HCBS Waiting List and Caregiver Survey Interim Report

IDD Waiting List

KU CENTER ON DEVELOPMENTAL DISABILITIES

STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Kansas
Department for Aging and Disability Services

CENTER for RESEARCH on AGING & DISABILITY OPTIONS
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UNIVERSITY OF KANSAS • SCHOOL OF SOCIAL WELFARE

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Introduction

The Kansas Department for Aging and Disability Services (KDADS) contracted with an interdisciplinary team, led by Dr. Evan Dean at the University of Kansas, to study the waiting lists for intellectual and developmental disability (IDD) and physical disability (PD) Home and Community Based Services (HCBS) waivers. The purpose of this report is to share interim, preliminary findings from two surveys developed to understand the experiences and needed supports people on the waiting list for the IDD HCBS waiver and their caregivers.

We stress that the results presented in this interim report are preliminary results based on 1,456 responses (764 Waiting List survey and 692 Caregiver survey) for people on the IDD waiting list received to-date. Survey data collection is still in progress, with a final goal of a sample size of 1,850. We are releasing this brief report early to help inform time-sensitive policy planning, including planning for state budget needs, workforce capacity, and designing the proposed Community Supports Waiver. However, it should be considered preliminary and non-final. Further, the newly proposed waiver was not being discussed when the HCBS Waiting List study was designed and initiated, nonetheless, our findings may help inform this new development. In releasing interim results, it is important to keep in mind that results may change as data collection is completed. Additionally, initial findings are primarily descriptive in nature and final analysis with the full sample will allow more advanced analysis that examines relationships between variables and connects survey findings to other lines of inquiry completed as part of this project.

Purpose of the Kansas Waiting List Survey

The purpose of the Kansas Waiting List survey was to understand the current and future needed supports of people on the waiting lists for the Intellectual and Developmental Disabilities (IDD) and Physical Disabilities (PD) Home and Community Based Services (HCBS) waiver services We collected data on needed supports, employment outcomes, health status, and current and preferred living situations. Our focus in this report is on interim findings for the HCBS-IDD surveys.

While we were developing the initial survey, we learned from family members and our crisis exceptions analysis that we also needed to understand the perspective of caregivers supporting people on the waiting lists. In particular, we needed to understand the amount of support provided by the caregiver, the availability of additional supports for the person, and the health, emotional wellbeing, and financial outcomes for the caregiver. We created a second survey based on the U.S. Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation's *Survey for Caregivers Supporting a Person with a Disability Outside of the Disability Support Service System* to learn more about these factors from caregivers. Survey development and analysis were guided by the following questions:

1. What do people on the IDD waiting lists identify as their needed supports for home living, community living, lifelong learning, employment, health, safety, and social

participation?

2. What are the needed supports of people on the waiting list who are (a) at risk for entering services in the next 5 years through a crisis exception, and (b) served by each CDDO (for IDD waiver)? (This analysis will be included in the final report)
3. How do employment, functional, and health outcomes differ for people on the waiting list when compared to people receiving HCBS services? (This analysis will be included in the final report)
4. What are the emotional, financial, and health impacts on caregivers providing support for the person on the waiting list?
5. What supports do caregivers receive and what supports do they need to support the person on the waiting list?

Survey Development and Analysis

To develop the surveys, we:

- Conducted a nationwide search of strategies for surveying waiting lists
- Developed the survey based on widely used, research-based tools as well as extensive input from self-advocates, caregivers, providers, and other stakeholders
- Conducted a plain language review with the Self Advocate Coalition of Kansas (SACK)
- Engaged KDADS, CDDOs, CILs, and family members to review the survey
- Conducted pilot study to ensure cognitive accessibility

Analyses for this interim report were descriptive and provide response percentages to the questions asked in the survey for the current sample. Ongoing data collection is in progress. These preliminary findings can provide initial information as part of ongoing discussions and planning for the community supports waiver and support KDADS to understand the needs of people on the waiting list.

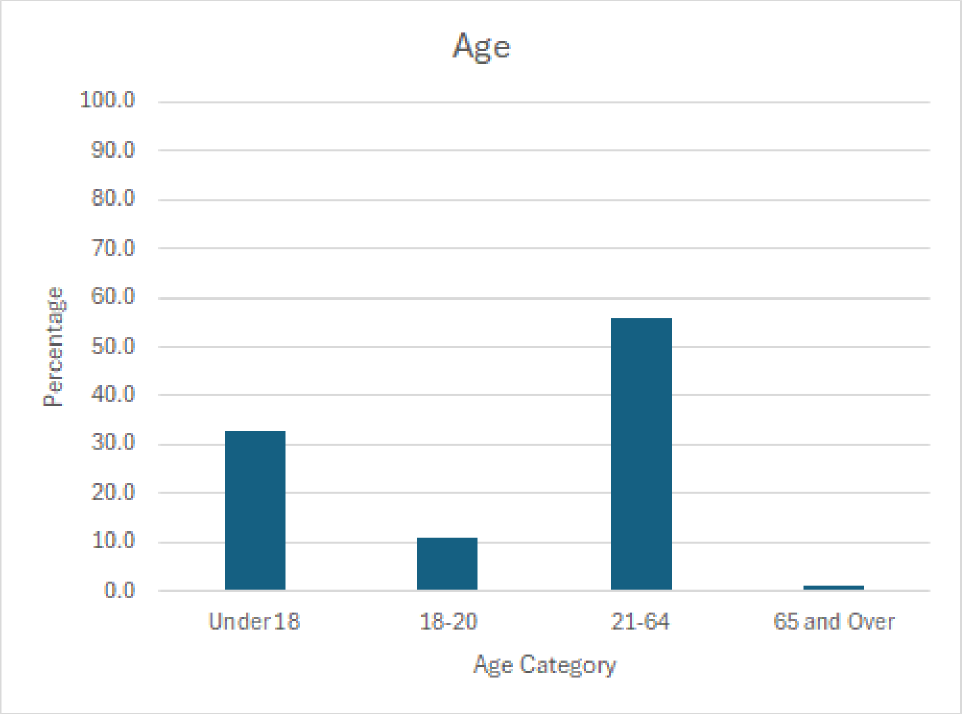
Waiting List Survey Demographics of Person on the Waiting List

As of June 6, 2024, we have collected 764 Waiting List surveys.

