KANSAS WAITING LIST STUDY

FINAL REPORT

KU CENTER ON DISABILITIES

CENTER for RESEARCH on AGING & DISABILITY OPTIONS
CRADO
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Kansas
Department for Aging
and Disability Services

State of the States
In Intellectual and Developmental Disabilities

Institute for Health and
Disability Policy Studies
The University of Kansas

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Please reach out if you have any questions or would like to learn more about this report. You can reach us at kucddcomunity@ku.edu.

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Acronyms Used in This Report

ADRC: Aging and Disability Resource Center

CDDO: Community Developmental Disability Organization

CDPS: Chronic Illness Disability Payment System

CRADO: Center for Research on Aging and Disability Options

CIE: Competitive Integrated Employment

CIL: Center for Independent Living

CMS: Centers for Medicare and Medicaid Services

DCF: Department for Children and Families

DRC: Disability Rights Center

EPSDT: Early and Periodic Screening, Diagnostic, and Treatment

FE: Frail Elderly

HCBS: Home and Community Based Services

I/DD: Intellectual and Developmental Disabilities

IEP: Individualized Education Program

IHDPS: Institute for Health and Disability Policy Studies

KAMIS: Kansas Assessment Management Information Systems

KEFOC: Kansas Employment First Oversight Commission

PD: Physical Disabilities

PRTF: Psychiatric Residential Treatment Facility

TCM: Targeted Case Management

SACK: Self Advocate Coalition of Kansas

SED: Serious Emotional Disturbance

WORK: Work Opportunities Reward Kansans

Executive Summary

The Kansas Department for Aging and Disability Services (KDADS) contracted with an interdisciplinary team at the University of Kansas, led by Dr. Evan Dean, to study the waiting lists for Intellectual and Developmental Disability (I/DD) and Physical Disability (PD) Home and Community Based Services (HCBS) waivers. To fund this study, KDADS allocated funds received through the American Rescue Plan Act (ARPA), which provided new, time-limited dollars to be strategically invested in HCBS services in the state. This executive summary briefly describes the purpose of the project, an overview of findings from each aim of the study, and a summary of recommendations provided throughout the report.

Overall, this project learned a great deal about the experiences and needed supports of people on the waiting lists. Additionally, we worked alongside KDADS staff to better understand the data system and processes KDADS uses to manage the waiting lists and learned from other states about their processes. We engaged people served by the I/DD and PD waivers, family members, and providers to ensure our recommendations were grounded in their experiences using and providing waiver services. The outcome was data-informed recommendations that KDADS and the state can use to inform future waiver development, enhancement of policies and procedures, and planning for ensuring people with intellectual and developmental disabilities, people with physical disabilities, and their family members and caregivers get the support they need to live the life they want to live in their communities.

Background on HCBS services

The Kansas Department for Aging and Disability Services (KDADS) provides oversight for a system of community-based supports and services for people with disabilities in Kansas. These supports and services are funded through Medicaid Home and Community Based Services (HCBS) waiver programs, which allow states to provide long term services and supports (LTSS) to support people with disabilities to receive services and supports in their home and community. Kansas currently serves people with disabilities through seven HCBS waivers that have been approved by the federal Centers for Medicare and Medicaid Services (CMS).

Two HCBS waivers pertain to this project because they have waiting lists: the Intellectual and Developmental Disabilities (I/DD) and Physical Disabilities (PD) waivers. At the time that this project was approved, there were approximately 4,500 Kansans on the waiting list for the Intellectual and Developmental Disabilities (I/DD) HCBS waiver program and approximately 2,000 Kansans on the waiting list for the physical disability (PD) HCBS waiver. By January of 2024 (just after we received administrative data of people on the waiting lists), those numbers had increased to 5,240 Kansans on the I/DD waiting list and 2,271 Kansans on the PD waiting list. Since then, the 2024 Kansas Legislature funded waiver slots to serve an additional 500 people on the I/DD waiting list and 500 people on the PD waiting list. This has reduced the waiting lists to 4,549 people waiting for I/DD services and 1,069 people waiting for PD services as of October 10, 2024.

Unfortunately, much is unknown about the individuals on the waiting list for both waivers. While KDADS can track their basic information (e.g., age, address), there is not a process established to gather information about current needs or anticipated needs. Further, a significant number of people are moving off the waiting list because of a crisis, through the KDADS crisis and exception policies. Experiencing a crisis as the mechanism for accessing services is not an ideal situation for the individual served or their families. Additionally, crisis enrollment makes it difficult for Community Developmental Disability Organizations (CDDOs) and service provider organizations to plan for effective support.

Purpose of the Project

To support KDADS' efforts to inform data-driven decision-making regarding effectively and efficiently serving people on the I/DD and PD waiting lists, our team from the University of Kansas (KU) partnered with KDADS to (1) gather, manage, and analyze currently available administrative data from KDADS and Kansas Department of Health and Environment (KDHE) and (2) forecast service needs over the next five years by collecting and analyzing data on current and future support needs of people on the I/DD and PD waiting lists.

This project was divided into two aims. Aim 1 was to collect, integrate, and analyze existing data to (1) understand the overall makeup of people on the I/DD and PD waiting lists to aid in planning for services that will meet the needs of people on the waiting lists, and (2) understand the reasons people enter services through crisis exceptions, which will inform primary data collection as part of Aim 2.

Aim 2 was to collect primary data from people on the waiting lists to (1) understand the demographics, experiences, and needs of people on the I/DD and PD waiting lists, (2) forecast service and support needs at the CDDO and Aging and Disability Resource Center (ADRC) level up to five years out, and (3) identify important health, employment, community living, and support need trends of people on the waiting lists.

To inform our recommendations and to identify successful practices in other states, we also conducted a national study of waiting list management strategies in other states. This study included a survey that was sent to states with waiting lists for HCBS services that support people with intellectual and developmental disabilities and/or people with physical disabilities. We then conducted information exchange meetings with state administrators to better understand practices in those states.

After this project began, the Kansas Legislature convened a Special Committee on Waiver Modernization. One outcome of this Special Committee was the commitment to develop a new Community Support Waiver that could serve a large number of people on the I/DD waiting list who may not need all of the services provided under the comprehensive waiver. Given the high priority of the Community Support Waiver, the researchers at the University of Kansas leading this study modified the aims of the study to also focus on providing detailed information and recommendations for the development of the Community Support Waiver.

This project was conducted in close collaboration with community partners, including the Self-Advocacy Coalition of Kansas (SACK), CDDOs, ADRCs, and Centers for Independent Living (CILs). We are grateful for the time given by the members of these organizations and others who enhanced the study through sharing their experience and expertise.

The purpose of this report is to share findings from the project, including results from an analysis of administrative data and two surveys that were developed to understand the experiences and needed supports of people on the waiting list for the I/DD and PD HCBS waivers and their caregivers. In this report, we provide detailed information regarding findings from the study as well as the systematic processes used to ensure the results are trustworthy.

Synopsis of Findings and Recommendations from the Study

In this section, we summarize the findings and recommendations from the study. We have organized the findings based on the aim of the study (Administrative Data, Waiting list and Caregiver Surveys, and National Study of States with Waiting Lists).

Overall, we have noted, and discussed with KDADS, that Kansas needs a *transparent, secure, integrated, and interoperable data system for HCBS system and Waiting list management*. For example, currently crisis exceptions are tracked through a tracking system maintained on individual computers of waiver managers that is not integrated into the KAMIS system. The data fields collected and maintained do not have consistent definitions or procedures and are not consistent across waiting lists, leading to problems with reporting of participant status. A thoughtful process should be undertaken, including input of providers and other stakeholders, to ensure development of a system that works for all users and consumers and provides data compatibility across different IT systems. This system would save considerable administrative time and allow KDADS to be more responsive to consumers, families, and other stakeholders regarding waiting list status as well as meet new reporting requirements from CMS. A public-facing dashboard utilizing aggregated, de-identified data with cell size considerations (to ensure people served in less populated counties cannot be identified) should also be created.

Findings from Administrative Data

We analyzed administrative data received from KDADS in December 2023, to understand the overall makeup and reasons for crisis exceptions of people on the waiting list. We received data for 5,121 people who were on the Intellectual and Developmental Disabilities (I/DD) waiting list and 2,360 on the Physical Disability (PD) waiting list.

- In this study, we found that approximately 40% of people on the waiting list for I/DD services are under the age of 21 and are also on Medicaid. These youth qualify for Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services that, while not waiver services, could address many of the needs of youth on the waiting list if fully utilized.

- PD crisis exceptions are driven almost entirely by individuals who are at imminent risk of a nursing facility (NF) placement. People on the I/DD waiting list are eligible for state plan services like Targeted Case Management (TCM) to support people to better coordinate their health care needs and connect them to community resources. People on the PD waiting list do not have access to TCM services, which could reduce risk for NF admission. We recommend that people on the PD waiting list have access to TCM services as well as capped personal attendant care services through state plan services, as is offered in many other states, which may also help people avoid risk of much costlier NF placement.
- The top reason influencing the need for a crisis exception for individuals on the I/DD waiver was caregiver needs, which was defined as when caregivers can no longer adequately support the person with I/DD due to their own advancing age, declining health, or employment obligations. This category also included death of a primary caregiver. To support the person with I/DD, it will be critical that the Community Support Waiver provide respite services for family members as well as key personal care services that will enable many individuals with I/DD to remain in their family home or own home as their caregivers age.
- Individuals with behavior support needs as well as criminal justice system involvement were another major driver of crisis exceptions on the I/DD waiver. Ensuring the system has adequate capacity for supporting people's emotional and behavioral needs in a way that prevents crisis situations and involvement in the criminal justice system is needed. A robust system that involves a comprehensive approach to supporting the emotional and behavioral support needs of people on the waiting list is needed. This needs to include enhancing the capacity of the community mental health system to more fully serve people with intellectual and developmental disabilities; expanding provider networks for occupational, speech, behavioral, and other therapies; expanding and enhancing mobile crisis response teams; and ensuring direct support

providers have the training needed to support the emotional and behavioral needs of people with I/DD.

Findings from Waiting List and Caregiver Surveys

We created two surveys (a Waiting List survey and a Caregiver Survey), which were sent electronically to people on the I/DD and PD waiting lists. Results were tracked and analyzed separately for the I/DD and PD waiting lists so that we could understand the unique needs and experiences of people on each waiver. The Waiting List survey was developed to understand the experiences and support needs of people on the waiting list. This survey was intended for people on the I/DD and PD waiting lists to complete. To develop the survey, we worked closely with self-advocates at the Self-Advocacy Coalition of Kansas (SACK) to develop questions that were in plain language and of relevance to people on the waiting list. The Caregiver survey, while not originally proposed by the research team, was added based on discussions with family members, professionals, and findings from the analysis of crisis exceptions for the I/DD waiting list that one of the main contributors to the need for a crisis exception was caregiver needs. This survey was designed for caregivers of people on the I/DD and PD waiting lists to complete and gathered information on the supports caregivers provide, the resources they access, and the experiences and challenges caregivers have related to caregiving. For both surveys, we worked closely with representatives from CDDOs, CILs, ADRCs, Families Together, and the Disability Rights Center to ensure the information gathered in the survey was relevant for family members, providers, and advocates.

We received a total of 1258 responses to at least one survey for the entire sample of 5644 people on the I/DD and PD waiting lists. The overall study response rate was 22%.

From the I/DD waiting list, 4162 participants were sent invitations to complete the surveys. Of that, 1031 consented and responded to at least one survey (25% response rate). We received 760 responses to the Waiting List survey and 641 responses to the Caregiver Survey. 370 individuals responded to both surveys and are included in the response totals for both surveys.

We recruited 1482 participants from the PD Waiting list. Of that, 227 consented and responded to at least one survey. The response rate for the PD Waiting list was 15%. We received 208 responses to the Waiting List survey and 56 responses to the Caregiver Survey. 37 individuals responded to both surveys and are included in the response totals for both surveys.

- Few people who completed the survey indicated that the person on either the I/DD or PD waiting list were employed or attending post-secondary education (e.g. trade school, community college, university). Yet, working a paid job in the community and continuing their education were high priorities for people on both waiting lists. There is a need for enhanced collaboration between employment service providers, such as Vocational Rehabilitation and Workforce Centers, as well as educational institutions, to provide employment and transition services for people on the waiting lists. Access to a care coordinator or TCM is critical for facilitating connections to these services.
- We asked respondents about where the person on the I/DD waiver preferred to live. People indicated 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. There is a need for more services that support people to live in the community and fewer group homes may be needed.

- Further, when we compared results for people on the I/DD waiting list based on who completed the survey (either the person on the waiting list or their caregiver), we found that living preferences changed slightly. Regardless of respondent, most people preferred living with a parent or relative; however, more people on the waiting list indicated they would prefer to live alone, with roommates, or with a partner, spouse, or child. This finding highlights the need for using person-centered planning to determine the preferred living situation for the person on the waiting list.
- This report gives us new information about the frequency of support needed by people on the I/DD and PD waiting lists. In each area of life, the majority of people indicated that they needed hourly or daily support to be successful. We recommend the state revisit and study the funding cap on the Community Support Waiver, which may not be sufficient to cover the cost of support for many on the waiver.
- Technology, Family and Friends, and Paid Supports were types of supports needed by people on the I/DD and PD waiting lists. For people on the PD waiting list, Durable Medical Equipment was also highly needed. For the Community Support Waiver, building in technology as an allowable expense will be important. Additionally, given the individualized nature of the supports needed, Individualized Budget Authority will be critical to ensure each person gets the supports they need.
- Through conversations with CILs as well as people on the PD waiting list, we learned that once people are deemed eligible for services by an ADRC, people on the PD waiting list have very little opportunity to connect with the service system. There is no defined mechanism for an ADRC or CIL to follow up about needs and no services the person can receive while waiting for their PD waiver slot. This means that many people lose contact with the service system. This disconnect can be seen in the lower-than-expected response rate to the surveys. Since people on the PD

waiting list must qualify for Medicaid, they are financially under sourced, and often have difficulty maintaining a residence and a consistent phone number. More systematic efforts need to be taken to maintain contact with people on the PD waiting list. As described above, the most cost-effective way to maintain contact would be to provide a limited amount of care coordination and personal care assistance so that the person can maintain their health while on the waiting list.

Findings from National Study of States with Waiting Lists

We identified states with current or recent I/DD or PD HCBS 1915(c) waiting lists based on Kaiser Family Foundation (KFF) reports that have tracked HCBS waiting list sizes over time (KFF, 2023; Musumeci et al., 2020; Ng et al., 2016). Seventeen states (out of 35) with current or recent waiting lists for waiver services for people with intellectual and developmental disabilities and 10 states (out of 21) with current or recent waiting lists for waiver services for people with physical disabilities responded to our invitation to participate in this study.

- We learned that most states offer targeted case management or care coordination to all individuals on waiting lists. Kansas only offers these services to people on the I/DD waiting list who are on Medicaid (approximately 70% of people on the I/DD waiting list). People on the PD waiting list cannot receive these services. We recommend offering TCM or care coordination services to all people on the waiting lists, which has the potential to reduce the risk of much more costly medical expenditures in the future.
- Kansas also stands out from other states by offering little additional support or Long-Term Services and Supports (LTSS) to people on the I/DD and PD waiting lists. Aside from TCM services mentioned in the previous bullet, other states also offer some LTSS, such as personal care

services, Medicaid state plan services, or state/local funded services. Access to these services, even if capped, coupled with TCM services, could prevent health and functional decline that will be much more costly to treat once the person begins receiving waiver services.

- Waiting list management strategies in other states are also driven by robust data collection and data management. Kansas would benefit from modernizing its data systems and allowing better integration across KDADS, KDHE, and MCO data systems to produce accurate, real-time reports that can be accessible to stakeholders across systems.

Introduction to the Waiting List Study Final Report

The findings and recommendations summarized above and described in detail below were the result of robust and systematic data collection and analysis processes that were grounded in the experiences of people and families utilizing waiver services as well as providers providing waiver services. This report details the processes we used to collect and analyze data and reports detailed findings from our analyses. We have included recommendations throughout the report based on the findings in each section and we summarize the findings at the end of this report. This study was undertaken by a thoughtful and dedicated team of researchers at the University of Kansas, in partnership with KDADS, people using I/DD and PD services, family members, and providers of services. Our goal was to provide Kansas with data and recommendations that can be used to inform enhancements to HCBS waiver service delivery. Please contact us with any questions you may have.

Background on HCBS services

The Kansas Department for Aging and Disability Services (KDADS) provides oversight for a system of community-based supports and services for people with disabilities in Kansas. These supports and services are funded through Medicaid Home and Community Based Services (HCBS) waiver programs, which allow states to provide long term services and supports (LTSS) to support people with disabilities to receive services and supports in their home and community. Kansas currently serves people with disabilities through seven HCBS waivers that have been approved by the federal Centers for Medicare and Medicaid Services (CMS).

Two HCBS waivers pertain to this project because they have waiting lists: the Intellectual and Developmental Disabilities (I/DD) and Physical Disabilities (PD) waivers. The I/DD waiver serves around

9,000 individuals ages five and older who meet the criteria for an intellectual disability or have a developmental disability, are eligible for care in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID) and are Medicaid eligible. The PD waiver serves around 6,000 people ages 16 to 64 years who meet the level of care criteria for nursing facility placement, who are determined to be physically disabled by Social Security standards, and who are Medicaid eligible.

At the time that this project was approved, there were approximately 4,500 Kansans on the waiting list for the Intellectual and Developmental Disabilities (I/DD) HCBS waiver program and approximately 2,000 Kansans on the waiting list for the Physical Disability (PD) HCBS waiver. By January of 2024 (just after we received administrative data of people on the waiting lists), those numbers had increased to 5,240 Kansans on the I/DD waiting list and 2,271 Kansans on the PD waiting list. Since then, the 2024 Kansas Legislature allocated resources to fund waiver slots for an additional 500 people on the I/DD waiting list and 500 people on the PD waiting list. This has reduced the waiting lists to 4,549 people waiting for I/DD services and 1,069 people waiting for PD services as of October 10, 2024.

Unfortunately, much is unknown about the individuals on the waiting list for both waivers. While KDADS can track their basic information (e.g., age, address), there is not a process established to gather information about current needs or anticipated needs. Further, a significant number of people are moving off the waiting list because of a crisis, through the KDADS crisis and exception policies. Experiencing a crisis as the mechanism for accessing services is not an ideal situation for the individual served or their families. Additionally, crisis enrollment makes it difficult for Community Developmental Disability Organizations (CDDOs) and service provider organizations to plan for effective support.

Purpose of the Project

To support KDADS' efforts to inform data-driven decision-making regarding effectively and efficiently serving people on the I/DD and PD waiting lists, our team from the University of Kansas (KU) partnered with KDADS to (1) gather, manage, and analyze currently available administrative data from KDADS and Kansas Department of Health and Environment (KDHE) and (2) forecast service needs over the next five years by collecting and analyzing data on current and future support needs of people on the I/DD and PD waiting lists.

This project was divided into two aims. Aim 1 was to collect, integrate, and analyze existing data to (1) understand the overall makeup of people on the I/DD and PD waiting lists to aid in planning for services that will meet the needs of people on the waiting lists, and (2) understand the reasons for crisis exceptions, which will inform primary data collection as part of Aim 2. Aim 2 was to collect primary data from people on the waiting lists to (1) understand the demographics, experiences, and needs of people on the I/DD and PD waiting lists, (2) forecast service and support needs at the CDDO and Aging and Disability Resource Center (ADRC) level up to 5 years out, and (3) identify important health, employment, community living, and support need trends of people on the waiting lists.

To inform our recommendations and to identify successful practices in other states, we also conducted a national study of waiting list management strategies in other states. This study included a survey that was sent to states with waiting lists for HCBS services that support people with intellectual and developmental disabilities and/or people with physical disabilities. We then conducted information exchange meetings with state administrators of waiting lists to better understand practices in those states.

After this project began, the Kansas Legislature convened a Special Committee on Waiver Modernization. One outcome of this Special Committee was the commitment to develop a new

Community Support Waiver that could serve a large number of people on the I/DD waiting list who may not need all of the services provided under the comprehensive waiver. Given the high priority of the Community Support Waiver, the researchers at the University of Kansas leading this study modified the aims of the study to also focus on providing detailed information and recommendations for the development of the Community Support Waiver.

This project was conducted in close collaboration with community partners, including the Self-Advocacy Coalition of Kansas (SACK), CDDOs, ADRCs, and Centers for Independent Living (CILs). We are grateful for the time given by the members of these organizations and others who enhanced the study through sharing their experience and expertise.

The purpose of this report is to share findings from the project, including results from an analysis of administrative data and two surveys that were developed to understand the experiences and needed supports of people on the waiting list for the I/DD and PD HCBS waivers and their caregivers. In this report, we provide detailed information regarding findings from the study as well as the systematic processes used to ensure the results are trustworthy.

Aim 1: Information About People on the Waiting Lists

We analyzed administrative data received from KDADS in December of 2023 to understand the overall makeup and experiences of people on the waiting list. At that time, 5,121 people were on the Intellectual and Developmental Disabilities (I/DD) waiting list and 2,360 on the Physical Disability (PD) waiting list.

Approximate Age of People on the Waiting Lists

We received the birthyear of each person on the waiting list. We calculated the approximate age of people on the waiting list by subtracting 2023 (the year we received the waiting list data) by the person's birthyear. The approximate average age of people on the I/DD waiting list was 21.12 years old, with a standard deviation of 12.23 years old. Table 1 shows the breakdown of approximate ages for people on the I/DD waiting list based on milestone ages for services (e.g. leaving high school at 18, leaving 18-21 school services at 21, entering the Frail Elderly (FE) Waiver at 65).

Table 1

Numbers of People in Age Categories on the I/DD Waiting List

Age Group	Total
0-17	2,370
18-20	672
21-64	2,038
65+	41

Notably, 60% of people on the I/DD waiting list are under the age of 21. Appendix A breaks out the ages by year and indicates the number of people in each age group who are on Medicaid. Of this youth population on the waiting list, about 2/3 (67.8%), receive Medicaid state plan services.

Youth under the age of 21 who receive Medicaid are eligible for Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) state plan services that, while not waiver services, could address many of the needs of youth on the waiting list. States are obligated to ensure Medicaid recipients under 21 receive EPSDT services, which:

- Are medically necessary
- Provide needed supports that increase health and participation, including:
    - Medical and mental health care
    - Occupational, physical, and other therapies
    - Assistive technology (AT)
    - Support for activities of daily living

The average age of people on the PD waiting list was 52.43 years old, with a standard deviation of 10.29 years. Table 2shows the breakdown of ages for people on the PD waiting list based on milestone ages for services (e.g. leaving high school at 18, leaving 18-21 school services at 21, and opportunity to enter the Frail Elderly (FE) Waiver at 65). Most people on the PD waiting list are between the ages of 21 and 64.

Table 2

Numbers of People in Age Categories on the PD Waiting List

Group-Age	Total
0-17	1
18-20	9
21-64	2,346
65+	4

Both waiting lists contain people who are 65 or older and who likely qualify for the Frail Elderly (FE) waiver. Based on early, preliminary findings from this study that people over 65 were on the I/DD and PD waiting lists, beginning mid-2023, KDADS has instituted a policy of informing people receiving services and on the waiting list who are eligible for FE waiver that they can apply for the FE waiver.

Appendix B shows the approximate number of people on the waiting list in each Aging and Disability Resource Center (ADRC) region.

Recommendation:

- Ensure EPSDT eligible youth on the I/DD Waiver Waiting list have access to and can receive EPSDT Services, including in rural areas of the state.

Analysis of Crisis Exceptions

A primary purpose of this study is to better understand the needs of people on the waiting list. A foundational component of that understanding is to understand the reasons that people enter services through a crisis exception. This section explains the background, methods, and findings of our analysis of crisis exceptions for both the PD and I/DD waivers. The findings from this analysis were instrumental in developing the waiting list and caregiver survey. Additionally, through this analysis and ongoing conversations with KDADS, CDDOs, CILs, family members, advocates, and other stakeholders, the research team identified specific recommendations for policy and practice that are highlighted in this section.

