



August 7, 2023

TO: Senator Beverly Gossage and
Members of the 2023 Special Committee on IDD Waiver

FR: Matt Fletcher, Executive Director, InterHab

RE: Kansas IDD Funding Needs and Upcoming Reimbursement Review

Chair Gossage and members of the committee, thank you for the opportunity to share information regarding the challenges faced by the Kansas IDD service system due to chronic underfunding caused by irregular updates to provider reimbursement over the past several decades. I'd also like to share our membership's recommendations for what would comprise a meaningful review of costs providers incur and adequate funding levels that are needed to ensure future viability of the IDD service network.

Policy makers are faced with two ever-present challenges that threaten adequate services and supports for Kansans with intellectual and developmental disabilities (IDD). Both challenges are borne of the same root cause – a lack of strategic vision for the growth and preservation of a network that promotes positive outcomes for this vulnerable population. These two challenges include chronic underfunding that threatens the ability of the existing IDD provider network to serve the 9,000+ persons with IDD already in services, and thousands of persons with IDD who have been forced to wait for the services they need.

In 1995, the Kansas Developmental Disabilities Reform Act (KSA 39-1801 et seq.) was passed by the Legislature and signed into law by Governor Bill Graves. This law was – and continues to be – a landmark measure that seeks to develop a strong network of community-based supports for persons with IDD. Chief among the many positive tenets of the DD Reform Act is its establishment of outcomes for the network: *Independence, Inclusion, Integration, and Productivity*. Further, the statute calls for the development of “adequate and reasonable funding” for the IDD network. Unfortunately, since its passage 28 years ago, the promise of the Kansas DD Reform Act remains largely unfulfilled.

The IDD system has never had financial sustainability. First, the system relied on grants and goodwill. Then, trickles of state and federal funds. The HCBS IDD Waiver made the largest impact on the system, but subsequently was not adjusted properly to account for increasing costs of doing business. By the second decade of the twenty-first-century, IDD service providers were far behind inflation in terms of adjustments received to the HCBS IDD Waiver. Increases have come in spurts, such as in the past few years. While IDD service providers appreciate the hard-fought efforts of legislators during the past few sessions to increase funding, we can surely agree that this should not be how the future funding needs of a vital service system are determined on a year-to-year basis.

The IDD service providers need to be provided with regular funding adjustments that keep pace with rising costs they experience. They also need a sense of stability as they plan for upcoming budget cycles. IDD service providers are dependent on the State of Kansas as the sole source of funding for the services they provide. Unlike a business, they cannot raise prices to cover increased costs.

Therefore, the State must establish a mechanism by which the IDD service network receives regular, annual funding adjustments. This is not a new concept, and similar mechanisms exist for IDD service systems in other states.

Legislators need the information necessary to understand current and future IDD service network funding needs so that funding and policy decisions can be considered at regular intervals instead of allowing the system to fall years behind where it should be.

The Kansas DD Reform Act and Funding Reviews:

The Kansas Developmental Disabilities Reform Act is particularly important to this Special Committee's work, as it contains language compelling the State to conduct regular funding reviews of the IDD service system. The Act's language regarding such a review process is strong:

"39-1806. Establishment of system of funding, quality assurance and contracting. To carry out the provisions of this act, the secretary shall establish after consultation with representatives of community developmental disability organizations and affiliates thereof, and families and consumer advocates:

(a) A system of adequate and reasonable funding or reimbursement for the delivery of community services that:

(3) requires an independent, professional review of the rate structures on a biennial basis resulting in a recommendation to the legislature regarding rate adjustments. Such recommendation shall be adequate to support: (A) A system of employee compensation competitive with local conditions; (B) training and technical support to attract and retain qualified employees; (C) a quality assurance process which is responsive to consumers' needs and which maintains the standards of quality service; (D) risk management and insurance costs; and (E) program management and coordination responsibilities..."

Several studies have been performed in accordance with the above statute since the passage of the Act, but – in the opinion of InterHab's membership – have never been of much use as tools for the legislators in planning for the system's funding needs. The last study to be performed was completed in 2016 and yielded no useful outcomes.