The majority of people on the waiting list who completed the survey were between the ages of 21 and 64.

Figure 1

Age of People on the Waiting List



55% of waiting list survey consumer respondents were women. The race of the majority of respondents was White (77%), followed by Black (7%); 6% of respondents identified as multiple races; 11% of respondents identified as Hispanic or Latino/a/x.

Support for Completing the Waiting List Survey

To ensure all people on the waiting list had access and opportunity to complete the survey, we offered the following supports:

- Survey was available in Spanish
- Survey could be read to respondents
- Survey could be mailed to respondents with prepaid return envelopes included
- Respondents could also identify a trusted support person to assist with completing the survey

Each of these supports were used by respondents, including:

- 3% of surveys were completed in Spanish.
- 4 surveys were read to respondents by the research team
- 4 surveys were mailed to respondents
- 60% of respondents reported receiving support from a trusted person to complete the survey. Most often, the person received support from a relative who lived with them (88% of the time).
    - For 70% of respondents who received support, the supporter answered the questions for them. Other common supports included reading the survey to the person (14%) and clicked on or wrote down the answer they gave (7%).

NOTE: Because of the large number of respondents who completed the survey on behalf of the person on the waiting list (most often a family member), respondents and respondents in the findings described below could be people on the waiting list or family members or others who completed the survey on their behalf. For some answers below, we describe results based on respondent (person on the waiting list or other). In the final report, we will present more findings based on participant.

What Respondents said about the Current Living Situation

We asked respondents where the person on the waiting list currently lives:

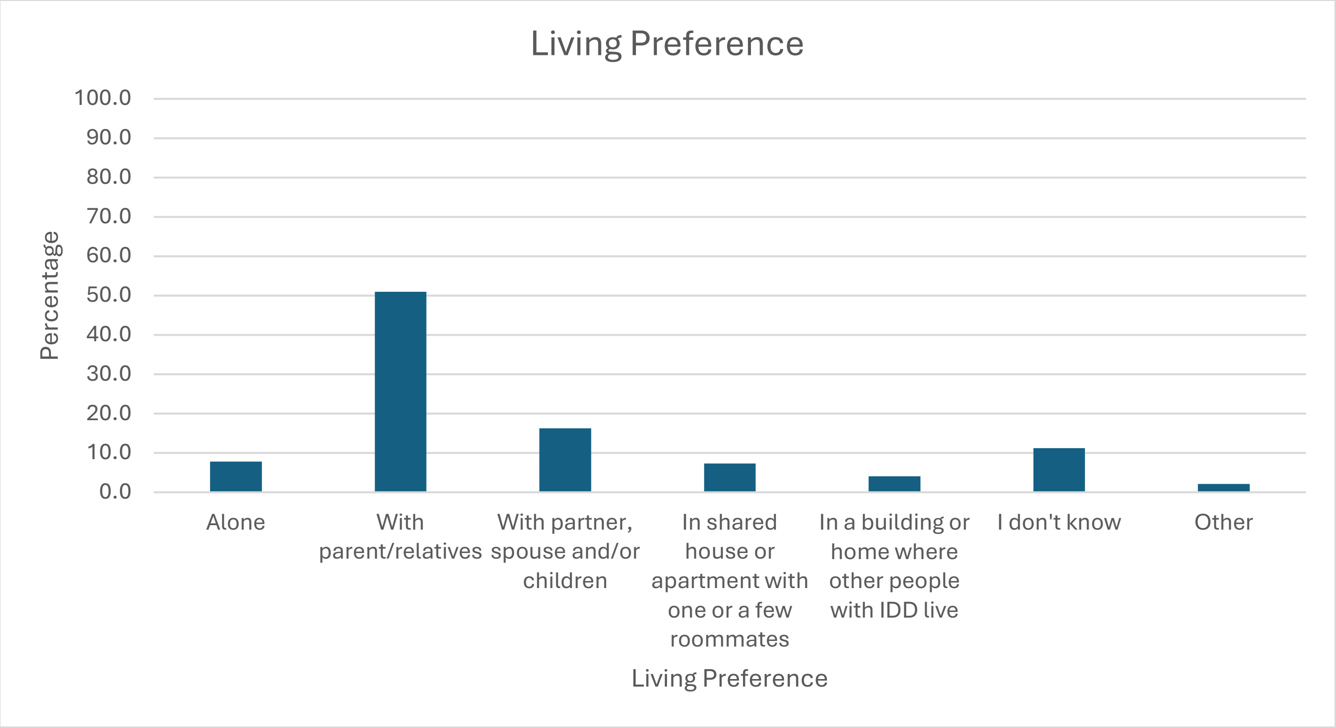
- 60% of respondents reported that the person on the waiting list lived with a parent or relative.
- 20% lived with a partner, spouse, or children.
- 10% lived alone.
- The remaining 10% lived either in shared housing, a building or home with other people with disabilities (e.g. a group home), or a large residential care facility.

Living Preferences

We asked respondents where the person on the waiting list would like to live. Figure 2 shows people on the waiting list's living preferences.

Figure 2

Living Preferences



Deciding where to live can be a complex decision and could be influenced by many factors. To better understand people's responses, we further investigated living preference based on who responded to the survey (person on the waiting list or caregiver). Parents and guardians were the most frequent responders to the survey, and overwhelmingly indicated that the person's preference was to live at home. Responses from people on the waiting list who responded for themselves, however, were more evenly distributed between preferring to live alone; live with a spouse, partner, or child; and live with a parent or relative.

Recommendations:

- These results suggest a strong preference for living with family or relatives, living with a spouse or partner, and living alone. Few respondents indicated they wanted to live in a shared living arrangement or in a home with other people with disabilities (e.g. group home).
- Flexibility in living situations will be needed to accommodate the living preferences of people on the waiting list.
- Using person-centered planning to determine the preferred living situation for the person on the waiting list is critical. More supports for community living and fewer group homes may be needed.

Needed Supports of People Waiting for the IDD HCBS Waiver

We asked respondents to indicate the type and amount of support the person on the waiting list would need in key areas of life (Home, Community, Learning, Work, Health, Social) in their life. Below are the results from those questions. Table 1 lists the descriptions used in the survey for each of these areas of life.

Table 1

Key Areas of Life Descriptions

Area of Living	Description used in Survey
Home	Doing the things you want to do around the house (like getting ready in the morning, preparing your food, cleaning around the house)
Community	Doing the things you need to do in the community (like shopping, going to the library, doing hobbies, seeing friends, going to church, getting to where you need to go)
Learning	Continuing your education (like going to school, college, or trade school, learning new health and exercise skills, learning new self-advocacy or self-management skills)
Work	Working in the community (like learning new job skills, accessing accommodations, completing job assignments)
Health	Maintaining your health (like taking medication, going to doctor appointments, exercising, maintaining your well-being)
Social	Being social (like making friends, seeing your friends, talking about your personal needs, or participating in recreation activities with others)

We first asked respondents to indicate whether or not the person on the waiting list needed support in each area of living. Table 2 lists the percentage of respondents who indicated that the person on the waiting list needs support in each area.

Table 2

Support Needs by Area of Life

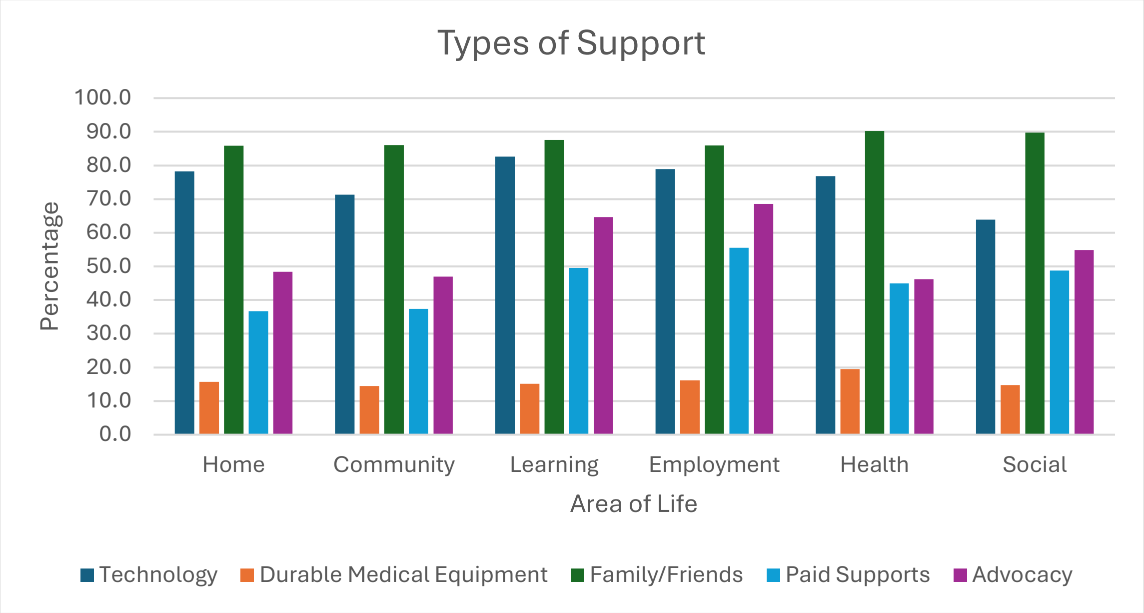
	Home	Community	Learning	Employment	Health	Social
Need	73%	85%	70%	71%	81%	78%

Needed Supports Across Domains

In the survey, supports were defined as ***things (like technology or other people) you need to live in your home, work at your job, and learn at school***. Figure 3 shows the percentage of responses for each type of support in each area of living.

Figure 3

Types of Support



Key findings from our analysis of needed supports include:

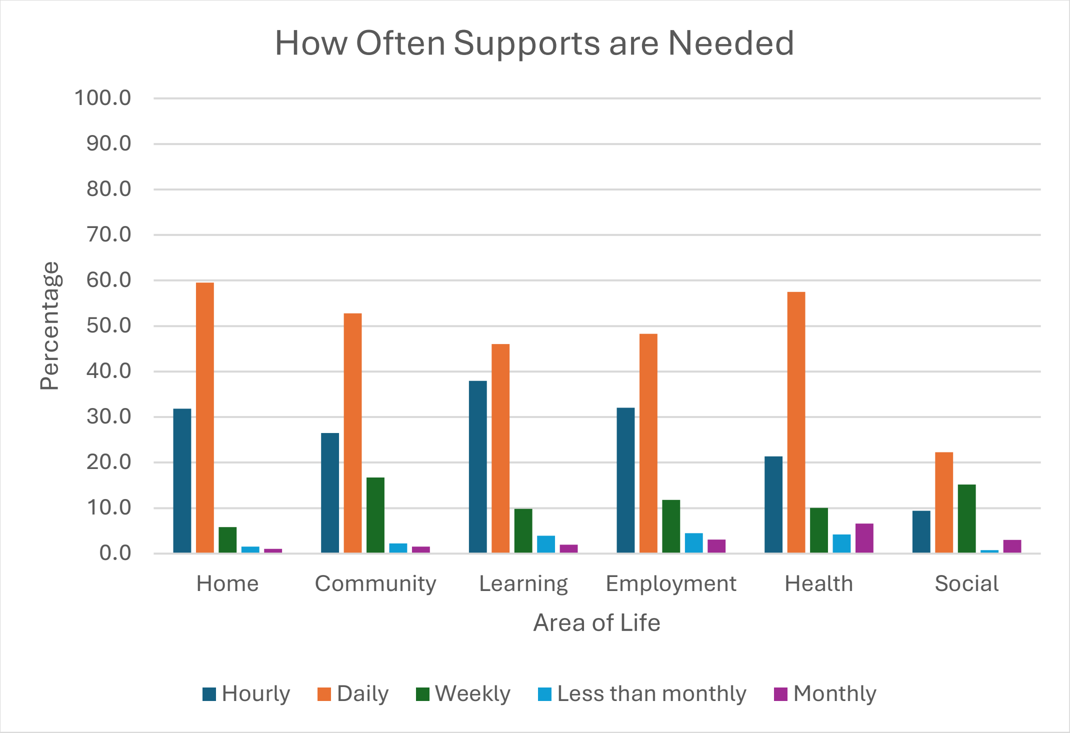
- In each area, the most common two types of supports needed were Family/Friends and Technology.
- In the Learning and Employment domains, almost half of respondents also indicated paid supports and advocacy were needed.
- The least common support in each domain was durable medical equipment (DME). It should be noted, though, that while few respondents indicated a need for DME, DME is a critical support for those who do need it.

- In open ended questions about needed supports, respondents frequently noted transportation was a critical support, particularly for community living, school, employment, and being social.

For each area of life, we asked respondents: How often do you usually need support? Figure 4 percentages of responses in each area of life.

Figure 4

Frequency of Needed Supports



Key findings regarding frequency of support include:

- In each area of life, about half of respondents indicated the person on the waiting list need support every day.
- Between 20-30% of respondents in each life area also indicated that the person on the waiting list needs support hourly.

We then asked respondents to reflect on the current services the person on the waiting list receives. We asked respondents: On most days, how satisfied are you with how often support is provided?

Overall, many respondents indicated that the person on the waiting list needs more support in different areas. Employment and Social were two areas where the majority of respondents indicated the person on the waiting list needs more support than they are currently receiving. However, at least 40% of respondents indicated the person on the waiting list needs more support in each, with the exception of Home, which was slightly under 40%.

Recommendations:

- Family/Friends and Technology were the types of support most respondents identified as needed. When developing the community supports waiver, it will be important to include procedures that allow family members to be paid as caregivers.. During COVID, Kansas enacted changes to Medicaid policies to, among other things, expand the type of family members who could be paid caregivers. Families reported very favorable outcomes from this policy change (Shogren et al., 2023, Wendel et al 2023) and KDADS is moving to make this policy change permanent across the existing waivers.
- This report gives us new information about the frequency of support needed by people on the waiting list. In each area of life, over 20% of respondents indicated that the person on the waiting list needed hourly support. Given preliminary findings on the reported extent of support needed and the expense of providing support, we recommend the state revisit the funding cap on the Community Supports Waiver, which may not be sufficient to cover the cost of support for many on the waiver.
- Building in funding for technology will also be important. The examples of technology used in the survey included timer on your phone, calendar app, reminders, communication device, alarm clock. Durable Medical Equipment was listed under a separate category. While DME is critical for those who need it, our survey suggests that other more common types of technology, like apps on cell phones, are also important supports for people’s daily living. It will be important to ensure that people can use waiver funds to pay for all types of needed technology and DME (including setting up, subscribing to, learning how to use, and maintaining the technology) to support their autonomy, and thus it is important that technology and DME are included in methodologies to set personal budgets.

Caregiver Survey Preliminary Findings

Goals and Concerns

We asked caregivers of people on the waiting list for IDD HCBS services, in their own words, to describe their goals and concerns for the person they support over the next 5 years. We begin this report with a summary of those responses.

The three most frequent goals caregivers had for the person they supported were Community Living, Education, and Employment. Table 3 provides examples of caregivers responses related to each of these areas.

Table 3

Caregiver Goals for Community Living, Education, and Employment

Community Living	Education	Employment
To live independently with some support	To go to the Job corps and get a trade or some more education	To have a job and live independently
To live independently with supports to manage money and paying bills, transportation, rental assistance	To graduate high school and find a job in the community	To find meaningful work, to find a group of friends who will provide for him socially and emotionality, find a group of people who will love and care for him when I am gone, and find appropriate and adequate housing for him once I'm gone.
To be able work and live independently	To go to college and have a vocation/job that gives her meaning and purpose. At some point live in her own home.	To be able to get into a career, and be more independent with his transportation and daily living.

The three most frequent concerns caregivers had for the person they supported were Access to Services, Community Living, and Education. Table 4 provides examples of caregivers responses related to each of these areas.

Table 4

Caregiver Concerns for Access to Services, Community Living, and Education

Access to Services	Community Living	Education
We as parents are doing everything we can all the time to help our son. Expenses of care continue to increase, our insurance doesn't cover many of the things that he needs (DME, certain therapies), though we pay for the premium and most inclusive plan. Affordability of care is a real concern especially now that I have decreased hours to be part time so I can be more available to support him. We are tired and isolated.	My daughter would benefit from more support with regular community activities, such as shopping; and home activities, such as bathing, dressing; and participating in chores such as laundry to develop independent living skills.	She needs support at the college level.
That he won't be fully supported to live in the community.	The older and bigger he gets, the less able we are to go places with him and the less options we have for supporting our son. The older he gets, the smaller our world becomes.	Lack of school options after high school.
Si si podrá tener lo que ella necesita para que pueda independizarse. (She will be able to have what she needs so that she can become independent.)	Not having the support in place to help him become a person that can contribute to society in a positive manner	Finding schools that are inclusive and willing to accept her as she is

Caregiver Demographics

As of June 6, 2024, we have collected 692 Caregiver surveys.

The average age of caregivers who completed the survey was 47 years old (Standard Deviation =11.4).

86% of respondents were women. The race of the majority of respondents was White (86%), followed by Black (4%) and Asian American (3%); 3% of respondents identified as multiple races; 8% of respondents identified as Hispanic or Latino/a/x.

Marital Status

- 67% of caregivers were married

- 15% were divorced or separated
- 13% were never married
- 4% were widowed
- 1% preferred not to answer

Figures 5 and 6 display the highest educational attainment (Figure 5) and the annual household income (Figure 6) of caregivers who completed the caregiver survey.

Figure 5

Highest Education

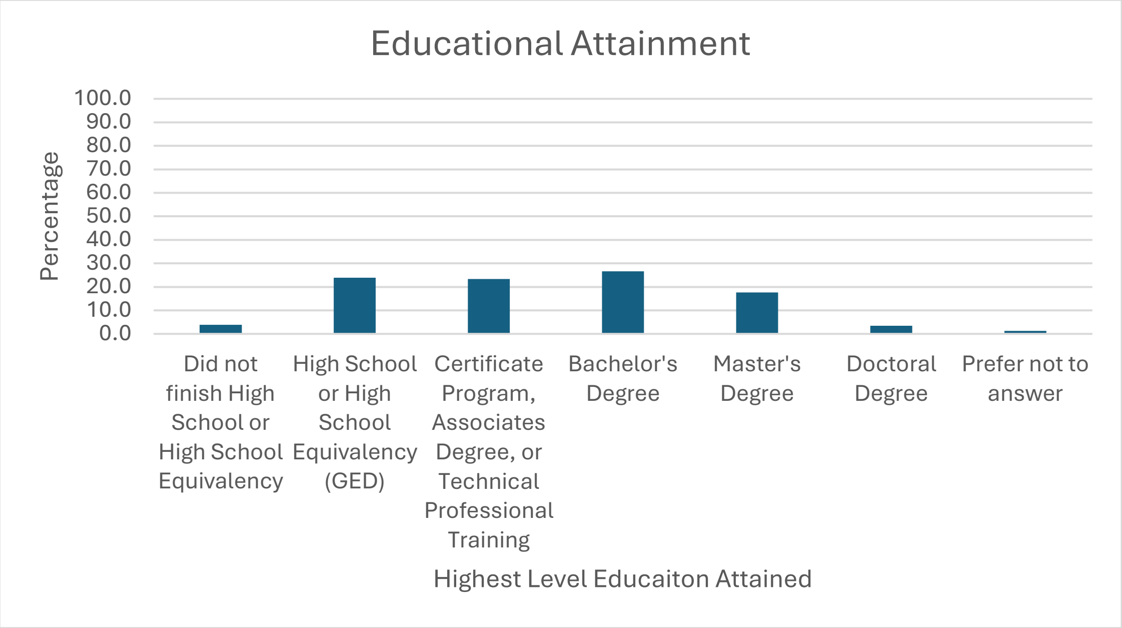
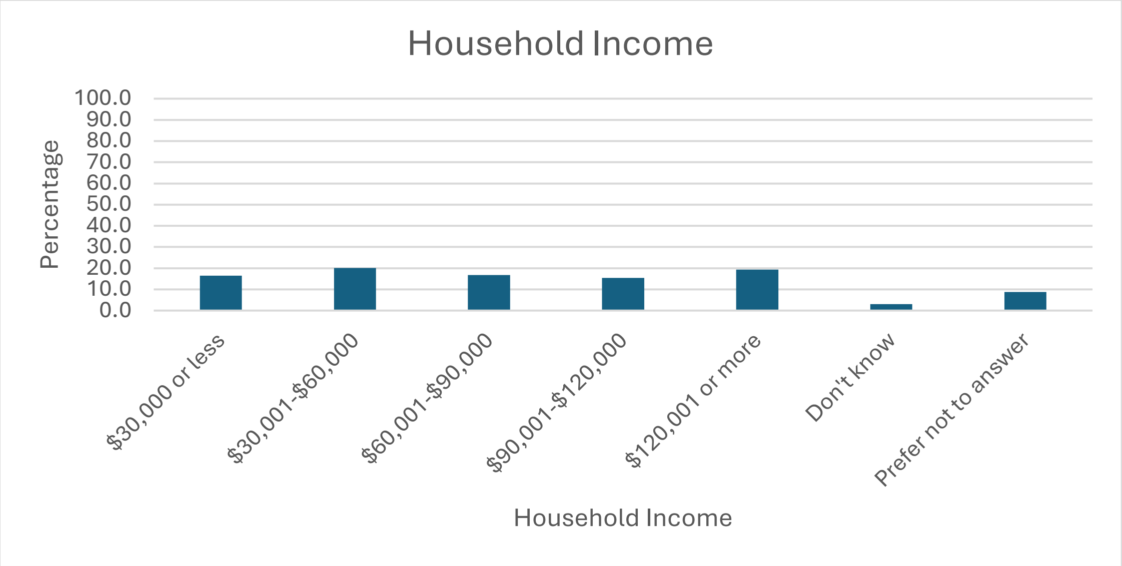


Figure 6

Annual Household Income



88% of caregivers were the parent of the person on the waiting list. 3% were grandparents and 2% were foster parents.

We asked caregivers about the support they provide the person on the waiting list. These questions included how many people they provide support for, how long they have been providing support for the person on the waiting list, whether or not they are the primary caregiver, and if something happened to the caregiver, is there someone else who could support the person.