Background

Waiver policy permits two different types of exceptions to the waiting lists: crisis exceptions and priority populations (also known as "reserved capacity"). Crisis exceptions allow qualified individuals who are on the waiting list to move into services if they are experiencing a crisis. Priority populations, also known as “reserved capacity,” based on waiver application language, allow qualified waiver applicants to bypass the waiting list altogether. In theory, priority populations do not impact the size of the waiting list because there are reserved capacity slots held open for them, as specified in each waiver application to CMS. The allowable categories for crisis exceptions and priority population vary across waivers and are defined in policy. Table 3, below, indicates the crisis exception and priority population categories for the PD and I/DD waivers. Waiver managers review and approve both crisis exceptions and reserved capacity requests. Our research focused primarily on crisis exceptions; however, the I/DD data set combined these categories, as further described below.

Table 3
Crisis Exception and Reserved Capacity Categories

PD Waiver	
Crisis Exceptions	*Priority Populations (i.e., Reserved Capacity)*
• Abuse, neglect, or exploitation • Imminent risk of NF placement • Terminal illness (end stages) • Imminent risk of family dissolution • Domestic violence	• Department of Children and Families (DCF) custody • WORK transfer (previously on waiver) • Temporary institutional stay (previously on waiver) • HCBS waiver transitions • Military inclusion
I/DD Waiver	
Crisis Exceptions	*Priority Populations (i.e., Reserved Capacity)*
• Abuse, neglect, or exploitation • Risk of harm to self or others	• DCF custody, risk of, or transition • Work Opportunities Reward Kansans (WORK) transfer (previously on waiver) • Temporary institutional stay (previously on waiver) • HCBS waiver transitions • Military inclusion • Vocational Rehabilitation transition • Psychiatric Residential Treatment Facility (PRTF) transition • Institutional transitions

Methods

Crisis exceptions and priority population requests are managed by KDADS waiver program managers, including data tracking. This data is tracked in Excel spreadsheets, and not entered into Kansas Assessment Management Information Systems (KAMIS) (that is, the reasons are not in KAMIS but an approved exception is recorded in KAMIS). This data was used to examine crisis pattern trends, presented in this subsection, and these results were used to inform survey questions to understand the potential for future crisis exceptions.

The type of data tracked by the program managers varied widely across the two waivers. The PD program manager tracked all crisis exceptions based directly on the five crisis categories permitted in policy (as shown in Table 3, above). The PD program manager does not track priority population cases but shared that these are minimal and remain well within the number of waiver slots allotted for reserved capacity. The PD crisis data did not require re-coding by the KU team and only needed tabulation and linking to other data sets; however, since detailed notes about each crisis exception were not included in the original data source, we could not analyze the underlying factors contributing to the crisis exceptions.

The I/DD crisis data set contained detailed notes about each person’s circumstances related to the crisis exception, which required more substantial coding. This data set was more complex compared to PD, reflecting several factors such as larger number of cases, crisis category definitions that relied more heavily on professional judgement, conflation between crisis exceptions and priority populations, a request and approval process that involves extensive communication between CDDOs and KDADS program manager, and turnover of I/DD program managers who adopted somewhat different tracking approaches over time. It was not uncommon for individuals on the I/DD waiver to have multiple, combined reasons for requesting a crisis exception or reserved capacity slot. Finally, the I/DD crisis and priority population in the original Excel data set consisted mostly of notes rather than codes directly linking the reason to a specific crisis or reserved capacity category as defined in policy. The I/DD crisis and priority population data needed to be coded by KU researchers as part of the analysis. Although this was a more complicated analysis, the notes were also a very rich data source that provided more insight into the underlying factors that contribute to waiting lists exceptions.

To support reliability, the I/DD data set was coded and analyzed by two members of the KU research team with expertise in qualitative coding. The coders first reviewed a subset of the data and identified all the different reasons they found in the notes for crisis or priority population reasons. The crisis reasons were assigned a data code for analytics. The two coders then coded all crisis/priority requests independently for the first two years of data and had a 72-74% rate of agreement. Coding discrepancies were discussed and re-coded based on consensus. Coding definitions were refined through this process, and a single coder then coded the third year of data but flagged ambiguous cases for discussion and resolution with the other coder. See Table 4 for final codes and coding definitions.

Table 4

Codes and Definitions

Code	Definition	CE or PP*
Abuse, neglect, exploitation	Involvement in the adult protective services or child protective services system, or high risk of	CE
Caregiver needs	Family caregivers cannot provide adequate care due to their advancing age, declining health, or work obligations; also includes death of caregiver	CE
Criminal justice involvement	Involvement in the criminal justice system of any type, including arrest, court dates, incarceration, or release from incarceration	CE
Crisis denial reconsideration	Previous crisis request was denied and an administrative reconsideration was requested; need to link back to original request to see underlying reason	CE
Dementia/cognitive decline	Individual is experiencing cognitive decline due to dementia or other aging related cognitive declines	CE
DCF/Foster care	DCF or foster care involvement, including risk of DCF placement or transitioning out of DCF placement	PP

Homelessness, or risk of	Individual is homelessness or at risk of homelessness due to pending eviction or being removed from a family home	CE
Institutional transitions (not school, waiver, incarceration)	Transitioning out of a temporary institutional stay, such as ICF-II/DD, NF, or hospital; does not include waiver, school, or incarceration transitions as those covered under their own codes	PP
Mental health or emotional support need	Individual has mental health or emotional support needs that are severe enough to place person at risk of self-neglect or harm	CE
Military inclusion	Child/dependent of an active member of the military	PP
PRTF transition	Person is transitioning out of a Psychiatric Residential Treatment Facility (PRTF)	PP
SED waiver transition	Individual is leaving SED (Serious Emotional Disturbance) waiver; SED waiver is not included in waiver transition policy, but these individuals may be a risk to self or others.	CE
School transitions	Transition aged youth who is leaving the school system but has a ANE or harm risk without services	CE
Significant behavioral support needs	Significant behavioral needs such as aggression, self-harm, or predatory sexual behavior, indicating risk of harm to self or others	CE
Significant physical health support needs	Decline in physical health status, for example, due to age, major injury, or chronic health condition that is worsening, and support is needed to improve or maintain health	CE
Supported Employment	Transition back to the waiver from the WORK or transitioning from the Vocational Rehabilitation program and waiver supports needed to maintain employment	PP
Unknown	Insufficient information in exception data spreadsheet to assign any of the above codes	n/a

*CE: Crisis Exception; PP: Priority Population

It is important to note that it was not initially apparent to the research team that crisis exceptions and priority populations were combined in the same data set. Stakeholders called this fact to our attention when preliminary results were shared with them during a partners meeting, noting that some of the reasons we identified as crisis exceptions were actually priority population cases. KU researchers then delved further into the data and policy documents, and also met with KDADS I/DD program staff to clarify this distinction. A second layer of coding was then added to the data set to distinguish crisis exceptions from priority populations, as shown in table 4. A third layer of coding was also added to separate approved from denied crisis or reserved capacity requests. The KU team met with KDADS program staff several times to discuss and resolve coding ambiguities.

Results

For individuals on the PD waiting list, imminent risk of nursing facility placement was by far the top reason for entering waiver services through a crisis exception, at nearly 92%. The data did not provide additional detail on the underlying reasons why individuals were at risk of nursing facility placement. About 5% of individuals received a crisis exception due to involvement in the Adult Protective Services system. Combined, one-half of one-percent (0.5%) received crisis exceptions due to terminal diagnosis or domestic violence. Although imminent risk of family dissolution is an approved crisis exception reason in policy, no crisis exceptions for this reason were granted during the time period analyzed.

Table 5

Reasons People Entered PD Services Through a Crisis Exception, from January 2020 – December 2023

PD Crisis Reason from January 2020-December 2023	Total	%
Imminent Risk of Nursing Facility Placement	1,035	91.8%
Adult Protective Service Involvement	49	4.5%
Terminal Diagnosis	3	0.3%
Domestic Violence	2	0.2%
Total	**1,089**	

Turning to the I/DD waiting list, the most common reason for entering services through a crisis exception, was caregiver needs at 20%. This category was broadly defined to include caregivers with advancing age or declining health or whose employment was at risk due to their caregiving responsibilities. It also included individuals whose caregiver recently died. Caregiver risk is not in and of itself a crisis exception category, per policy, but is approved when caregiver risks are serious enough to meet the definition of abuse, neglect, and exploitation; or risk of harm to self or others. This reason is followed by significant behavior support needs, at 14%, which generally meets the crisis exception category of risk of harm to self or others. Abuse, Neglect, and Exploitation and Criminal Justice System involvement were also more common reasons for a crisis exception. Health related reasons included physical health, mental health, and dementia/cognitive decline, which while not leading reasons individually, if combined, represent 11%. Crisis exceptions related to risk related to homelessness, or risk thereof, represent 5%.

Turning to priority population reasons for individuals bypassing the I/DD waiting list, these are not as prevalent as crisis exceptions. Further, these cases largely fall within the number of slots reserved in the waiver for each reserved capacity category, but as will be discussed below, the state may consider updating the WORK reserved capacity category in the I/DD waiver.

Table 6

Reasons People Entered I/DD Services Through a Crisis Exception or Priority Population, from FY2021 – 2023

I/DD Crisis Reasons from Fiscal Year 2021-2023	Total
Crisis Exceptions	
Caregiver Needs (aging, death, health, working)	110 (20%)
Significant Behavioral Support Needs	73 (14%)
Abuse, Neglect, Exploitation	68 (13%)
Criminal Justice Involvement	61 (11%)
Significant Physical Health Support Needs	32 (6%)
Homelessness/Eviction/Risk of	25 (5%)
Mental Health and Emotional Support Needs	22 (4%)
School Transitions	11 (2%)
Transfers from SED waiver	7 (1%)
Dementia/Cognitive Decline	5 (1%)
Priority Populations	
DCF/Foster Care Involvement	49 (9%)
Supported Employment	42 (8%)
Institutional Transitions (not school/waiver/incarceration)	13 (2%)

I/DD Crisis Reasons from Fiscal Year 2021-2023	Total
Military Exceptions	6 (1%)
PRTF Transition	3 (1%)
Other	
Not enough information to code	12 (2%)
Total Number of Reasons for Crisis Exceptions*	**539**

* Each crisis exception case could have more than one reason for a crisis exception

Implications and Recommendations

Practice and Policy Recommendations for the PD Waiting list. PD crisis exceptions are driven almost entirely by individuals who are at imminent risk of a nursing facility (NF) placement. It may also indicate that individuals experience declines while awaiting services, which is consistent with findings from the CDPS (Chronic Illness and Disability Payment System) risk analyses, detailed below. ***Efforts to reduce crisis exceptions for the PD waiting list could focus on proactive strategies to reduce risk of nursing facility admission by offering supports to individuals on the waiting list. Targeted Case Management (TCM) services for individuals on the waiting list, as is offered for individuals on the I/DD waiting list, would help individuals better coordinate their health care needs and connect them to community resources, which could reduce risk for NF admission. Capped personal attendant care services for individuals on the waiting list through state plan services, as is offered in many other states, may also help people avoid risk of much costlier NF placement.***

The administrative data indicates a significant number of people die while waiting for services. Quality of data collection (e.g. lack of definitions and procedures) prevents us from knowing the exact number. Additionally, the crisis exception data indicates that only 0.3% of crisis exception reasons are due to terminal illness. This indicates that the crisis exception process is being underutilized for individuals facing death, which in turn may reflect an inadequate system for supporting and monitoring individuals on the waiting list. ***Individuals on the PD waiting list do not have consistent access to information and support services while awaiting services, which contrasts with the I/DD waiting list as well as approaches taken in many other states.*** At a minimum, we recommend that all individuals receive a plain-language document that details crisis exception reasons and how to initiate a crisis exception request when they are placed on the waiting list and at regular intervals thereafter. A higher level of service would be to offer Targeted Case Management (TCM) to all individuals on the waiting list, as also suggested above, in which the TCM could monitor for any changes in condition that may make them eligible for a crisis exception. A mid-level service approach would be to contract with a community agency to reach out to individuals on the waiting list on a regular basis, such as quarterly, to screen for a change in condition. In the subsection on waiting list management in other states, below, we provide examples of how other states provide support to individuals on the waiting list.

Practice and Policy Recommendations for the I/DD Waiting List. The top crisis exception reason for individuals on the I/DD waiver was caregiver needs. These crisis exceptions occur when caregivers can no longer adequately support the person with I/DD due to their own advancing age, declining health, or employment obligations. This category also included death of a primary caregiver. ***This data suggests that people on the waiting list, as well as people receiving HCBS services, would benefit from services that support the primary caregiver to support the person served. We expect crisis exceptions related to caregiver needs to grow as our society continues to age. It will be critical for the Community Supports Waiver, to provide key personal care services that will enable many individuals with I/DD to remain in their family home or own home as their caregivers age. Additionally, respite services that can be accessed across the state are needed to support caregivers and people receiving services.***

Individuals with behavior support needs as well as criminal justice system involvement were another major driver of crisis exceptions on the I/DD waiver. As noted in the recommendations from survey results, ensuring the system has adequate capacity for supporting people's emotional and behavioral needs in a way that prevents a crisis situation and involvement in the criminal justice system is needed. A robust system that involves a comprehensive approach to supporting the emotional and behavioral support needs of people on the waiting list is needed. This needs to include enhancing the capacity of the community mental health system to better serve people with intellectual and developmental disabilities; expanding provider networks for occupational, speech, behavioral, and other therapies; expanding and enhancing mobile crisis response teams; and ensuring caregivers and direct support providers have the training needed to support the emotional and behavioral needs of people with I/DD. Improved access to training on positive behavior supports can help family caregivers and direct support providers better support individuals with challenging behaviors

The priority population results indicate that the use of reserved capacity is largely in line with the number of slots reserved for each category in the I/DD waiver. The one exception may be for supported employment, for which the waiver only sets aside ten reserved capacity slots for the WORK program. This finding may reflect that our coding captured all types of supported employment and not just the WORK program, based on the data tracked in the exceptions spreadsheet. ***It may be prudent for the state to expand the number of slots in this category – and support people on the waiting list to access employment services - as well as revise this category definition in the waiver application to capture other supported employment programs, such as Vocational Rehabilitation. Additionally, it would be prudent for KDADS to review other priority population reasons in their written policy for providers as it compares to the reserved capacity categories as defined in the I/DD waiver, as there are some inconsistencies across these documents (as has been previously shared with KDADS in a separate document).***

Data system and tracking recommendations. The coding and analysis process revealed opportunities for improved data tracking. ***Our first recommendation is to track crisis data in KAMIS***

rather than on individual spreadsheets managed by program managers. This change would support consistency in data definitions, better safeguard the data set, and ensure the data is available to any team member with KAMIS access. This change is also important for combining all waiver information into a single data warehouse, which would improve administrative efficiency and enable robust data analysis. For example, crisis exceptions, functional eligibility assessment data, waiting list data, and demographic data could be more easily combined when assessing and monitoring trends and program needs.

The second recommendation is to develop uniform crisis and priority population data tracking coding and data collection processes across all waivers with a waiting list. We found that the PD and I/DD waiting list data sets varied and therefore required different methodological and statistical approaches for analyses. The PD data was easier to work with and left less room for coder interpretation; however, it was not as detailed as the I/DD data, and therefore, did not as clearly elucidate program and policy needs. In addition, PD waiver reserved population data is not being systematically tracked. While this lack of tracking is not a pressing problem for the program, tracking may still be useful to assess reserved capacity trends and to ensure those reserved slots are right-sized. There were also inconsistencies in the dates that were recorded (e.g. request date vs. decision date) as well as the outcomes of these requests (e.g., approved, denied, pending). If crisis and reserved capacity or priority population data was moved into KAMIS, as recommended above, this would be a key opportunity for standardizing data collection.

The final recommendation is to make waiting list exception data more precise and less ambiguous by, 1) Clearly distinguishing crisis exceptions and reserved capacity (i.e., priority populations) in the data set; and 2) Clearly connecting each case to the waiver policy category, while also capturing the more specific underlying factors. Crisis exceptions and priority populations have different impacts on the waiting lists, and thus it would improve policy planning to be able to more easily track and trend these broader categories separately. The PD and I/DD waiting list data demonstrated very different approaches, in which the PD data clearly delineated the applicable crisis policy category for each case, but did not consistently include information on underlying factors, whereas the I/DD data set captured the specific underlaying factors that were contributing to a crisis, but did not clearly delineate which crisis category was applicable. For example, caregiver risk could fall into both crisis exception categories (representing either an imminent risk of abuse/neglect/exploitation or a risk of harm to self/others). On the flip side, it was more defined in the PD data set if the crisis exception was due to abuse, neglect, or exploitation. However, from a policy and practice intervention perspective, a neglect risk due to a caregiver who is aging or in poor health is very different, for example, from more deliberate abuse or exploitation of an individual. The nuanced data more clearly points to needed policy and practice interventions.

Health Risk Analysis

To better understand the experiences of people on the waiting list, we analyzed Medicaid claims data to assess the health changes of people on the waiting list over time. In the Fall of 2023, Medicaid claims were obtained from the Kansas Department of Health and Environment (KDHE) through a Business Associate Agreement (BAA). KU-IHDPS staff requested claims data for calendar years 2017-2022 for I/DD and PD waiting list members with Medicaid IDs (from KDADS waiting list data provided to KU in January 2023). The claims were requested to complete analyses using the Chronic Illness and Disability Payment System 7.0 (CDPS, https://hwsph.ucsd.edu/research/programs-groups/cdps.html). CDPS is a medical diagnosis-based computer program developed in 2000 with updates and revisions completed in 2009 and 2014. CDPS is widely used for risk assessment of Medicaid beneficiaries. While often used by state Medicaid agencies to determine capitated payments, it can also be used in research to examine and compare the health risks and needs of Medicaid beneficiaries. CDPS also takes into account demographic factors, such as age and gender.

For the purposes of the Waiting List Study, CDPS was used to calculate both health risk scores and illness/disease burden scores by year for individuals on the Kansas I/DD and PD waiting lists. The CDPS health risk score uses Medicaid claims data to assess the risk of poor health outcomes in the coming year. The CDPS illness/disease burden score is based on the number of the 19 major diagnosis categories found in an individual's Medicaid claims during a 12-month period (Min score = 0, Max score = 19). See Appendix C for a list of the major diagnosis categories. For both health risk and illness/disease burden, the greater the score the more risk of high costs and poor health outcomes for the individual.

In general, the analyses of CDPS health risk scores for people on the Kansas I/DD and PD waiting lists showed that the longer a person is on the waiting list for HCBS services, the more their health risk and illness/disease burden scores increased. These increases over time in health risk and illness/disease burden scores are statistically significant[1]. In addition, individuals who were removed from the I/DD and PD waiting lists due to <u>any</u> type of crisis exception had significantly higher illness/disease burden scores than people remaining on the waiting list[2], indicating that they developed more medical conditions as they waited for services.

These findings suggest that individuals on the waiting lists, even when having access to Medicaid health-related services, are subject not only to becoming increasingly more ill and at-risk for poor health outcomes as they wait for HCBS services, but ultimately will have higher overall Medicaid costs when they come off the waiting list.

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[1] chi-square, *p<.01*

[2] chi-square, *p<.001*

Aim 2: Waiting List and Caregiver Surveys

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 (I/DD) 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.

While we were developing the initial survey, we learned from family members and our crisis exceptions analysis that we also needed to understand the perspectives and experiences 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 I/DD waiting lists identify as their needed supports for home living, community living, lifelong learning, employment, health, safety, and social participation?
2. How do employment, functional, and health outcomes differ for people on the waiting list when compared to people receiving HCBS services?
3. What are the emotional, financial, and health impacts on caregivers providing support for the person on the waiting list?

4. 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 (e.g. Supports Intensity Scale, National Core Indicators, Behavioral Risk Factor Surveillance System) 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

The survey was initially made available to participants as an online link and sent to participants via text message. However, 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 by phone
- 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

We received a total of 1258 responses to at least one survey for the entire sample of 5644 people on the I/DD and PD waiting lists. The overall study response rate was 22%.

From the I/DD waiting list, 4162 participants were sent invitations to complete the surveys. Of that, 1031 consented and responded to at least one survey (25% response rate). We received 760 responses to the Waiting List survey and 641 responses to the Caregiver Survey. 370 individuals responded to both surveys and are included in the response totals for both surveys.

We recruited 1482 participants from the PD Waiting list. Of that, 227 consented and responded to at least one survey. The response rate for the PD Waiting list was 15%. We received 208 responses to the Waiting List survey and 56 responses to the Caregiver Survey. 37 individuals responded to both surveys and are included in the response totals for both surveys.

Caregiver Goals and Concerns for the Person on the I/DD and PD Waiting Lists

Caregivers for people on the I/DD waiting list who completed the survey were given the opportunity to share both their Goals and Concerns for the individual on the waiting list to whom they provided support. Caregivers who completed the survey were given the opportunity to answer the following open-ended questions:

- What are your goals (for the recipient's name) over the next five years?
- What concerns you the most regarding the supports (the recipient's name) will have over the next five years?

Caregivers provided 288 responses to the question regarding their goals for the person they cared for over the next five years, and 281 responses to the question regarding their concerns for the person they cared of over the next five years.

A systematic coding process was employed to qualitatively analyze these two open-ended survey questions about caregivers' dreams/goals and primary concerns for Kansans on waiting lists. The first step involved reviewing the responses and categorizing them based on thematic areas. In this case, the responses were initially coded by two independent reviewers who used the areas of emphasis outlined in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) as a framework. The DD Act was used as a framework for analyzing goals and concerns for people on the PD and I/DD waiting lists because of the Act's focus on service delivery models that support people with disabilities to live their life in the community. The areas of emphasis outlined in the DD Act was chosen as a framework to evaluate caregiver responses because,

> "…programs authorized by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) empower individuals with developmental disabilities and their families to help shape policies that impact them. DD Act programs conduct important research and test innovative new service delivery models. They work to bring the latest knowledge and resources to those who can put it to the best use, including self-advocates, families, service providers, and policymakers." (ACL, 2021)

The areas of emphasis found in the DD Act included the following themes:

- Employment
- Education
- Health
- Housing
- Transportation
- Recreation
- Quality Assurance
- Community Living
- Self-Advocacy

The reviewers, however, also recognized that some responses might fall outside these predefined categories, allowing for the identification of new or unexpected themes relevant to the caregivers' perspectives such as friendships, access to services, behavioral/mental health, safety, communication, autonomy, family supports, and financial security.

When the coding by the two reviewers did not match, a reconciliation process was used to resolve discrepancies. This involved establishing clear rules for how to handle differences in coding, ensuring that both reviewers reexamined the responses with these rules in mind. The rereviewing process helped to achieve greater consistency and reliability in the coding, ensuring that the final analysis accurately reflected the content and emphasis of the caregivers' responses. This approach not only provided a structured method for capturing the main concerns and aspirations of caregivers but also allowed for the flexibility needed to incorporate diverse and nuanced perspectives. It should be noted that given the open-ended nature of the questions, responses could be assessed as having multiple codes.

The top four goals that caregivers had for the person on the waiting list that they supported were Education, Community Living, Self-Advocacy, and Employment. Table 7 lists the goals, number of times caregivers mentioned the goals, and sample responses that were coded as the goal.

Table 7

Caregiver Responses to Open Ended Survey Questions Regarding their Goals for the Individual on Waiting Lists

Goal	**Count (out of 288 responses)**	**Sample Responses**
Education	85	• Complete school... • College or trade school... • Continue school and begin transition to adulthood...
Community Living	83	• Continue to build social relationships outside home, find work/hobbies that make him happy and give him fulfillment...

		• (P)articipate in community events, continue to have an active social life... • (C)ontinue being a part of the community...
Self-Advocacy	78	• (L)earn to communicate emotions, wants & needs better. • A stronger social/emotional awareness and better able to communicate needs. Self-advocacy. • I want her to develop her Interpersonal, Self-Advocacy and self management skills.
Competitive Integrated Employment	73	• I would like for (my son) to be employed in an appropriate job (in) the community. • I would like to have (my son) working a steady job. • I would love for him to find a job.
Friendships	52	• Make friends! • Find and socialize with friends. • Have friends that support him and not hurt him.
Health	36	• That she would remain healthy... • Getting rid a feeding tube. • Just to stay healthy...
Other	30	• Learn to tolerate lawnmowers so we can stay home when neighbors mow instead of having to leave. • (L)ess challenging behaviors. • Improvement in Time management.
Autonomy	23	• More self sufficient with self care. • To be able to manage understand most (i)f not all his daily living skills with little to no help if possible. • Walk independently.
Quality Assurance	18	• To have reliable state issued health insurance... • To get him the supports he will need as an adult with a disability. • My goals for (my son) is for him to get HCBS services.
Communication	17	• Being able to communicate... • Grow in Communication, Social, and Learning Skills. • I’d love to see him speak but I don’t know if he ever will.
Recreation	10	• ...stay involved in Special Olympics... • ... become active in whatever recreational activities she likes. • More frequent family road trips and camping trips... travel and camping are stimulating, enjoyable
Transportation	7	• ...if able learn to drive... • ... be more independent with his transportation... • ... reliable transportation (not driving herself)...
Safety	4	• To be secure in her life and surroundings. • Personal care. Safety.

		- Happiness, security and safety
Housing	3	- To move into a provider based supportive housing program - Apartment or group living with non family assistance
	519	

Access to Services was by far the most common concern among caregivers, representing about 25% of concerns. Other top concerns included Financial Security, Community Living, Education, and Behavioral/Mental Health. Table8 lists the goals, number of times caregivers mentioned the goals, and sample responses that were coded as the goal.

Table 8

Caregiver Responses to Open Ended Survey Questions Regarding their Concerns for the Individual on Waiting Lists

Concern	**Count (out of 281 responses)**	**Sample Responses**
Access to Services	137	- As kids with disabilities age, supports decrease. - Being on waiting lists for additional services and not being able to get them because he "ages out". - Caregiver demand / continuing to receive no services from the I/DD waiver/ waiting list
Financial Security	44	- Hoping I can get more financial help and can give (my son) all the support he needs. - I worry about the added costs of fighting insurance for coverage that is deemed medically necessary every six months. We have to hire a lawyer to fight the external appeal to continue to win, no question, however, it shouldn't take thousands of dollars on our end to make sure that insurance provides medically necessary coverage. - Money worries
Community Living	37	- Lack of supports and opportunities for (my daughter) in our community. - That besides his family there will be other supports available 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 having anyone help with (my son); the older he gets, the smaller our world becomes.
Education	34	- Even with IEP he is having a hard time at school

		• Finding schools that are inclusive and willing to accept her as she is • Her school seems lacking in experienced workers
Behavioral/Mental Health	32	• As she gets older and bigger her behavioral problems have gotten worse. • Being able to maintain his behavior to keep him out of legal system. • I am concerned that he could pick up legal charges due to his aggressiveness.
Other	29	• All of it. • Guardianship as he ages over 18... • Jail, death
Self-Advocacy	21	• Communicating his needs, neglected or isolated if not in a good care program. • Not being able to advocate for himself... • Not learning how to self advocate because he misunderstands so many things that he appears to understand
Employment	20	• If he will have the community support he needs to transition into adulthood including job opportunities... • Keeping a job... • To have a job and live independently.
Health	20	• She'll always need help with her...medication management • That none of the supports will manage to get to him in time and his condition will go from critical to hospice or worse... • My health would worsen and I couldn't care for him.
Family Supports	19	• The lack of a true family to step in if my husband and I are no longer here. • That something would happen to her dad or I and that her siblings wouldn't step in the way she needs... • That something will happen to her father or I and we won't be here to make it all happen.
Safety	16	• ... being taken advantage of.... • Maintaining safety of him and others in our home. • Keeping him safe, not having enough support.
Friendships	14	• ... finding friends when we currently have to go with him everywhere he goes. • As kids with disabilities age, supports decrease, and friend support decreases due to peer pressure • Not sure, but (my son) needs a regular routine in which he can meet the same people in order to build friendships.
Autonomy	9	• He will not be prepared for adulthood. • Learn daily activities. • When (my son) doesn't like something he's a quitter he wants it his way I need him to understand that it's not always what you want.
Housing	6	• That he will not have his own place...

		- Out of pocket costs for housing outside the home due to 10+ waiting list for state funding to help support an independent lifestyle. - ... finding adequate housing with appropriate supports.
Transportation	5	- Transportation to appointments and work. - Puberty in conjunction with ASD, high school, driving - Transportation...
Quality Assurance	5	- Lack of supports and lack of oversight of companies providing support, more accountability needed for them to provide services according to PCSP etc. - I do not trust the current systems. I am afraid she will be abused when not in my care.
Communication	4	- It's super helpful if people can communicate with him in American Sign Language as he is extremely hard of hearing. - Communication - Being able to communicate/ being able to say if he's sick and what's wrong and etc.
Recreation	2	- Having sufficient funds to bring (my son) on cross-country road trips and camping trips. This is, by far, what he loves most, but there is no funding assistance for such trips. - Lack of community events, summer camps, or sport activities for autistic children with moderate to serious support needs.
	454	

Findings from I/DD Waiting List and Caregiver Surveys

Demographics

The majority of people on the I/DD waiting list who completed the Waiting List survey were between the ages of 21 and 64 (see Table 9). 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 (see Table 10).

Table 9

Age of People on I/DD Waiting list Waiting List Survey Participants

Age Group	Total
Under 18	56%
18-20	12%
21-64	32%

Table 10

Race of I/DD Waiting list Waiting List Survey Participants

Race	I/DD(N=760)
Asian/Asian American	29 (4%)
Black/African American	66 (9%)
Native American or Alaska Native	21 (3%)
Native Hawaiian or Pacific Islander	2 (.3%)
White/European American	620 (82%)
Prefer not to answer	22 (3%)
Other	45 (6%)

Note: Some participants identified as more than one race. They were classified here as each race they identified with. Thus, the percentages add up to greater than 100%.

Here is further information regarding caregivers of people on the I/DD waiting list:

- The average age of caregivers of someone on the I/DD waiting list who completed the survey was 48 years. 93 (14.5%) caregivers reported being over the age of 60.
- Eighty-eight% percent respondents to the caregiver survey indicated that they were the parent of the person on the I/DD waiting list. 3% were grandparents and 2% were foster parents.
- Eighty-six percent of respondents to the Caregiver survey were women. The race of the majority of respondents to the Caregiver survey 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.

- Sixtey-seven percent of respondents to the Caregiver survey indicated that they were married. 15% indicated that they were divorced, 11% were never married, and 4.2% were widowed.
- Tables 11 and 12 display the highest educational attainment (Table 11) and the annual household income (Table 12) of caregivers who completed the caregiver survey.

Table 11

Highest Education of Respondents to the Caregiver Survey

Highest education completed							
	Did not finish High School or High School Equivalency	High School or High School Equivalency (GED)	Certificate Program, Associates Degree, or Technical Professional Training	Bachelor's Degree	Master's Degree	Doctoral Degree	Prefer not to answer
I/DD	3%	20%	20%	23%	16%	2%	1%

Table 12

Annual Household Income of Respondents to the Caregiver Survey

Annual Household Income							
	$30,000 or less	$30,001-$60,000	$60,001-$90,000	$90,001-$120,000	$120,001 or more	Don't know	Prefer not to answer
I/DD	14%	18%	14%	12%	16%	2%	8%

We asked caregivers about the support they provide to 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.

- 86% 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. People with lower incomes or who were not married were less likely to have someone else available to provide support.

Support for Completing the Waiting List Survey

Each of these supports were used by respondents, including:

- 3% of surveys were completed in Spanish.
- Six surveys were read to respondents by the research team.
- Eight 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.
    - For 81% 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).

Employment for People on the Waiting List

Only 52 survey respondents on the I/DD waiting list indicated that they had jobs. Of those, over 80% said that they made at least minimum wage. Most indicated that they liked their job and worked 10-20 hours.

53% of respondents said that they either had some support but needed more or did not have any support for finding a job. This finding indicates a critical area of need for people on the waiting list – to ensure they have access to job development supports, such as Vocational Rehabilitation, pre-Employment Transition Services, and WIOA services through the Workforce Centers.

Education

Half of respondents indicated that the person on the I/DD waiting list was a student. Of those, 56% were in elementary or middle school, 36% were in high school or receiving 18-21 transition services, and 3% were either in vocational school, college, or university.

In terms of future plans, 50% of respondents said that they wanted to continue their education after high school and another 33% said that they were not yet sure of their plans. Yet, 67% said that they do not have enough support for continuing their education.

Health

54% of respondents indicated that their health was either fair or poor, while 44% indicated they were in excellent health. There were no statistical differences based on age, region of the state, or population density.

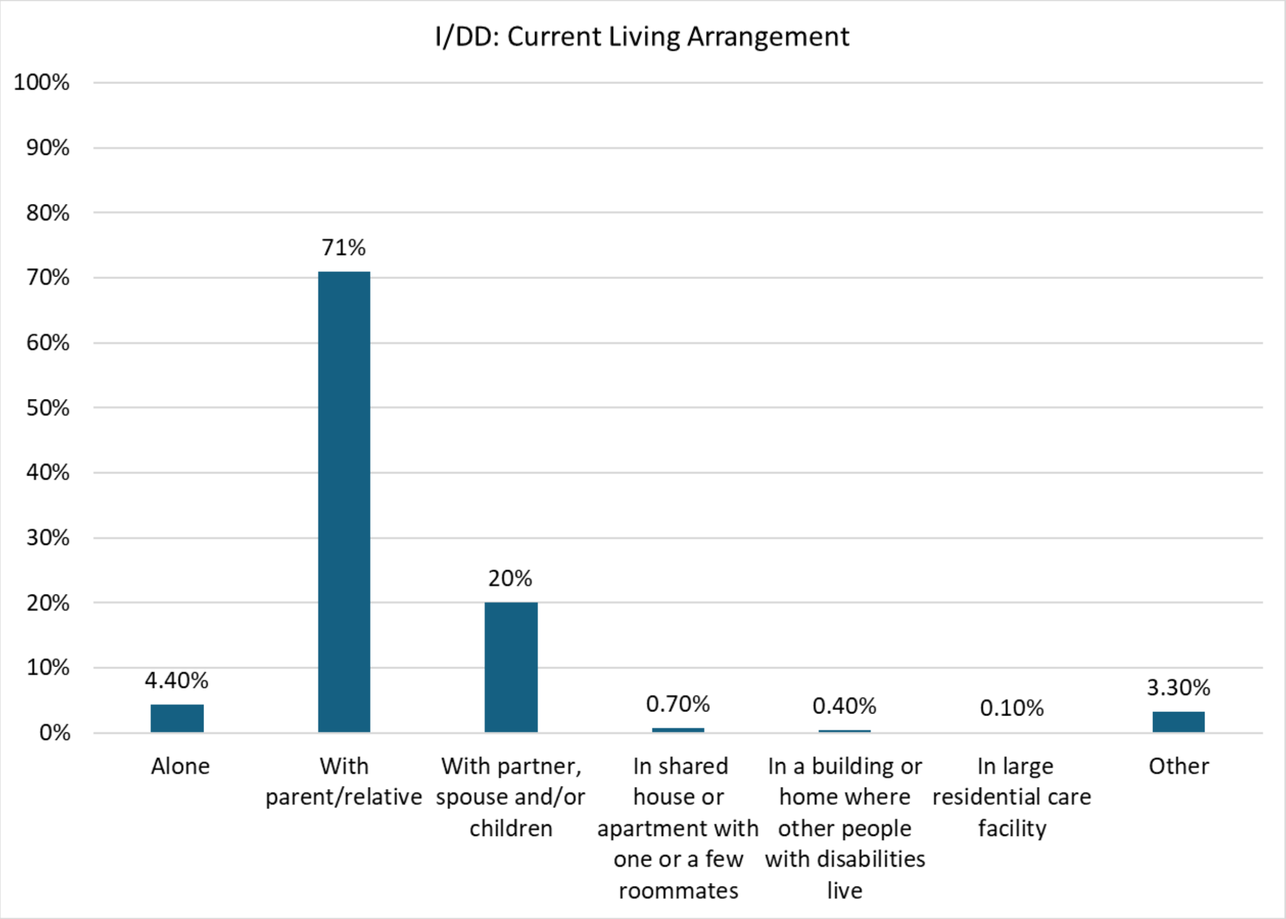
Current Living Situation

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

- 70% of respondents reported that the person on the waiting list lived with a parent or relative.
- 20% lived with a partner, spouse, or children.
- 4% lived alone.
- The remaining 15% 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.

Figure 1

I/DD Current Living Arrangement

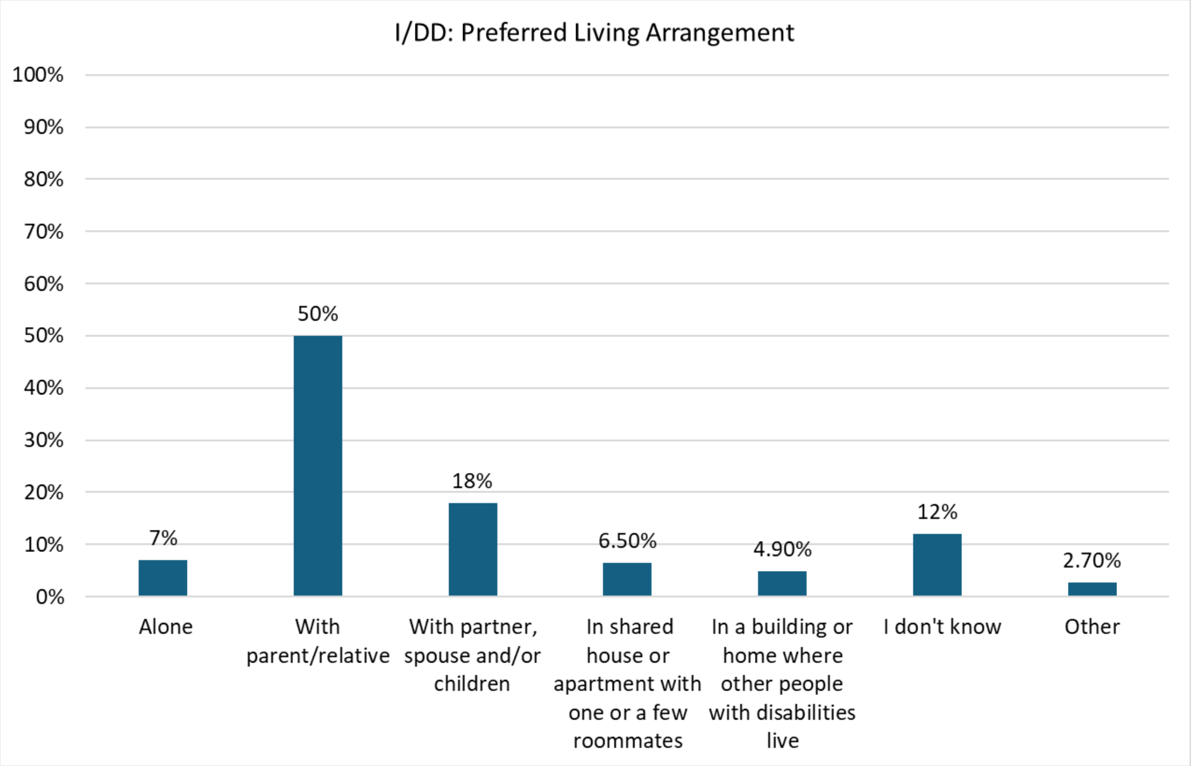


Living Preferences

We asked respondents where the person on the I/DD waiting list would like to live. Figure 2 shows people on the waiting list's living preferences. Of note, few respondents indicated that they prefer to live in a building or home where other people with disabilities live.

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). Statistical comparisons of responses based on age and respondent were statistically significant[3] (see Figures 3 and 4). 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. Further, there was a stronger preference for living

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[3] Age: Chi-square(df)=102.54 (12); p<.001; Respondent: Chi-square(df)= 30.45 (4); p<.001

alone or with one or a few roommates as the person on the waiting list got older. The most preferred living situation for all respondents was living with a parent or relative.

Figure 3

Living Preferences by Respondent

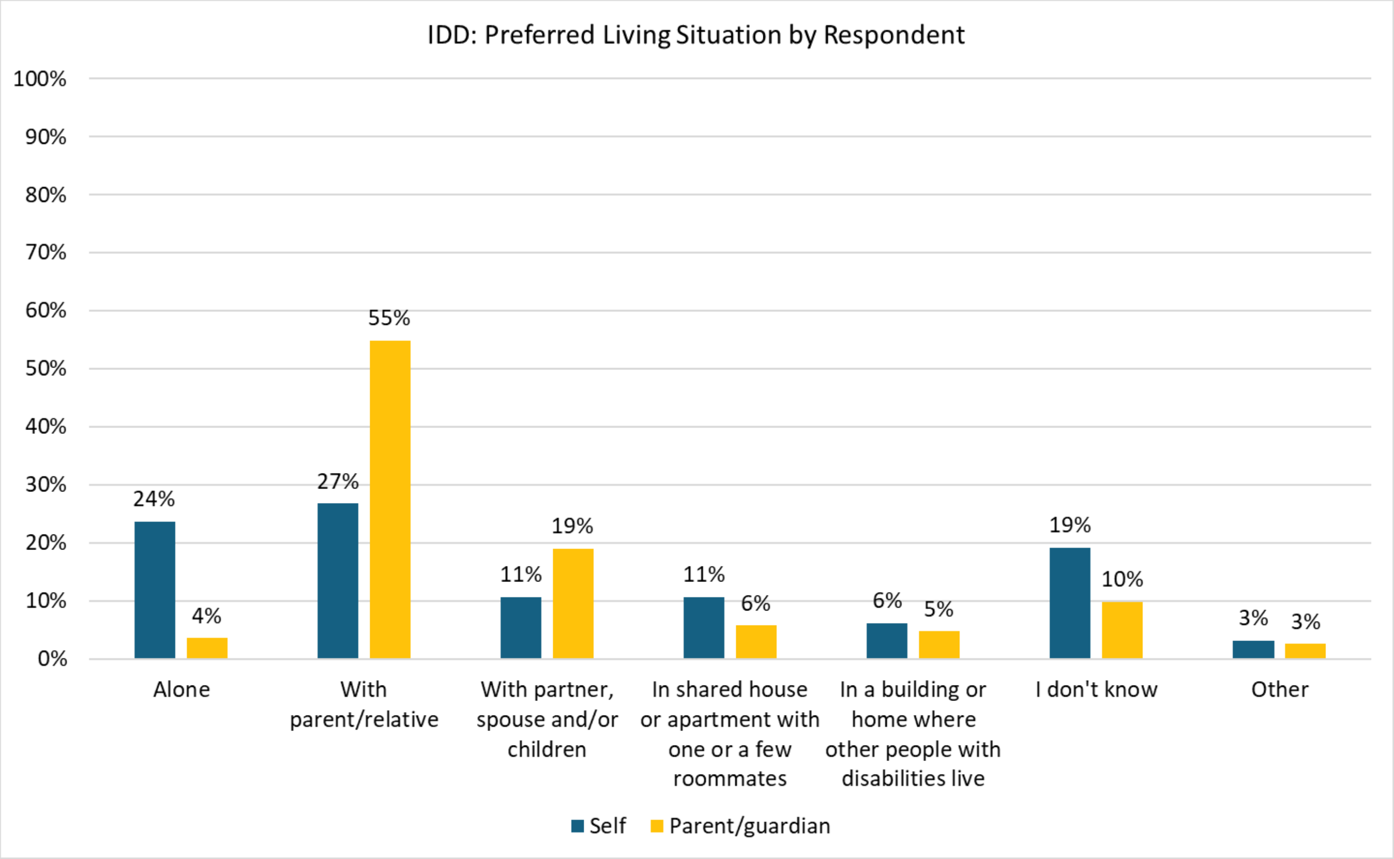
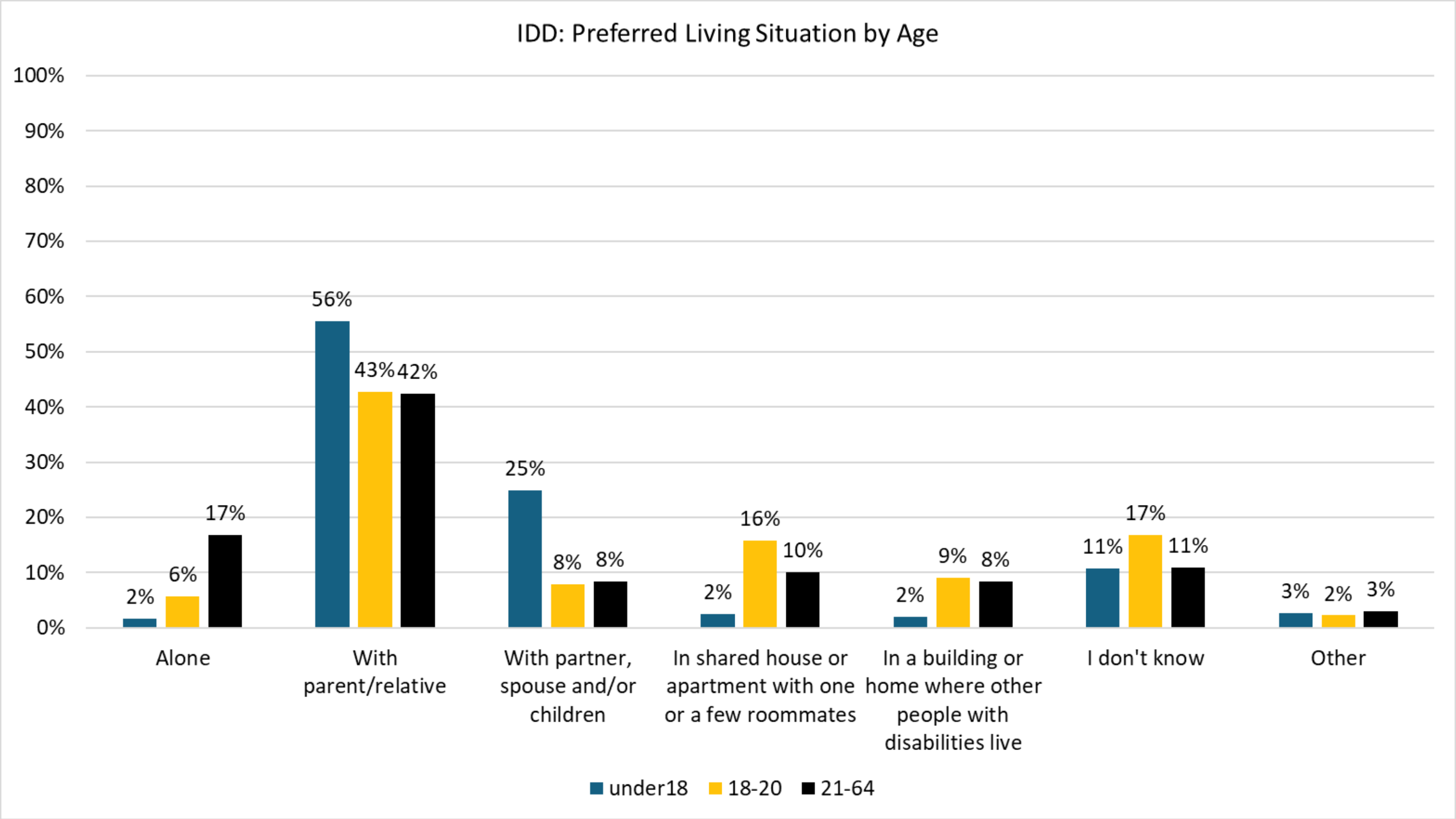


Figure 4

Living Preferences by Age



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.

