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Researching Provider Solutions for People with Intellectual and Developmental Disabilities

Final Study Report for the Florida Developmental Disabilities Council, Inc.

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Researching Provider Solutions

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I. Introduction

The intellectual and developmental disabilities (IDD) community is adversely affected by the widespread shortage of direct care service providers. People with IDD often require direct care services to perform activities of daily living or instrumental activities of daily living. These activities may include assistance with preparing meals, taking medications, or managing finances. The inability to access direct care supports can compromise the health and well-being of people with IDD. In addition to family members and friends, people with IDD rely on paid direct care workers (DCW) for services. In recent years, demand for direct care services throughout the U.S. has exceeded the amount of people in the DCW labor force (Harootunian et al. 2023; Kinder 2023; O'Malley Watts et al. 2022; Shockman 2022; Wenner 2023). This DCW shortage has created hardships for people with IDD and their families as they struggle to find assistance to meet basic care needs.

In its Five-Year State Plan (2022–2026), the Florida Developmental Disabilities Council, Inc. (FDDC) set a priority to help people with IDD and their families obtain direct care support (FDDC 2021). The FDDC focuses their efforts on three groups who obtain their own direct care support:

- Consumer-Directed Care Plus (CDC+) beneficiaries
- People on a Medicaid Home- and Community-Based Services waiver waitlist
- Individuals unknown to Florida's Agency for Persons with Disabilities (APD).

iBudget Florida and CDC+ are the primary waiver programs that pay for home- and community-based services for Floridians with IDD. APD administers both waiver programs. iBudget beneficiaries do not find their own direct care support, whereas CDC+ beneficiaries do. To become a CDC+ beneficiary, an individual must first be an iBudget beneficiary. In January 2023, 22,372 Floridians with IDD were on the iBudget waitlist (Florida's Developmental Disabilities Waitlist Campaign 2023). People not in a waiver program—those on the iBudget waitlist or unknown to APD—must find and typically pay for their own direct care support.

This report describes the methods, findings, and recommendations of the Researching Provider Solutions (RPS) project. FDDC contracted with Mathematica in January 2023 to conduct the project. RPS used multiple workstreams—an environmental scan of relevant literature, a web-based survey, interviews, and a workgroup—to understand the direct care experiences of Floridians with IDD and their families. The project team analyzed the information collected across each workstream to develop ideas and strategies that could help the IDD community in Florida recruit and retain paid direct care support. Completed in July 2023, Mann and Nath (2023) describe their findings and recommendations from the environmental scan. This report, however, focuses primarily on the survey, interview, and workgroup workstreams.

We organized this report into three sections: methods, findings, and policy implications. Chapter II describes the methods for, and Chapter III presents the findings from the survey, interview, and workgroup workstreams. In Chapter IV, we combine the findings from Chapter III and Mann and Nath (2023) to develop policy and project recommendations for FDDC. The appendices include English versions of the survey and interview guide, along with tables presenting the survey results.

II. Methods

The project used four methods across workstreams to gather and analyze information about the direct care experiences of people with IDD and their families. Mann and Nath (2023) contain a description of the methods for the environmental scan. In this chapter, we describe the three methods used to conduct the other data collection and analysis activities. We obtained approval from the institutional review board at Health Media Labs before fielding the survey and interviews (Health Media Labs IRB approval #2299).

A. Survey

We developed and fielded a web-based survey to collect information about the direct care experiences of people with IDD and their families. To capture the varied experiences of people with IDD and caretakers who recruit their own direct care support, we collected information across four groups: CDC+ beneficiaries, iBudget waiver beneficiaries, people on the iBudget waiver waitlist, and those unknown to APD. However, we did not report findings for the iBudget waiver group because it is beyond the scope of the project. Within each group, we further categorized survey respondents based on whether they had an IDD or were a caregiver of someone with an IDD and whether the person with IDD had paid direct care support. To prioritize themes and content for the survey, we utilized information gathered from our workgroup discussions, environmental scan, and FDDC's project team. To the extent possible, we used public surveys and prevalidated survey instruments to design the survey questions. However, some existing questions required revisions to add response options specific to the project, increase readability, or improve clarity. For topics with no prevalidated survey questions, we designed new survey questions to obtain the information we wanted. Because the survey had two types of respondents, we created two versions to ensure the question wording was appropriate for each group. Mathematica applied its experience developing surveys for people with disabilities to streamline the survey questions, creating a clear and concise survey instrument in QuestionPro. The English version of the survey instrument is available in Appendix A.

The survey was designed to obtain information in a format that was accessible to the Florida IDD community and to minimize burden (Exhibit II.1). People with IDD or their primary caregivers could respond to the survey, but all respondents had to be at least age 18, legally able to give consent, and focus on a person with IDD residing in Florida. If someone with IDD was unable to give consent due to their disability, then only their primary caregiver could respond to the survey. To not exhaust respondents, we capped the survey at 10 to 15 minutes and utilized skip logic throughout the instrument so that respondents only answered questions that were relevant to their experience. To further promote accessibility, the survey text met plain language guidelines, with versions in both English and Spanish. We pretested the English version of the survey instrument to assess flow, comprehension, length, and any new or heavily adapted questions. We also pretested the Spanish version of the survey for translation quality, flow, and comprehension.

Exhibit II.1. Survey design summary

Survey design	Information
Population of interest	People with IDD who reside in Florida and are either CDC+ beneficiaries, on the iBudget waiver waitlist, or are unknown to APD
Respondents	A person with IDD or a primary caregiver who can proxy for someone with IDD; respondents must be age 18 or older and legally able to give consent
Field period	June 6, 2023, through July 28, 2023
Target number of completes	No cap on the number of respondents
Mode	Self-administered web survey in QuestionPro
Language	English and Spanish
Survey length	10 to 15 minutes
Average number of questions a respondent received	30 to 40 questions
Incentive	$0

Mathematica worked with FDDC to recruit survey respondents. No traditional sampling frame or database was available to facilitate a probability sampling methodology. Consequently, we used a nonprobability (that is, convenience) sampling approach. The survey asked demographic questions at the beginning of the survey to track priority groups and representativeness during fielding. Because of the convenience sampling approach, we used a variety of methods to recruit survey respondents who could provide an informed perspective. These sources and methods included using partners or champions in the IDD community to disseminate the survey, messaging FDDC's current mailing list, posting a survey link on the FDDC's website and social media sites, posting in social media support groups focused on the IDD community, and using internet-based recruitment and focused ad campaigns to expand past the FDDC contacts. Mathematica developed communication materials to solicit participation from eligible individuals and mostly relied on FDDC to disseminate the communications through its contacts, email list serves, social media, and website.

We used unadjusted descriptive statistics to analyze the data, producing percentages, means, and counts. The statistics describe 69 respondents who completed most or all of the survey: 20 CDC+ beneficiaries, 23 people on a Medicaid Home- and Community-Based Services waiver waitlist, and 26 people unknown to APD. Because the number of respondents varied across questions, we report the number of respondents (N) for different questions in some tables. We did not produce standard errors or statistical tests for the survey results, because the small number of respondents limits our ability to use statistical inference to understand the larger respondent population.

B. Interviews

The project conducted interviews to obtain in-depth information that survey data could not capture well. For example, surveys are unable to spontaneously develop follow-up questions based on respondent answers or ask respondents to elaborate because their initial responses were unclear. Focusing on the groups of interest identified for the survey, Mathematica and FDDC worked together to determine what other qualitative information was important to gather from each group. Mathematica then created interview guides whose content aligned with the data collection priorities. The interview guides are available in Appendix B.

Implementation of the interviews shared several characteristics with survey implementation (Exhibit II.2). The data collection efforts primarily gathered information from people with IDD or their primary caregivers who were able to provide consent. However, we also interviewed professional community advocates from local nonprofits who helped people with IDD find or access direct care support. Both the interviews and survey also tailored wording to account for the literacy needs of participants, provided data collection opportunities in English and Spanish, and did not provide a financial incentive in alignment with FDDC requirements. Contrary to the survey, however, the project restricted the maximum number of interview respondents to 18.

