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House Committee On Judiciary
82nd Oregon Legislative Assembly
900 Court St. NE, H-276
Salem, Oregon 97301

February 13, 2024

OPPOSITION TO HOUSE BILL 4088

Dear Honorable Members of the House Committee On Judiciary:

The National Council on Severe Autism represents the interests of families affected by severe forms of autism and related disorders. We have reviewed House Bill 4088, a proposal that may result in vulnerable persons with developmental disabilities being charged with felony assault while seeking treatment in a hospital. We join the Oregon Developmental Disabilities Coalition, Disability Rights Oregon, and other disability advocacy groups in opposition.

First, we share the sponsors' concerns for the health and welfare of hospital staff. Individuals with severe forms of autism require emergency department visits and hospitalizations at a much higher rate than the general public. Thus, we appreciate their devoted service and agree they deserve a work environment free from intentional assaults. We disagree that criminalizing disability will keep hospital staff safe. The criminalization and incarceration of people with intellectual and developmental disabilities (IDD), such as severe or profound autism, is not the answer.

Challenging behaviors such as aggression, self-injury, elopement, property destruction, and PICA are common symptoms of IDD, autism spectrum disorder (ASD), and other related conditions. Thousands of research publications over decades confirm these as symptoms of disability in many developmental conditions. A 2019 study published in the *Journal of Behavioral Education* performed a systemic review of many studies to analyze the prevalence of challenging behaviors and concluded that the overall prevalence of challenging behaviors in people with IDD was 48% to 60%.ⁱ Some genetic identifiers associated with ASD, such as Fragile X, Prader-Willi Syndrome, and SynGAP1 regularly show prevalence rates of 80% or higher for challenging behaviors.^{ii,iii,iv}

The likelihood of someone with severe or profound autism, IDD, or related disorders comprehending the nature of law or even the consequences of his/her actions is exceptionally low. The manifestations of challenging behavior symptoms are typically impulsive, driven by sensory overload, an inability to regulate emotions, in response to underlying pain, or a myriad of reasons, due to no fault of the individual experiencing these symptoms.^v Therefore, a law like this can have no deterrent effect, nor from a legal standpoint can it address the near complete lack of *mens rea* in these individuals.

Though HB4088 does make exception for intellectual or developmental disabilities in subsection 3, it is too narrow. We urge the legislature to apply this exception to the entire bill, as we strongly oppose the criminalization of involuntary symptoms of disability.

We agree that hospital staff are often woefully unequipped and undertrained to manage these complex conditions. Both hospital staff and people with IDD / ASD suffer the consequences of this. Hence, we advocate for the creation of specialized units that can meet the needs of this special population. Moreover, we encourage hospitals to adopt the ER IDD Stabilization Protocols endorsed by the Center for START Services.^{vi} These protocols serve as proactive measures to help reduce and prevent challenging behaviors in hospital settings. Enhanced support for family caregivers, stabilizing the workforce with higher Direct Support Professional wages, and ensuring a full continuum of care also will help to reduce hospital encounters with this special population.

We all want to keep people with autism and hospital staff safe, but incarcerating people for symptoms of disability is unproductive, immoral, unethical, and frankly un-American. Daily, countless family caregivers across the nation manage these complex and often dangerous symptoms on their own without appropriate support. When they seek help from a hospital for symptoms that are beyond what they can manage alone, they must be able to receive help from trained professionals. Improving access to quality specialized healthcare delivery systems for this special population is the solution, not criminalization.

Very truly yours,

A handwritten signature in black ink that reads "Jackie Kancir". The signature is written in a cursive, flowing style.

Jackie Kancir

Policy Director

ⁱ Simó-Pinatella, D., Mumbardó-Adam, C., Alomar-Kurz, E. *et al.* Prevalence of Challenging Behaviors Exhibited by Children with Disabilities: Mapping the Literature. *J Behav Educ* 28, 323–343 (2019). <https://doi.org/10.1007/s10864-019-09326-9>

ⁱⁱ Simó-Pinatella, D., Mumbardó-Adam, C., Alomar-Kurz, E. *et al.* Prevalence of Challenging Behaviors Exhibited by Children with Disabilities: Mapping the Literature. *J Behav Educ* 28, 323–343 (2019). <https://doi.org/10.1007/s10864-019-09326-9>

ⁱⁱⁱ Schwartz, L., Caixàs, A., Dimitropoulos, A. *et al.* Behavioral features in Prader-Willi syndrome (PWS): consensus paper from the International PWS Clinical Trial Consortium. *J Neurodevelop Disord* 13, 25 (2021). <https://doi.org/10.1186/s11689-021-09373-2>

