

For SB 348:

Carolyn McGinn, Chair and Members of the Senate Ways and Means Committee

Thank you for the opportunity to share our thoughts regarding both community service providers' long-term capacity to meet the ever-increasingly complex needs of Kansans with intellectual and developmental disabilities (I/DD) and our daily struggle to address today's demands. We need your support for SB 348.

I am Cottonwood Inc.'s Residential Director. Since 1994, I have overseen the licensed residential services provided in over 50 locations throughout Lawrence. We have experienced many feast and famine cycles in those 26 years, coming through the hard times thriving and continuously improving in spite of stagnant reimbursement rates.

Cottonwood has long invested in scheduling sufficient Direct Support Professionals (DSPs) to partner with persons served to fully engage with their community rather than just meeting minimum care requirements (this was done even when funding fell far behind the staffing expense). We made sure everyone had the opportunity to pursue individually meaningful relationships and activities. People served didn't just get by, they grew in experience and diversity. This was a sustainable model when unemployment rates were high. That is not our reality today.

We are barely keeping our collective head above water in a perfect storm of years' long underfunding, attempting to serve individuals with critical needs (both behavioral and health-related, particularly as individuals age), and an increasingly desperate competition for qualified applicants when we cannot even come close to paying wages high enough to compete with every other business out there seeking front line workers.

Instead of two staff working during waking hours to allow for individuals' wishes to be fulfilled, often there is one DSP scrambling to meet the needs of multiple people. The residential service parameters have shrunk from expansive, "living your best life" abundance to a narrow essential health and safety focus. Ensuring even this lessened staff support level is a daily struggle. Rather than having a consistent staff person working a regular schedule, many shifts are patched together with willing but unfamiliar DSPs who do the best they can but do not know the people they are supporting in a deep, mutual, therapeutic degree. Persons served are affected by the uncertainty, experiencing increased anxiety and decreased confidence that their valued rituals, routines, and preferences will be preserved. Their unrest is exhibited in countless ways- agitation, aggression, refusal of medication, sadness, insecurity...the list goes on and on.

The diminished employee pool coupled with the increased work load poses a real risk to the safety of persons served and DSPs. One DSP being responsible for administering medication as well as trying to respond to people's various needs in real time is more likely to make a mistake, which could be harmful for the person served. The lack of a second DSP prohibits inviting a person who is in the escalation cycle to take a walk or a ride to separate from housemates, thus minimizing the risk to others. A skilled, dedicated DSP who has worked many overtime hours to help fill service gaps may be exhausted and at the end of her rope, reacting uncharacteristically impatiently to a person with challenging behavior.

I raised my hand to volunteer to submit this testimony on behalf of Cottonwood at the end of a week that I wish I could say was unusual, but sadly it is not. Here are some of the highlights from it:

Cathy, a 69-year-old woman with moderate I/DD and diabetes, has a neurotropic corneal ulcer in her left eye. In spite of administering multiple prescription eyedrops 24 hours/day (even during sleep hours), the ophthalmologist determined it is non-healing. Her vision is threatened. The ophthalmologist worked with a pharmaceutical company to supply the only FDA-approved treatment for this condition. As she was to begin this regimen, she was hospitalized for lower-extremity edema. After nearly a week in the hospital, testing shows masses on her liver and bile duct in locations that are challenging to biopsy. She was discharged on a Friday (heading into the weekend where there will be limited support available to the residential direct support staff caring for her) with follow up to occur with specialists soon. The eyedrop regimen continues (19 daily doses spaced out over 12 hours- this is in addition to different eyedrops administered to both eyes for other conditions). Her residential DSPs will do their very best to provide the needed care to Cathy and her four housemates. Two out of the 12 DSP positions at this house are vacant.

Mat, a 32-year-old man with severe I/DD, cerebral palsy, and a seizure disorder requires 100% support with mobility. He spends his days either in his costly, specialized wheelchair or a recliner. Mat is vulnerable to skin breakdown and pressure sores. His dedicated DSPs both at home and in day services scrupulously help him re-position throughout the day and monitor his skin for warning signs. Mat still develops open wounds. He is currently being treated for one on his ankle. Mat is one of Cathy's housemates, who you met above. The same DSPs strive to meet Mat's complicated needs as well as hers (the remaining three housemates have severe I/DD, one is also prone to pressure sores due to her non-weight bearing status, another has seizures, and the third needs significant mealtime support).

TJ, a 34-year-old woman with a congenital brain disorder, quadriplegia, and mild I/DD also has Post-Traumatic Stress Disorder (caused by childhood trauma) and major depressive disorder. She can escalate from calm to attacking others with little warning, using her wheelchair as a weapon. The episodes are unpredictable and high intensity. She has injured her DSPs and three housemates. Two of the three housemates are actively seeking new homes, which further stresses the household and increases the likelihood of additional aggression. DSPs who have been attacked (some repeatedly) no longer have the resilience to work closely with her. Knowledge of the aggression has spread and the few available DSPs looking for extra shifts will fill in there only reluctantly. TJ, her housemates, and the DSPs who work there are in a setting fraught with worry, trepidation, and potential harm. Two out of six DSP positions at her house are vacant. A third hangs in the balance, this particular DSP having been attacked multiple times. While she is taking a break from this house for a time, we are not sure it will be in her best interest to return. She has worked with these women for many years- the loss of her knowledge of and insight into the women living there will be great.

Nicole, a 42-year-old woman with Smith-Magenis Syndrome (SMS), moderate I/DD, and severe scoliosis displays challenging behavior multiple times a day, every day. People with SMS are argumentative, possessive, do not recognize personal boundaries, seek unwavering attention, become aggressive when the attention is divided, and are most successful in highly structured settings with consistent staff responses to questions and behaviors. After a disastrous attempt to serve Nicole in a group home (resulting in harm to housemates and DSPs), Cottonwood committed to serve Nicole one-on-one in a privately-leased setting. Housemates' safety is no longer a factor, but the sole DSP on duty is the constant focus of Nicole's attention and frequent target of her aggression. ***There are 4 DSP positions assigned to Nicole's site. All 4 are vacant.*** She is served solely by an ever-changing roster of substitute DSPs which almost guarantees that she will not experience the structure and consistency that best supports her. It is understandable that staff would rather work in a setting where potential harm and constant stress are less likely. It is Friday noon when I started working on this testimony. We do not know at this time who will care for Nicole throughout the weekend.

I've had the privilege to submit testimony to legislative committees in the past. I thought at those times that the I/DD service system was under-supported and the quality of life for Kansans with I/DD was at risk. From this vantage point, those times are looking pretty good by comparison.

I know that SB 348 has multiple objectives, both addressing the current hiring emergency as well as building capacity to serve the hundreds of people waiting for services. I feel for these individuals and their families, but I'll leave the advocacy for serving everyone on the waiting list to others. My fear for and concern about the people I know by name and talk to daily is all I can worry about today.

Please vote yes for SB 348. At the risk of sounding melodramatic, actual lives depend upon it.