Exhibit II.2. Interview design summary

Focus group design	Information
Population of interest	People with IDD who reside in Florida and are either CDC+ beneficiaries, on the iBudget waiver waitlist, or are unknown to APD
Respondents	A person with IDD, a primary caregiver who can proxy for someone with IDD, or case managers who helped people with IDD access direct care support. Respondents must be age 18 or older and legally able to give consent.
Field period	June 6, 2023, to October 6, 2023
Target number of completes	Up to 18 participants
Mode	Virtual focus groups via WebEx, video encouraged
Interview type	Semistructured interviews
Language	English and Spanish
Interview length	60 - 90 minutes
Estimated number of questions	20 questions
Incentive	$0

The effort required to participate resulted in a challenge to recruit interview participants. Interviews were either 60 minutes (individual) or 90 minutes (group), required obtaining informed consent, and needed to be scheduled. In addition, not all people attended their scheduled interviews. Similar to survey recruitment, no database was available to facilitate interview recruitment.

We used communication materials, direct outreach, and follow up to recruit interview participants. Mathematica developed communication materials to solicit participation from eligible individuals and mostly relied on FDDC to disseminate the communications through its contacts, email list serves, social media, and website. We created an interview screening survey to determine whether someone was a strong interview candidate. If a screening survey respondent was identified as such, Mathematica contacted them and asked if they would be willing to participate in an interview. We connected people to the communication materials and screening survey by: requesting champions in the IDD community to disseminate the opportunity, asking workgroup members to refer potential participants, messaging FDDC's mailing list, posting a link to the screening survey on the FDDC's website and social media sites, posting the opportunity in social media support groups focused on the IDD community, and using internet-based recruitment and focused ad campaigns. After exhausting these efforts, Mathematica worked with FDDC to draw from other projects and networks to identify potential interview participants.

FDDC referred several potential participants to Mathematica, which then contacted the potential participants and asked them to participate. Mathematica also solicited survey respondents, workgroup members, and participants from other FDDC-funded projects to participate in an interview.

An experienced moderator and assistant conducted the interviews. Each interview was held on WebEx to allow for optional video displays and easy audio recording. The interviews had one or multiple participants. Before each session, Mathematica provided participants with instructions about how to access WebEx and asked participants if they required accommodations. The moderator facilitated the discussion and built rapport with the participants while the assistant documented observations and responses, asked follow-up questions, moderated the chat function, and provided technology support. To facilitate the analysis, we recorded all interviews after obtaining participant consent. Mathematica removed all personally identifiable information before analyzing the transcripts.

Mathematica interviewed 14 participants through one-on-one interviews (*n*= 10) and two group interviews (*n* = 4) (Exhibit II.3). The respondents fell into three categories—people with IDD, caregivers, and community advocates—and had a variety of waiver experiences. Despite our best efforts, no Spanish-speaking individuals responded to our interview invitations, including those who initially expressed interest when responding to the screening survey. Hence, we conducted all interviews in English.

Exhibit II.3. Interview respondents by waiver type

Respondent type	CDC+ waiver	Waitlist	Unknown to APD	Other	Total
People with IDD					
Had regular paid DCW in the last 12 months	0	0	0	n.a.	0
Did not have paid DCW in the last 12 months	0	0	1	n.a.	1
Caregiver					
Had regular paid DCW in the last 12 months	3*	0	2	n.a.	5
Did not have paid DCW in the last 12 months	1	2	2	n.a.	5
Community advocate					
Advocate	n.a.	n.a.	n.a.	3	3
Total	4	2	5	3	**14**

Note: Two community advocates were also caregivers with loved ones on the CDC+ waiver. In their interview, they spoke about both of their roles. We list these two people in the caregiver category, using an asterisk to note what cell they are described in.

n.a. = not applicable

Mathematica analyzed the interviews by coding interview transcripts to identify key themes. The interview team manually reviewed and cleaned the transcripts obtained from WebEx. We then used the narratives to separate each interview into self-contained prepositional statements. Staff coded each statement for the presence of primary themes. There was no limit to the number of themes that could be coded for each statement. Within each primary theme, we analyzed statements for secondary themes, which provided more context and depth to the overarching primary themes.

