers, public health officials, and the public.

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2.9. Will this data be used to improve services and funding for individuals with autism? If so, how, especially given the multitude of issues in this type of data collection? For example, this could over represent the need for funding (i.e., possibly by capturing cases of autism so mild that state-based services are not required). While this may seem innocuous, state funding is not without limits and increased funding in one area will likely mean reduced funding of another type of disability. Or if reports are not made due to lack of clarity in the law, fears of breaking patient confidentiality, parents choosing not to bring kids in, etc., the database could underrepresent cases of autism, leading to underfunding. Have these issues been considered and how are they being addressed?

The legislature did not address these issues. The purpose of the database is to conduct epidemiologic studies, research and analysis, and to provide services for individuals with ASD. To address concerns of mandatory reporters and individuals or families with ASD, the NDDoH will be assembling an ASD Database Advisory Group to help guide administration of the ASD Database.

2.10. The database is being "sold" as a way in which the state can determine how many individuals in ND have autism. However, the law clearly states that research could be done with the data that is collected, if this is indeed also the purpose.

NDCC states that the purpose of the database is to conduct epidemiologic studies, research and analysis, and to provide services for individuals with ASD.

2.11. What research questions are we trying to answer?

At this time, there are no plans for research; however, the NDDoH must collect enough information in order to fulfill the law's purpose. If there are requests for data from entities for research purposes, these entities would have to follow the NDDoH's Institutional Review Board (IRB) process. Through the IRB process, any investigators would have to provide special protections for vulnerable populations consistent with federal regulations (e.g., children, pregnant women, prisoners, persons with disabilities, and those with impaired English language skills). For more information about the IRB process, visit [www.ndhealth.gov/irb/](http://www.ndhealth.gov/irb/).

2.12. How (or would) people on the registry be informed of this research that is being conducted with their personal information?

With research projects that have Institutional Review Board (IRB) oversight, informed consent would be required if identifiable data is requested. Options to obtain informed consent vary and depend on the specific research proposal. Informed consent may not be required if aggregate, de-identified data is requested (e.g., number of ASD cases reported in ND).

2.13. Will interested providers and parents be kept informed about how the information is being used?

Providers and parents will be kept informed about the ASD database through various strategies (e.g., presentations, reports, website content, news releases, social media, topical calls, etc.).

2.14. Some of us have been told that parents can have input into what or if research is done on this data by following the legislative process that would be required to approve this research. However, how would they know to follow this process if they do not even know their child has been registered (as there does not seem to be any requirement that they be informed)?

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Individuals or parents/guardians of the individual would have the choice as to whether or not they participate in any research opportunities. Any potential research project would have to be approved through the NDDoH's Institutional Review Board (IRB) process, which includes obtaining informed consent. For more information pertaining to the IRB process, visit [www.ndhealth.gov/irb/](http://www.ndhealth.gov/irb/).

NDCC and NDAC do not require mandated reporters to inform individuals or parents/guardians of the individual about being reported into the ASD database; however, the NDDoH encourages reporters to discuss the reporting requirements for the database with the reported individual or the parents/guardians of the individual.

2.15. Will personal information from the database ever be aligned with other information from other agencies (i.e., DHS) in order to track progress, etc? If so, will parents/individuals with autism be made aware of this use of the data?

At this time, the personal information from the database is not aligned with other information from other agencies. Based on the HIPAA Privacy Rule, a covered entity may, without the individual's authorization, use and disclose PHI for treatment, payment, and health care operation activities.

2.16. Will people from the database ever be contacted in any fashion?

NDCC and NDAC do not specify whether or not people reported into the database can be contacted. NDDoH staff have not contacted any individuals that have been reported into the database. NDCC references service provision to individuals with ASD. At this point in time, the NDDoH has not determined what role, if any, the Autism Database Administrator will have in linking individuals to direct services. Currently, related efforts by the ASD Database Administrator have included ASD conference planning and development of an ASD Resource Booklet.

### **3. Legal Questions**

3.1. What is the penalty for not reporting?

Under NDCC 23-12-07, a person who does not comply with the ASD reporting requirements is guilty of an infraction. Under NDCC 12.1-32-01(7), the penalty for an infraction is a fine up to \$1,000. However, the same law, states that if the person was convicted of another infraction within the past year, that person may be sentenced for the second infraction as though it were a class B misdemeanor. Individual prosecutors have discretion whether to treat it as a misdemeanor in that case. Under NDCC 12.1-32-01(6), the penalty for a class B misdemeanor is up to 30 days imprisonment, a fine up to \$1,000, or both.

3.2. What is the penalty for incomplete reports (e.g., a report without names)?

Refer to response under 3.1.

3.3. Is this a Class B Misdemeanor like failure to report abuse and neglect?

Refer to response under 3.1.

3.4. What legal protection do mental health professionals have against board complaints or civil suits from angry parents? A lawsuit can be brought for any reason and a clinician would be

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required to defend himself, even if the lawsuit were not successful. Would there be funding available to assist in this defense?

The NDDoH performed due diligence to address concerns regarding potential ethical issues with reporting. The NDDoH consulted with the Assistant Attorney General Claire Ness, who contacted attorneys representing the North Dakota State Board of Psychologist Examiners, the North Dakota Board of Counselor Examiners, and the North Dakota Board of Social Work Examiners. Following these discussions, Claire Ness advised the NDDoH to contact the boards to determine their position on whether reporting is allowed under their regulations. Subsequently, the NDDoH requested the boards' positions on the reporting mandate, but the boards were unable to give legal advice. Boards will respond to inquiries regarding the ASD reporting issue by citing the relevant provisions of the law and instructing individuals to seek private legal counsel if they should need assistance with interpreting the law.

3.5. We are based on the New Jersey model. Have there been lawsuits or board complaints in NJ about this?

According to Dr. Sandra Howell, Research Scientist 1, from the New Jersey Department of Health and Senior Services, no lawsuits or board complaints have been filed based on the mandatory reporting of ASD.

#### **4. Other Questions**

4.1. Did you talk with researchers at UND, NDSU to see if there were cheaper, less intrusive measures to get the same data?

No. The legislature determined who has the responsibility of implementing the law.

4.2. What are the current numbers of individuals in the state with autism and what incidence do you expect to find with this database?

The exact numbers of individuals diagnosed with ASD in the state is unknown. For children, the closest approximation comes from the Department of Public Instruction based on educational determinations only. The 2015 child count indicates 1,031 youth with ASD, ages 3-21. This is a 9.4 percent increase from the 2014 child count.

4.3. Why are national incidence numbers not sufficient? Is there a belief that ND has a considerably different incidence of autism than the rest of the country? If not, why can't we rely on those numbers as a guideline? This would be considerably cheaper and less intrusive.

We have no opinion on the use of national data, although it is likely that data will also be utilized by departments. The legislature determined that reporting to the ASD database is mandatory. The database will contribute to the overall understanding of ASD in ND. The database will identify and follow patterns of ASD diagnoses (e.g., average age of diagnosis, familial risk factors and co-morbidities, etc.). Over time, this database will be an invaluable tool in planning for the future needs of the ASD population by providing information to policy-makers and public health officials so that they can make informed decisions.

4.4. There are a considerable number of children on the waiting list to receive the autism waiver in ND. How many children could have been funded with the amount of money spent on establishing the database and paying related personnel?

We do not have the answer to that question. The legislature passed the law.

4.5. Many parents and professionals were very caught off guard by the establishment of this database. What efforts did you make to reach out to mental health professionals and parents? During the 2013 legislative session, a comprehensive autism bill was passed, House Bill 1038. In that bill, the NDDoH was given the responsibility of establishing and administering an ASD database. It also required that the NDDoH convene an expert panel to determine reporting requirements. An expert panel consisting of 29 individuals was convened October 2014. Panel members included physicians, psychologists, state agency staff, therapists, payers, legislators, university, tribal, and family representatives, etc. When the NDDoH convened the expert panel meeting, it was determined by the expert panel that the language used in HB 1038 was too restrictive, and therefore might hinder reporting to the ASD database. The ASD expert panel recommended that issues be addressed during the 2015 legislative session before the ASD database could be implemented. Senate Bill 2176 was put forth during the 2015 legislative session to address the challenges that were recognized by the expert panel in order to ensure the success of the ASD database. During both of these legislative sessions, interested parties were given the opportunity to testify regarding the ASD database. During the Administrative Rules process, the NDDoH gave notice to the ND Newspaper Association for publication in all county newspapers regarding the public hearing. Additionally, the public hearing date was shared with various stakeholders by NDDoH staff. The public hearing was open to the public but no comments were received. The public hearing was followed by a 10-day open comment period where additional comments could be submitted to the NDDoH for consideration. During the 10-day open comment period, the NDDoH received a letter of support from the North Dakota Autism Spectrum Disorder Advocacy Coalition and no comments expressing concerns.