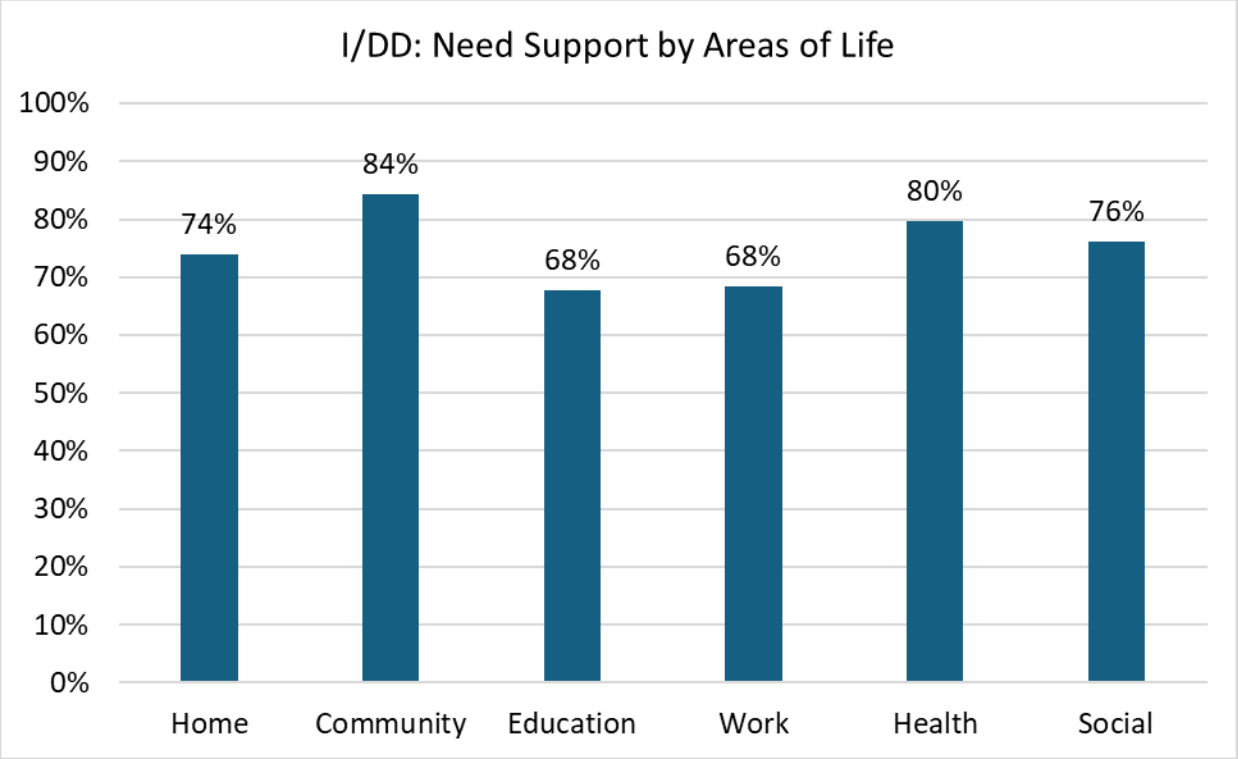
Needed Supports of People Waiting for the I/DD HCBS Waiver

We asked respondents to indicate the type and amount of support the person on the I/DD 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. Appendix D lists the descriptions used in the survey for each of these areas of life.

We first asked respondents to indicate whether or not the person on the waiting list needed support in each area of living. Figure 5 lists the percentage of respondents who indicated that the person on the I/DD waiting list needs support in each area. Figure 7 displays the frequency of needed supports in each area of life.

Figure 5

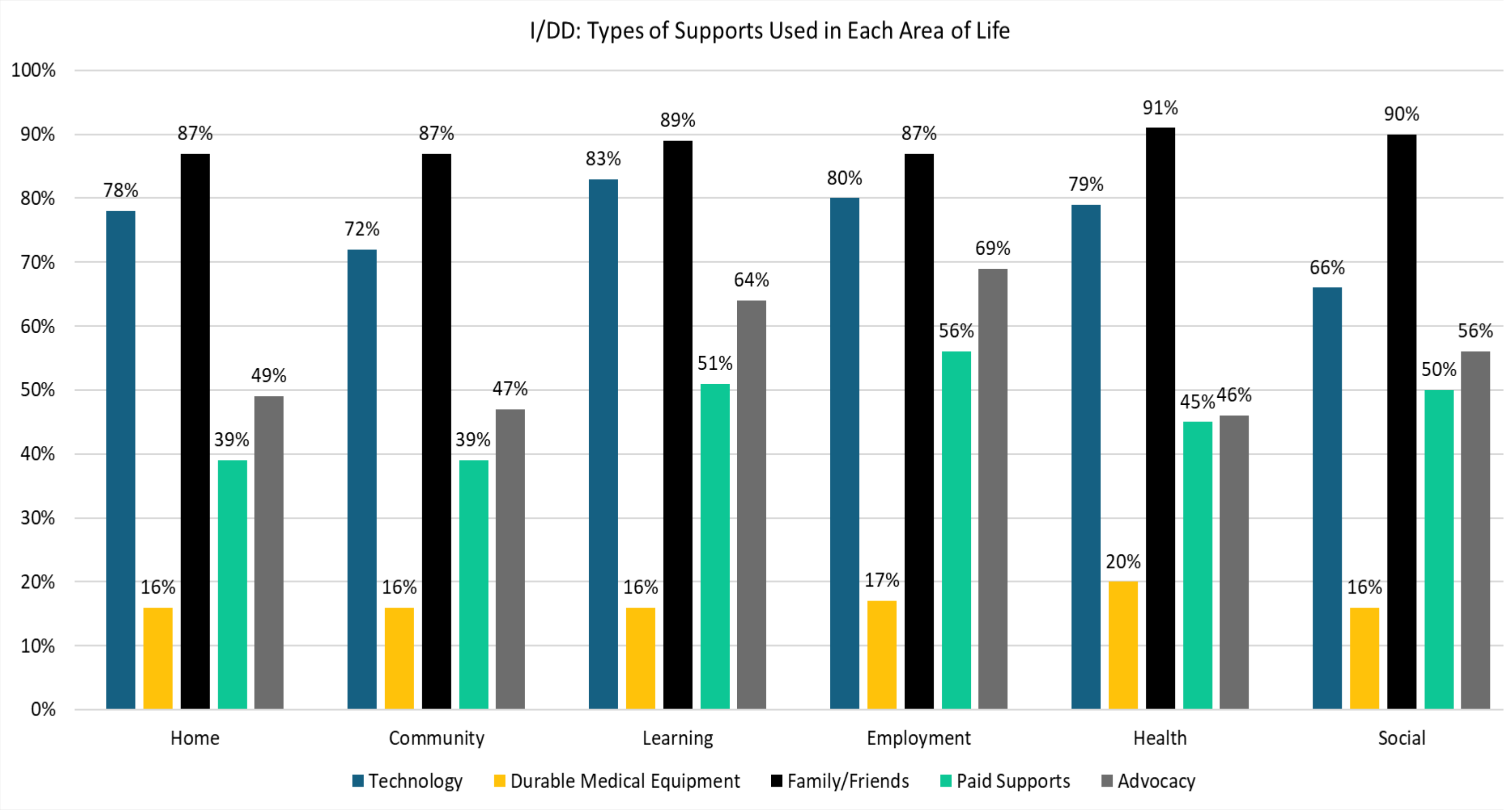
Needed Supports Across Areas of Life for individuals on the I/DD Waiting List



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 6 shows the percentage of responses for each type of support in each area of living.

Figure 6

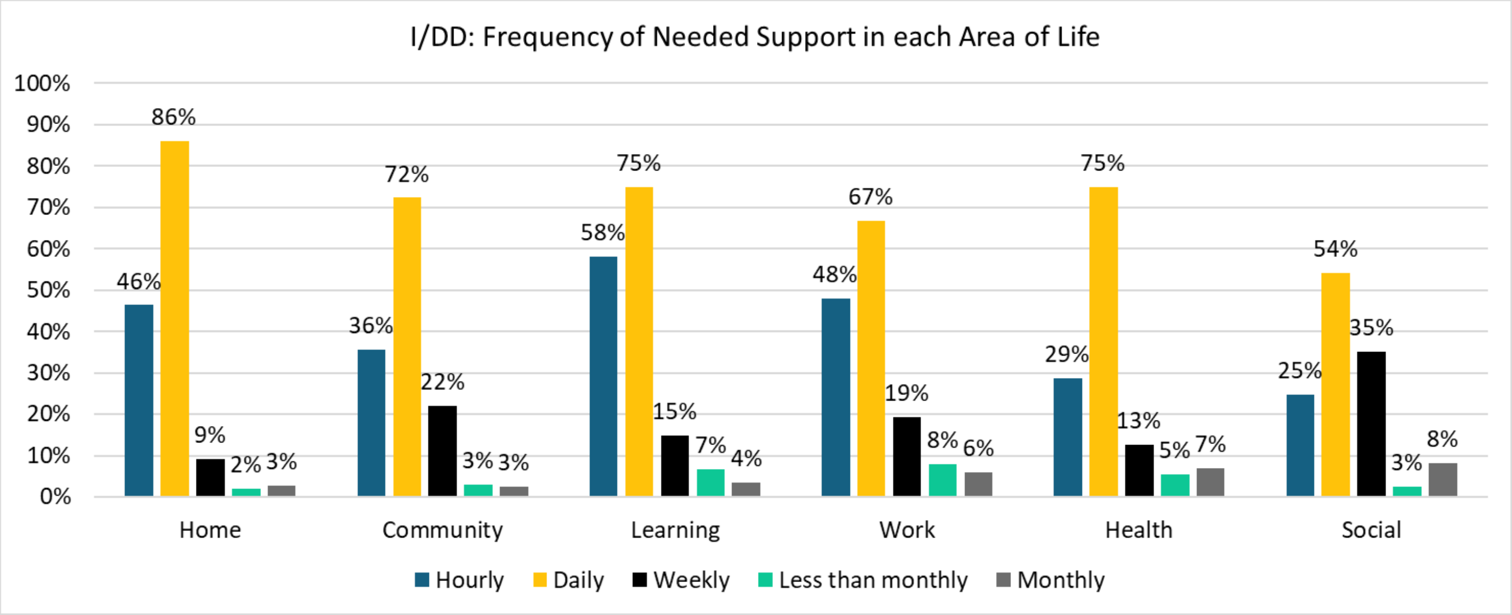
Types of Support



For each area of life, we asked respondents: How often do you usually need support? Figure 7 percentages of responses in each area of life.

Figure 7

Frequency of Needed Supports Across Areas of Life for Individuals on the I/DD Waiting List



Key findings from our analysis of needed supports for individuals on the I/DD waiting list include:

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

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 I/DD 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. In 2017, the President's Committee for People with Intellectual Disability recommended "technical assistance and financial or programmatic incentives to states to promote the use of technology solutions in LTSS" (p. 9). 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 solutions, 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 technology solutions 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 solutions and DME are included in methodologies to set personal budgets.

Support Caregivers Provide to People on the I/DD Waiting List

In the Caregiver Survey, 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 8 and 9 show the frequency (how often) and duration (amount of time) of support provided by caregivers.

Figure 8

Frequency of Support in Each Area of Life

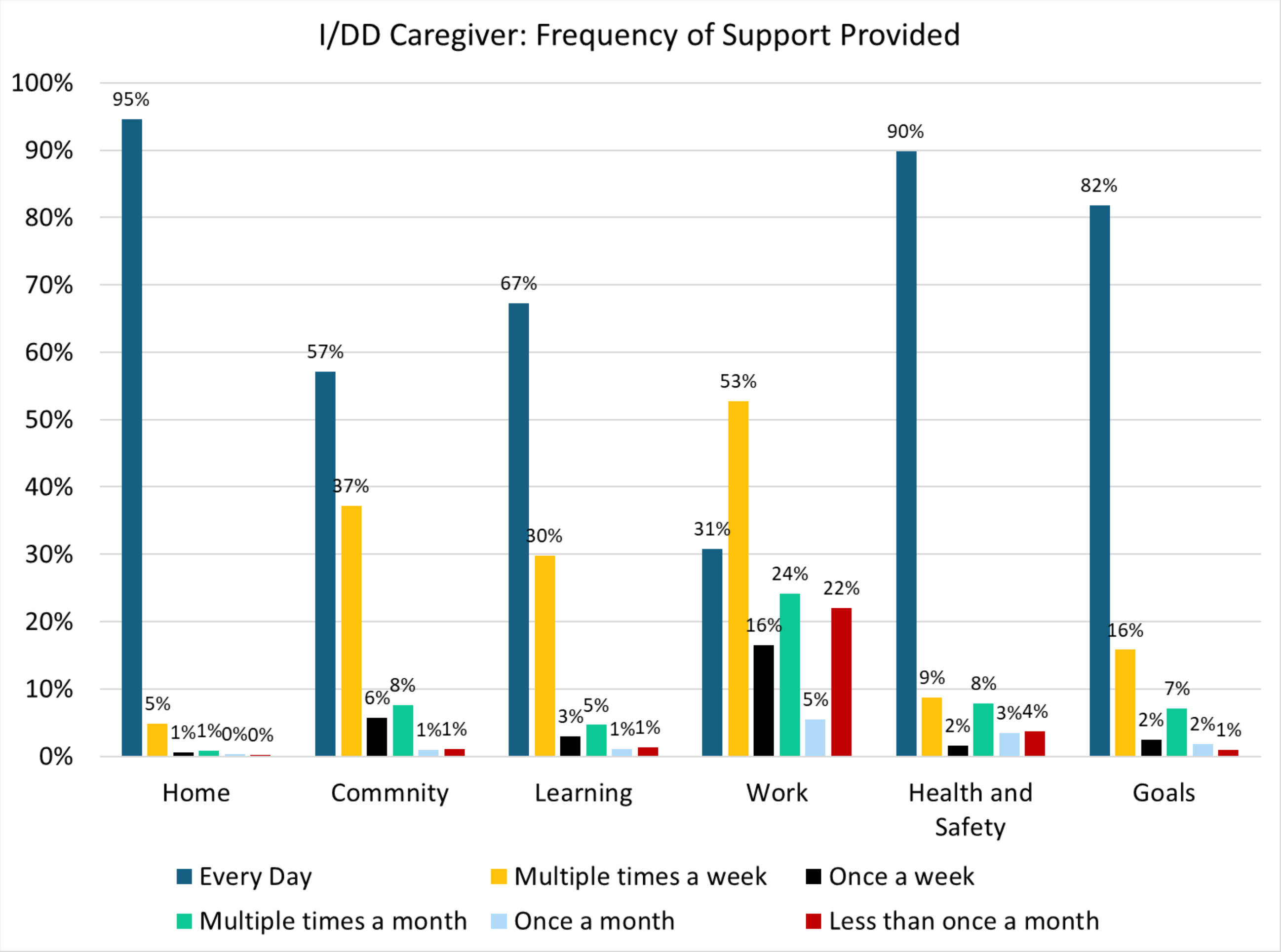
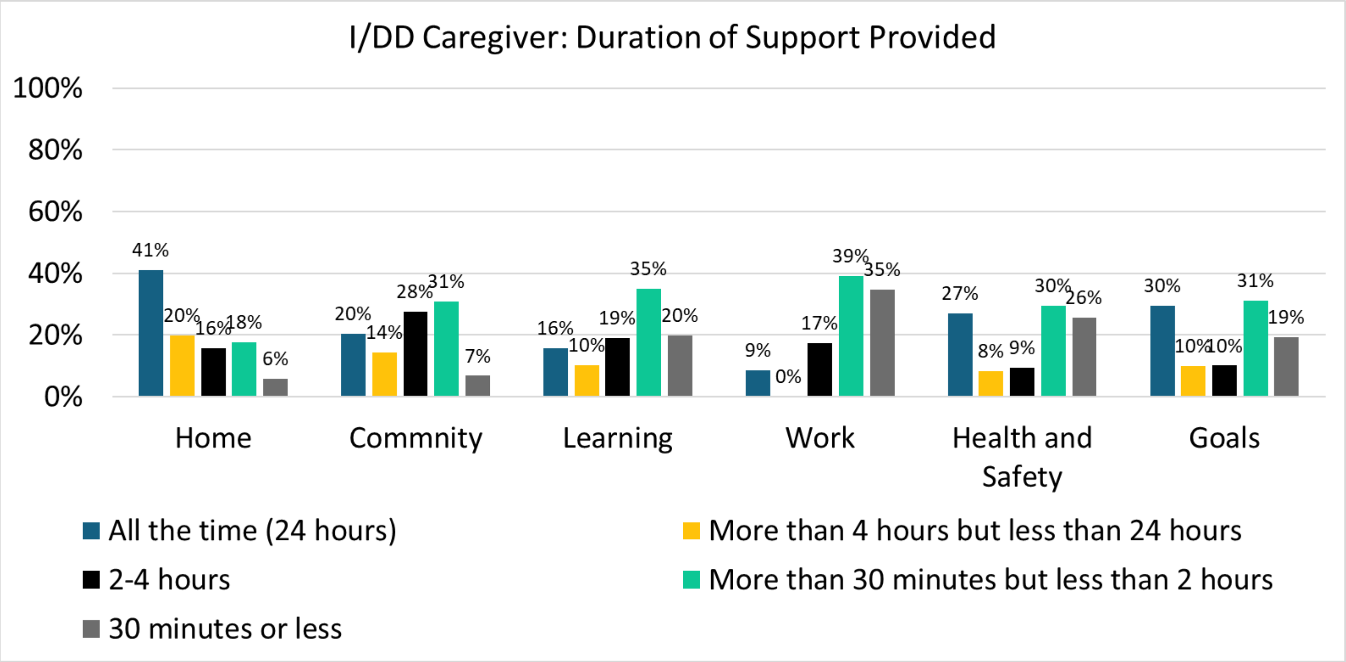


Figure 9

Duration of Support for Each Area of Life When Needed by individuals in the I/DD Waiting List



Key Findings

- 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 I/DD waiting list indicated were areas where more support was needed.
- Nearly all caregivers indicated that they are providing support every day in the family 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 indicated that they provide 24-hour support.

Recommendations:

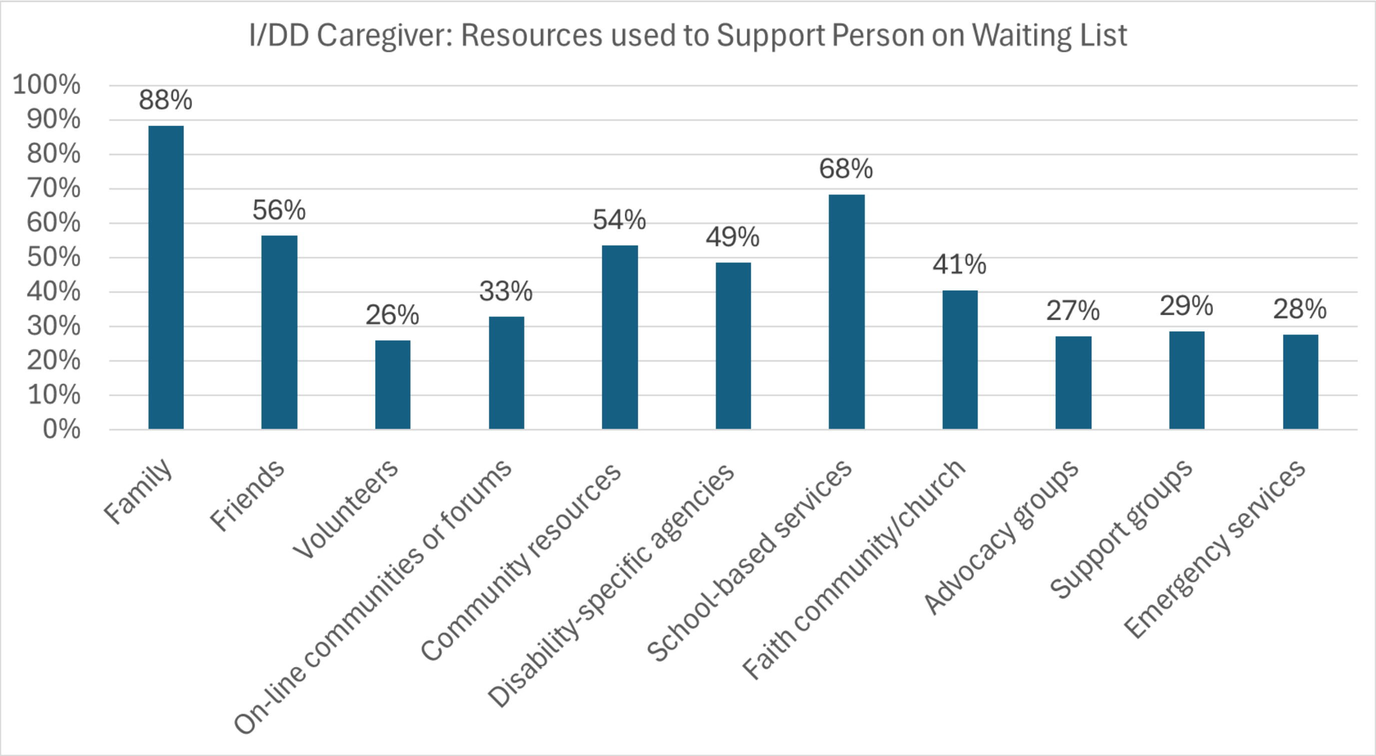
- We found that family members are providing a large amount of unpaid support for the person, which can cause emotional, physical, and financial challenges for the family. Our analysis of crisis exceptions indicated that caregiver stress is a key factor in requesting many crisis exceptions. Thus, a highly 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 they are providing 24 hours of care indicates that a higher cap may be needed for the Community Support Waiver to ensure waiver respondents get the level of support needed.

Resources Caregivers are Accessing in the Community

We asked caregivers about resources they have used to support their caregiving. Figure 10 displays caregiver responses regarding resources. Caregivers could select more than one response.

Figure 10

Resources Used by Caregivers



- Family members were by far the resource most used by caregivers.
- Many caregivers also reported seeking support from schools, community services, friends, and disability-specific organizations (e.g. CDDOs, CILs).
- Of note, about a third of caregivers reported using emergency services.