C. Workgroup

Mathematica formed a workgroup of organizational representatives and community members to gather feedback about project analyses and findings. In collaboration with FDDC, we identified and contacted potential workgroup members, including people with IDD and their families as well as staff from APD, Disability Rights Florida, and the Family Care Council. Workgroup members received email messages about project activities and participated in virtual meetings. For each project task, the workgroup reviewed plans and provided input. For example, the workgroup members pre-tested the survey and interview instruments before they were released. The workgroup also assisted with data collection by sharing the survey with their networks and suggesting people to contact for interviews. Finally, workgroup members shared with Mathematica their personal and community experiences to provide context for project findings.

D. Considerations for interpreting findings

Interested groups should remember three important considerations when interpreting the findings. First, the survey and interview samples were not randomly selected. Consequently, they may not be representative of the entire IDD community in Florida. For example, because the survey was web-based, it may not have captured the perspectives of older people with IDD or older caregivers who cannot readily access web-based surveys. Second, the relatively small number of survey respondents limited our ability to use statistical inference to generate precise measures that represent the perspectives of the respondent population. Hence, we do not present standard errors or statistical tests with the survey results. Third, correlations between groups and outcomes do not necessarily represent causal relationships. For instance, if people on the CDC+ waiver are less likely to pay out of pocket for DCW services than the Unknown group, we cannot automatically attribute the difference to group membership even though (in this case) group membership is likely driving this result. Only a study that isolates causal relationships can unquestionably attribute outcome differences to group membership.

III. Findings

In this chapter we present key themes from the survey, interviews, and workgroup. We analyzed the results from each workstream to develop the findings. In Chapter IV, we describe cross-cutting implications of the findings presented in this chapter.

A. Survey results

In this section, we highlight key findings from the survey and display the results across three waiver status groups—approved for the CDC+ waiver (CDC+ waiver), on the waitlist for waiver services (Waitlist), and unknown to APD if respondents have not applied for the waiver (Unknown to APD). Within each group, we report descriptive statistics—either counts or percentages—for each survey question. We report the number of respondents by question because some respondents did not answer some questions. Appendix C has a complete description of the survey results.

In total, 69 people—20 in CDC+ waiver, 23 in Waitlist, and 26 in Unknown to APD—responded to the survey (Exhibit III.1). The majority (85 percent to 87 percent in each group) of survey respondents were parents of a person with IDD. Seven respondents (10 percent to 13 percent in each group) were people with IDD. The remaining respondents (3 percent to 5 percent in the Unknown and CDC+ groups) were siblings or other family members of a person with IDD.

Exhibit III.1. Survey respondents by type and waiver status

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**20**	**23**	**26**
People with IDD	10%	13%	12%
Parents	85%	87%	85%
Other family members	5%	0%	3%

Source: Project-administered survey

Notes: Rows containing respondent counts for answers are noted with (N).

Though a few characteristics were similar, several characteristics among people with IDD varied in ways that seemed correlated with waiver status (Exhibit III.2). Most respondents were White, with 23 percent to 33 percent in each group reporting their ethnicity as Hispanic or Latino/a. Older people seemed better connected to direct care support programs. Two-thirds of people with IDD in the CDC+ waiver group were age 31 or older. About 77 percent of the Waiver group were age 18 to age 45. The majority (56 percent) of people with IDD Unknown to APD were children age 0–17. People with IDD in the CDC+ waiver group were relatively more likely to live in suburban communities whereas people with IDD in the Unknown to APD group were relatively more spread across urban, suburban, and rural areas. No one in the Waitlist and Unknown to APD groups lived on their own while receiving direct care services, compared to 30 percent of the CDC+ waiver group (Appendix C, Exhibit 1).

Health status varied substantively across waiver status groups (Exhibit III.2). Caregivers reported that most people with IDD (72 percent to 100 percent in each group) had good to excellent health. On average, people with IDD in the CDC+ waiver group had better health than those in the other groups. About 22 percent of people with IDD Unknown to APD had poor health, whereas no one in the other two groups had poor health.