Additional input and outreach was accomplished with the following:

- ASD Expert Panel
- Governor-appointed ASD Task Force
- Children Special Health Services (CSHS) Medical Advisory Council
- CSHS Family Advisory Council
- ND Chapter of the American Academy of Pediatrics
- ND Autism Spectrum Disorder Advocacy Coalition
- CSHS Medical Director
- ND Interagency Coordinating Council
- Individuals with Disabilities Education Act Advisory Committee
- NDDoH Attorney General's office
- Family Voices Topical calls for Autism
- Pathfinder's Parent Involvement conference presentation
- ND ASD Conference presentation
- Health Alert Network (HAN) notification
- CSHS's Multidisciplinary Clinic Directory mailing
- Practice boards of mandatory reporters
- Department of Human Services (DHS) Provider Autism Briefings
- DHS Family Autism Briefings

In addition, the NDDoH has disseminated ASD database brochures and created an ASD database website page.

4.6. Parents who were aware of the database being created appear to have been caught off guard about the details of what is being required in the reports (i.e., many believed it would be anonymous and/or voluntary). What information were they given about the database prior to it becoming a law?

A draft of the law was public record and was discussed publicly during both legislative sessions. The legislature determined an ASD database was needed in ND after significant discussion and public input. The ASD report form developed by the NDDoH and approved by an ASD expert panel contains the information that was determined to be relevant and appropriate. Additional input was solicited from various entities (e.g., ASD Task Force, Children's Special Health Services Medical Advisory Council, ND Autism Spectrum Disorder Advocacy Coalition, etc.).

4.7. Who is going to pay me and/or how will I make up for the time I spend filling out the form on each client? For some clinicians who work with lots of kids on the spectrum this could take quite a lot of time. For example, if a clinician were to average two cases per week and the form were to take 20 minutes and the clinician talks to the family about the registry for an additional 10 minutes, we are talking about approximately 60 minutes of patient time lost per week. Most clinicians do not have this built into their schedules and therefore this will mean revenue will be lost and, more importantly, fewer patients can be seen. Was this considered?

In order to address time constraints of mandatory reporters, NDCC permits the use of a designee to report into the database. Prior to the implementation of the ASD report form, several reporters completed it in its entirety to determine how long it took to fill out the form. According to these reporters, an average of 10 to 12 minutes was required to complete the form.

4.8. Were cultural differences between North Dakota and New Jersey in the acceptance of a mandated database considered? We sometimes struggle to get people in the door to see therapists due to negative stereotypes of therapists and those who need to seek our services. A mandatory registry of this kind will not help, not only in the case of autism, but also as it relates to general trust of our field. The idea of "what is next?" is sure to come to the minds of some of our potential patients. They are likely to see this as a dangerous precedent. Was this considered? The legislature determined an ASD database was needed in ND after significant discussion and public input.

4.9. How do you know the data stays accurate? What about a family that moves out of state? A patient dies (the data includes patients of all ages)? This data would say they are still living here and would inflate the numbers.

The registration information on the ASD report form can be updated.

4.10. If a client sees 6 medical doctors and 4 therapists in a year, that means that 9 people filled out this form for nothing. How many people are wasting time filling out forms that will just get shredded?

There is a potential for duplicate entries in the database. The NDDoH recognizes the inefficiency of multiple entries and is trying to find solutions to this issue. Options to help reduce duplicate reporting include scanning a copy of the report form into the individual's medical record, adding

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a comment into the notes field stating that the patient/client has been reported into the database, giving a copy of the report form to the individual or the parents/guardians of the individual that can be taken to other appointments, etc.

4.11. Did you think about parents who do not want their child "cataloged" who might respond by not taking them for services? How will those kids be impacted by this mandate?  
The NDDoH is implementing the law as required.

4.12. If this information is so important, why were psychologists not even informed of their obligations related to this law for more than two years after it was adopted?  
The NDDoH followed the appropriate processes to inform the public regarding the law. Refer to response under 4.5.

4.13. NDCC 21-01-41 (2) "The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database." What are the criteria and what level of training is required to make this diagnosis? The law is unclear simply stating a "reporter be a 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 of" ASD.  
The criteria and level of training is determined by each of the practice boards in the state of ND. Additionally, the NDDoH staff worked with payers to identify who qualifies as a reporter based on their ability to function independently in order to diagnose, treat, and bill for a specific disease or medical situation. Those that qualify include physicians, psychologists, nurse practitioners, clinical nurse specialists, licensed independent clinical social workers, and licensed professional clinical counselors.

4.14. Not all psychologists feel comfortable making this diagnosis. At what point are they "required" to do so?  
NDCC and NDAC do not require providers to diagnose ASD if they normally refer to another health care professional who has specialized training or education in diagnosing ASD. However, mandatory reporters are required to report any patient or client of theirs who has a confirmed case of ASD into the database. Additionally, if the provider refers their patient or client to someone else for diagnostics, then the providers should communicate as to who will report into the database.

4.15. Most physicians do not have specific training in this area. Are they required to report highly suspicious cases of ASD or those with a previous diagnosis?  
Mandatory reporters are required to report any individual with an ASD diagnosis into the database, including those previously diagnosed. Suspected cases of ASD are not to be reported into the database.

**Dear Madam Chair Lee and Members of the Senate Human Services Committee:**

**For the record, my name is Angela Cavett, PhD. I am a Licensed Psychologist and Registered Play Therapist-Supervisor and Certified Trauma Focused Cognitive Behavioral Therapist. I am co-owner of Beacon Behavioral Health Services and Training Center. Currently I am President-Elect of the North Dakota Psychological Association.**

I started my career in 1989 while an undergraduate at North Dakota State University (NDSU), working with people with developmental disabilities including Autism and throughout my career have worked with children with autism at several sites including Children's Residential Services in Brooklyn Park, MN and Astor Home for Children in New York. **Throughout my career as a psychologist, I have seen children in practice that I have diagnosed and/or treated with autism.**

**As a citizen, psychologist and as a part of North Dakota Psychological Association, I applaud you Senator Lee and the legislature for considering the needs of individuals with mental health concerns. We support and appreciate the Autism Taskforce and the legislators and the intent behind the law related to autism services.** The autism waiver, for instance, is beneficial for patients and their families. The intent of the registry was also noble. We all have a shared goal: I, like you, want children and adults with mental health diagnoses to be able to access services for diagnosis and treatment. **However, I have serious reservations about aspects of the reporting process.**

**The focus of my verbal testimony today will be about confidentiality. This will be followed by my respected colleagues Drs. Catherine Yeager and Jennifer Garaas discussing diagnosis/misdiagnosis and prevalence rates respectively.**

#### **CONFIDENTIALITY:**

**Our practice, as psychologists, is directed by our adherence to the Ethical Principles of Psychologists and Code of Conduct.** I will refer to this as the Ethics Code throughout this letter. You can find it on-line at <http://www.apa.org/ethics/code/>. The reservations we have are due to the discrepancy between the law and our Ethics Code. The main concerns relate to confidentiality.

**As psychologists, confidentiality is our obligation to patients and the cornerstone of practice. Confidentiality is the foundation that allows families to tell us their struggles and experiences. Breaching confidentiality can lead to a decrease in the public's trust of psychologists.**

#### **IMPEDES SERVICES:**

**Due to the breach of confidentiality, the mandate to report patients with autism impedes people seeking out services. Patients and their guardians do care about confidentiality. I have had two cases where the child and parents came to the intake and decided during the time that we discussed the psychologist-patient agreement about confidentiality and limits due to the autism mandate, that they would not be seen for assessment.** One of the purposes of the registry was to improve access to services for children with autism. However, when families feel strongly about confidentiality and do not want that violated, the mandate to report may interfere with their getting what they need.

There were a few families that had parents who were interested in testifying here today. They decided, in part because of confidentiality, that they did not want to testify. Our families often communicate that the mandate is an infringement on their rights and their treatment.

#### **PREVALENCE OF AUTISM:**

**Of the two reasons given for the mandate to report one is to have an accurate number of those who may need services. We can find those numbers by using base rates and population data. Dr. Garaas will provide more information about this in her testimony.**

Population of ND (July 1, 2015 per  
<https://www.census.gov/quickfacts/table/PST045215/38> )

756,927

Persons under 18:

23%

174,093 of our citizens in ND are children under 18 years of age

Prevalence of Autism according to the CDC:

<https://www.cdc.gov/ncbddd/autism/data.html>

1 in 68 (2012)

1.47% (2560 children with autism)

Prevalence of Autism according to DSM V 1%

17409 children (1740 with autism)

Many question the rates of autism and this is discussed in numerous sources including the DSM in this statement about the prevalence of autism.

