

LAURA KELLY, Governor • KATHY KECK, Chairperson • SARA HART WEIR, Executive Director

## "To empower individuals with I/DD and their families to lead systems change, build capacity, and advocate for inclusive, integrated, accessible communities where everyone belongs and thrives."

## Kansas Senate Committee on Public Health and Welfare March 20, 2023 Testimony in Favor of SB 287

Dear Chairwoman Beverly Gossage and other members of the Committee:

Thank you for the opportunity to provide testimony regarding Senate Bill (SB) 287, a bill to add developmental disabilities, including Autism Spectrum Disorder, to the Kansas silver alert plan.

My name is Kathy Keck - I wear three important hats today - I am a mother from Wakarusa, Kansas of 5 children, 3 with disabilities, I am a dedicated advocate passionate about ensuring Kansas prioritizing the interests and needs of all Kansans with disabilities; and I am the Chairwoman of the Kansas Council on Developmental Disabilities (KCDD).

Due to our children's disabilities, we have to stay hypervigilant about their whereabouts at all times. While our son who is ambulatory is at most risk of wandering away, we have to be very aware of both guys. My children have communication styles not understood by unknown caretakers and both can have unwanted behavioral reactions when they become anxious and/or are not understood. Amending Senate Bill 287 would expand the current silver hair alert to include vulnerable persons with developmental disabilities, including those with Autism Spectrum Disorder who are over the age of 18 will give Kansas families a much needed peace of mind should the unthinkable event occur.

Currently, the system works by establishing public notice that disseminates information regarding a missing elderly person who may have dementia. The public notice allows state-wide coordination with all relevant departments within the state to work together to find the missing elderly. It relies on working with local law enforcement, news media, and the public to provide information on the missing elderly with the goal of locating the person before serious harm.

Research shows that individuals with Autism tend to 'wander' similar to individuals with Alzheimer's or Dementia<sup>[1]</sup>. The term "wander" is used to describe the act of moving without a specific destination or clear purpose, indicating a lack of self-awareness on the part of the person. The Centers for Disease Control and Prevention reports that one in 44 children have autism spectrum disorder and that more than half, or about 60%, were reported to wander<sup>[2]</sup>. Over a five-year period, a third of those with Autism who did wander ended up in harm's way and needed serious medical intervention or, sadly, died. This is often due to individuals being

drawn to water or areas of high traffic<sup>[3]</sup>. Therefore, it is critical that individuals with Autism be included in the emergency response system.

We look forward to working with Kansas to make this necessary change. Thank you for considering the testimony of the KCDD and my family as this bill moves forward.

If you have any questions, please contact Kathy Keck at <u>kappylight@gmail.com</u>.

<sup>&</sup>lt;sup>[1]</sup> Solomon, Olga, and Mary C. Lawlor. "Beyond V40.31: Narrative phenomenology of wandering in autism and dementia." *Culture, medicine and psychiatry 42*, no. 2 (2018): 206. https://doi.org/10.1007/s11013-017-9562-7. <sup>[2]</sup> Centers for Disease Control and Prevention. "Disability and Safety: Information on Wandering (Elopement)." 2019.https://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html.

<sup>&</sup>lt;sup>[3]</sup> McIlwain, Lori, and Wendy Fournier. "Mortality & Risk In ASD Wandering/Elopement 2011-2016". *National Autism Association (2017)*.

https://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf