

## Written Testimony of Sam Silvey, President of Autism Society--The Heartland Submitted to Kansas Senate Committee on Public Health and Welfare

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Autism Society-The Heartland (ASH) is the state affiliate of <u>Autism Society of</u> <u>America</u> for Kansas and Missouri. At ASH we are focusing on the whole person and the family. We are creating opportunities for training, self-advocacy, and support. We create connections, empowering everyone in the Autism community with the resources needed to live fully. Dear Chairwoman Beverly Gossage and other members of the Committee,

Thank you for the opportunity to submit written testimony regarding SB 287, a bill to add developmental disabilities, including Autism Spectrum Disorder, to the Kansas silver alert plan.

Senate Bill 287 amends the pre-existing Kansas silver alert plan to include vulnerable persons including those with a developmental disabilities, such as Autism Spectrum Disorder who are age 18 and up. 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>.

Less than three weeks ago, my own son, Brooks, whom is on the autism spectrum, wandered out of our house without our knowledge. We have guardian locks on all of our external doors, but one did not get latched after his older brother came in. While I was in the restroom, he let himself out of the house and climbed into an unlocked car trunk. He pulled it down enough to make it appear closed, so in a panic, we did not notice it was ajar and split up running the neighborhood in opposite directions. After three to five minutes (that felt like an eternity) we realized he was happily watching his Ipad in the trunk. Tears of relief and joy for us, and just a huge smile on our non-verbal son's face. We are lucky. But not all are so lucky. When there are systems in place to help when this unfortunate situation occurs, it can be literal life-saving. Our son is ten, so still young for this specific bill's request, but neurotypical ten year olds would likely not wander like our Brooksie. So, do I think it could continue until he's 12, 18, 25 and

<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>&</sup>lt;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

beyond? I do. That is why 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 as this bill moves forward. If you have any questions, please contact *me, Sam Silvey, at ashofficemgr15@gmail.com or 816.737.5353.*