*"It remains unclear whether higher rates reflect an expansion of the diagnostic criteria of DSM-IV to include subthreshold cases, increased awareness, differences in study methodology, or a true increase in the frequency of autism spectrum disorder" (p. 55)*

Although it is important for us to know how many children have autism, there may be other ways to support this information being researched within entities that have the resources and statistical/research background to do so.

#### **EXTENT OF INFORMATION GATHERED AND INTENT FOR ITS USE:**

When we do give information to someone from that intimate, trust-based therapeutic relationship, we need to know what it is going to be used for. Our ethics state that as psychologists, we are obligated to discuss with the patient (or guardian) the limits of their confidentiality and the "foreseeable uses of the information generated through their psychological activities." As the ND law and North Dakota Department of Health- Children's Special Health Services currently have documentation stated the use of information we give is vague. We have asked questions about the use for the data and have been told that it is possible it will be used for research and it is possible that the patients will be contacted in the future. The extent of the information the mandate requires seems to exceed what our ethics permit.

Our APA Ethics Code states

*"(a) Psychologists include in written and oral reports and consultations, only information germane to the purpose for which the communication is made. (b) Psychologists discuss confidential information obtained in their work only for*

*appropriate scientific or professional purposes and only with persons clearly concerned with such matters."*

Our APA Ethics Code also indicates that disclosures are made only under certain circumstances. Although we realize that 4.05 (b) allows for disclosure due to the law, we believe the law, although based in good intent, may not be in the best interest of every patient.

*4.05 Disclosures "(a) Psychologists may disclose confidential information with the appropriate consent of the organizational client, the individual client/patient or another legally authorized person on behalf of the client/patient unless prohibited by law. (b) Psychologists disclose confidential information without the consent of the individual only as mandated by law, or where permitted by law for a valid purpose such as to (1) provide needed professional services, (2) obtain appropriate professional consultations; (3) protect the client/patient, psychologist, or others from harm..."*

#### **REPORTING DOES NOT REFLECT NEED:**

Children with autism are across a continuum. Some children with autism need residential services throughout their lives. They need and benefit from therapies and respite care. Yet, across the continuum many will be successful. They may be your pediatrician, technology professionals and the engineer who designed the infrastructure in your area may be on the continuum. It seems concerning that everyone with the diagnosis must be reported even if there is no benefit to being reported for many of them. This makes the benefit/cost analysis of reporting skewed towards not mandating reporting of all.

#### **POTENTIAL FOR HARM:**

Several scenarios should be considered when thinking of the ethical and moral implications of a mandated registry. This should be done with great forethought into the possible impact on patients.

1. A middle aged man with mild autism (what may have been diagnosed as Asperger's Disorder before the Diagnostic and Statistical Manual, Fifth Edition (DSM IV)) presenting with marital concerns would, according to current law, have to have their information given to the state registry. Would this violation of privacy benefit anyone and would there be a possible detrimental effect?
2. A young adult diagnosed with mild autism as a young child could be contacted by someone at a much later date. How would this impact the child if he had not been told what his diagnosis was and had not met criteria for the diagnosis for most of his life.
3. A child who has Bipolar Disorder but had been misdiagnosed with autism two years earlier may be on the registry and he or his parents contacted about his diagnosis.

In each of these cases, one has to consider whether there is a benefit of reporting each of these people. Is there a cost associated with the breach of trust in psychologists when their confidentiality is broken? Is there a cost associated with avoiding services due to not wanting to be reported? Is there a cost associated with being told about a diagnosis that may or may not be valid at a different time in the person's life?

#### **STATE COMPARISONS FOR REPORTING:**

**Information about the reporting requirements for other states suggests that North Dakota mandates that professionals report more than almost all other states. New Jersey for instance, allows for the parent to consent to reporting the child's name or opt out of**

**reporting this information. This can be found on the NJ website in the parent brochure.**

<http://www.autismnj.org/document.doc?id=467>

A review of states that have reporting of autism suggests that Rhode Island's registry is voluntary, New Jersey allows parents to opt out of giving the person's name, New Hampshire and West Virginia both do not require names. Utah is voluntary and is a self-registry. Delaware is mandatory but only requires those under 18 years of age to be reported and Illinois is mandatory but the name of the person does not have to be given.

## **CONFIDENTIALITY AND RESEARCH**

**One of the stated purposes of the mandate to report is to be able to do research on the people on the registry. Our Ethics Code also gives us clear boundaries related to research.**

One important factor is that to do research related to psychology on human subjects, prior approval must be given. There is no clear research that has been proposed and accepted by an Institutional Review Board (IRB) for this registry. **Our Ethics Code 8.01 applies to this. I have included it in my written testimony for your review.**

### ***8.01 Institutional Approval***

*When institutional approval is required, psychologists provide accurate information about their research proposals and obtain approval prior to conducting the research. They conduct the research in accordance with the approved research protocol.*

As clinicians and researchers, psychologists must adhere to rigid standards also dictated in the Ethics Code. There are several important factors in 8.02 that show that our participating in the reporting of potential research participants is a problem. The patient should know many things and have specific protections as spelled out in this section, which with the ND law, they do not know/have.

### ***8.02 Informed Consent to Research***

*(a) When obtaining informed consent as required in Standard 3.10, Informed Consent, psychologists inform participants about (1) the purpose of the research, expected duration and procedures; (2) their right to decline to participate and to withdraw from the research once participation has begun; (3) the foreseeable consequences of declining or withdrawing; (4) reasonably foreseeable factors that may be expected to influence their willingness to participate such as potential risks, discomfort or adverse effects; (5) any prospective research benefits; (6) limits of confidentiality; (7) incentives for participation; and (8) whom to contact for questions about the research and research participants' rights. They provide opportunity for the prospective participants to ask questions and receive answers.*

*(b) Psychologists conducting intervention research involving the use of experimental treatments clarify to participants at the outset of the research (1) the experimental nature*

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of the treatment; (2) the services that will or will not be available to the control group(s) if appropriate; (3) the means by which assignment to treatment and control groups will be made; (4) available treatment alternatives if an individual does not wish to participate in the research or wishes to withdraw once a study has begun; and (5) compensation for or monetary costs of participating including, if appropriate, whether reimbursement from the participant or a third-party payor will be sought.

#### **8.04 Client/Patient, Student, and Subordinate Research Participants**

(a) When psychologists conduct research with clients/patients, students or subordinates as participants, psychologists take steps to protect the prospective participants from adverse consequences of declining or withdrawing from participation.

(b) When research participation is a course requirement or an opportunity for extra credit, the prospective participant is given the choice of equitable alternative activities.

#### **8.05 Dispensing with Informed Consent for Research**

Psychologists may dispense with informed consent only (1) where research would not reasonably be assumed to create distress or harm and involves (a) the study of normal educational practices, curricula, or classroom management methods conducted in educational settings; (b) only anonymous questionnaires, naturalistic observations or archival research for which disclosure of responses would not place participants at risk of criminal or civil liability or damage their financial standing, employability or reputation, and confidentiality is protected; or (c) the study of factors related to job or organization effectiveness conducted in organizational settings for which there is no risk to participants' employability, and confidentiality is protected or (2) where otherwise permitted by law or federal or institutional regulations.

#### **MISUSE OF PERSONAL HEALTH INFORMATION:**

It is unlikely the information will be intentionally misused. However, we must remind ourselves that within my lifetime the United States Department of Public Health has done research on human subjects without informed consent and the results were tragic. To think this would not or could not happen again, is naïve. <https://www.cdc.gov/tuskegee/timeline.htm> Mandatory reporting opens the door to misuse of information and possible limits on civil liberties. I, as a psychologist, do not want to be a part of that.

#### **PROTECTION FOR REPORTERS:**

We have concerns given that there are not protections for the reporter noted in the law related to the mandate to report people diagnosed with autism. In the ND Century Code, related to reporting child abuse, professionals including psychologists are protected against repercussions for reporting. For some states, professionals are also given this protection when reporting people with autism. In ND, we inquired about this and were told that for discrepancies between the law and our ethics we could consult with our own private attorneys.

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**DISORDERS WITH EQUAL NEED BUT NO SUPPORTS:**

Another concern I have with reporting and addressing the needs of children with autism and NOT identifying and addressing the needs of children with other disorders that have equal or even greater need for services, is that parents want to be part of the group that is getting services. I work with children with developmental trauma and histories of child and maltreatment. Often these children are diagnosed with Reactive Attachment Disorder. They look similar to children with autism in many respects. At times, they have been diagnosed with autism by someone who is not well-versed in Reactive Attachment Disorder. Sometimes parents have not had their child diagnosed with autism but they ask repeatedly to have the diagnosis for their child so that they can access services. The last thing we would want is for children with autism to NOT get their funding. However, I have seen a phenomenon that will continue if one disorder is singled out for identification and assistance. This will inevitably lead to inaccurate numbers of people diagnosed (accurately or inaccurately) with autism.

