



The Perfect Storm

Across the nation a perfect storm is brewing. Waiting lists for services are growing exponentially, driven by increases in autism and I/DD populations, baby boomer retirees seeking services, and longer life expectancies (e.g., Larson et al., 2018). Labor costs are high and rising at an unprecedented rate, fueled by historically low unemployment, a dramatically shrinking direct care workforce, and increases in both minimum wage and insurance costs (President's Committee for People with Intellectual Disabilities, 2018). Despite the growth in need and expense, funding for services adjusted for inflation is in decline (Gerhardt, 2009).

Providers of community services are expected to provide more costly support with less money. As a result, many providers are struggling to make ends meet. Community caregiver turnover exceeds 85%, in what has become one of the lowest paid industries in the country; services are progressively truncated to stay within available funds. On the federal front, mental health funding at its current level is insecure. While KS state expenditures dedicate 75% for in-community mental health services, vs 25% for inpatient (Hamdorf & Bruffett, 2017), further cuts to an already lean KS mental health budget would detrimentally impact the system of care. Dramatic swings from state support for mental health threaten cuts for providers, creating a cloud of funding insecurity (McClean, 2016; Kite, 2018). Throughout 40 years of service, GoodLife has not achieved a break-even budget from operational funding alone. GoodLife's gap is made up through entrepreneurial services as well as fundraising for startup and capital needs.

Access to mental health services is on the decline. In 2019, the ratio of the population to mental health providers in Kansas was 530:1, a marked decrease from 470:1 in 2017 and 454:1 in 2015, as well as well below the national average of 440:1 (County Health Rankings & Roadmaps, 2019).

Perhaps the biggest barometer to the current status of the community support system is the percentage of families who have opted (due to lack of quality alternatives) to provide care themselves. The most recent data available suggest that nearly 40M Americans, 16% of the U.S. population, provide unpaid care for their aging, chronically ill, or disabled family members (National Alliance for Caregiving & American Association of Retired Persons, 2015). Moreover, over 50% of persons with I/DD are served by family members. As these caretakers age (67% of family caregivers are now over age 50), they will require aging support. (Anderson et al., 2018).

Collectively, these trends forecast the coming of a disheartening tsunami of challenges on the heels of a community service-delivery system that is already fragile. Further, community care is being outsourced by state governments to managed care entities nationally whose profits are largely based on finding savings in the care delivery system. Squeezing more value out of traditional approaches to care is not the answer. Current methods are expensive, often unstable, require people to relocate each time more care is needed, and are ineffective in promoting or maintaining independence.



A closer look at the reasons people lose their independence reveals important insights. GoodLife's research group reviewed and conducted research on the barriers to independent living and discovered variances across populations (DiGennaro Reed, Strouse, Jenkins, Price, Henley, & Hirst, 2014). Despite these differences, there is consensus that fairly independent people are often forced to move to more restrictive care settings simply because they have important needs that happen at unpredictable times. Primary barriers include personal safety concerns, medication compliance, assistance with household skills, falls, confusion, and wandering. The end result is that large populations of seniors and persons with I/DD feel compelled to trade their independence for the safety and security of more expensive care settings, due to "just in case" needs that may happen intermittently.

"We need a safe and reliable way to predict and/or detect the intermittent needs of people in their typical homes; we need help to be deployed only at the "moment of need;" we need to leverage resources among people who live in close proximity to each other; we need to offer a better way of life for community members." - Michael C. Strouse, Ph.D.

GoodLife's proposed programming presents a new model of affordable care for the next generation of need, providing a preferable and less costly solution to meet the needs of millions of semi-independent people in their own home, while leveraging billions of dollars of public funding.



References Cited

Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018) Family and Individual Needs for Disability Supports (v.2) Community Report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

County Health Rankings & Roadmaps (2019). Kansas. Retrieved from <https://www.countyhealthrankings.org/rankings/data/KS>

DiGennaro Reed, F. D., Strouse, M., Jenkins, S. R., Price, J., Henley, A. J., & Hirst, J. M. (2014). Barriers to independent living for individuals with disabilities and seniors. *Behavior Analysis in Practice, 7*, 70-77. doi:10.1007/s40617-014-0011-6

Gerhardt, P. (2009). *The current state of services for adults with autism*. Retrieved from http://www.affaa-us.org/storage/documents/OAR_NYCA_survey_Current_State_of_Services_for_Adults_with_Autism.pdf

Hamdorf, J., & Bruffett, K. M. (2017). *Understanding the mental health system in Kansas*. Retrieved from <http://www.khi.org/assets/uploads/news/14789/understanding-the-mental-health-system.pdf>

Health Resources & Services Administration Data Warehouse (n.d.). *HPSA find*. Retrieved from <https://datawarehouse.hrsa.gov/tools/analyzers/HpsaFind.aspx>

Larson, S. A., Eschenbacher, L. A., Pettingell, S., Hewitt, A., Sowers, M., Bourne, M. L., Taylor, B., & Agosta, J. (2018). In-home and residential supports for persons with intellectual or developmental disabilities: Status and trends through 2016 residential information systems project report. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

McClellan, J. (2016). Kansas budget cuts 'devastating' mental health system, providers say. *KCUR*. Retrieved from <http://kcur.org/post/kansas-budget-cuts-devastating-mental-health-system-providers-say#stream/0>

National Alliance for Caregiving. (2015). Caregiving in the U.S. Washington, DC: National Alliance for Caregiving. Retrieved from http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.

President's Committee for People with Intellectual Disabilities (2018). America's direct support workforce crisis: Effects on people with intellectual disabilities, families, communities and the U.S. economy. Washington, DC: Administration for Community Living. Retrieved from https://acl.gov/sites/default/files/.../2018.../2017%20PCPID%20Full%20Report_0.PDF