Funding Review Recommendations:

The above statutory language clearly intended for regular reviews to be conducted to provide recommendations for rate adjustments adequate to support five elements of sustainability for the IDD provider network across a two-year time span. We recommend that:

- The review should incorporate appropriate inflationary indexes as part of its examination of service costs.
- All service-related costs should be examined.
- All five elements for review that are included in statute must be adjusted based on inflationary data.
- The review must include an examination of all services within the IDD system, not just those delivered via the HCBS IDD Waiver.
- The review should recommend – at a minimum – inflationary increases experienced during the previous fiscal year.

Reasons Why Regular Funding Adjustments are Critical - Workforce:

Capacity challenges within the IDD network are largely related to workforce needs. The IDD service network relies heavily upon the thousands of Direct Support Professionals who provide vital direct care services 24 hours a day. Direct Support Professionals are vital in ensuring that Kansans with IDD can remain out of costly state institutions. They provide support in day and residential settings, often without direct supervision, and must handle demanding tasks such as changing feeding tubes, as well as bathing and clothing people who need their assistance. These professionals perform a difficult but necessary job and deserve all the support we can give them. In many organizations, Direct Support Professionals are also required to have up to and exceeding 30 hours of training, much of which must occur within the first three months prior to the professional working independently with consumers.

The typical Direct Support Professional:

- Is female (87%)
- Is an ethnic minority (62%)
- Between the ages of 25 and 54 (58%)
- Is responsible for a dependent under the age of 18 (25%)
- Has a high school-level of education (62%)
- Has a full-time (62%) rather than a part-time (38%) position
- 17% live in a household below the federal poverty line
- 39% do not live in affordable housing
- 16% lack health insurance
- 50%+ receive some form of public assistance

Source: "Direct Care Workers in the United States: Key Facts" PHI (Paraprofessional Healthcare Institute)

"...About 45 percent of direct-care workers live in households earning below 200 percent of the federal poverty level income, making them eligible for most state and federal public assistance programs... Nearly half of all direct-care workers (46 percent) live in households that receive one or more public benefits such as food stamps; Medicaid; or housing, childcare, or energy assistance."

Source: PHI (Paraprofessional Healthcare Institute) "Who are Direct-Care Workers?" 2011

The IDD population continues to grow, which will require a workforce to match. Additionally, the State's response to federal initiatives such as the Medicaid HCBS Final Rule may require more individualized services that will greatly increase the need for workers.

Reasons Why Regular Funding Adjustments are Critical – Complex Needs:

The IDD system today is serving a population with much more complex needs than it was originally designed to serve. At the time funding for the IDD system was initially structured, persons with IDD who had significant behavioral or physical care needs often still resided within institutional settings. Further, the IDD population's life span has increased during the past 50 years to a point where it now approximates the general population, which means the IDD system now serves a significant number of persons with Alzheimer's and dementia. Serving individuals with these complex needs consumes a great deal of the IDD system's resources.

Major progress must be made in developing behavioral health resources for the IDD population. Behavioral supports can prevent behavioral episodes from occurring. Mobile crisis services can de-escalate episodes when they do occur. Regional respite services can help persons served (and their families and staff) recover after an episode occurs. And fundamental to all of the above, is a universal training that can be given to both mental health clinicians and IDD service professionals to prepare them for providing behavioral health assistance to the IDD population.

Specialized resources must also be built for persons with IDD who have high levels of physical care, or who have age-related illnesses such as Alzheimer's and dementia.

Reasons Why Regular Funding Adjustments are Critical – Increased Independence:

There is a workforce shortage in America, however, we often see those with IDD overlooked as employable. Many barriers exist in hiring someone with a disability. Although it is illegal to discriminate against those with disabilities, businesses are not always able to make accommodations. Businesses have different reasons for not being able to accommodate, but there are some methods that can be done to promote this population as employable. Financial incentives can be offered to employ those with disabilities. Campaigns can be designed to decrease stigma or increase compassion surrounding those with a disability. Both of which would have a positive effect on employment.