What is the difference between children with autism and those with other mental health disorders? It is that their parents tend to be more educated, they have access to resources and they advocate for them. Children with autism have what I wish all children with mental health problems had. But sadly, many children do not. **I would like to see our state continue in the pursuit of providing for all children with mental health needs.**

**RECOMMENDATIONS: I admire the efforts made for children with autism and hope we can work together to guarantee that the needs are assessed and treatments provided.** In terms of a registry, I believe that supporting researchers interested in collecting information in accordance with an IRB may be an option. **If the state decides to continue with the registry, I recommend that it not be mandatory, that the protections are made for professionals who do report, that a clear IRB-approved research study be stated, and that individuals have the rights given to research participants by our Ethics Code.**

Thank you.

Angela M Cavett, PhD

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RI - voluntary  
NJ - mandatory can opt out name  
NH - no names  
WV - no names  
UT - Voluntary; self registration  
VA - voluntary  
Delaware - mandatory - only under age 18  
Illinois - mandatory - can choose not to include name

My name Catherine Yeager and I am clinical psychologist and co-owner of Assessment and Therapy Associates of Grand Forks. I have been licensed in North Dakota since 2002.

I will first say that I have no doubt that this registry was created to ultimately benefit individuals with autism in our state. However, as a provider who specializes in the diagnosis and management of autism, I have concerns about this registry and the information it will provide.

Like Dr. Cavett, I am concerned about the requirement to report confidential patient information without consent. Further, my personal experiences with diagnostic trends in autism leads to concern that the data provided by this registry may inflate the prevalence of this disorder in our state.

As you may know, autism diagnoses have been rising at an alarming rate – Autism Speaks reports a 600% increase in the last two decades. This increase has received a great deal of media attention and caused understandable fears about a possible “epidemic” of autism. However, what is discussed less often is the fact that humans change very slowly over time, making a true increase of this degree unlikely. In fact, most scientists believe that this increase is largely the result of other factors, such as the loosening of diagnostic criteria and increased autism screening. Additionally, the diagnosis of autism is somewhat arbitrary and there is no definitive test to confirm this disorder. Consequently, young children with delays are susceptible to misdiagnosis; a 2007 study found that over 30 percent of children diagnosed with autism at age two no longer met the criteria at age four. Children with other childhood disorders also often present with symptoms like those seen in autism, leaving them prone to misdiagnosis.

Further complicating matters is the fact that given the high demand for autism evaluations due to increased public awareness and fear, undertrained clinicians and schools increasingly rely on symptom checklists to assess and diagnose autism. This is extremely problematic as these checklists generally fail to emphasize the importance of the hallmark symptoms of autism and do not account for variation in symptom expression depending on age and developmental level. Kids are also sometimes given diagnoses of autism instead of other learning problems because of the greater availability of services for autism spectrum disorders. This combination of factors has undoubtedly led to children who do not have autism being diagnosed with this disorder. It is not an exaggeration to say that I personally see children who have been misdiagnosed with autism on a weekly basis.

Given these diagnostic problems, use of the registry as currently mandated is likely to lead to inflated incidence of this disorder in North Dakota. I believe there is evidence of this type of inflation in other states, including New Jersey, the state after which our registry is modeled. New Jersey currently has the highest rate of autism in the nation. Although some may argue that this means that more children with autism are being identified, for the reasons described above, I believe this high incidence is more likely the result of overdiagnosis. If our registry reveals similar numbers, it will be impossible to determine if these represent misdiagnoses or true cases of autism. This fact significantly limits the registry’s value in accomplishing its stated goals.

SB2241  
Attal #4

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Dear Madame Chair Lee and Members of the Senate Human Services Committee,

My name is Jennifer Garaas. I am a licensed psychologist and co-owner of Beacon Behavioral Health Services in West Fargo North Dakota. I have been licensed in the state of North Dakota since 2008.

Like many of my colleagues, I have serious concerns about SB2241, the Autism Registry Bill. According to the North Dakota Autism Spectrum Disorder Database website: "The information collected will be used to complete epidemiologic surveys, research and analysis, and provide services to individuals with an ASD." The website reports that North Dakota wants to study the prevalence of ASD in North Dakota over time for the following reasons: inform public policy decisions, improve community awareness, assist in identification of risk factors, and improve services and support for people with ASD. At the surface, these are good reasons to assess the prevalence of ASD in ND. However, with further evaluation, one will be able to see that the goal of the database will not fully meet its intent. I believe the risks outweigh the benefits and taxpayer money will be spent on something that will not be useful.

First, I am concerned that the patient/provider trust will be compromised and there may be no benefit for the patient. We were informed by NDDoH that it may or may not contact the individual and the individual's information may be shared with other state agencies. (NDDoH responses, 1.5 & 2.5) On the ND ASD Database website, it informs parents/individuals: "Strict security precautions are used to prevent outside access to the information and only those authorized by the NDDoH will be able to view the data. The NDDoH follows all rules required by the Health Insurance Portability and Accountability Act of 1996 (HIPAA)." We have concerns about how this information will be secured, shared and used. I understand ND also has a cancer registry. When one looks at this website, the procedure of how the information is used is stated very clearly. Unfortunately, this is not the case for the Autism registry.

Second, I believe ND prevalence rates could be easily determined by looking at base rates. According to the DSM-5, ASD occurs in 1% of the population across US and non-US countries. The CDC noted that it occurs in about 1.5% of the population. According to the 2016 US Census Bureau, ND population was 757,952. Taking this estimate, ASD prevalence rate in ND would be 7,579-11,369. This estimate includes children and adults with varying levels of ASD severity. According 2015 US Census Bureau, 23% of the population was under the age of 18 giving the estimate number of 174,093 children in ND. If we took this estimate, there would be roughly, 1,740- 2,611 children with varying levels of ASD severity. Not all children and adults with ASD need services. If the state of ND looked at base rates instead of creating a database, more funding could be used for treatment of ASD.

Lastly, the ND ASD Database wants to conduct epidemiological studies on ASD. Risk factors according to the DSM-5 and CDC for ASD include genetics, low birth weight, advanced parental age, and fetal exposure to valproate (a medication). The ND ASD Database may try to look at cluster areas of those diagnosed with ASD like the ND Cancer registry looks at clusters of cancer. With cancer, either the individual has cancer or does not. This is not the case with mental health diagnoses. An individual may look like they meet criteria for ASD, but the symptoms may be the result of another diagnosis (e.g., Social Anxiety Disorder, Reactive Attachment Disorder). If the ND ASD Database does find a cluster, this does not necessarily mean that there is an environmental cause. For instance, there could be a provider in that area who diagnoses ASD more liberally than providers in another part of the state. In addition, the data most likely will be incomplete because individuals with ASD may get services in another state (e.g. MN) or the individual is functioning and does not need services. ND would spend money on collecting and researching data; though, the results would not be beneficial to the state of ND because many variables could be affecting the results. Instead, the money would be better spent towards treating individuals diagnosed with ASD in need of services.



SB 2241  
Attach #5  
2/8

**Senate Human Services Committee**  
**SB 2241**  
**February 8, 2017**

Good morning Chairperson Lee and Committee Members. I'm Courtney Koebele and I represent the North Dakota Psychiatric Society, the professional membership organization for the state psychiatrists.

NDPS support SB 2241, which makes some necessary changes to the autism spectrum data base. However, it is our position that the database itself is not necessary, and causes an unfunded mandate to providers. More importantly, it causes undue heartache to the families of people with autism.

Parents and individuals who are being reported feel as if they are being treated like they have a sexually transmitted disease and that intrusive information-gathering appears to be becoming counter-productive, in that it alienates them from continuing to come to the provider who "reported them."

These amendments are necessary to reduce the negative consequences of the implementation of the statute, while still attempting to preserve the spirit of it - to use the collection of data to better understand the prevalence of the illness and address needs for treatment.

Thank you for your time today. I would be happy to answer any questions.

**Vote YES on SB 2241**

Thank you for listening to us, those who have to translate this law into everyday practice.

If we do it, we could harm our patients. If we don't, we will be handsomely fined.

As a science person, I salute the idea of a registry. My understanding is that it is driven by the good intention of learning what, where, when, how many autistic people are, so we can provide them with resources.

As a practicing physician, I will present you with **3 ways in which this registry, in its current format, can harm my patients** and I cannot accept it.

**1. Confidentiality**

All of us would like to keep our records private and confidential. This is the reason why practices and hospitals invest an inordinate amount of resources in implementing and maintaining internet security, firewalls, privacy laws, etc.

I would like to know that my patients' autistic report is kept with the same scrupulous care for privacy as their medical records. At this point I do not have that peace of mind and I do not feel comfortable taking their information and sending it ..... where?!

Let's not play naïve: autism comes with a heavy price already: **stigma[1, 2]**. Our society still harbors, by and large, negative and inaccurate views on autism[3]. At the highest levels[4].

Are we ready to propose even more hurt to the people with autism and their families?

Security breaches do happen. If you have a family member with autism, how would you feel about that?

**2. Ongoing Relevance:**

Autism criteria have changed recently, and there are already efforts to change them again in the future. How will this registry be updated to reflect those changes? How will this registry be a living, breathing document like a registry should be?

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Primum non nocere  
Hippocrates (460-377 BC)

### 3. Unnecessary burden

My colleague Dr. Pathak is the sole psychiatrist for about 2000 children. He sees them at 30-minute intervals. He stays 2 hours after hours to document their visit. He told me that each autism report takes about 15-20 min at best, 60 min sometimes due to the required digging into the old records.

He has already faced harsh words from parents who accused him: "this doc is reporting our child".

He had a child whose parents were separated and their opinion about the registry was opposite: mother was very apprehensive about the social repercussions of "reporting" and dad was ok with it, since he was not taking care of the child on a regular basis anyway.

If my colleague decides to leave a high burden, medium pay, high stress position, we have NOBODY to take care of these children. We have been advertising for a child psychiatrist position for 25 months now with ZERO hires. I propose that burning him out is not helping our kids. Is serving other people's distant and possibly fruitless interest in children.

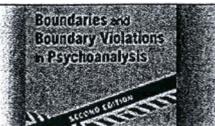
Last but not least, I know this is **unnecessary**:

**We already have a registry:** why duplicate efforts?

The APA registry[5] of mental health was created and perfected over a decade and is fully functional now, getting entries as we speak. There is minimum operator work involved, no doctor time, and the security is... well... at the national level.

1. Farrugia, D., *Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder*. *Social Health Illn*, 2009. **31**(7): p. 1011-27.
2. Kinnear, S.H., et al., *Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives*. *J Autism Dev Disord*, 2016. **46**(3): p. 942-53.
3. Chambres, P., et al., *Adult Attitudes Toward Behaviors of a Six-year-old Boy with Autism*. *Journal of Autism & Developmental Disorders*, 2008. **38**(7): p. 1320-1327.
4. Willingham, E., *Donald Trump Will Be A Disaster For Autistic People*, in *Forbes Magazine*. 2017, Forbes Media: Jersey City, NJ.
5. Moran, M., *APA Approves Development of Registry, Takes Other Major Actions*, in *Psychiatric News*. 2016, American Psychiatric Association.

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## Association News

### APA Approves Development of Registry, Takes Other Major Actions

Mark Moran

Published online: April 08, 2016

APA's Board of Trustees tackles an issue-laden agenda at its March meeting.

Health care reform—especially the development of a clinical database to track outcomes—telepsychiatry, and expansion of APA continuing medical education accreditation were among the issues addressed by APA's Board of Trustees at its meeting last month in Arlington, Va.



APA President Renée Binder, M.D., leads a discussion about whether APA should continue to produce videotaped messages from APA candidates and make them available to members on APA's website. Trustees voted to do so for one more year and then reevaluate their decision on the basis of detailed usage metrics.

David Hathcox

business case for a registry and then a business plan.

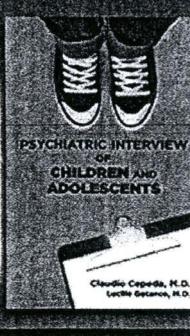
lly, the registry will help psychiatrists meet the growing quality-reporting requirements for insurance payments and board certification. Over time, a registry can also allow for the collection of uniform, clinically rich data including risk factors, treatments, and outcomes at key points for a particular disease or procedure (see sidebar). These data could be used in future research to develop new diagnostics, therapeutics, and quality measures that capture the value of psychiatric care. Registries are increasingly viewed as vital to the goals of the so-called Triple Aim: improving the patient experience of care (including

Importantly, APA Trustees voted to proceed with the development and implementation of a mental health clinical data registry, with the Board receiving detailed updates at each of its regularly scheduled meetings.

The Board's vote on the registry is another step toward creation of a database that will help psychiatrists conveniently meet the growing requirements to track quality and outcomes of their patients with mental illnesses. The initial recommendation to create a mental health registry came from a Registry Work Group report to the Board in July 2015. The Board also heard about the benefits of a registry for membership from multiple medical associations that had established registries. As a result of these discussions, the Board directed the APA administration to develop a

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quality and satisfaction), reducing the per capita cost of health care, and improving the health of populations.



Resident-Fellow Member Trustee-elect Stella Cai, M.D., notes that younger members need new ways to become informed about the candidates running in APA's election.

David Hathcox

"Our Board of Trustees is continuing to move judiciously toward the development of a registry," said APA President Renée Binder, M.D. "An APA registry has the potential to be enormously useful to members and our profession by giving us data that will demonstrate value-based care, while allowing us to know what works and what doesn't work in helping our patients achieve recovery.

"The Board took an initial step toward ensuring that we use our resources in the wisest possible way in the pursuit of this endeavor, which is likely to be costly. The Board of Trustees and the APA administration will continue to keep members apprised at every step as we work toward the development of a registry."

## Other Actions

In other business, the Board approved the establishment of the Committee on Telepsychiatry under the Council on Healthcare Systems and Financing to continue the work of the Board's ad hoc work group on telepsychiatry. The committee will be charged with advising APA on policy, legislative, and regulatory initiatives; developing educational tools for members on telepsychiatry; and creating resource documents for members on the use of telepsychiatry.

## What Is a Clinical Data Registry?

Clinical data registries serve as a way to help physicians monitor and report on their patients' progress. Registries are being developed by medical specialty organizations to help physicians comply with requirements for quality reporting and avoid financial penalties up to 9 percent, as well as to submit Performance-in-Practice data to obtain MOC Part IV credit.

In a registry, physicians report information about a patients' condition, treatments, and the progress they are making. Patients can also participate by reporting on how they feel. The data from both physicians and patients is carefully protected and includes only unidentifiable data within the registry. The anonymous data, often transferred from an EHR, can also be used for research to identify better treatment options and develop new quality measures.

Medical specialty organizations have established 123 registries. The AMA's recent National Quality Reporting Network survey found that nearly all medical specialties have developed or are developing registries. In addition, registries have also been established by large health systems and systems using a collaborative care approach.

APA members who have questions or comments about the development of the mental health clinical data registry are invited to send them to [registry@psych.org](mailto:registry@psych.org).

activities. These include online CME activities put on by district branches and affiliated organizations, which are of increasing interest to APA members, he said.

"Because APA will be able to use existing APA resources, we can charge lower fees than alternative CME-granting entities, and this will allow district branches and affiliated organizations to provide CME less expensively," Summers said.

Funding CME -- As Pharma Retreats Who Pays the Price?  
Bradley P. Fox, MD, et al.,  
Medscape, 2010

The Didact Is Dead: Long Live CME Interactivity?  
Robert M. Centor, MD, et al.,  
Medscape, 2010

Future of Board Certification in a New Era of Public Accountability

Kevin B. Weiss, MD, Medscape, 2010

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## PSYCHIATRIC NEWS UPDATE

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The work group's chair, Jay Shore, M.D., also recommended to the Board that "APA should take a leadership role in advocating for and educating about telepsychiatry at the national and state levels to improve access to care." The group also said that APA should consider the following policy issues, among others, for further discussion: developing model state legislation around telepsychiatry, introducing legislation around parity reimbursement for telemedicine services, collaborating with the American Telemedicine Association on a joint telepsychiatry guideline, and collaborating with the American Association of Directors of Psychiatric Residency Training on providing educational materials on telepsychiatry for residency training programs.

Additionally, Trustees approved a 12-month pilot expansion of the Joint Sponsorship Program to grant CME accreditation of up to 20 online programs, up to 10 affiliate programs, and up to five outside programs approved by the Council on Medical Education and Lifelong Learning.

In comments to *Psychiatric News*, Richard Summers, M.D., chair of the APA Council on Medical Education and Lifelong Learning, said the Joint Sponsorship Program will allow APA to grant CME for real-time



< [Registry](#)

< [Mental Health Registry Home](#)

## Frequently Asked Questions

Learn about the development and benefits of a mental health registry as well as find answers to questions about accessing and using data, security and privacy, cost and requirements, and how to enroll.

### General

What is a clinical registry?

A clinical registry is an organized system that collects data (reported by patients and providers) which are then used to better understand patients' health care history and experiences, as well as the quality of care they are being provided. With the increasing usage of electronic health records (EHR), registries have emerged as a valuable method of using the latest information technology to capture data that will aid psychiatrists in making decisions about the most optimal patient care. Such registries are already being successfully used within other medical specialties and medical associations, including the American Academy of Neurology, American College of Cardiology, American Society of Clinical Oncology and many others.