Recommendation:

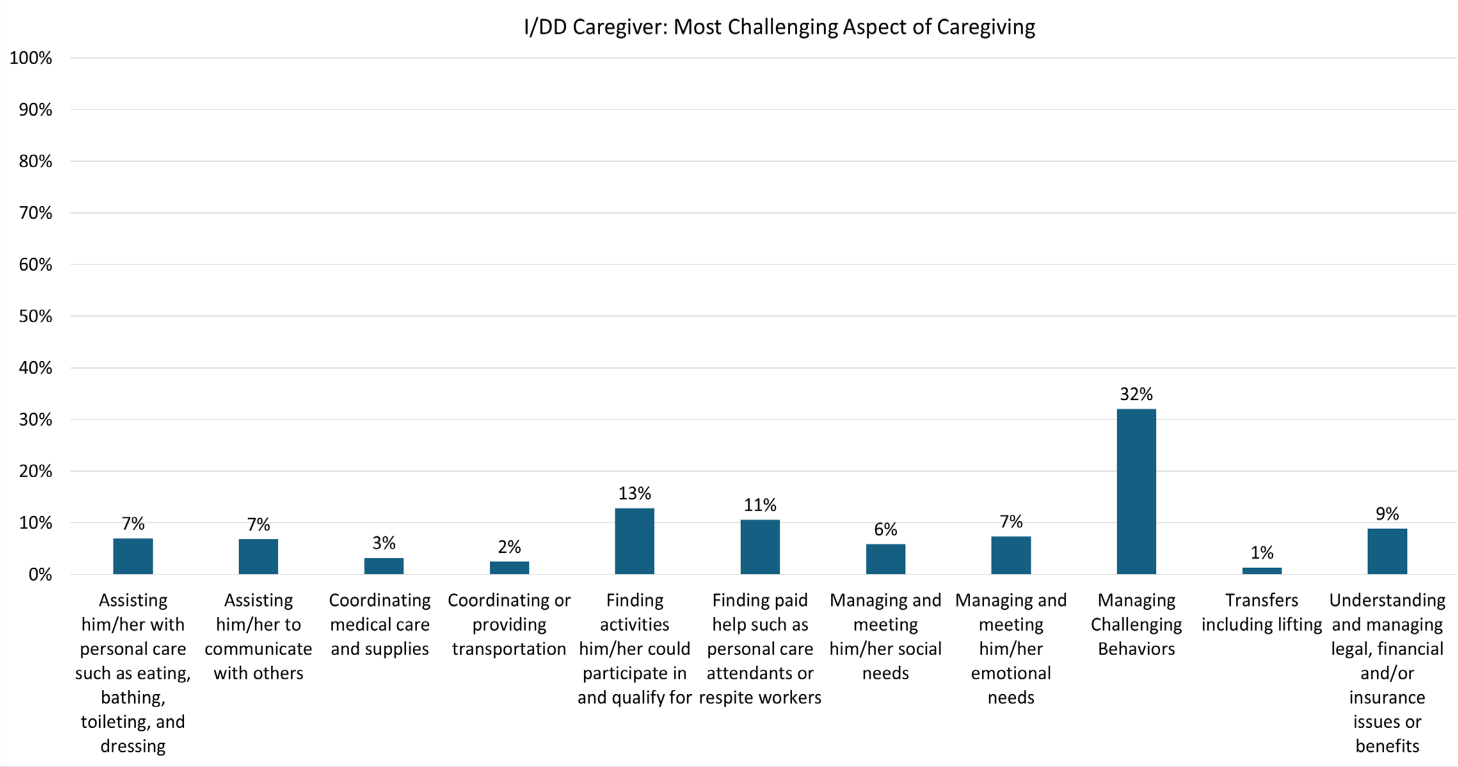
- 30% of caregivers report using emergency services, which are more expensive – higher cost for people being on the waiting list than receiving services – and impacts family wellbeing. Based on this data there needs to be more analysis about frequent use of emergency services by people on the waiting list. It is possible that providing a caped amount of services to people on the waiting list for connecting to services and maintaining their health would cost the state less than people accessing emergency services for care.

Challenges For Caregivers of Individuals on the I/DD Waiting List

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 11 shows the most challenging caregiving tasks. Caregivers could only choose one option.

Figure 11

Most challenging caregiving tasks



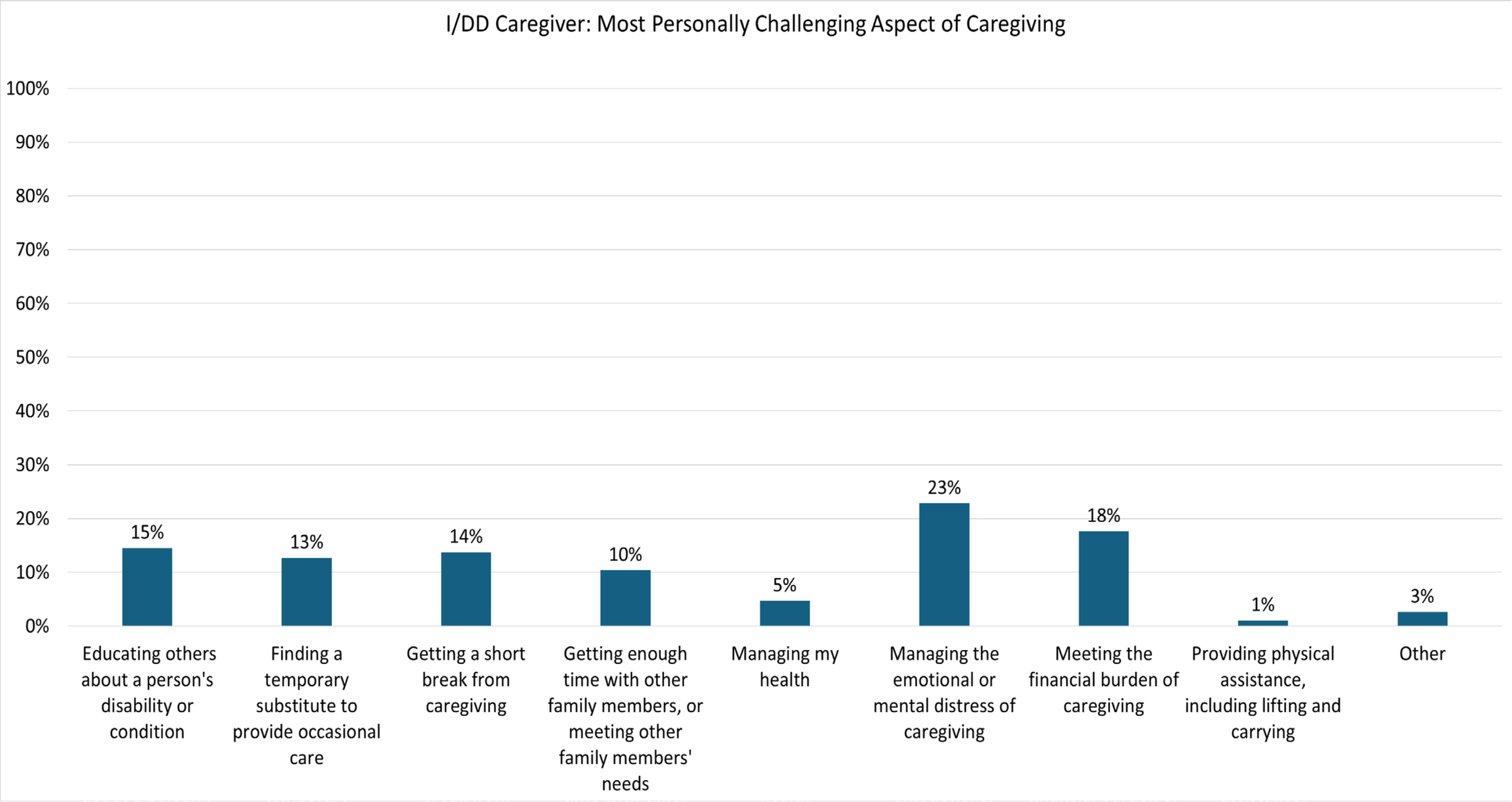
- 30% of caregivers identified managing challenging behavior as the most challenging aspect of caregiving.
- The next two most challenging aspects of caregiving were finding activities (12%) and finding paid supports (11%).

- 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 12 depicts the most challenging aspects of caregiving. Caregivers could only choose one option.

Figure 12

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 this data, there is a need to ensure caregivers (including direct support workers and family caregivers) have adequate support for behavioral needs.
- It is critical that budget authority for the Community Support Waiver includes funding to pay for training to administer the program.
- There is 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.
    - As caregivers age, it may also be valuable to consider a family supports program that supports and facilitates caregiver transitions.

Supporting Health and Community Participation

We asked caregivers about services the person on the I/DD 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:

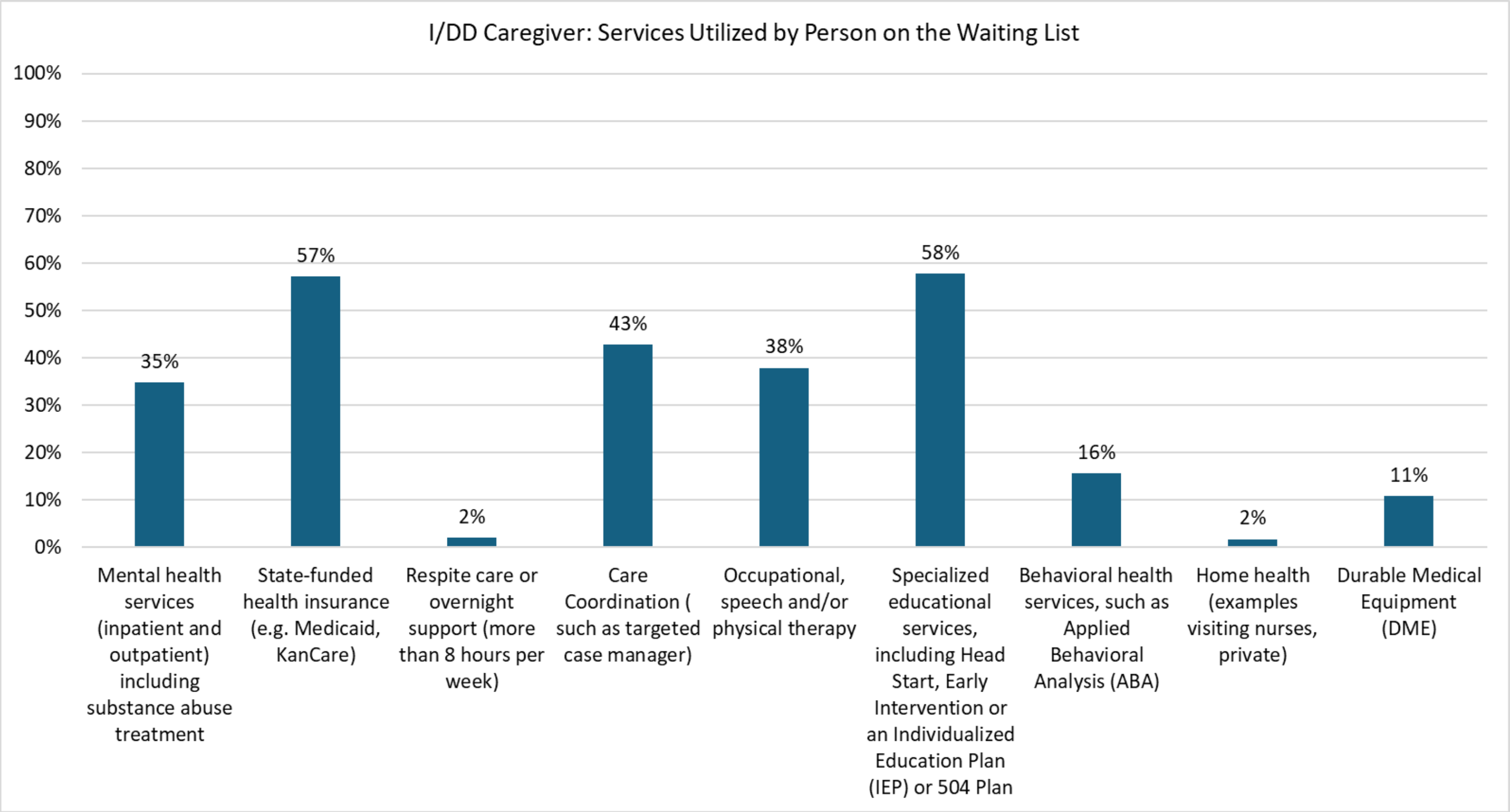
- Caregivers rated the above services as important for supporting the health and participation of the person on the waiting list. It will be important to consider these services as allowable services in the community support waiver or to ensure that some of these services are adequately covered in the state plan. Additionally, for the approximately 40% of people on the I/DD waiting list that qualify, these services can be accessed through EPSDT.
- There is a need to ensure an adequate network of qualified providers of physical, mental and behavioral health services across that state that have the training and capacity to serve people with intellectual and developmental disabilities and other complex physical disabilities.

Services Received by Person on the Waiting List

We asked caregivers about the services the person on the waiting list is receiving. Figure 13 shows caregiver responses. Respondents could select more than one option.

Figure 13

Services Received by Person on the Waiting List

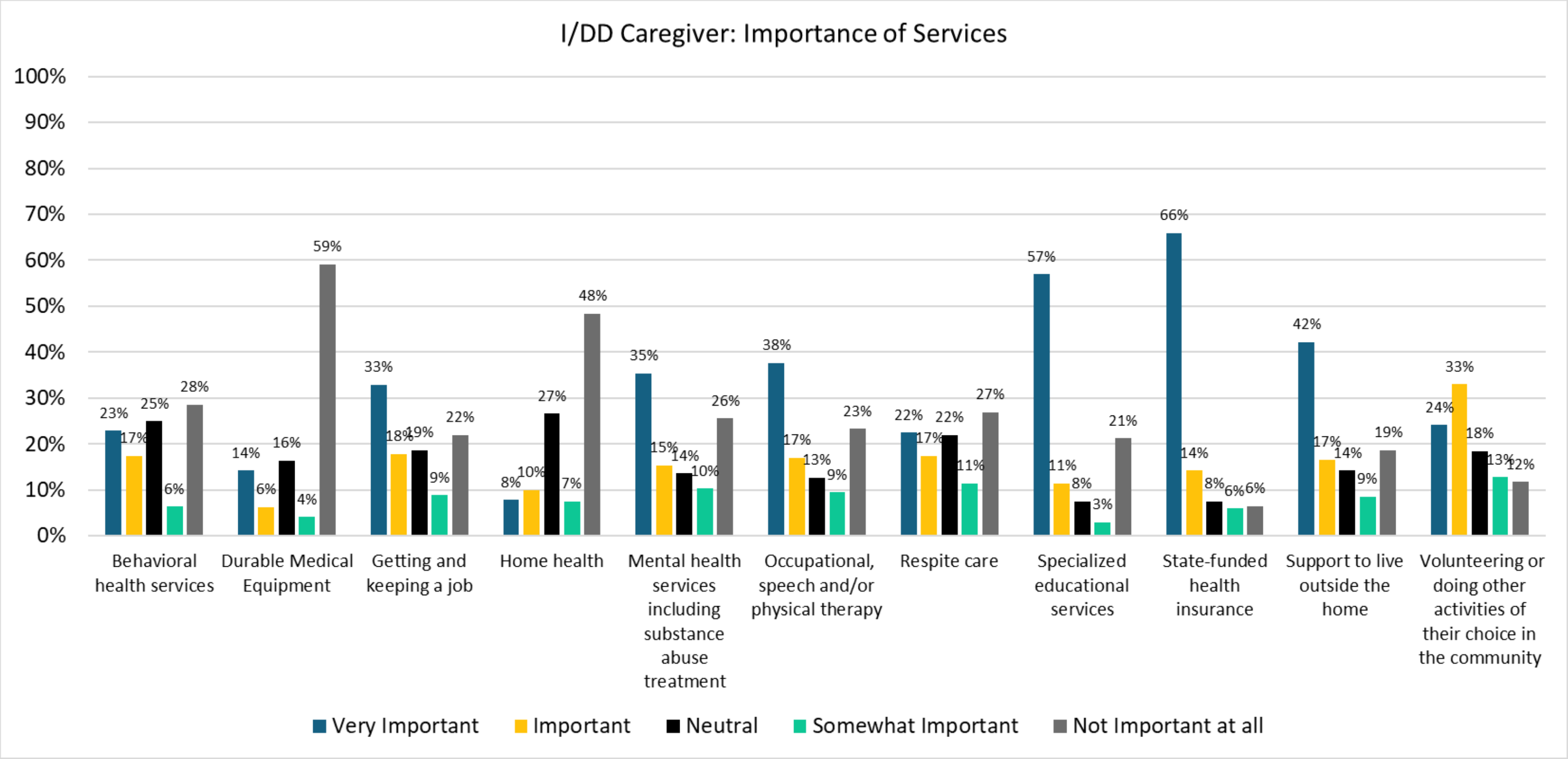


Importance of Services

We asked caregivers about the importance of services for the person on the waiting list. Figure 14 shows caregiver responses. Respondents could select more than one option.

Figure 14

Importance of Services for I/DD Caregiving



Financial Impact of Caregiving

We asked caregivers, about the impacts on their employment due to their caregiving responsibilities, and for an average month, how much do you pay for medicine, medical care, durable equipment, diets or specialized foods, and other types of assistance that is not covered by insurance/benefits (excluding health insurance premiums). Figure 15 shows the impact on caregiver employment. Figure 16 shows the monthly expenditures.

Figure 15

Employment Impact from Caregiving

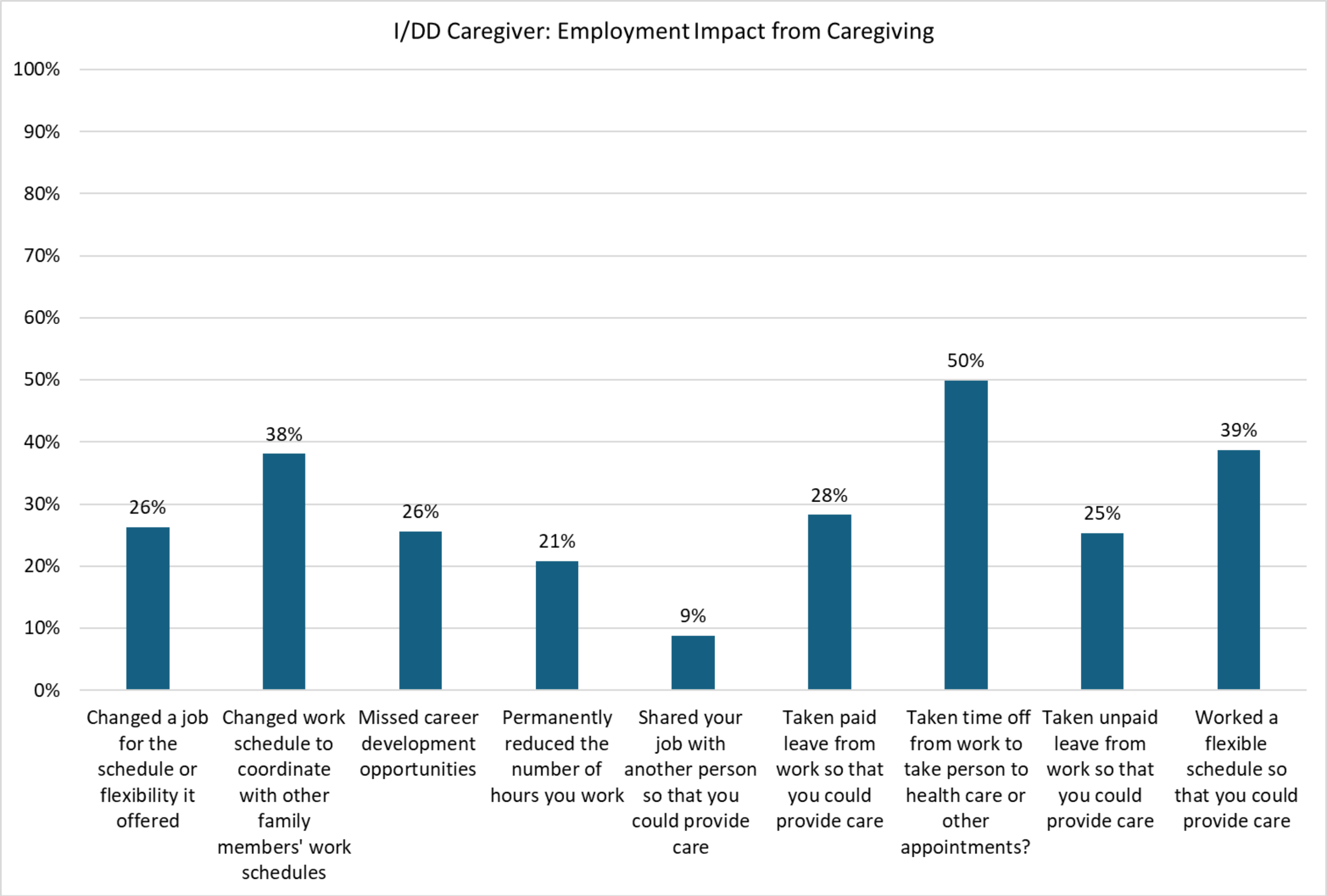
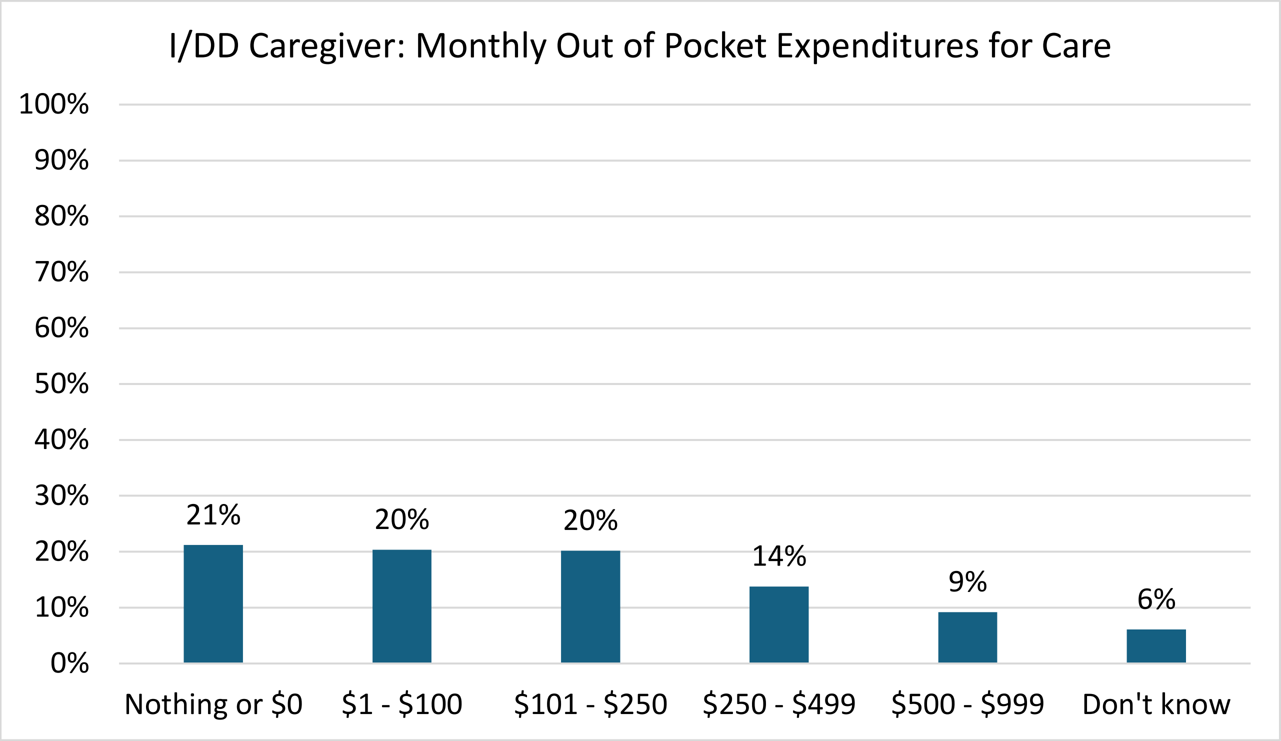


Figure 16

Monthly Caregiver Expenditures to Provide Care



Findings from PD Waiting List and Caregiver Surveys

Demographics

Ninety-nine percent of respondents to the PD waiting list survey were between the ages of 18-64. 72% of Waiting List survey consumer respondents were women. The race of the majority of respondents was White (74%), followed by Black (13%); 8% of respondents identified as Hispanic or Latino/a/x.

Here is information regarding the demographics of caregivers for someone on the PD waiting list who responded to the survey:

- Fifty-six caregivers for people on the PD waiting list completed the Caregiver survey. The average age of caregivers who completed the survey was 44.
- 66% of respondents to the Caregiver survey were women. The race of the majority of respondents to the Caregiver survey was White (71%), followed by Black (13%) and Native American or Alaska Native (5%); 9% of respondents identified as Hispanic or Latino/a/x.
- Thirty-four percent of respondents to the Caregiver survey for someone on the PD waiting list indicated that they were married. 21% indicated that they were divorced, 36% were never married, and 0 were widowed. Marital Status
- Tables 13 and 14 display the highest educational attainment (Table 15) and the annual household income (Table 16) of caregivers who completed the PD Waiting List survey.

Table 13

Highest Education of Respondents to the PD Caregiver Survey

Highest Education of Respondents to the PD Caregiver Survey							
	Did not finish High School or High School Equivalency	High School or High School Equivalency (GED)	Certificate Program, Associates Degree, or Technical Professional Training	Bachelor's Degree	Master's Degree	Doctoral Degree	Prefer not to answer
PD	5	30	12	5	2	0	2

Table 14

Annual Household Income of Respondents to the PD Caregiver Survey

Annual Household Income of Respondents to the PD Caregiver Survey								
	$30,000 or less	$30,001-$60,000	$60,001-$90,000	$90,001-$120,000	$120,001 or more	Don't know	Prefer not to answer	Not respond
PD	33	11	5	2	1	2	2	0

We asked caregivers about the support they provide to the person on the PD 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.

