

North Dakota Department of Health (NDDoH) Response to Questions from Mandatory Reporters 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

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?

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

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

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.

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/.

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)?

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/.

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

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

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.