

Virtual Testimony of

Autism Society of America and Autism Society - The Heartland Submitted to Kansas Senate Committee on Public Health and Welfare

February 5, 2024

Autism Society of America
6110 Executive Boulevard, Suite 305
Rockville, Maryland 20852
1 (800) 328-8476

Autism Society- The Heartland 12600 Quivira Rd. Regnier Hall, Suite 270A Overland Park, KS 66213 913-706-0042 Dear Chairwoman Beverly Gossage and other members of the Committee,

Thank you for the opportunity to submit written testimony regarding SB 371, a bill to add intellectual disabilities to the Kansas Silver Alert plan.

The Autism Society of America is the nation's oldest and largest grassroots organization representing individuals on the Autism spectrum and their families. The Autism Society envisions a world where individuals and families living with Autism can maximize their quality of life, are treated with the highest level of dignity, and live in a society where their talents and skills are appreciated and valued. Along with our 70+ affiliates nationwide, we provide advocacy, education, information and referral, support, and community engagement opportunities at national, state, and local levels. Our Kansas affiliate, Autism Society- The Heartland has served Kansas since 2009 by offering grants and scholarships, information and referral services, educational workshops, social and support groups.

Senate Bill 371 amends the pre-existing Kansas Silver Alert plan to include vulnerable persons including those with intellectual disabilities who are age 18 and older. Kansas statute defines an intellectual disability as one with "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior". Currently, the system works by establishing a 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 person. 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, including those who may also be intellectually disabled, tend to 'wander' similar to individuals with Alzheimer's or Dementia¹. 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 36 children have autism spectrum disorder and that more than half were reported to wander². 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.

¹ 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.

² Centers for Disease Control and Prevention. "Disability and Safety: Information on Wandering (Elopement)." 2019. https://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html.

This is often due to individuals being drawn to water or areas of high traffic³. Therefore, it is critical that individuals with intellectual disabilities be included in the emergency response system.

Our research shows that 30 states have expanded their missing alert system to include people with Autism. States that have done so in the Midwest or Western region include <u>lowa</u>, <u>Texas</u>, <u>Colorado</u>, and <u>New Mexico</u>. We are also glad to see how strong Kansas's current <u>protocol</u> and <u>enforcement</u> for the Silver Alert system is. The alert prioritizes self-determination and ensures the individual wants to be reunited with the party submitting the alert, to limit the risk of abuse.

We look forward to working with Kansas to make this necessary change. Thank you for considering the testimony of the Autism Society of America as this bill moves forward. If you have any questions, please contact Delancy Allred, State Policy Coordinator at dallred@autism-society.org.

³ 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