Exhibit III.2. Characteristics of people with IDD according to caregivers

	CDC+ waiver	Waitlist	Unknown to APD
Age (N)	**12**	**13**	**18**
0–17	17%	15%	56%
18–30	17%	54%	33%
31–45	50%	23%	11%
46–60	17%	8%	0%
Race (Choose all that apply) (N)	**13**	**15**	**18**
American Indian or Alaska Native	0	0	0
Asian	0	2	0
Black or African American	0	0	0
Native Hawaiian or/and Other Pacific Islander	0	1	0
White	13	15	17

	CDC+ waiver	Waitlist	Unknown to APD
Ethnicity (N)	**13**	**15**	**18**
Hispanic	23%	20%	22%
Latino/a	0%	7%	11%
Not Hispanic or Latino/a	77%	73%	67%
Region (N)	**13**	**15**	**18**
Urban	15%	33%	28%
Suburban	77%	67%	50%
Rural	8%	0%	17%
I don’t know	0%	0%	6%
Health status (N)	**13**	**15**	**18**
Poor	0%	0%	22%
Fair	23%	0%	6%
Good	54%	53%	61%
Very good	15%	33%	11%
Excellent	8%	13%	0%

Source: Project-administered survey

Notes: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

We found a stark contrast in access to paid direct care service across waiver status groups (Appendix C, Exhibit 8). Nearly all (90 percent) members of the CDC+ waiver group reported receiving paid direct care services at the time of survey response. Conversely, at least 85 percent of people with IDD in the Waitlist or Unknown to APD groups did not have access to paid direct care services. When they did have access, nearly everyone rated the quality of that care as good to excellent (Appendix C, Exhibit 10). Most (82 percent to 86 percent) of primary paid DCWs of people on the CDC+ waiver had a lengthy employment history by providing direct care services for three or more years to respondents and their families.

People with IDD in the Waitlist group experienced long wait times for waiver services, often with serious associated effects. Nearly three quarters of respondents for the Waitlist group had waited 6 to 20 years for waiver approval and more than 40 percent had experienced an extremely or very serious effect because of the length of the wait (Exhibit III.3). About 42 percent of respondents for the Unknown to APD group stated they did not apply for services because they did not know how (Appendix C, Exhibit 7).

Exhibit III.3. Waitlist duration and effects

	Waitlist
Number of years waiting for direct care waiver approval (N)	**19**
0–5	21%
6–10	37%
11–20	37%
21+	5%
Effects of waiting for direct care waiver approval (N)	**23**

	Waitlist
Extremely or very serious effect	43%
Somewhat or slightly serious effect	39%
No effect	13%
Unsure	4%

Source: Project-administered survey

Notes: This question is applicable only for people responding to the survey about their experiences on the Waitlist. Rows containing respondent counts for answers are noted with (N).

Potentially because of their access to paid direct care support, members of the CDC+ waiver group had several better outcomes than people in the other waiver status groups. Nearly two-thirds (61 percent) of the CDC+ waiver group regularly received care by more than one paid DCW (Exhibit III.4). Most (88 percent and 74 percent) members of the CDC+ waiver and Waitlist groups received the assistance they believed they needed, compared to 35 percent of members from the Unknown to APD group (Exhibit III.5). Differences in access to direct care support were also correlated with other care-related outcomes. For example, when asked about the steps caregivers had taken to prepare for future support needs, six caregivers for the Unknown to APD said none (Appendix C Exhibit 20). In contrast, all caregivers in the other two waiver status groups had made some sort of preparations.

Exhibit III.4. Number of paid DCWs that provide support every week

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**18**	**2**	**2**
1	39%	50%	50%
2	22%	0%	50%
3–5	28%	0%	0%
6 or more	11%	50%	0%

Source: Project-administered survey

Notes: This question is applicable only for people responding to the survey about their experiences with paid DCWs. Rows containing respondent counts for answers are noted with (N).

Exhibit III.5. Respondents receiving the help needed in past 12 months

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**17**	**19**	**23**
Yes	88%	74%	35%
No	12%	26%	65%

Source: Project-administered survey

Notes: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. Rows containing respondent counts for answers are noted with (N).