Why is the APA developing a registry, and how will it benefit psychiatrists?

APA is committed to helping psychiatrists meet new Medicare quality reporting requirements and maintain professional recertification—all in a way that avoids significant administrative burdens. Specifically, this registry will help members avoid payment penalties associated with failure to meet quality reporting requirements set by the Centers for Medicare & Medicaid Services (CMS) and by the future Merit-Based Incentive Payment System. These payment penalties will increase progressively each year from 2019 to 2022 from 4% to 9%. A registry will give psychiatrists an easy and effective way to transmit quality reporting data to CMS and help them avoid these penalties.

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A registry also gives psychiatrists a simple method of submitting Performance-in-Practice data and obtaining ABPN Maintenance of Certification (MOC) Part IV credit. Maintenance of Certification is critical to maintaining board certification and hospital credentialing. The registry's software will generate automated reports and transmit them electronically to easily fulfill MOC Part IV.

Finally, the APA is developing this registry to help decrease routine administrative reporting burdens by consolidating and simplifying the production and submission process for the various regulatory and administrative demands faced by psychiatrists. This includes generating patient and progress reports, which help busy psychiatrists track patients' outcomes and provide clinical decision-support tools to inform evidence-based care.

— How does the APA registry work?

Pertinent data will be extracted automatically from the EHR and transmitted on a scheduled basis directly to the APA registry. Participating psychiatrists can then access the data in the form of calculated quality measures that will help them examine their own patient population and benchmark practice performance to uncover potential areas for quality improvement. Quality measure results can also be compared to higher levels of aggregated data to answer questions, such as: "How are my patients with Major Depressive Disorder doing compared to patients with depression in the city, region, state, or nationally?"

— Is the APA mental health registry currently in full operation?

No, we are in the process of developing the registry. Development of the registry involves 3 phases:

1. Proof of Concept (POC) testing (60 days);
2. Pilot cohort testing (90 days); and
3. Full-scale launch

We are currently in the POC phase, where we are inviting practicing psychiatrists with an EHR system in place to test the basic set up of the registry and linkages.

## Data

— What data would I have access to as an APA registry participant?

The APA registry allows you to view run quality reports that provide clinician-, practice- and national-level results for all measures. Participants have access to their own performance metrics. In addition, the registry participants can use the registry to compare their performance and outcomes to similar practices at the regional and national level. It is also possible to make comparisons over time within a physician's own practice.

- Is it necessary to have an EHR system to participate in the APA registry?

Initially, we will need participants using an EHR regardless of the setting in which they work (i.e., in solo or group practices or academic settings or larger systems of care). Eventually, we plan to be able to accommodate physicians who do not use an EHR to either 1) enter through a web-based portal, or 2) be able to accept scanned paper and pencil information into the registry.

- Can the registry data be used for the Merit-Based Incentive Payment System reporting?

Yes, the APA is taking steps to become a Qualified Clinical Data Registry in 2017.

## Quality Measures

- What are the quality measures included in the registry?

The APA is currently working with FIGmd the registry developer, to implement 25 Merit-based Incentive Payment System (MIPS) measures. These measures have been chosen to provide registry participants with a broad group of measures from which to pick and report on those that best reflect their process of care and the patient population served. The current list of 25 quality measures encompasses both adult and child populations and well as hospital and outpatient settings.

## Security and Privacy

- How does the registry handle patient information and other confidential data?

Practices that join the APA registry enter into an agreement with the APA, which includes a HIPAA-compliant Business Associate Agreement. Protected Health Information and identifiable provider information will be captured and stored by the APA registry in accordance with federal and state laws and regulations.

The APA registry will not publish any identifiable provider or practice data without permission. The registry will not have direct access to a patient's Protected Health Information (PHI) but rather to a limited set of de-identified data that correspond to the actual PHI. Only the provider's home institution or practice will have access to the PHI data, which they can use for their own needs and for quality reporting to CMS. To ensure confidentiality of patient information, data in the registry will be stored separately, in compliance with federal and state laws.

- Who will have access to my data?

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No one will have access to your data without your written permission. The process will be similar to that for data submission to CMS for PQRS in that each provider must sign a Data Release Consent Form allowing the registry to submit your data on your behalf. The APA registry collects, stores and reports data on a psychiatrist's behalf, taking every measure possible to safeguard it. The APA's technology partner, FIGmd, compliant with all local and federal regulations governing these areas, including HIPAA provisions and the recently updated provisions as part of the American Recovery and Reinvestment Act/Health Information Technology for Economic and Clinical Health Act.

– How will the APA use the data in the registry?

Based on the limited data set in the registry, the APA will be able to publish benchmarks that can be used to assess psychiatrists' outcomes, practice patterns and utilization of new technology to look at overall trends in outcomes for the patient population. Mental health registry data will also allow the APA to better focus its educational programming and service offerings for members.

## Cost and Requirements of Participation

– What are the costs for participating in the APA Registry?

There will be no cost for those participating in the proof of concept, pilot testing and initial scaling phase of the registry. These phases began in July 2016 and we anticipate they will conclude on Dec. 31, 2017. After this time, the value of the registry may be fully realized by capturing bonuses, fulfilling MOC part IV, and being able to better measure quality of care. APA members will continue to enjoy these benefits at no cost. To make it self-sustainable, non-members will be asked to pay a fee that will be determined based on what other specialty registries are doing at the time. For successful research grants, participants in the APA Registry and their institutions would be provided with data access at a reduced cost.

– What are the time commitments for my office staff?

The APA registry will be easy to use, timely and responsive to the needs of the profession. It is designed to require minimal input and data entry from your staff. Using an EHR, you or a staff person can expect to spend an average of 1 hour per week for about 3 weeks to assist in the installation. Following installation, there is no additional work required unless the practice's EHR software is updated.

## Enrollment

+ How do I get started?

+ What are the initial steps for me or my site to participate or join the registry?

+ Is Institutional Review Board (IRB) approval needed for participation in the registry?

● Can I join the registry and leave the registry at any time?

+ As an international psychiatrist, can I participate?

+ Do all physicians in a practice need to participate in the APA registry?

## Research

+ How can the APA registry be used for research?

### Want to volunteer for the pilot project?

APA is currently seeking member volunteers. Complete the form if you're interested in participating in the pilot project.

[Sign Up >](#)



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Chairperson Senator Lee  
Senate Human Services Committee

February 6<sup>th</sup>, 2017

SB 2241

Chairperson Senator Lee and Members of the Senate Human Services Committee:

Hello, my name is Vicki Peterson, I am a single mother of a son with Autism/Intellectual Disability and chronic health conditions. I am sending you testimony today on SB 2241, the ASD Database.

Although I am in favor of the database and to most portions of this bill; I do have an issue with the portion of confidentiality and reporters able to search and amend the database.

In this amendment to including in SB2241 it states:

**Be searchable and allow a reporter to update or amend the diagnosis or status of a previously reported case of autism spectrum disorder.**

As a parent of a child with autism and whom has already been recorded in the ASD database, I have many concerns on the fact that if this bill passes as it is written would allow a reporter to amend an already reported diagnosis of autism. Autism is a spectrum disorder, can range from very mild to severe. Autism is not always easily diagnosed and can take many months even years for a medical professional to diagnose autism. In some instances medical professionals may disagree about the diagnosis, even the tools used to make the diagnosis of autism. If a reporter is allowed to amend a diagnosis, how would a parent or the person with autism themselves know a reporter amended the diagnosis? Autism Spectrum Disorder is a lifelong disorder, it could not just go away. Could a diagnosis of autism been made and that was a mistake? Possibly but there is no blood test to prove that, no genetic test at this time to dispute that diagnosis. What happens if this child is already receiving services from an autism diagnosis and the state agencies share information, but a reporter enters the database and amends that diagnosis? Would that child loose services? Could that happen? My view on how this bill has been written, the answer would be yes. For a parent in

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search of a diagnosis for their child who they may suspect or not of having autism is very daunting, emotional, and consuming. Then possibly at the same time of a diagnosis of autism this child may be entered into a database at that time. Then to learn that the diagnosis truly could be amended, just add to the complexity of diagnosing and the confidentiality of the process. I do understand that correct diagnostics could be an issue, but this is not a way to prevent that. That should be addressed in how physicians use the tools available to them for the diagnostic procedure. Along with this seems to me there will be a real issue of confidentiality if reporters are allowed to search this database. There are many now in the state that actual can be reporters, this would be a large number of professionals in a database. In the other portions of the bill it is suggested to strengthen the confidentiality and then this portion seems to open it up again. As a parent, and someone who was selected to be part of the advisory committee that originally looked at the contents of the reporting form and who would be allowed into this software, I felt very comfortable that it would truly be 1 person at the Department of Health. I do believe that it should be the advisory committee that looks at the reasons for not reporting to the database. Could there be reasons? I would have to say there could be, religious reasons, I guess possibly. How broad would or could those reasons be? Would the database still hold the information then to gather the numbers of persons with autism in our state and how can we serve them better. I do not think however it should be left up to the reporter. A reporter could encourage someone not to be reported if they feel this database is against something they have issues with. I support that there could be reasons, but it should go to the advisory committee. I most certainly believe this database is extremely important for those with autism in our state and supported the creation of this database and continue to support the intentions of the database.

I am in favor of a fee placed upon those who do not comply with this mandate, for that reason alone this is a mandate.

I truly believe this database can help those with autism, in creating more programs designed for those with autism, increase the education on autism, look at how we could do better in the job market for those adults with autism and truly to better our communities. I would hope this database could help policy

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● makers understand how many individuals are affected by autism and their extended families.

I thank you for your work and time on SB 2241.

Vicki L Peterson

Parent



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**Testimony**  
**Senate Bill 2241**  
**Senate Human Services Committee**  
**Wednesday, February 8, 2017**  
**North Dakota Department of Health**

Good morning, Chairman Lee and members of the Senate Human Services Committee. My name is Kodi Pinks and I am the Autism Database Administrator in the Division of Children's Special Health Services, which is located in the North Dakota Department of Health (NDDoH). I am here to provide information regarding SB 2241.

The NDDoH was charged with establishing an autism spectrum disorder (ASD) database during the 2013 legislative session. An ASD expert panel that was convened in 2014 determined that language used in the original bill was too restrictive and might hinder reporting. These issues were subsequently addressed in SB 2176 during the 2015 legislative session.

The NDDoH uses the disease surveillance system known as MAVEN for several mandatory reportable conditions such as Influenza and HIV. The ASD database is a module contained within the MAVEN system and was first implemented in February 2016.

The ASD database has been progressively fine-tuned based on recommendations from an expert panel, input from mandatory reporters, public comment through the administrative rule-making process, and implementation experience to date. The NDDoH plans to convene an ASD Database Advisory Group this spring to continue engagement efforts and address changes to the ASD Report Form (SFN 60804 is available electronically on-line or as a fillable PDF at <http://www.ndhealth.gov/cshs/autism.htm>).

The NDDoH would like to provide information regarding the following sections of SB 2241:

Section 1, Part 3c – The NDDoH has concerns in this area because of issues with confidentiality, data quality, and security access and management. This section requires the database to be searchable and would allow a reporter to update or amend the diagnosis or status of a previously reported case of ASD. There are three main reasons why this section is problematic.

1. Confidentiality is a concern if mandatory reporters are allowed to access the database. First of all, there is no way to audit reasons why reporters or their

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designees are accessing an individual's information. Secondly, there is no way to monitor whether or not reporters or their designees are sharing their usernames and passwords with others.

2. The quality of the data could be affected if mandatory reporters or their designees are allowed to update or amend a diagnosis or the status of a reported case of ASD if they are not familiar or trained on how to use the database. For example, a reporter could enter information incorrectly or inconsistently, or override a previous entry.
3. Security access and management of the database is also a concern. Based on the number of licensed mandatory reporters practicing in the state, there are potentially 4,800 external users. All of these users would require a secure user name, password, and supportive services or help desk functions. However, out of the 4,800 potential users, the NDDoH estimates 912 will be active users based on the number of licensed physicians and psychologists in the state. These two professions are currently the majority of database reporters.

NDCC Chapter 23-07 also addresses reportable diseases and the collection of public health information by the NDDoH. Reportable diseases are to be disclosed only to the extent necessary to protect the health or life of an individual.

Section 1, Part 4a – This section allows a reporter to decline to provide mandatory reportable data if the reporter files an articulable rationale. By giving reporters the option of selective reporting, the integrity of the data could be compromised by reporting bias. Reporting bias is the reluctance to report based on attitudes, beliefs, and perceptions which can lead to underreporting. Another concern arises when reporters are given the opportunity to opt-out of reporting. It sets an undesirable precedent for other mandatory reportable conditions in North Dakota. Lastly, the term articulable rationale is ambiguous. Acceptable reasons for not reporting would need to be determined.

Section 1, Part 4c – Although section 23-01-41 4.c states that a provider who violates this subsection may be subject to a civil fee, not to exceed one hundred dollars per occurrence, the NDDoH is unable to determine the providers who may be violating this subsection or the number of violations that might occur.

There is a fiscal note attached to this bill totaling \$64,149. The NDDoH anticipates additional costs to allow users to access the system, ITD server costs, security

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configuration costs, and increased staff time to assist users. Estimated expenditures are as follows:

- ITD user costs for mandatory reporters to access MAVEN -  $\$1.35 \times 912 \text{ users} \times 24 \text{ months} = \$29,549$
- ITD server costs – 1 additional server at  $\$400/\text{month} \times 24 \text{ months} = \$9,600$
- Security configuration costs (e.g., estimate for user account set-up for an autism reporter group through Conduent) – 100 per hour “bucket” at  $\$130/\text{hour} = \$13,000$
- Temporary salary costs to handle “help-desk” like functions for new MAVEN users -  $\$25/\text{hour} \times 20 \text{ hours/month} \times 24 \text{ months} = \$12,000$

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

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**NDLA, S HMS - Johnson, Marne**

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Lee, Judy E.  
Sent: Wednesday, February 08, 2017 9:20 PM  
To: NDLA, S HMS - Johnson, Marne  
Subject: FW: Testimony for SB 2241

Senator Judy Lee  
1822 Brentwood Court  
West Fargo, ND 58078  
home phone: 701-282-6512  
e-mail: jlee@nd.gov

**From:** Eric and Cassandra Torstenson  
**Sent:** Wednesday, February 8, 2017 11:16 AM  
**To:** Lee, Judy E. <jlee@nd.gov>; Kilzer, Ralph L. <rkilzer@nd.gov>  
**Subject:** Testimony for SB 2241

**CAUTION:** This email originated from an outside source. Do not click links or open attachments unless you know they are safe.



mony in SUPPORT OF SB 2241

My name is Eric Torstenson. I am a parent of a child with Autism Spectrum Disorder. I would like to support a **DO PASS on SB 2241.**

We, as an autism community, support an autism database that is limited to collecting *non personally identifiable information* and are not in agreement with confidential information being shared from our children's physicians to the Department of Health. Line 18 of Senate Bill 2241 states that the records may not include personally identifiable information, as sharing of this information is a violation of HIPPA and a violation of our rights to confidentiality. This bill would not remove reporting of items such as child's age, zip code, and diagnosis.

When my child or family go to the Doctor, we are supposed to be protected by HIPPA and Patient Privacy and Confidentiality Laws. The type of information that is currently collected on our autistic children and *required* to be reported to the Department of Health violates these protections. In the current law, when a child receives an autism diagnosis the doctors are required to report personally identifiable information to the Department of Health including the child's name, address, age, zip code, place of birth, race, parents age, parents race, hospital  
h, and more.



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Further, the doctors are also **not required** to tell the parents that they are reporting personally identifiable information to the autism database and the parents **are not allowed to opt out**. I have consulted with an attorney and physicians that state that this is a violation of patient confidentiality, HIPPA, and is violates physician's rules on patient confidentiality. However, I was also informed that if a physician does not report then they are charged criminally for not reporting.

When this was further investigated on how this information would be used, it was described by the Department of Health that the Department of Health could not guarantee that they would not contact these individuals that have autism now or in the future. This further violates our children's and families HIPPA rights.

As a parent to a child with autism, I ask that you DO PASS SB 2241.

*[Faint, illegible text]*

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Attachment #1 pg1



**Autism Spectrum Disorder Report**  
North Dakota Department of Health (NDDoH)  
Children's Special Health Services (CSHS)  
SFN 60804 (2-2017)

Children's Special Health Services  
600 E. Boulevard Ave., Dept. 301  
Bismarck, ND 58505-0200  
701.328.4832 or 1.800.755.2714  
Fax: 701328.1645  
Website: www.ndhealth.gov/cshs/autism.htm

Instructions: Within 30 days of diagnosis, complete the form in its entirety to notify the NDDoH of any case of autism spectrum disorder (ASD) as required by NDCC 23-01-41. Submit the form electronically or use a fillable pdf version that can be printed and returned to CSHS via mail or fax.