- 64% of respondents indicated that no one was paid to provide supports to the person on the waiting list. 36% 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, 32% of respondents said that someone else was available. 42% said that no one else was available, and 13% said they were not sure.

Employment for People on the Waiting List

Only 6% of respondents to the Waiting List survey indicated that they had jobs. Of those, over 90% said that they made at least minimum wage. Most indicated that they liked their job and worked 10-20 hours.

57% of respondents said that they either had some support but needed more or did not have any support for finding a job. This finding indicates a critical area of need for people on the waiting list – to ensure they have access to job development supports, such as Vocational Rehabilitation, pre-Employment Transition Services, and WIOA services through the Workforce Centers.

Education

Only 1% of respondents to the waiting list survey indicated that the person on the PD waiting list was a student. Few respondents on the PD waiting list completed survey questions about continuing their education, making the educational support needs of people on the PD waiting list difficult to determine.

Health

Over 90% of respondents indicated that their health was either fair or poor. There were no statistical differences based on age, region of the state, or population density, indicating that people on the PD are in fair to poor health regardless of age or location.

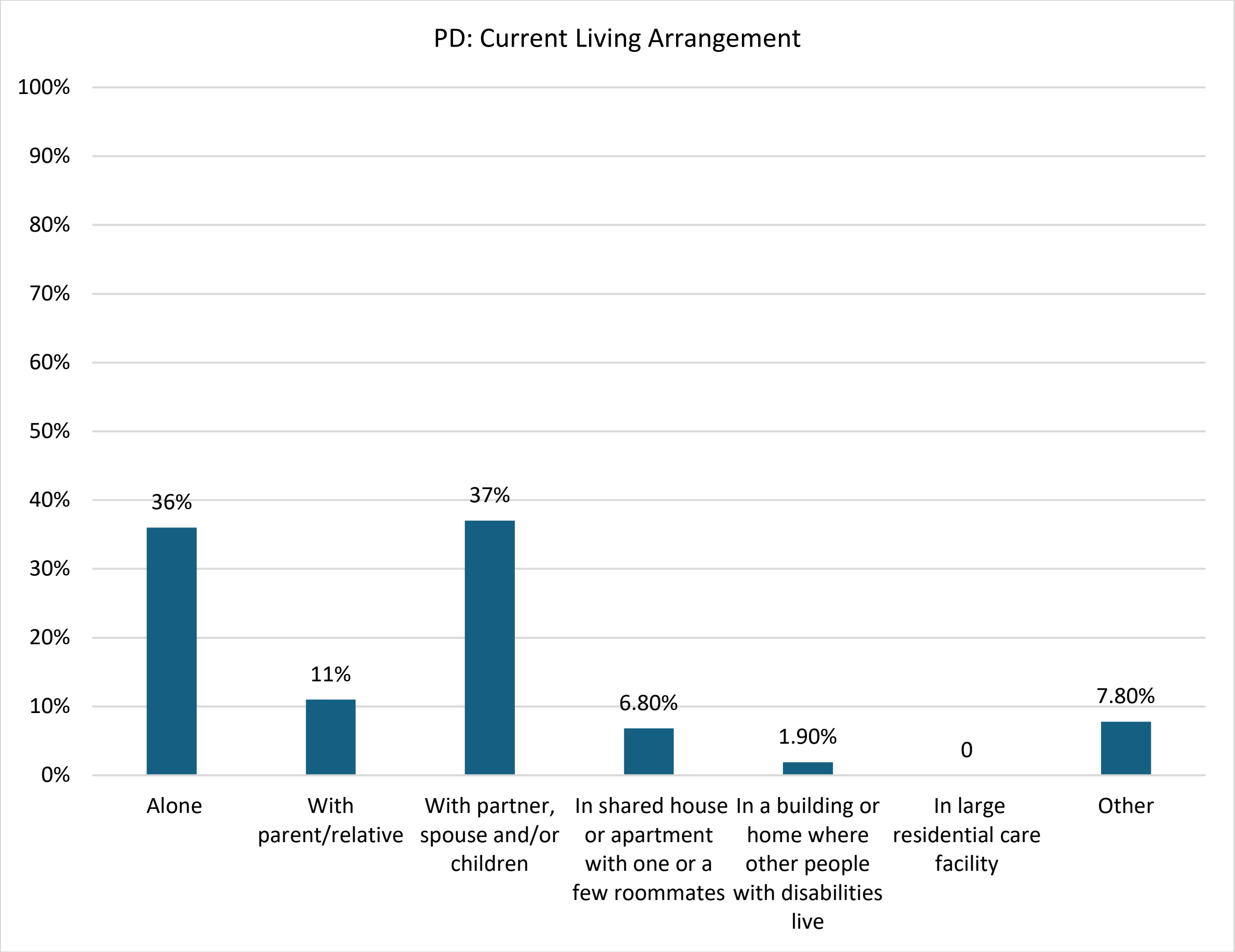
Current Living Situation

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

- 37% lived with a partner, spouse, or children.
- 36% lived alone.
- 11% of respondents reported that the person on the waiting list lived with a parent or other relative.
- The remaining 16% lived either in shared housing, a building or home with other people with disabilities (e.g. a group home),.

Figure 17

PD Current Living Arrangement

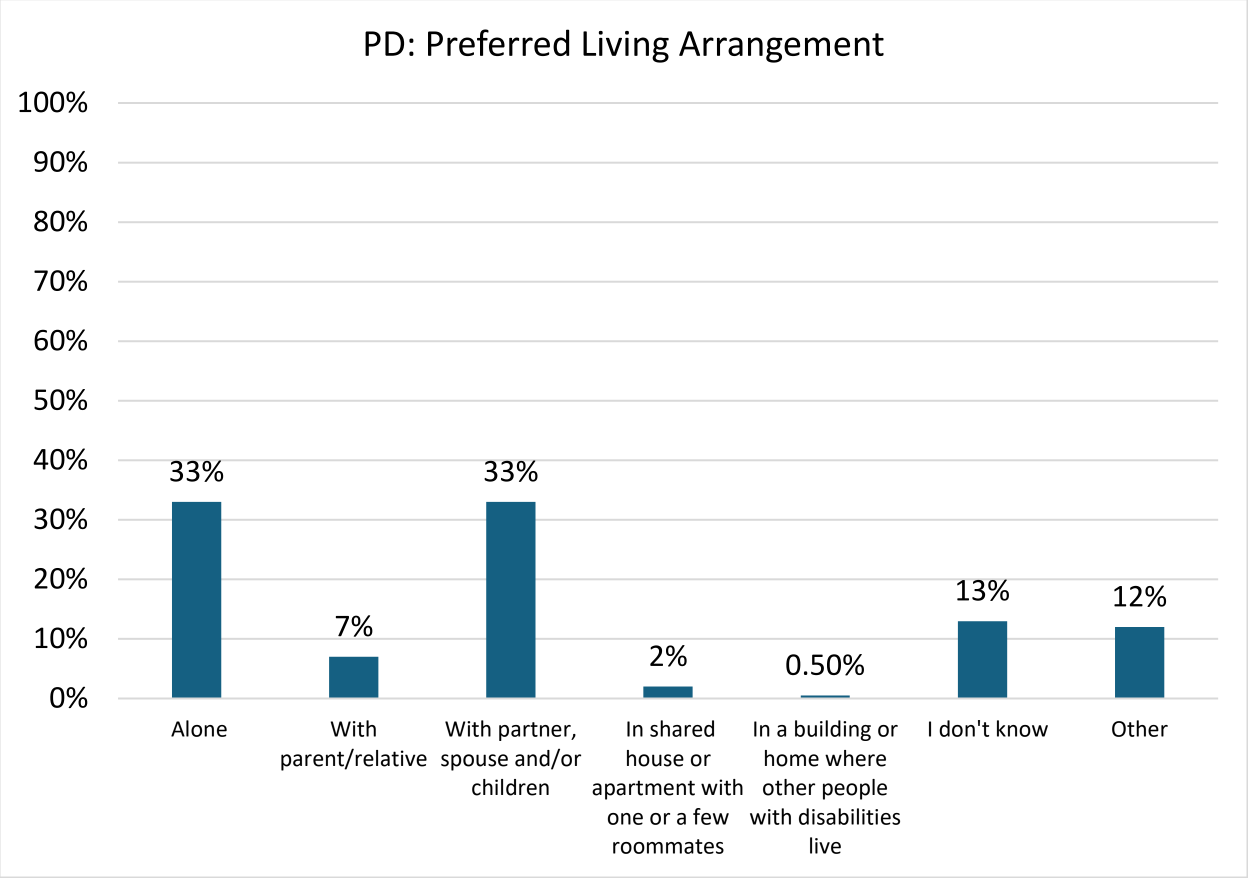


Living Preferences

We asked respondents where the person on the PD waiting list would like to live. Figure 18 shows people on the waiting list's living preferences. Of note, few respondents indicated that they prefer to live in a building or home where other people with disabilities live.

Figure 18

Living Preferences



Statistical comparisons of responses based on age and geographical location were not statistically significant meaning that the living preferences for people on the PD waiting list were similar across the state.

Recommendations:

- These results suggest a strong preference for 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.

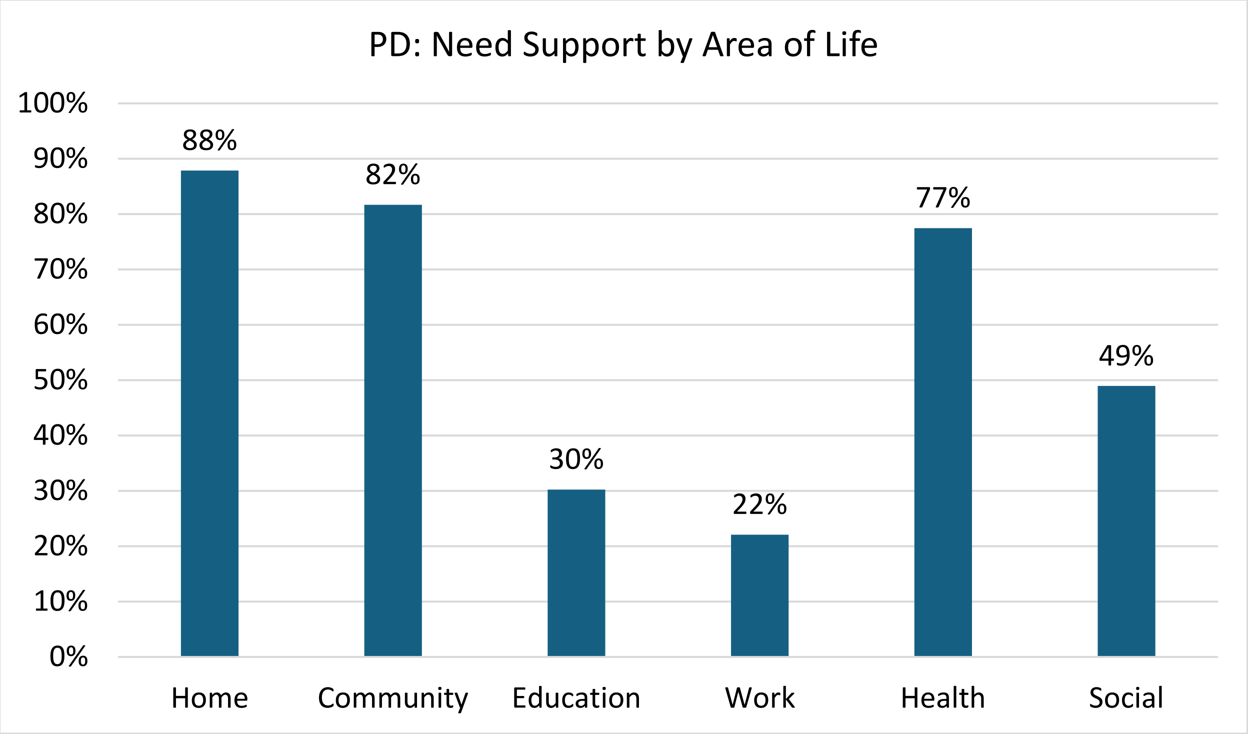
Needed Supports of People Waiting for the PD HCBS Waiver

We asked respondents to indicate the type and amount of support the person on the PD 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. Appendix D lists the descriptions used in the survey for each of these areas of life.

We first asked respondents to indicate whether or not the person on the waiting list needed support in each area of living. Figure 19 lists the percentage of respondents who indicated that the person on the PD waiting list needs support in each area. Figure 21 displays the frequency of needed supports in each area of life.

Figure 19

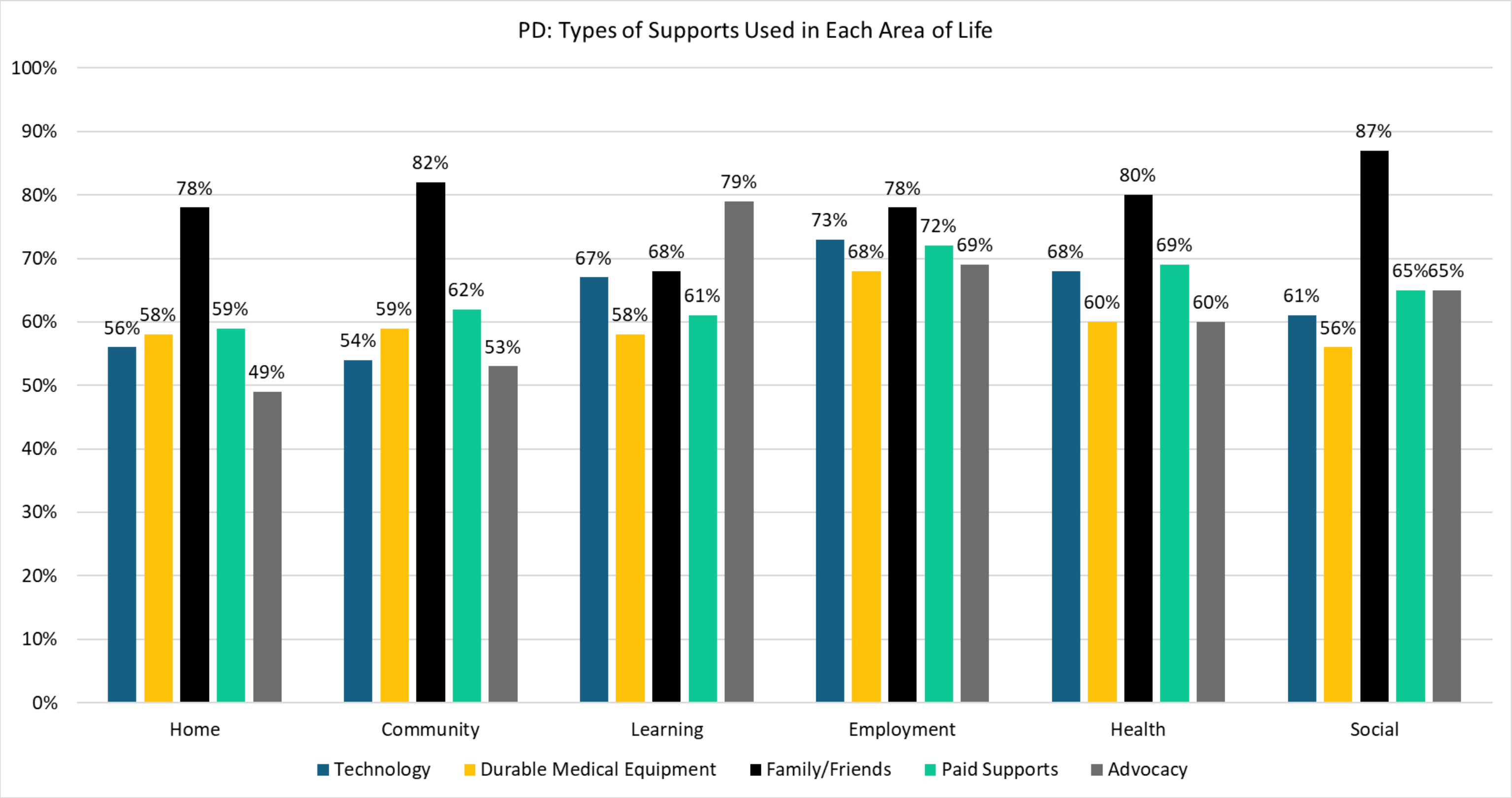
Needed Supports Across Areas of Life for individuals on the PD Waiting List



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 20 shows the percentage of responses for each type of support in each area of living.

Figure 20

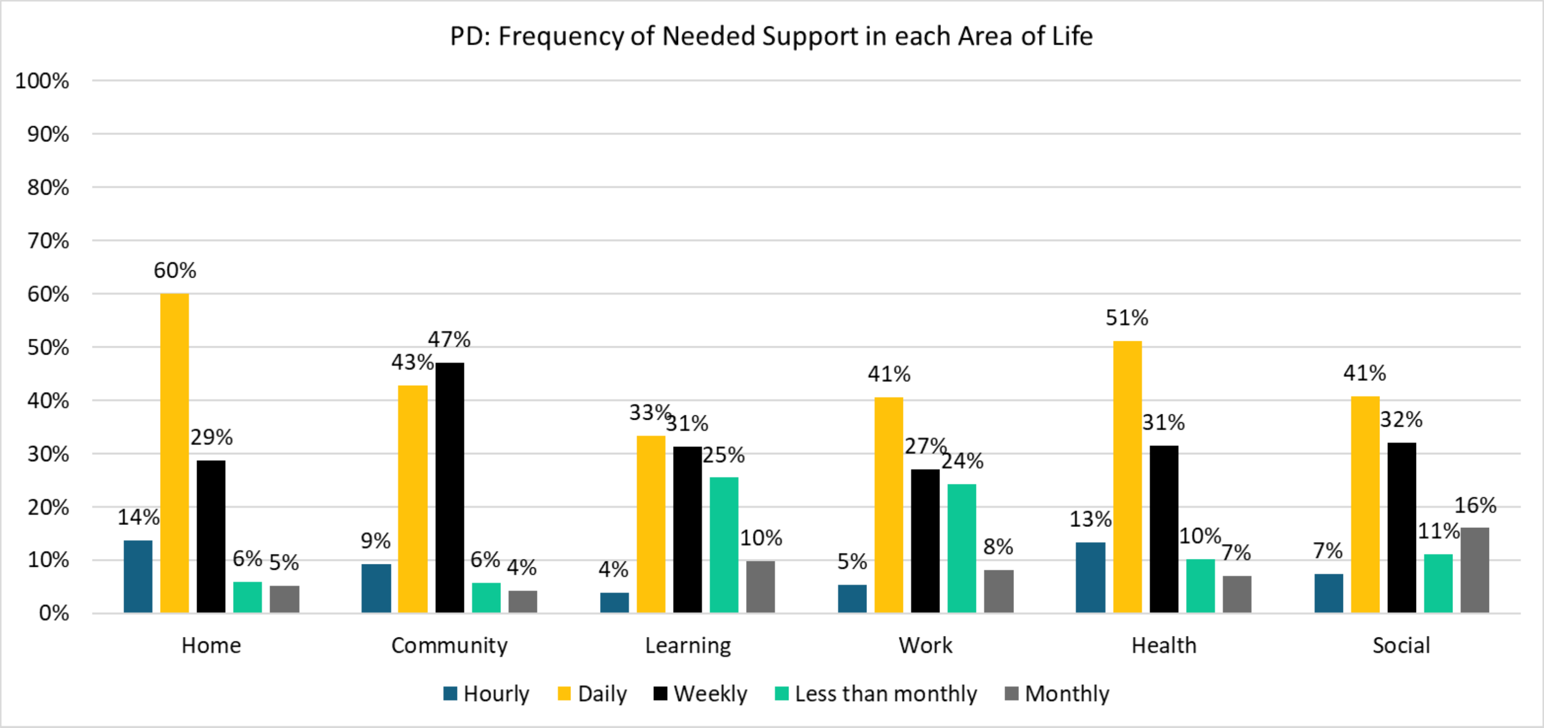
Types of Support



For each area of life, we asked respondents: How often do you usually need support? Figure 21 percentages of responses in each area of life.

Figure 21

Frequency of Needed Supports Across Areas of Life for Individuals on the PD Waiting List



Key findings from our analysis of needed supports for individuals on the PD waiting list include:

- In each area of life, between 40% and 60% of respondents indicated the person on the waiting list needed daily support.
- Between 24-47% of respondents in each life area also indicated that the person on the waiting list needs support weekly.
- In each area, Family and Friends were the most common type of support needed, however all types of support were needed frequently.

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

Recommendations:

- This report gives us new information about the frequency of support needed by people on the PD waiting list. In each area of life, the majority of respondents indicated that the person on the waiting list needed daily support. Given the difficulty that people on the PD waiver already experience finding paid caregivers, this finding is further evidence of the need to address the caregiver crisis. One potential solution is to allow people receiving services to pay caregivers a competitive wage for their services.
- Although a majority of participants needed daily supports, a substantial portion indicated they needed supports weekly or less. This group could be well-served by a state LTSS plan offering personal care services.

Support Caregivers Provide to People on the PD Waiting List

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 22 and 23 show the frequency (how often) and duration (amount of time) of support provided by caregivers.