Caregivers for people on the CDC+ waiver were relatively better off than those for the other two groups (Exhibit III.6). About one-third (36 percent) of caregivers for the CDC+ waiver group rated their caregiving responsibilities as extremely or very stressful. Among caregivers for the other groups, the percentage reporting that level of stress was higher—51 percent for the Waitlist group and 74 percent for the

Unknown to APD group. A majority (68 percent to 69 percent) of caregivers in the Waitlist and Unknown to APD groups had some or major problems ensuring the safety of the person they cared for, compared with 41 percent of caregivers in the CDC+ waiver group. Nearly one third (29 percent) of caregivers of people with IDD in the Unknown to APD group rated their personal health as poor. Conversely, no caregivers for the CDC+ waiver group reported a poor health rating. Caregivers for the CDC+ waiver group were also relatively more likely to obtain additional financial assistance to pay for direct care services. More than half (54 percent) of caregivers in the CDC+ waiver group received federal caregiver tax credits, compared to 11 percent to 13 percent of caregivers for the other two groups.

Exhibit III.6. Characteristics and experiences of caregivers

	CDC+ waiver	Waitlist	Unknown to APD
Level of stress of caregiver responsibilities (N)	**14**	**16**	**19**
Extremely stressful	29%	13%	41%
Very stressful	7%	37%	32%
Moderately stressful	21%	37%	11%
Mildly stressful	36%	13%	16%
Not at all stressful	7%	0%	0%
Ensuring the safety of the person you care for/support (N)	**13**	**16**	**19**
Major problem	33%	25%	47%
Some problem	8%	44%	21%
Not a problem	50%	19%	21%
Don't know/Not applicable	8%	13%	11%
Health rating of caregiver (N)	**13**	**16**	**17**
Poor	0%	0%	29%
Fair	38%	13%	18%
Good	31%	44%	29%
Very good	31%	25%	6%
Excellent	0%	19%	18%
Experiences of caregivers* (N)	**12**	**16**	**18**
Received money from government programs for your caregiving duties	31%	0%	5%
Received any federal caregiver tax credits (e.g., caregiver tax credit, infirm dependent tax credit, medical expense tax credit)	54%	13%	11%
Requested information about how to get financial help for the person you care for/support	54%	50%	39%
Received services or supports that have reduced your out-of-pocket expenses for the person you care for/support	58%	31%	39%

Source: Project-administered survey

Notes: In the section marked with *, each percentage indicates the proportion of respondents who selected "yes" to the statement. Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. Rows containing respondent counts for answers are noted with (N).

Despite several key disparities, people with IDD and their caregivers had some similar experiences regardless of waiver status (Appendix C, Exhibit 7). At least 75 percent of respondents across groups who had paid direct care support shared that it was somewhat or very hard to find a satisfactory DCW. Support needs—such as meal preparation, light housework, shopping, and transportation—were similar across groups (Appendix C, Exhibit 16). Both paid and unpaid direct care services were most often received at home (Appendix C, Exhibits 10 and 17). Most people with IDD (73 to 89 percent) had at least one unpaid DCW, who was usually a parent or sibling. The majority of family members (56 percent to 78 percent) said that caregiving always or usually interfered with daily life (Appendix C, Exhibit 19). Most caregivers would apply to be a paid DCW for their loved one if a government program allowed it (Appendix C, Exhibit 20).

B. Interview themes

Our qualitative analysis of the interview transcripts identified six primary topics, each with multiple secondary topics. We describe these topics below; primary themes are bolded and secondary topics are italicized.

1. Types of direct care support

Various professionals and nonprofessionals provide direct care support to people with IDD. Their responsibilities vary depending on the setting and the needs of the people with IDD that they assist.

In-home direct care supports. Both paid and unpaid DCWs provided services in-home. The services included things like personal care, respite, and community integration. The unpaid in-home DCWs were almost always immediate family members or close friends who provided the care. Compensated DCWs were paid through a waiver or personal funds. The paid DCWs were usually either family members or individuals outside the family hired to provide direct care support.

Other direct care supports. Respondents described a variety of other direct care supports. Professional services, such as speech therapy, behavioral interventions, or medical services, were vital components of multiple care plans. These services were delivered at home or in a clinical setting. For people with IDD younger than age 22, the Florida Department of Education provided a variety of social, emotional, behavioral, and medical services around school hours. These services also provided a respite for primary caregivers. Community programs and nonprofits supplied sport, recreational, and social activities to people with IDD. Some of these activities were paid or discounted whereas the others were free.