**REGISTRATION INFORMATION**

New  Update

**INSURANCE INFORMATION**

None  Private  Medicaid  Medicare  Tricare  Other  Unknown

**INDIVIDUAL'S INFORMATION**

Name as it Appears on Birth Certificate (Last, First, MI)		Date of Birth	Sex <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Indeterminate	
Address: (Street)		City	State	Zip Code
Telephone Number	<input type="checkbox"/> Home <input type="checkbox"/> Cell	Social Security Number (Optional)		

**BIRTH INFORMATION**

Birth Weight ____ Grams -OR- ____ Lbs., ____ Oz. -OR- <input type="checkbox"/> Unknown	Mother's Age at Time of Delivery	Father's Age at Time of Delivery
Weeks of Pregnancy <input type="checkbox"/> Early Term (between 37 weeks 0 days and 38 weeks 6 days) <input type="checkbox"/> Post Term (between 42 weeks 0 days and beyond) <input type="checkbox"/> Late Term (between 41 weeks 0 days and 41 weeks 6 days) <input type="checkbox"/> Other, Specify: _____ <input type="checkbox"/> Full Term (between 39 weeks 0 days and 40 weeks 6 days) <input type="checkbox"/> Unknown		
Plurality <input type="checkbox"/> Single <input type="checkbox"/> Twin <input type="checkbox"/> Other Multiple <input type="checkbox"/> Unknown	Hispanic/Latino <input checked="" 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"/> American Indian/Native Alaskan <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> Refused <input type="checkbox"/> Black/African American <input type="checkbox"/> Asian <input type="checkbox"/> Other, Specify: _____ <input type="checkbox"/> Unknown		

**PARENT/GUARDIAN INFORMATION IF INDIVIDUAL IS UNDER THE AGE OF 18**

Name of Parent/Guardian A (Last, First, MI)		Telephone Number		
Address: (Street) <input type="checkbox"/> Same as individual's current address		City	State	Zip Code
Name of Parent/Guardian B (Last, First, MI)		Telephone Number		
Address: (Street) <input type="checkbox"/> Same as individual's current address		City	State	Zip Code

**DIAGNOSTICIAN INFORMATION (PERSON WHO MADE THE ASD DIAGNOSIS)**

Name of the Diagnostician (Last, First, MI) <input type="checkbox"/> Unknown		Degree of Diagnostician (Select One) <input type="checkbox"/> M.D. <input type="checkbox"/> D.O. <input type="checkbox"/> Psy.D. <input type="checkbox"/> Ph.D. <input type="checkbox"/> Masters		
Specialty of Diagnostician <input type="checkbox"/> Clinical Genetics <input type="checkbox"/> Internal Medicine <input type="checkbox"/> Pediatrics <input type="checkbox"/> Social Work (e.g., LICSW) <input type="checkbox"/> Counseling (e.g., LPC) <input type="checkbox"/> Neurology <input type="checkbox"/> Psychiatry <input type="checkbox"/> Other, Specify: _____ <input type="checkbox"/> Family Practice <input type="checkbox"/> Nursing (e.g., NP, CNS) <input type="checkbox"/> Psychology				
Name of Diagnostician's Practice/Facility		Diagnostician's Telephone Number		
Diagnostician's Address: (Street)		City	State	Zip Code

**DISTRIBUTION:** Submit original to CSHS. Retain a copy for your records.

INFORMATION ON PERSON SUBMITTING REPORT FORM

Relationship to Individual Being Reported into the Database <input type="checkbox"/> Diagnostician <input type="checkbox"/> Mandated Reporter <input type="checkbox"/> Reporter's Designee		Name of Person Submitting Report Form <i>if Different from Diagnostician (Last, First, MI)</i>		
Name of Reporter's Practice/Facility		Reporter's Telephone Number		
Reporter's Address: (Street)		City	State	Zip Code

DIAGNOSTIC INFORMATION

Date of Diagnosis	Age at Diagnosis ___ Yrs. <input type="checkbox"/> <12 months <input type="checkbox"/> Unknown	Age Symptoms First Noted by Anyone ___ Yrs. <input type="checkbox"/> <12 months <input type="checkbox"/> Unknown
-------------------	---	---

Diagnosis Information	Diagnosed using <b>DSM-5</b>	Diagnosed using <b>DSM-IV or DSM-IV-TR</b>	Diagnosed using <b>DSM-III or DSM-III-R</b>
	<input type="checkbox"/> Autism Spectrum Disorder (ASD)	<input type="checkbox"/> Asperger's Disorder <input type="checkbox"/> Autistic Disorder <input type="checkbox"/> Childhood Disintegrative Disorder	<input type="checkbox"/> Pervasive Developmental Disorder NOS <input type="checkbox"/> Rett Syndrome <input type="checkbox"/> Autistic Disorder <input type="checkbox"/> Infantile Autism

Diagnosed using **DSM-5**, Indicate the Levels of Support Needed For:

<b>Restricted, Repetitive Behavior Severity Levels:</b> (Choose One)	<b>Social Communication Severity Levels:</b> (Choose One)
<input type="checkbox"/> Level 3: "Requiring very substantial support"	<input type="checkbox"/> Level 3: "Requiring very substantial support"
<input type="checkbox"/> Level 2: "Requiring substantial support"	<input type="checkbox"/> Level 2: "Requiring substantial support"
<input type="checkbox"/> Level 1: "Requiring support"	<input type="checkbox"/> Level 1: "Requiring support"

Instruments/References Used (*check all that apply*)

<input type="checkbox"/> Adaptive Behavior Assessments (e.g., Vineland Adaptive Behavior Scales (VABS))	<input type="checkbox"/> Intellectual/ Cognitive Testing (e.g., Stanford-Binet Intelligence Scale (SBIS))
<input type="checkbox"/> Autism Behavior Checklist (ABC)	<input type="checkbox"/> Gilliam Aspergers Disorder Scale (GADS)
<input type="checkbox"/> Autism Diagnostic Interview-Revised (ADI-R)	<input type="checkbox"/> Gilliam Autism Rating Scale (GAR)
<input type="checkbox"/> Autism Diagnostic Observation Schedules (ADOS)	<input type="checkbox"/> Modified Checklist for Autism in Toddlers (M-CHAT)
<input type="checkbox"/> Autism Spectrum Rating Scale (ASRS)	<input type="checkbox"/> Pervasive Developmental Disorder Screening Test-II
<input type="checkbox"/> Childhood Autism Rating Scale (CARS)	<input type="checkbox"/> Social Communications Questionnaire
<input type="checkbox"/> Childhood Autism Spectrum Test (CAST)	<input type="checkbox"/> Screening Tool for Autism in Two-Year Olds
<input type="checkbox"/> Clinical Impressions	<input type="checkbox"/> Social Responsiveness Scale
	<input type="checkbox"/> Other, Specify: _____

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

<b>Physical Evaluation completed</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Hearing Test Done	<input type="checkbox"/> Yes <input type="checkbox"/> No
Have Excluded Organic Causes	<input type="checkbox"/> Yes <input type="checkbox"/> No
Other, Specify: _____	<input type="checkbox"/> Yes <input type="checkbox"/> No

Co-morbidities (*check all that apply*):

<input type="checkbox"/> ADHD	<input type="checkbox"/> Fetal Alcohol Syndrome	<input type="checkbox"/> Microcephaly/Macrocephaly	<input type="checkbox"/> Seizures/Epilepsy
<input type="checkbox"/> Anxiety	<input type="checkbox"/> Fragile X Syndrome	<input type="checkbox"/> Obesity	<input type="checkbox"/> Sleep Disorders
<input type="checkbox"/> Depression/Bipolar/Mood	<input type="checkbox"/> GERD or other Gastro Conditions	<input type="checkbox"/> OCD	<input type="checkbox"/> Tic Disorders
<input type="checkbox"/> Down Syndrome	<input type="checkbox"/> Hydrocephalus	<input type="checkbox"/> ODD	<input type="checkbox"/> Tuberous Sclerosis
<input type="checkbox"/> Feeding/Eating Disorders	<input type="checkbox"/> Intellectual disability	<input type="checkbox"/> Schizophrenia	<input type="checkbox"/> Other, Specify _____

What State Services Have Been Utilized

<input type="checkbox"/> ASD Medicaid Waiver	<input type="checkbox"/> HCBS/DD Waiver	<input type="checkbox"/> Unknown	Age When Services First Started ___ Yrs. <input type="checkbox"/> <12 months <input type="checkbox"/> Unknown
<input type="checkbox"/> ASD Services Voucher Program	<input type="checkbox"/> Early Intervention	<input type="checkbox"/> None	

If **None**, Why Not

<input type="checkbox"/> Aged out before services could be utilized	<input type="checkbox"/> Didn't qualify for services	<input type="checkbox"/> Other, Specify: _____
<input type="checkbox"/> Didn't know about available services	<input type="checkbox"/> Didn't need services	

Have Any Siblings Been Diagnosed with Autism? <input type="checkbox"/> Yes <input type="checkbox"/> No If so, how many: _____	<b>EACH SIBLING WITH AUTISM SPECTRUM DISORDER DIAGNOSIS SHOULD BE REGISTERED ON A SEPARATE FORM</b>
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