^{iv} Frazier, T. W., Busch, R. M., Klaas, P., Lachlan, K., Jeste, S., Kolevzon, A., Loth, E., Harris, J., Speer, L., Pepper, T., Anthony, K., Graglia, J. M., Delagrammatikas, C., Bedrosian-Sermone, S., Beekhuizen, J., Smith-Hicks, C., Sahin, M., Eng, C., Hardan, A. Y., & Uljarević, M. (2023). Development of informant-report neurobehavioral survey scales for PTEN hamartoma tumor syndrome and related neurodevelopmental genetic syndromes. *American Journal of Medical Genetics Part A*, 191A: 1741–1757. <https://doi.org/10.1002/ajmg.a.63195>

^v https://sparkforautism.org/discover_article/severe-behavior-autism/

^{vi} <https://centerforstartservices.org/sites/default/files/media/2023-02/er-idd-stabilization-protocol.pdf>

ER - IDD STABILIZATION PROTOCOL

CARING FOR PATIENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

DO	DON'T
Talk directly to the patient, using a soothing, calm voice tone	Talk around or over patients or talk about the “problem” or what happened in front of the person if it is re-escalating the crisis.
If limited verbal ability – ask how the patient communicates (device, ASL, writing, etc.)	Assume paid caregivers know them well - explore who is the best informant
Use their family member/caregiver as a resource	Miss the value in what patients have to say or are displaying
Actively listen and validate their concerns	Assume the patient will report concerns independently
Explain why you are recommending a medication, treatment, test in a way the patient can understand (may help to demonstrate what will occur on someone else)	Have the expectation that the patient trusts you – some individuals may respond negatively to doctors/hospitals/medical equipment (consider how you can minimize this component-ask the person or caregiver, see environmental considerations below)
Ask a lot of exploratory questions using plain language beyond yes/no answers, ask to elaborate in their own words, and check for understanding of the question	Assume everyone with a particular disability has the same needs - understand how it impacts each person individually
Build rapport and trust with the patient and caregiver for greater insight/disclosure	Focus solely on reducing/resolving the primary symptom – instead, work to identify what it is a symptom of
Take a whole person approach to evaluate contributing factors (medical or medication issues, mental health, social/meaningful relationship and engagement, environmental, recent stressors, trauma history, etc.)	Assume a presenting symptom is normal for them – ask!
Practice patience and kindness at all times, both the patient and caregivers may be in crisis	Avoid approaching the patient from the front which may cause anxiety and fight/flight
Explore baseline information – what is typical for the person, when was the last time they were doing well, how they typically respond to specific treatments, touch, possible challenges, increased frequency or stress, loss of skills, change in function, etc.	Assume the presenting symptoms are related to their IDD – evaluate missed underlying medical causes (constipation, UTI, dental, pain, med side effects, etc.) or mental health causes (depression, anxiety, etc. is more prevalent and under-treated in individuals with IDD)
Approach the patient calmly and from the side during physical exam and describe what you are doing	Ignore sensory sensitivities
Talk with them about their interests to briefly distract if needed during a procedure	Try to rush through your evaluation and treatment, if safe; it may escalate the patient
Ask if the person has a legal guardian/conservator that needs to be included in treatment decisions. The person may not have a conservator and be a competent adult able to make their own treatment decisions. In either scenario, they should be properly informed of their options.	Assume the person is unable to understand or participate in treatment options or provide assent or consent.

ENVIRONMENTAL CONSIDERATIONS

- Train all direct-care staff on how to communicate with people with IDD calmly without anger or reprimand and seek to understand what is causing their distress.
- Have sensory/calming items available such as stress balls, fidgets, noise cancelling headphones
- Make efforts to reduce sensory or other known triggers –
 - **Visual** - flickering, fluorescent lighting, bright contrasting colors (pastels/pale colors are more calming), a lot of items in the room
 - **Audio** - loud or unexpected sounds, loud TVs or music, humming mechanical noises, warn of any procedural sounds (e.g. blood pressure cuff deflating), repetitive noises
 - **Tactile** -light or firm touch, scratchy clothing, certain materials (latex, cotton, etc.), food and medication textures, tastes (strong, bitter, sour)
 - **Scents** – avoid strong scents (air fresheners, perfumes, ammonia, alcohol)
 - **IDEAL:** have a calm, low-sensory room available when needed
 - Ask about other known triggers (e.g. white lab coats, specific medical equipment, etc.)
- Understand that waiting may prove difficult for the patient. Communicate wait times and ask what would be helpful for them to reduce distress.

ADDITIONAL RESOURCES:

- TN START Assessment & Stabilization Teams | Contact Trey King: **615-440-3188** or trey.king@tn.gov
Statewide resource for individuals with IDD who have complex behavioral or mental health needs. Provides prevention and stabilization through 24/7 crisis response, stabilization planning, training and education, consultation, and formalized partnerships. IDD Training available for staff. Find out more: tn.gov/didd/ast
- Center for START Services Prescribing Guidelines for individuals with IDD and co-occurring mental health needs. Find out more here: centerforstartservices.org/IDD-MH-Prescribing-Guidelines