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North Dakota State Board of Psychologist Examiners

PO Box 1338

Bismarck, ND 58502-1338

CC: Doug Burgum, Governor of North Dakota

CC: North Dakota Department of Health

Dear Board Members:

This is an open letter to express ethical and legal concerns that I have about the North Dakota Autism Spectrum Disorder Database.

I was pleased to receive my license to practice as a psychologist in North Dakota. I have appreciated the support and assistance from the board in this process, and I am excited to help residents of North Dakota access mental health care, especially at a time when need for services is particularly high.

My concerns with the North Dakota ASD Database come from my commitment to the American Psychological Association Ethics code. Pursuant to APA ethical code 1.02, Conflicts between Ethics and Law, "If psychologists' ethical responsibilities conflict with law, regulations, or other governing legal authority, psychologists clarify the nature of the conflict, make known their commitment to the Ethics Code, and take reasonable steps to resolve the conflict consistent with the General Principles and Ethical Standards of the Ethics Code. *Under no circumstances may this standard be used to justify or defend violating human rights.*" (Emphasis mine)

According to the North Dakota Department of Health, the state of North Dakota established the North Dakota Autism Spectrum Disorder (ASD) Database in 2013, which requires a psychologist who has diagnosed ASD to complete an extensive form including contact and personal information about the client and provide this information to the database. I have serious ethical

concerns about this law and do not feel that I could comply with this law while remaining in compliance with my ethics code for the following reasons.

According to the American Psychological Association Ethical Principles of Psychologists Code of Conduct, Section 4.01, Maintaining Confidentiality, “Psychologists have a primary obligation and take reasonable precautions to protect confidential information obtained through or stored in any medium.” As such, requiring psychologists to disclose four pages of personal and identifying information directly conflicts with our commitment to confidentiality for our clients. Although information in the database is not freely available to the public, I am still passing on identifying client information to a third party without my client’s consent. I am not permitted to disclose client information to other members of their own treatment team without consent under the Health Insurance Portability and Accountability Act (HIPAA).

The APA Ethical Principles, Section 8.02, Informed Consent to Research, requires that human research participants must be given information about “their right to decline to participate and to withdraw from the research once participation has begun.” Because the Database is mandatory and does not allow autistic people to withdraw from their use in research, the Database is in direct violation of this principle. The Database requiring that psychologists submit this information even if the client cannot be informed also violates this principle as well as APA Ethics Code Section 4.02: Discussing the Limits of Confidentiality.

Furthermore, the International Covenant on Civil and Political Rights states, “no one shall be subjected without his free consent to medical or scientific experimentation.” As such, mandating that autistic residents of North Dakota be included in research without their consent is a violation of international human rights law.

The North Dakota Health Department states that they want this information for the following purposes: “Inform policy decisions; Improve community awareness; Assist in the identification of risk factors; [and] Improve services and support for people with ASD.” These goals could be reached by allowing interested autistic residents to opt into a database or participate in research with full informed consent.

I urge the Health Department (copied on this letter) to consult the Autism Self-Advocacy Network and speak with autistic advocates about appropriate research methods for this population. I urge Governor Doug Burgum (copied on this letter) to address this with the state legislature and appeal this law. I urge the Board to lobby with the state government to repeal this unethical law, which prevents North Dakota psychologists from evaluating for autism while staying in compliance with the APA ethics code, federal privacy laws, and international law regarding human subjects in research.

Thank you for your time. I trust that the Board’s commitment to the APA ethics code will inform their decisions regarding the concerns raised in this letter.

Respectfully,

A handwritten signature in black ink, reading "Amy L. Marschall Psy.D." The signature is written in a cursive style with a large initial "A" and "M".

Amy L. Marschall, Psy.D.