Figure 22

Frequency of Support in Each Area of Life

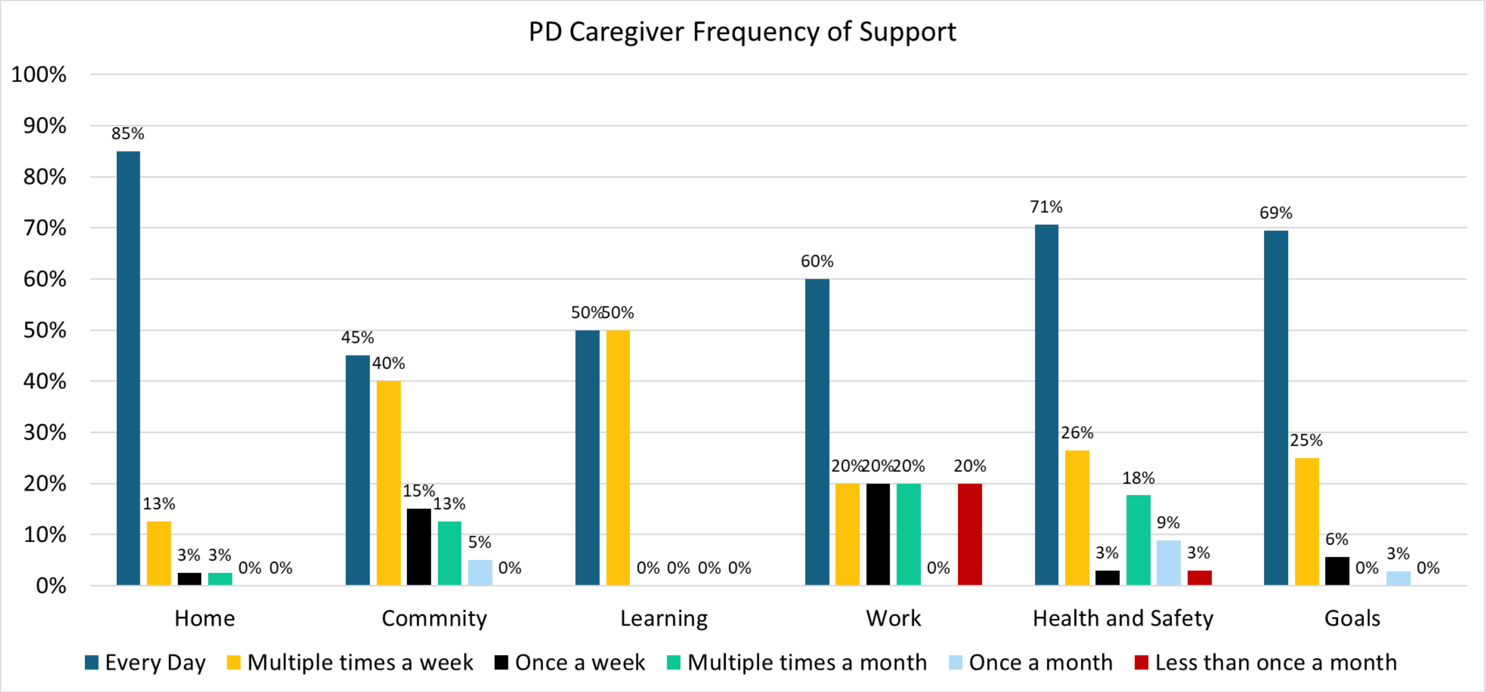
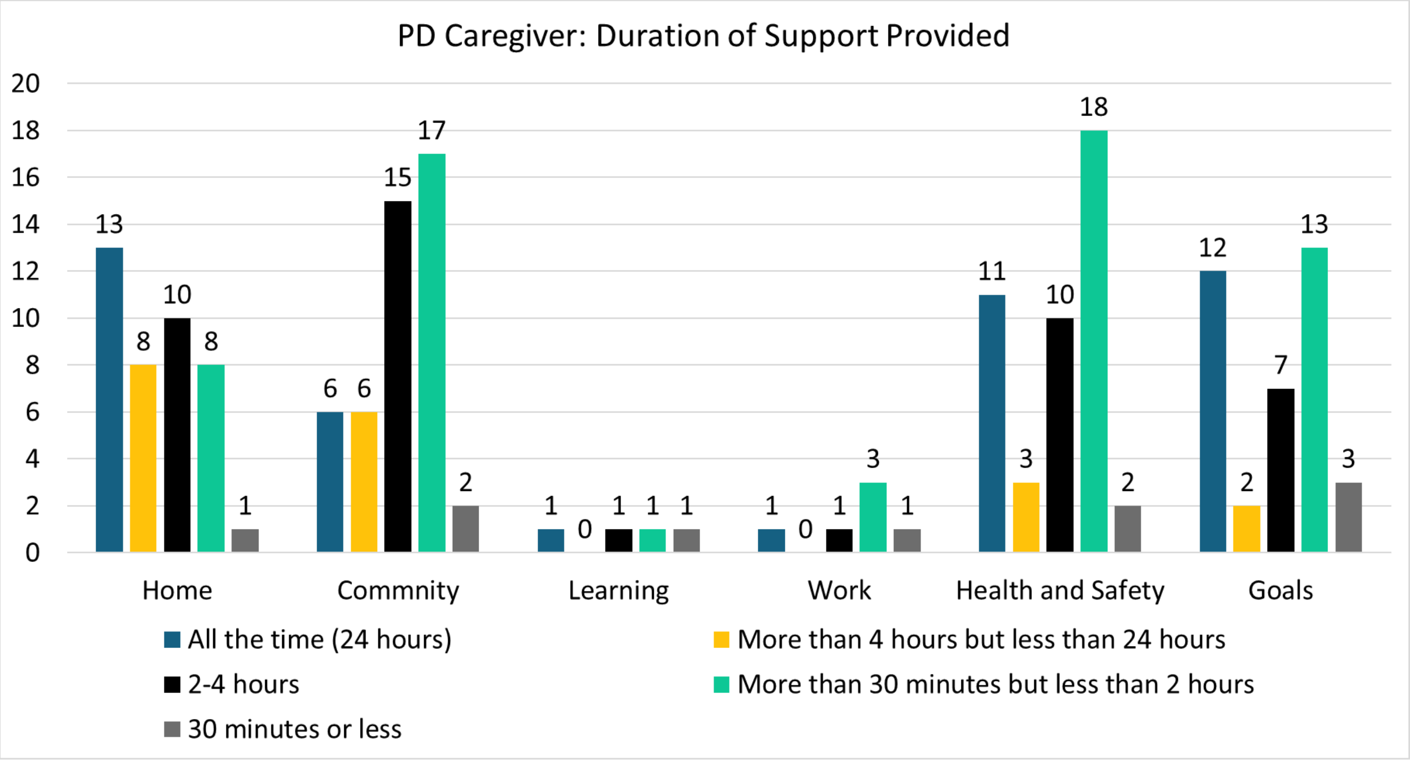


Figure 23

Duration of Support for Each Area of Life When Needed by Individuals on the I/DD Waiting List

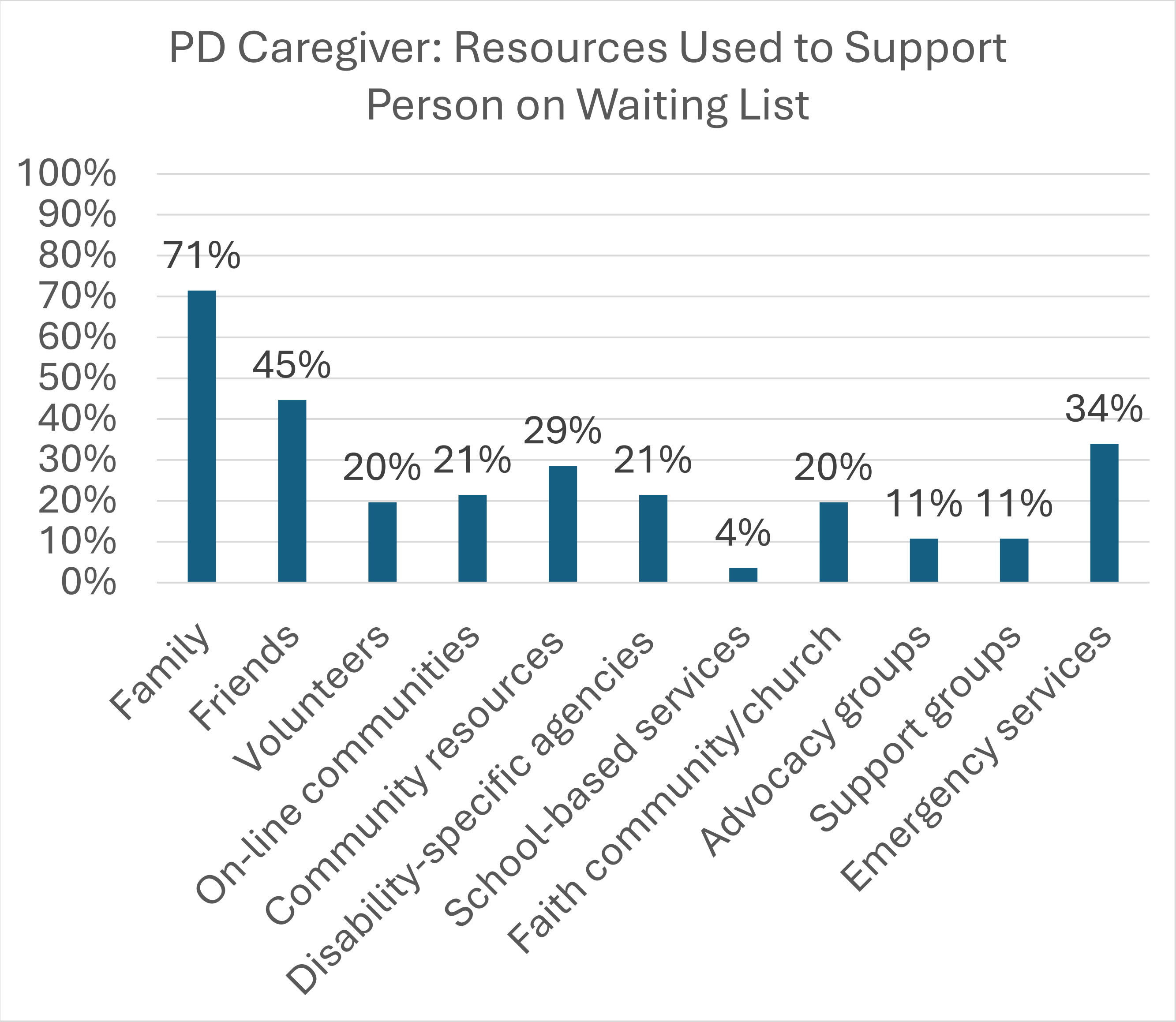


Resources Caregivers are Accessing in the Community

We asked caregivers about resources they have used to support their caregiving. Figure 24 displays caregiver responses regarding resources. Caregivers could select more than one response.

Figure 24

Resources Used by Caregivers



- Family members were by far the resource most used by caregivers.
- Of note, about a third of caregivers reported using emergency services.

Recommendation:

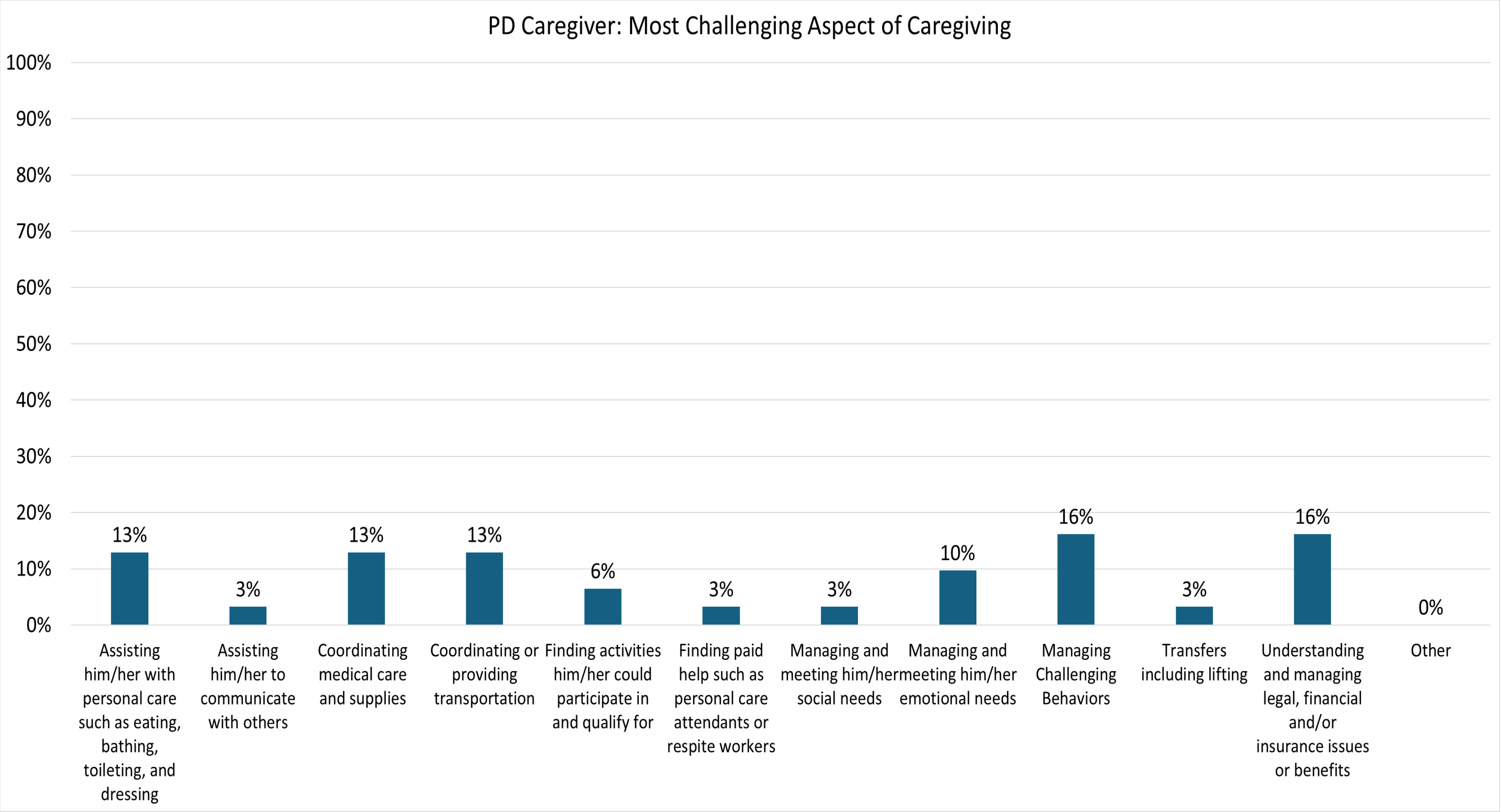
- 30% of caregivers report using emergency services, which are more expensive – higher cost for people being on the waiting list than receiving services – and impacts family wellbeing. Based on this data there needs to be more analysis about frequent use of emergency services by people on the waiting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

Challenges For Caregivers of Individuals on the I/DD Waiting List

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 25 shows the most challenging caregiving tasks. Caregivers could only choose one option.

Figure 25

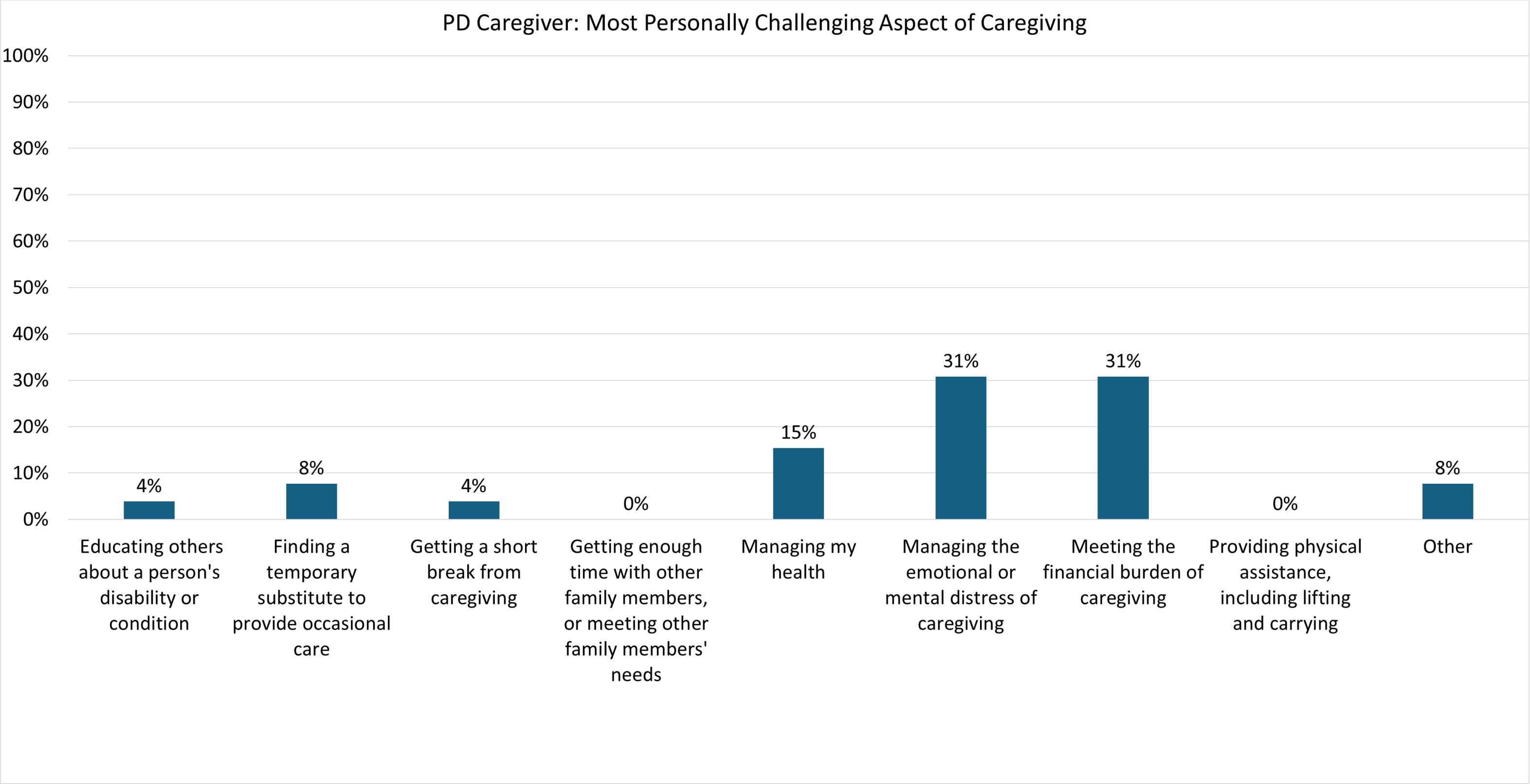
Most challenging caregiving tasks



We also asked caregivers to identify the MOST PERSONALLY CHALLENGING aspect of caregiving. Figure 26 depicts the most challenging aspects of caregiving. Caregivers could only choose one option.

Figure 26

Most Personally Challenging aspects of Caregiving



- The aspects of caregiving most highly endorsed by caregivers as MOST PERSONALLY CHALLENGING were managing the emotional or mental distress of caregiving and meeting the financial burden of caregiving (31%)

Supporting Health and Community Participation

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

Access to state-funded health insurance was the service used by most people on the PD waiting list (67%). Mental health services were used by 30% of people on the PD waiting list, 17% used care coordination services, and 14% used occupational, speech, and/or physical therapies. Respondents also rated these services as very important or important.

Recommendation:

- Caregivers rated the above services as important for supporting the health and participation of the person on the PD waiting list. It will be critical to ensure an adequate network of qualified service providers to ensure people across the state have access to these services

Employment Impact of Caregiving

We asked caregivers about the impacts on their employment due to their caregiving responsibilities. Figure 27 shows the impact on caregiver employment. Figure 27 shows the monthly expenditures.

Figure 27

Current Employment Status of Caregivers for Person on PD Waiver

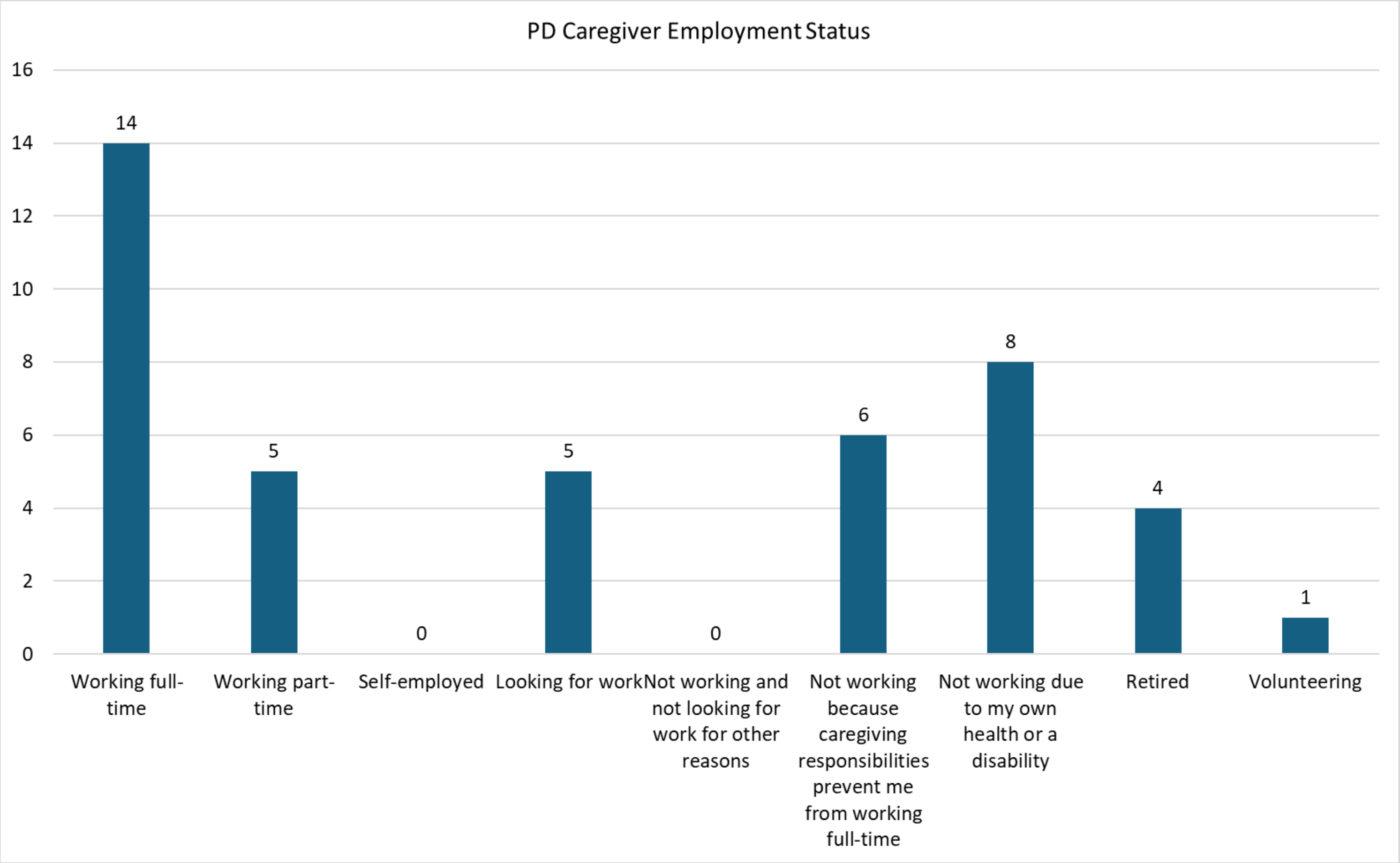
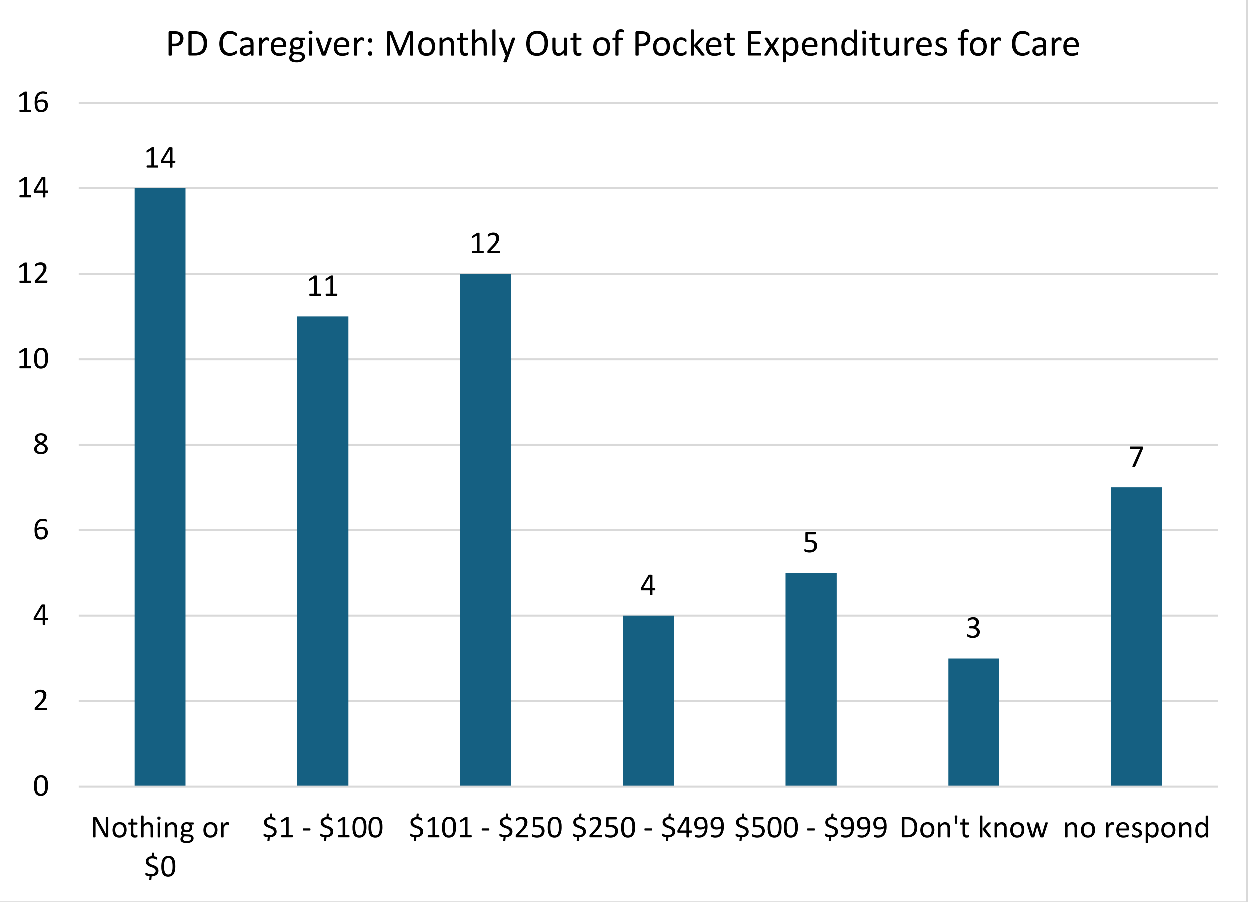


Figure 28

Monthly Caregiver Expenditures to Provide Care



Waiting Lists Management Strategies in Other States

To inform our recommendations based on this study, it was critical that we understand practices that other states use to manage their waiting lists. Many states are grappling with HCBS waiting lists, but information on waiting list management strategies across states is limited ((Burns et al., 2023)). Thus, we conducted a national study, consisting of a survey and semi-structured group meetings with state waiver representatives, to learn from other states' management of their I/DD and PD waiting lists. This project represented one of the most robust initiatives to understand how different states manage and seek to reduce their waiting lists.

