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To: Senator Vicki Schmidt and Members of the Senate Health and Welfare Committee

From: Colin McKenney, CEO, Starkey, Inc.

Re: Support for SB 332

The Kansas Developmental Disabilities Reform Act of 1995 was something of a masterpiece when it was passed nearly unanimously by our legislature almost 23 years ago. Routinely for the next ten years or so following its passage, stakeholders of intellectual disability services from across the country would marvel that Kansas could be so progressive as to commit to law the belief that individuals with disabilities should be served in their home communities, and not in an institution or facility in another part of the state, away from their families and familiar surroundings.

As other parts of our country came to that same realization and it became more generally accepted that individuals with disabilities belong in communities and not facilities, much of the amazement about the DD Reform Act subsided. Even in Kansas we began to realize that the ambitious policy statement of the mid-1990s no longer seemed so ambitious, and portions of the Act now reflect a reality that has changed substantially over the past two decades.

Make no mistake, SB332 has two leading components that reflect urgent needs for our state:

- **I/DD Services Do Not Belong in KanCare** -- Support services required by Kansans to live successfully each day cannot be watered down by applying the actuarial assumptions of insurance companies with the hope of finding a way to only assist someone five days a week instead of seven, or 20 hours out of the day instead of 24.
- **The Act is Just Words on Paper Without Appropriate Resources** – Enduring nine years with only funding cuts and no rate increases negatively affected the lives of Kansans. Those lives certainly include people with developmental disabilities, but also the amazing individuals who dedicate their lives to providing care, family members, employers, and so many others whose lives are affected by the availability of quality disability-support services.

Information provided by state officials indicates that tens of millions of administrative dollars are paid to the managed care companies related to I/DD services. It would appear that removing these services from KanCare and repurposing those administrative dollars to fund needed services may go hand in

hand. I will stop short of quoting those figures, as it has been suggested that the numbers are not what they appear to be. Perhaps you, as our elected leaders, could gain more insight than we have been able to related to the actual dollars paid to MCOs for administrative costs of I/DD services.

Beyond those two key issues, much has changed for Kansans with disabilities since 1995, and so it seems appropriate to also update the law that speaks to community-based services and better reflect our current reality. That effort has led to some concern about the need for other amendments, with some suggesting that the language has been basically the same since 1995, so why change it? The lack of recognition that the world and our state have changed pretty significantly over the past two decades may mean that we haven't done a very good job of communicating how things are so different today.

Prior to 1995, organizations like the one I work for were primarily tasked with helping people pursue their goals, earn a paycheck and be an active part of their community. They had been diagnosed at some point with a disability they were born with or that had occurred during their developmental years, but they most typically didn't need daily medical care, didn't require complex combinations of medications, weren't dependent upon others for personal hygiene care, and certainly didn't require specialized programs to minimize the chances they would harm themselves or others.

Those types of support needs are now common, and some of them are very common. Nearly all of our employees are required to attend multiple days of training to learn how to minimize the occurrences of violent, aggressive and destructive behaviors. Those same employees must learn how to administer the countless medications that the population we now serve requires, provide them nutrition through feeding tubes if needed, use lift systems, and meet their most personal daily needs.

If we could go back in time and describe the range of vital functions our direct support professionals would be responsible for in the year 2018, do you think the authors of the DD Reform Act would have crafted the vision the same way? Do you think they would have predicted that judges would have issued rulings to indicate that people would either have to enter our services or receive lengthy sentences in prison for the offenses they had committed? That state hospital representatives would indicate that they don't have the necessary facilities to address someone's aggressive or destructive behaviors, so the next-best option would be for a community service provider to attempt to do so? Or that a waiting list for services would grow to include nearly 4,000 people, and aside from a small handful of individuals who are funded from that list, the primary way to receive needed services is if you are at imminent risk of harm or of harming others?

As I mentioned, carving these services out of KanCare and also funding them appropriately are the key goals that we hope you will embrace from SB332. I do believe that this Act should reflect the world we now live in, and the population of individuals we are called upon to serve. It may take more time and discussion to update the Act in a way that makes sense to all who want great outcomes for Kansans with disabilities, but the effort will no doubt bring benefit to those who need these services the most.

Thank you for your consideration of this vital legislation, and the tens of thousands of Kansans whose lives will improve when it becomes law.