Most agencies already offer supportive employment and participate to some degree, but the reimbursement rates are not high enough to incentivize providers to optimize this program. Having a robust supportive employment program can give purpose, self-direction, and self-actualization to those served. Providers cannot continue to expect supportive employment direct support workers to continue to make far less than those that they help maintain a job. This dynamic results in an exodus of direct support workers.

Reasons Why Regular Funding Adjustments are Critical – Waiting List:

The State's waiting list for the HCBS IDD Waiver now totals more than 5,000 children and adults... a shameful number. We must develop a plan to end this list. However, individuals on the waiting list cannot be brought into the existing IDD service system because adequate capacity to serve them does not exist. Development of a Community Support Waiver will help develop capacity, but ultimately, the State will need to invest additional resources into the available array of service options to fully eliminate the waiting list.

Conclusion:

You and your peers have made much progress on the above IDD system issues during the past few legislative sessions. The work you engage in next in establishing a strong and consistent funding review process offers the promise of building a strong and stable foundation for Kansans with intellectual and developmental disabilities for decades to come. The members of InterHab greatly appreciate your focus on these critical funding challenges and stand ready to assist you in working to address them.

The Demand for Direct Support Professionals

The Long-Term Care Crisis

The demand for DSPs is changing. Demand for long-term services and supports (LTSS) will grow dramatically with the 65 and over population more than doubling and the 85 and over population more than tripling by 2050. In Kansas, the waiting list continues to grow for disability services, increasing the need to recruit and retain staff more than ever before.

26%
JOB GROWTH NEEDED BY 2029

What is the role of a DSP?



A **direct support professional** is a person who assists an individual with a disability or aging individuals to lead a self-directed life and contribute to the community, which encourages attitudes and behaviors that enhance community inclusion. Responsibilities include:

- Assisting individuals with daily living
- Providing assistance with basic tasks such as bathing, dressing, and eating
- Helping prepare meals, grocery shopping, and cleaning
- Teaching skills and connecting to the community
- Providing transportation

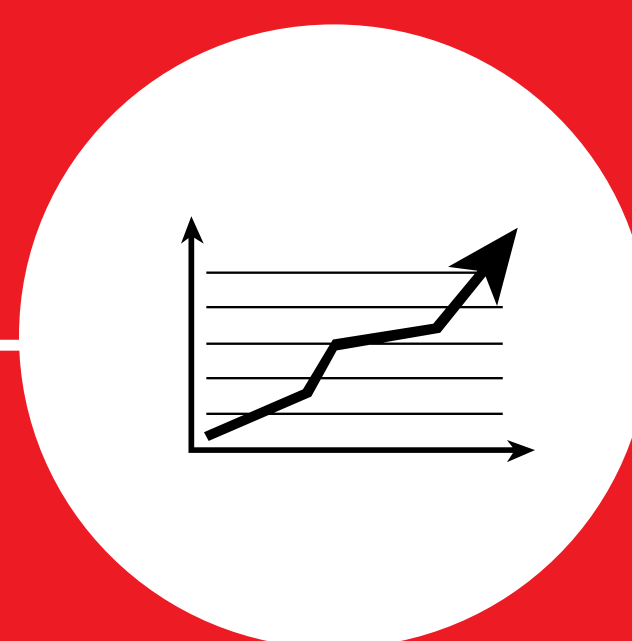
Did you know?



90%
of DSPs enjoy their job because they "make a difference"



42.6%
is the current average annual turnover rate for DSPs



26%
growth in the position and career field is expected by year 2029



20.6%
of DSPs say they are likely to leave their position to advance in opportunity in the next 1 - 2 years

Ongoing crisis

The direct support workforce is one of the highest in demand in the U.S. The expansion needed in this workforce is unlikely to take place without significant changes in how direct support professionals are recruited, trained and supported. The pipeline for people entering the Direct Support Profession is not keeping pace with the number of DSPs needed by Americans with I/DD and their families.