Methods

We identified states with current or recent I/DD or PD HCBS 1915(c) waiting lists based on Kaiser Family Foundation (KFF) reports that have tracked HCBS waiting list sizes over time ((KFF, 2023; Musumeci et al., 2020; Ng et al., 2016). Data from the State of States in Intellectual Disabilities project also informed data collection efforts. We contacted HCBS administrators in these states to invite them to complete a survey and participate in information exchange meetings on waiting lists characteristics and management strategies. Seventeen states (out of 35) with current or recent waiting lists for waiver services for people with intellectual and developmental disabilities and ten states (out of 21) with current or recent waiting lists for waiver services for people with physical disabilities participated in this effort (Table 15) Additionally, administrators from Wisconsin declined participation because they no longer had waiting lists but provided a brief email response on strategies used to eliminate their waiting lists. A few states participated in only the survey or the meetings, and not both.

Table 15

Participating States by Waiting List Type

Participating States on I/DD waiting lists	Participating States on PD waiting lists
1. Alaska	1. Alabama*
2. Colorado	2. California
3. Connecticut	3. Iowa
4. Georgia	4. Kansas
5. Iowa	5. Michigan
6. Indiana	6. Missouri*
7. Kansas	7. Montana
8. Kentucky	8. Nevada
9. Mississippi	9. Utah
10. Nebraska	10. West Virgina
11. North Dakota*	
12. Nevada	
13. Ohio	
14. Oklahoma	
15. Pennsylvania	
16. Utah	
17. Wyoming	

**Alabama and North Dakota eliminated their waiting lists in recent years and did not have a waiting list at time of participation; Missouri did not have a waiting list at the time of participation, but noted that they sometimes still have waiting lists develop.*

The surveys collected information on waiting list size and trends, policies, challenges, and strategies. The survey also asked state administrators to indicate questions they would like to discuss with other states during the information exchange meetings. Following the surveys, we hosted four meetings with state administrators about I/DD waiting lists and three for PD waiting lists, from June through August 2023. In these information exchange meetings, we summarized results from the surveys and moderated a discussion on strategies and challenges in waiting list management. The information provided by state administrators through either the surveys or information exchange meetings was complemented by reviewing their waiver applications for additional information on waiver criteria and capacity.

Findings

Waiting List Characteristics and Key Policies

PD waiting lists across participating states ranged from 53 to 7,995 individuals on the waiting list, with the longest length someone can be on the waiting list ranging from 1.5 months (Wyoming) to 22 years (Utah) but most states clustering between 1-3 years. For I/DD, waiting list sizes ranged from 235 to 12,600 individuals waiting, with the maximum time individuals can be on the waiting list ranging from one year (Ohio) to 16 years (Alaska) but most states clustering between 4-6 years.

It is important to note that waiting list sizes and lengths are not directly comparable across states as they reflect the impact of state-level policy decisions. These policy differences include the number of waiver slots relative to the population as directed by the state. Functional eligibility criteria, which vary widely across states, determine whether individuals meet the institutional level of care criteria for waiver services. Also important is whether functional eligibility is determined prior to being placed on a waiting list. Waiting lists tend to be larger in states that do not determine functional eligibility prior to placement on the waiting list, as many people on the list are not actually eligible (Burns et al., 2023). Most states, including Kansas, determine functional eligibility prior to placement on the waiting list and additional states have moved this direction in recent years as a strategy to better manage waiting lists. Alaska and Iowa place people on waiting lists prior to determination of functional eligibility, at the time of our study, but were in the process of revising their assessment policies.

Additionally, some states do not allow individuals to be placed on a waiver waiting list until other resources are exhausted, including other waiver or state plan options, whereas other states allow individuals to be on the waiting list even if they are already receiving long term services and supports (LTSS) through a different program. In the latter case, individuals on a waiting list are not unserved, rather, they are receiving services through a different program. Administrators in these states noted that when individuals already receiving LTSS services receive a waiting list offer, they often decline because they determine their current program is adequately meeting their needs. In most cases, declining an offer of services removes the individual from the waiver waiting list. When multiple LTSS programs are available, some states allow individuals to be on more than one waiting list simultaneously, which results in double counting those individuals who are on multiple waiting lists. Although most states maintain separate waiting lists for each waiver, some have a combined waiting list across multiple waivers, for example, Pennsylvania and Utah.

In some states waiting list size and length is also impacted by provider availability; that is, even after a person is offered funding for a waiver slot, they may remain on the waiting list if a provider is not available to serve them or select services required. This is in contrast to waiting lists based only on availability of waiver slots without also taking into consideration provider availability (which is the Kansas approach). For example, PD waiting lists in West Virgina grew during the pandemic due to a combination of continuous eligibility and provider shortages, rather than waiver slot availability, as this state does not cap waiver slots. However, their waiting lists were only around 1.5 months, and they expected the waiting list to disappear post-pandemic. To be certain, provider shortages were reported as a struggle across all states, but whether these shortages impacted waiting list size and length depended on waiting list management policies.

Finally, policies on how waiting list slots are prioritized are important. Waiting list slots can be prioritized on either: 1. a strictly first-come-first serve basis, 2. a first-come-first-serve but with crisis or priority exceptions basis, or 3. priority need. Most states, including Kansas, employ a first-come-first-serve but with crisis or priority exceptions approach. Utah is the state with the longest waiting list, and they utilize a priority only need approach and also manage a single waiting list across all their waivers. Therefore, individuals with PD who have relatively low support needs remain on the waiting list for a very long time, up to 22 years, while those with higher support needs bypass them on the waiting list.

Those states that utilize crisis/priority exceptions or priority need approaches to managing their waiting lists largely applied similar criteria for determining crisis or priority, including: risk of institutionalization, abuse, neglect, or exploitation; self-neglect; unmet health or safety needs; no informal support or loss of informal supports; behavior that puts self or others at risk; criminal justice system involvement, youth transitions, and homelessness. Several state administrators noted an increase in behavior needs or informal caregiver risks driving crisis and priority cases. Whereas there was a fair amount of consistency in crisis exception or priority need reasons, the processes for identifying and approving these cases varied widely. Some states rely on the professional judgement of a single administrator to review and approve cases based on the criteria outlined in policy, whereas others use a team-based approach or rely on a scorecard assessment.

Services Available to Individuals on Waiting Lists

Most states offer services and supports to individuals on the waiting list. As noted above, many states allow individuals to be on a waiver waiting list while they are actively receiving services through either another waiver or state program. Alaska (I/DD), Colorado (DD), Georgia (I/DD), Iowa (PD), Kentucky (I/DD), Mississippi (I/DD), Missouri (PD), Pennsylvania (I/DD), Wyoming (I/DD) are all examples of states in which individuals on waiting lists are often actively receiving services on a different waiver. Kentucky noted that 64% of people on their comprehensive community supports waiver are receiving supports under the Michelle P. waiver, which allows up to 40 hours of service per week. Many states offer personal care or home nursing LTSS services through a state plan service, such as Alaska (I/DD), California (PD), Kentucky (I/DD), Michigan (PD), Mississippi (I/DD), Missouri (PD), Montana (PD), Nebraska (I/DD), Nevada (PD), Ohio (I/DD), Oklahoma (I/DD), Utah (PD), West Virginia (PD), and Wyoming (I/DD). These state plan services are typically capped. Some states are also using state general funds or county funds to offer capped respite, caregiver compensation, or family support payments; for example, Georgia (I/DD), Iowa (PD), Ohio (I/DD), Oklahoma (I/DD), Utah (PD). These states noted that many people receiving LTSS through other programs do not seek waiver services or decline waiting list offers, as their needs are sufficiently covered under the alternative program.

For states that offer multiple LTSS programs, it can be beneficial to provide targeted case management or care coordination and a universal needs assessment to place the person into the program or on the waiting list that will best meet their needs. For example, Montana uses a case management team to establish that individuals on the waiting lists have first exhausted state plan services. They will permit an exception to state plan caps if this is the more cost-effective way of serving the person. They may also move someone to the comprehensive waiver temporarily to address a time limited need, for example, home modifications, and then return them to state plan services once this need is met. This fluidity has allowed them to keep their aging and disability waiver waiting list relatively small at only 354 individuals.

Some states contract with community-based organizations to provide information support, referrals, and health and functional status monitoring for individuals on waiting lists. This can be accomplished through targeted case management services. Utah provides an example of another approach, in which they contract with “The Parent Center” to provide information and referral services to individuals on the waiting list for all waivers. This approach helps fill care gaps for individuals on the waiting lists and also helps identify those in need of a crisis exception or priority need recalculation. Similarly, some states, such as Iowa and West Virginia, provide standardized information sheets or resource guides with information about waiting list policies, including crisis exception information, and alternative resources.

Key Challenges in Managing Waiting Lists

Most state administrators reported that a key challenge was not having sufficient data for better managing waiting lists and aligning their programs and services. Challenges with data system alignment, management, and interoperability were reported across states leading to limitations in data-driven decision making by administrators When data systems are unable to effectively communicate and exchange information, it is difficult to draw a comprehensive picture of the individual and their service needs. States struggle to consistently or reliably track the care needs of, or services received by, individuals on waiting lists, and some noted they also do not have good waiting list management data systems. This makes it difficult to assess and track longitudinal trends across populations served and programs offered. States desire better data systems to inform waiver and waiting list management policy decisions, including efforts to reduce waiting lists. State administrators also desired better data for enrolling individuals in the program that best meets their needs and understanding where unmet needs remain, which in turn would help states make more strategic targeted funding decisions for how to best allocate limited resources across various programs. Missouri is an example of a state that has made major investments in developing an integrated, comprehensive data system, which has been vital in reducing their waiting lists, as further detailed below.

Provider and workforce shortages continue to be a key concern facing states as noted in the 2017 President's Committee for People with Intellectual Disabilities Report (PCPID, 2017). State administrators also noted that many people on waivers remain underserved due to workforce shortages, including case manager and direct support worker shortages. There are no easy solutions to this problem, but states have used ARPA HCBS funds to invest in HCBS workforce development and some have passed historic rate increases, for example, Ohio, Rhode Island, Indiana.

Efforts To Reduce or Eliminate Waiting Lists

Many states reported substantial growth in their waiting lists in recent years, however, those states with active efforts to reduce or eliminate waiting lists often reported success. Three states recently eliminated waiting lists: Alabama (PD), Wisconsin (PD), and North Dakota (I/DD). This was largely accomplished through increased funding, including legislative funding to increase waiver slots (e.g. North Dakota and Wisconsin). Wisconsin, who did not complete a survey but sent an email response, made their waivers an entitlement which therefore requires it always be fully funded. Alabama used ARPA HCBS funds to eliminate their PD waiver, by adding 3000 slots, and anticipate funding these slots in the long run through reduced nursing home admissions. The state also implemented hospital-to-home diversion and medical care management programs to reduce nursing home admissions.

Nine states are actively working toward reducing or eliminating their waiting lists, including California (PD), Connecticut (I/DD), Missouri (PD), Nebraska (I/DD), Oklahoma (I/DD), Pennsylvania (I/DD), Michigan (PD), Utah (I/DD & PD), and Wyoming (I/DD). Again, increased funding is a key strategy. Missouri is a unique case as they have nearly, but not entirely, eliminated their waiting lists. They've ended waiting lists on some waivers through increased funding, but have other waivers that oscillate between having no active waiting list and a small waiting list. Wyoming appropriated funding in 2023 to cut their I/DD waiting list in half and Oklahoma appropriated funding that reduced their waiting list from approximately 5,500 to 2,100 over an 18-month period. The Pennsylvania Legislature implemented a sustained, multi-year commitment to eliminate the waiting lists over time by including waiting list initiative funds in their budget nearly every year since 2001. They have reduced their waiting list from about 24,000 to 12,000 since 2006, and decreased the median wait time from 4.1 to 2.6 years since 2016. They made this progress while also expanding eligibility for waiver services for individuals with autism. California has reduced waiting lists by using ARPA HCBS funding to open additional waiver slots, and expects to sustain this progress through reduced nursing facility admissions.

Another common strategy is to focus on connecting individuals to the most appropriate level of LTSS services, which has often included expanding state plan services or adding new waivers. Missouri and Mississippi for example focused on expanding state plan services, so that waiver spots are reserved for those with higher care needs. Nebraska implemented a new Family Supports Waiver in 2024 to provide a new service option for those with lower support needs, while also increasing slots on their comprehensive I/DD waiver. For this strategy, it is also important to have good data and care coordination systems to place individuals in the program that best meets their needs. As shared above, Montana is an example of utilizing comprehensive case management to place people into the most cost-efficient program that will meet their needs while also facilitating thoughtful transitions when needed.

Improved data collection and dissemination to facilitate better planning at legislative, state administrative, and provider levels is also a key strategy. For example, the Pennsylvania Department of Human Services Office of Developmental Programs produces an *Annual Waiting list Report*, which summarizes waiting list reduction strategies, waiting list trends, and characteristics of individuals on the waiting list and their caregivers. Oklahoma and Georgia also noted the importance of accurate, comprehensive data in requesting additional funding from their state legislature. Missouri now manages their state plan and waiver service authorizations in the same data system so that they can more easily see where the needs are and trends over time, which facilitates strategic allocation of funding across various programs. This was a major investment in modernizing their data systems, but they feel this investment has paid off. Wyoming has developed a funding calculator and waiting list dashboard to provide key information to advocates and legislators on what is needed to address their waiting lists.

Recommendations

Main take-aways from our outreach to other states include:

- Kansas stands out from other states in offering minimal-to-no support or LTSS services to individuals on waiting lists.
    - Many individuals on the I/DD waiting list can access targeted case management, but this service is not available to those without a Medicaid card. There is no targeted case management or care coordination, at all, for individuals on the PD waiting list. This is a vital service for connecting individuals on the waiting list to community resources and also monitoring for declining health or function that may qualify someone for a crisis exception and implementing crisis exceptions more equitably.
    - Nearly all of the other surveyed states offered at least some long-term services and supports, including personal care services, to individuals on the waiting list through other waivers, Medicaid state plan services, or state/local funded services, with some states offering a combination of these. With the exception of EPSDT state plan services for youth, Kansas offers no state plan personal care services. Access to alternative LTSS services could prevent health and functional decline among those on the waiting list, and many may not need more comprehensive waiver services if they can instead access key supports though state plan or light waiver services. This support should be coupled with comprehensive case management, universal needs assessment processes, and streamlined transition policies to ensure individuals are placed in the programs that best meet their needs and can move seamlessly across programs when their care needs change.

- Many states are actively working towards reducing their waiting lists, with some successfully eliminating their waiting lists in recent years. Ultimately, sustained funding is needed to reduce and eliminate waiting lists. Waiting list successes also reflect a multi-sectoral approach, informed by good data. Kansas would benefit greatly from modernizing their data systems to allow data to be integrated across KDADS, KDHE, and MCO data systems and produce real-time data reports accessible to stakeholders across the system.

Ultimately, eliminating waiting lists requires intentional collaboration and multi-faceted efforts across multiple stakeholders, including advocates, providers, state administrators, and state legislatures, to identify and implement solutions.

Key Recommendations from the Kansas Waiting List Study

Data Systems

1. Kansas needs a robust, integrated, and efficient data system for HCBS system and Waiting list management.
    - Data systems need to be interoperable across systems, e.g., KDADS and KDHE systems. Currently, data must be linked across various data systems which is a time-intensive effort that requires a high level of expertise. Therefore, it is difficult for state administrators to see the whole picture in the current systems.
    - Currently, crisis exceptions and priority populations are maintained on individual computers of waiver managers. The data fields collected and maintained are not consistent across crisis exception tracking, leading to problems with reporting of participant status. This data should be integrated into KAMIS or an upgraded data repository. Coding definitions need to classify crisis and priority populations, clearly link each to the policy, while also collecting information on the underlying factors that drive crisis exceptions (as defined in this study) for program planning purposes.
    - There are also data integrity and accuracy issues for waiting list data in KAMIS; for example, there were multiple dates in the KAMIS systems related to waiting list management that were not clearly defined, which made it difficult to calculate length of time on waiting lists, especially for those with multiple transitions on and off the waiting lists. Additionally, the permitted codes for “reason for removal” from the waiting list were not exhaustive, thus forcing program managers to sometimes select a code that was not a good fit and varied by

administrator. Further, these reasons were not consistent across I/DD and PD waiting lists. These codes were updated toward the end of the data period for this project, which resulted in more accurate data for those years, but also meant the data was no longer comparable across years. It is recommended that in data fields like this, where it is not possible to be exhaustive, an "other, specify" category is included for data integrity as well as to timely identify and implement needed updates based on data entered into the other category.

- A more comprehensive, integrated data system will also support the state in meeting the upcoming annual waiting list federal data reporting requirements under the Ensuring Access to Medicaid Services Final Rule, starting in July 2027 (CMS, 2024).

2. A thoughtful process should be undertaken, including input of providers and other stakeholders, to ensure development of a data system that works for everyone and provides data compatibility across different IT systems and agencies. This system would save considerable administrative time and allow KDADS to provide more responsive and accurate to consumers, families, and other stakeholders regarding waiting list status, as well as meet CMS reporting requirements. A public-facing dashboard utilizing aggregated, de-identified data with cell size considerations should also be created.
3. We encourage KDADS to explore existing public-facing dashboards already created and maintained by the State such as: https://www.kdhe.ks.gov/2225/Data-Dashboard , https://www.kdhe.ks.gov/2046/Data-Dashboards , and Kansas Department of Commerce Workforce Data Quality Initiative within KansasWorks.
    a. Public-facing dashboards provide policy makers, advocates and consumers themselves the information needed for transparency and equity.
4. Encourage the creation or modification of data systems include participation of people with disabilities to inform target outcomes, data elements, and accessibility.

Policy and Procedure

1. Kansas needs a coordinated process to stay in contact with people on the PD and I/DD waiting lists. This process would be most effectively managed by providing some level of coordinated services to people on the waiting lists – so people have a reason to stay in contact. Such a process is particularly important for waiting list members who are not KanCare members as well as people on the PD waiting list because they do not receive TCM.
2. People on all waiting lists need a minimum level of proactive and supportive services. This would support people to maintain their health and functioning while on the waiting list, potentially reducing crisis exceptions and pent-up need upon initiation of HCBS. For example, the PD waiver could offer case management services to people on the waiting lists, similar to the I/DD waiver.

Waiver Services

1. Individual Budget Authority is a cost-effective way to give people choice and control over the support they need to live their lives. 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). The vast majority of states (n=44) offer budget authority (Murray et al., 2024) and the state should consult experts who have successfully implemented this option and understand the complexities.
2. While budget authority can put people in more direct control of their services, 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.

3. 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. 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).
4. Kansas needs to work to create a robust network of licensed and qualified professionals, occupational therapists, physical therapists, speech and language pathologists, and behaviorists, all of whom can play a role in supporting the person's emotional, behavioral, and physical health. Our analysis shows that supporting people's emotional, behavioral, and health needs is critical, and people do not have access to enough qualified professionals.
5. Families and people with disabilities need clearly defined procedures and navigators to support them to identify the best program that meets their needs and support transition between waivers. The CSW waiver, while beneficial, also makes the system more complex. People will need support in determining the best waiver to meet their needs. People will need support to understand when and how to transition between waivers.

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Appendices

Appendix A – Number of Youth Under 21

Table A1

Counts of Youth Under 21

Those that have Medicaid qualify for EPSDT Services

Age	Total	Has Medicaid ID
20	195	123
19	240	168
18	237	169
17	241	166
16	223	157
15	237	170
14	237	176
13	245	183
12	237	158
11	202	126
10	164	103
9	174	115
8	145	92
7	121	73
6	90	53
5	54	31
Total	**3042**	**2036**

Appendix B - Number of People on the I/DD and PD Waiting Lists in Each CDDO (for I/DD) and CIL (for PD) Region

Table B1

Number of People on the I/DD Waiting List in Each CDDO Region

CDDO	On the Waiting list
Achievement Services for Northeast Kansas	25
Arrowhead West, Inc	91
Big Lakes Developmental Center, Inc	111
Brown County Developmental Services, Inc.	16
Butler County CDDO	97
CDDO of Southeast Kansas	178
Cottonwood, Inc.	179
Cowley CDDO	51
Developmental Services of Northwest Kansas, Inc.	113
Disability Planning Org. of Kansas	315
ECK Training Services, Inc.	62
Futures Unlimited, Inc.	33
Harvey-Marion County CDDO	125
Hetlinger Developmental Services, Inc.	91
Johnson County Developmental Supports	887
McPherson County CDDO	39
Nemaha County Training Center	7
New Beginnings Enterprises, Inc.	13
RENO County CDDO	100
Riverside Resources, Inc.	96
Sedgwick CDDO	932
Shawnee County CDDO	350
Southwest Developmental Services, Inc.	289
Tri-Ko, Inc.	61
Tri-Valley Developmental Services, Inc.	47
Twin Valley Developmental Services, Inc.	7
Did not Receive Information	663
Wyandotte County CDDO	161
Total	**5139**

NOTE: These numbers were calculated based on county from contact information and should be considered approximate. The county that someone lives in does not always mean that they are served by the CDDO in that region (for example, if they are in foster care). There are also a large number of people who we did not receive contact information for. They are classified as "Did not Receive Information" in these tables since we did not have information on the county in which they lived.

Table B2

Number of People on the PD Waiting List in Each CIL Region

ADRC	On the Waiting List
Central Plains	211
East Central	21
Jayhawk	117
Johnson County	53
Did not Receive Information	1440
North Central Flint Hills	106
Northeast KS	30
Northwest KS	33
South Central	81
Southeast KS	95
Southwest KS	48
Wyandotte Leavenworth	125
Grand Total	**2360**

NOTE: These numbers were calculated based on county from contact information and should be considered approximate. The county that someone lives in does not always mean that they are served by the ADRC in that region (for example, if they are in foster care). There are also a large number of people who we did not receive contact information for. They are classified as "Did not Receive Information" in these tables since we did not have information on the county in which they lived.

Appendix C – Categories of Illness/Disease Used to Calculate CDPS

Illness/Disease Burden Score

Table C1

Major Categories of Illness/Disease Used to Calculate CDPS Illness/Disease Burden Score

CDPS 19 Major Categories of illness/disease
Cardiovascular
Psychiatric
Skeletal and Connective
Nervous System
Pulmonary
Gastrointestinal
Diabetes
Skin
Renal
Substance Abuse
Cancer
Developmental Disability
Genital
Metabolic
Pregnancy
Eye
Cerebrovascular
Infectious Disease
Hematological

Appendix D – Descriptions of Key Areas of Life

Table D1

Descriptions of Key Areas of Life

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)