- 71% of respondents indicated that no one was paid to provide supports to the person on the waiting list. 28% of respondents indicated that they cared for 1-3 other people.
- When asked if someone else was available to provide support if they were unable to, 60% of respondents said that someone else was available. 20% said that no one else was available, and 17% said they were not sure.
- While most caregivers identified someone else that could provide support if they were unable, it is important to also consider the sample demographics. In this preliminary sample, people with lower incomes or who were not married were less likely to have someone else available to provide support.

Support Caregivers are Providing

We asked caregivers to rate the frequency (how often) and intensity (on a given day, how long) of support they are currently providing to the person on the waiting list. We focused the questions on important areas of life (Home, Community, Education, Work, Health, and Goals). Their responses represent the current level of support that people will need if they were entering services today. These answers are important for planning the level and type of services people will need when entering HCBS services. Figures 7 and 8 show the frequency (how often) and duration (amount of time) of support provided by caregivers.

Figure 7

Frequency of Support in Each Area of Life

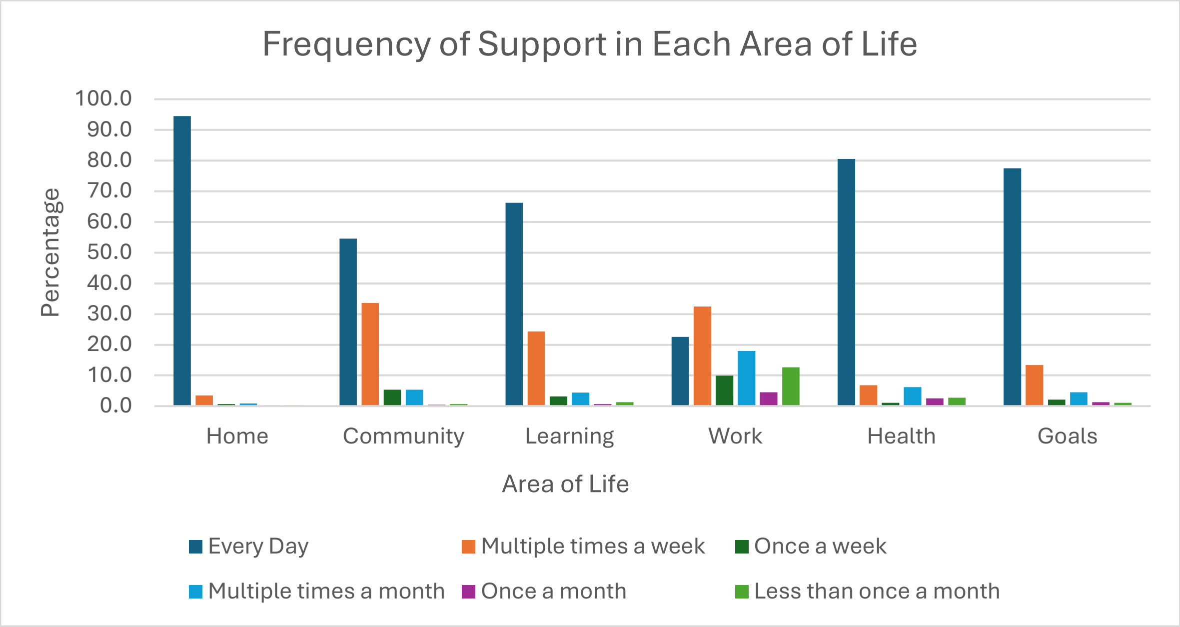
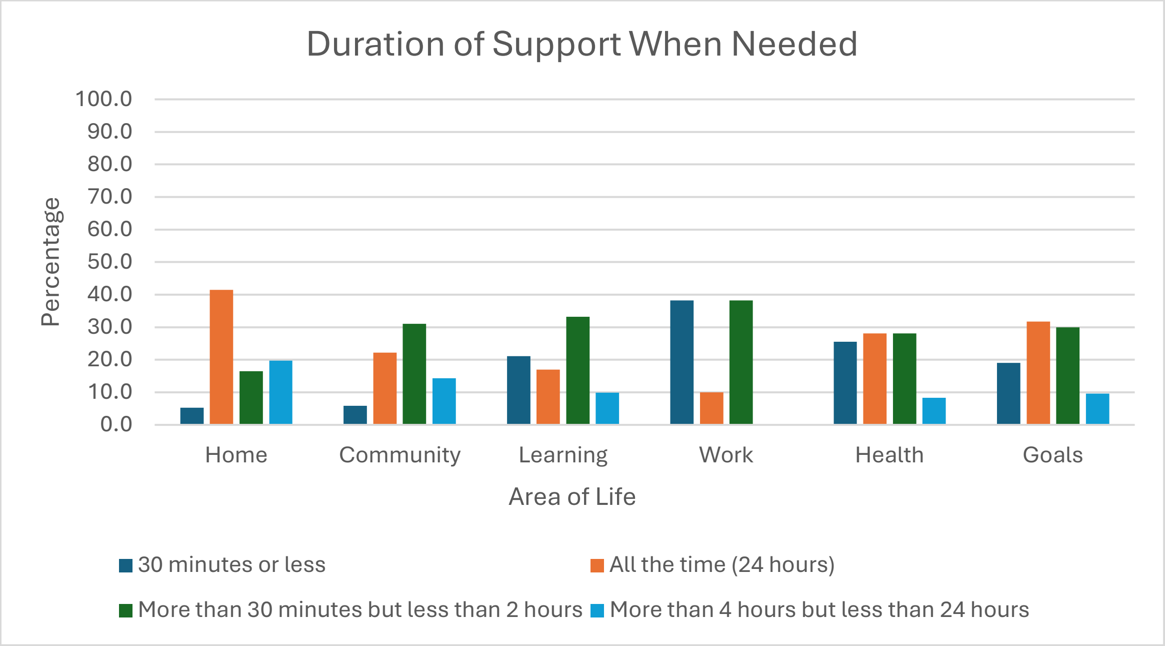


Figure 8

Duration of Support for Each Area of Life When Needed



- Nearly all (over 95%) caregivers indicated they are providing supports in the areas of Home, Community, Health, and Goals. Fewer caregivers indicated they were providing support for Education (66%) and Work (23%), which were areas people on the waiting list indicated were areas where more support was needed.
- Nearly all caregivers also indicated that they are providing support every day at Home. Most caregivers also indicated they are providing daily support in Community, Education, Health, and Goals.
- When asked about the amount of time each day they provide support, almost 40% of caregivers indicated they provide 24-hour support at home. In other areas of life, between 40% and 70% of caregivers indicated that they provided support for 30 minutes to two hours, however in each area of life, 10% to 30% of caregivers in each domain indcated that they provide 24 hour support.

Recommendations:

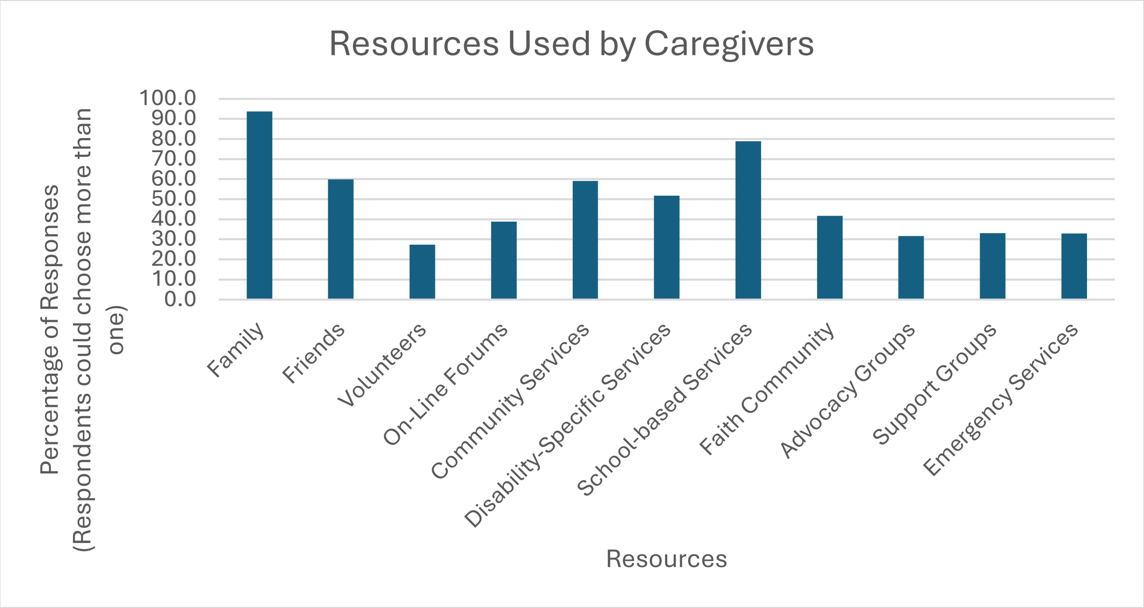
- We found that family members are providing a large amount of unpaid support for the person, which can cause emotional, physical, and financial challenges for the family. Our analysis of crisis exceptions indicated that caregiver burnout is a key factor in requesting many crisis exceptions. Thus, a highly trained and adequately paid workforce is needed to support families.
- The areas of life where the fewest caregivers indicated they were providing support were Education and Work. There is a need, therefore, to ensure the service system has a robust, highly trained workforce to support people to learn and work in integrated settings alongside supports in other areas so that families are not always the primary caregiver.
- The number of caregivers who responded providing 24 hours of care indicates that a higher cap may be needed for the Community Supports Waiver to ensure waiver respondents get the level of support needed, based on this preliminary data.

Resources Caregivers are Accessing in the Community

We asked caregivers about resources they have used to support their caregiving. Figure 9 displays caregiver responses regarding resources. Caregivers could select more than one response.

Figure 9

Resources Used by Caregivers



- 90% of caregivers reported seeking support from family members.
- Many people also reported seeking support from schools, community services, friends, and disability-specific organizations (e.g. CDDOs, CILs)
- Of note, 30% of respondents also reported using emergency services

Recommendation:

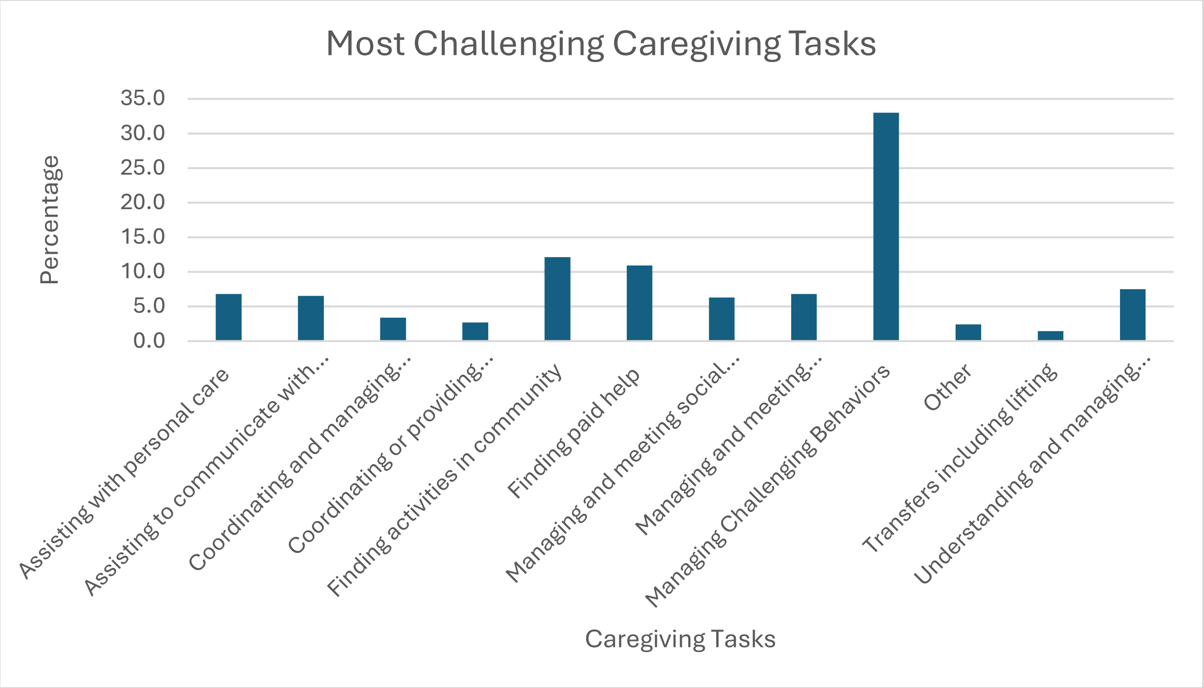
- 30% of caregivers report using emergency services, which are more expensive – higher cost for people being on the waiting list than receiving services – and impacts family wellbeing. Based on this preliminary data there needs to be more analysis about frequent use of emergency services by people on the waiting list.

Challenges For Caregivers

To help determine services that caregivers might need to better support the person they care for, we asked caregivers to identify the MOST CHALLENGING aspect of caregiving. Figure 10 shows the most challenging caregiving tasks. Caregivers could only choose one option.

Figure 10

Most challenging caregiving tasks



- 30% of caregivers identified managing challenging behavior as the most challenging aspect of caregiving.
- The next two most challenging aspects of caregiving were finding activities (12%) and finding paid supports (11%).
- Other aspects of caregiving that between 5% and 10% of caregivers identified as challenging included personal care, meeting the person's emotional needs, managing benefits, and assisting with communication.

We also asked caregivers to identify the MOST PERSONALLY CHALLENGING aspect of caregiving. Figure 11 depicts the most challenging aspects of caregiving. Caregivers could only choose one option.

Figure 11

Most Personally Challenging aspects of Caregiving

- The aspect of caregiving most highly endorsed by caregivers as MOST PERSONALLY CHALLENGING was managing the emotional or mental distress of caregiving (23%)
- Next was financial burden (18%), educating others about the person’s disability (15%), getting a short break (13%), finding temporary care (11%), and meeting the needs of other family members (10%).

Recommendations:

- Based on the preliminary data, there is a need to ensure caregivers and paid staff have adequate support for behavioral needs.
- It is critical that budget authority for the Community Support Waiver includes funding to pay for training
- There may be a need to strengthen the crisis response team across the state
- Over 20% of caregivers indicated managing the emotional or mental distress of caregiving as the most personally challenging aspect of caregiving.
  - It will be important to include respite care as a fundable service in the Community Supports Waiver
  - It is also critical for the state to work to ensure adequately trained respite providers are available across the state.

Supporting Health and Community Participation

We asked caregivers about services the person on the IDD waiting list is currently receiving to support the person's health and community participation and the importance of receiving those services.

Over 40% of caregivers rated the following services as important or very important for supporting the health and community participation of the person on the waiting list:

- Mental Health Services
- Respite Care
- Occupational, Speech, or Physical Therapy
- Specialized Educational Services
- Behavioral Health Services
- Peer to Peer Services

Recommendations:

- Caregivers rated the above services as important for supporting the health and participation of the person on the waiting list. It will be important to consider these services as allowable services in the community support waiver or to ensure that some of these services are adequately covered in the state plan.
- There is also a need to ensure that qualified providers of mental, physical, and behavioral health services are available across the state.

Key Takeaways for Community Supports Waiver Based On Preliminary Data

Budget Authority – Budget authority is a cost-effective way to give people choice and control over the support they need to live their life. The CSW needs to build in flexibility for individuals to identify goods and services that can be paid for through budget authority (support staff training and wages, transportation, technologies, family caregivers, community engagement, licensed and qualified professionals, gym memberships). This is complicated and the state needs to consult experts who understand the complexities.

Sufficient funding – While budget authority is cost-effective, the system needs to ensure that adequate funds are available to meet people's needs. This data shows that the services people need might be more expensive than originally thought. Also, services are becoming more expensive, so we need to be sure that funding is adequate to meet individual needs and is responsive to changes in the cost of living.

Care plans – Our analysis on preferred living situation showed differences in preferred living situation between caregivers and the person on the waiting list, with more people on the waiting list preferring to live alone or with a spouse or partner (along with many that preferred to live at home with their family). To ensure the person is being supported to live where they want to live, care plans and goal planning need to be guided by person-centered life course planning by trained facilitators so that the perspectives of the person as well as their family members inform the process with the ultimate purpose of supporting the person's life trajectory.

Access to qualified professionals: Our analysis shows that supporting people's emotional, behavioral, and health needs is critical, and people do not have access to enough qualified professionals. Kansas needs to work to create a robust network of licensed and qualified professionals, occupational therapists, physical therapist, speech and language pathologists, and behaviorists, all of which can play a role in supporting the persons emotional, behavioral, and physical health.

Next Steps

We plan to complete data collection on July 31, 2024. We will conduct analyses in August and prepare our final report, which we anticipate will be available in October. The final report will include additional analyses and recommendations from the survey as well as findings from our analysis of existing administrative data. We will also include findings from our analysis of our national data collection of practices used in other states to manage waiting lists.