2. Finding, hiring, and keeping paid direct care support

Finding quality direct care support from non-family members was a source of frustration. Factors such as level of care, pay rate, and waiver status affected the ability to hire and retain DCWs. Respondents also shared that there are limited methods available to recruit and hire DCWs. Combined, these factors have resulted in a DCW labor force that is limited and stressed.

Professional organizations. Respondents sometimes used professional organizations, such as healthcare staffing agencies and job websites, to acquire paid direct care support. Some DCWs provided by agencies started work immediately whereas others were interviewed and approved before they started work. The respondents noted that DCWs hired from an agency often exited the position within a year, usually because the DCWs provided low quality services, or they wanted higher pay. Also, the agencies sometimes created barriers to care. For example, agencies will usually not take a case if it has too few hours. A few respondents placed ads for direct care support on job websites, such as Care.com, Indeed, and LinkedIn. However, recruiting DCWs through ads was costly and required time to screen candidates.

Personal networks. The preferred and most successful method of recruiting direct care support was personal and community networking. This type of recruitment usually occurred by getting referrals from trusted contacts or invitation-only community groups on social media.

In addition to the limited methods for recruiting direct care support, respondents described various institutional barriers that made recruitment more difficult.

Low pay (waiver only). For those on a waiver, the most frequently mentioned barrier to recruiting quality DCWs was that waiver base pay was too low. Many did not consider $15 an hour to be a livable wage or competitive with low skill occupations, such as housecleaning. Respondents felt that $20 to $25 an hour was a more appropriate wage rate. To compensate and retain strong DCWs, some respondents provided overtime or holiday pay, higher base pay, and additional hours paid off the record. The misaligned compensation for the level of effort required created a negative perception about direct care work. It is not perceived as a long-term career, which increases turnover rates and prevents people from entering the DCW labor force.

> "Health care service workers need to have the respect of the community. It needs to be a valued job and they are not valued because they are grossly underpaid as compared with in-home housekeeping people. People who clean houses are paid anywhere between $50 and $75 an hour in my part of the country. If you have to hire somebody, it should be a valued enough profession that you aren't scraping the barrel. The compensation that you get through those [waivers] that provide $15 an hour? I mean, that's just absolutely ridiculous."
>
> Person with IDD

Improve waiver systems and onboarding process (waiver only). Those receiving waiver services were often frustrated about the program's complex systems and processes. When a DCW candidate is hired, the process to get the candidate approved and into the CDC+ system is complicated. This process goes through a CDC+ consultant rather than a web portal, lacks transparency or timely updates, and frequently results in administrative errors that must be corrected before the DCW starts work. Several caregivers shared that even after approval by APD, some DCWs were unable to be paid because they were not added to the payroll system. When this happened, the family often decided to pay the DCW directly. The waiver process is so notoriously difficult that some DCW candidates refuse to be paid under the waiver.

> "It's hard for a family that is fluent in English to find resources. The Hispanic community that can only speak Spanish? It's even harder."
>
> Community advocate

Language. Non-English speakers sometimes struggled finding direct care services because the process for finding such services usually requires English. For example, talking to a receptionist or navigating the website of a healthcare staffing agency usually involves English language skills.

Personal preferences and characteristics. Respondents noted that providing direct care services takes a special type of person because it is challenging and complex work. DCWs may have to physically intervene, need to incorporate therapy interventions that provide consistency and continuity, and must be creative in their active problem-solving. Respondents emphasized that many DCWs would benefit from additional education or training to help them succeed in the role. Lastly, many caregivers need DCWs to be flexible with their time because of appointments and therapies. However, many DCWs want a set schedule so they can plan their own lives.

Applicant quality. Many DCW applicants and some working DCWs lacked the characteristics needed to be high-quality DCWs. Respondents found that some DCWs lacked *professionalism* by not notifying them if the DCW would not be able to work a shift or consistently being late, *work ethic* by not having pride in their work and only doing the bare minimum, or *trustworthiness* by lying or placing people with IDD in unsafe situations.

Transportation. Some DCW applicants could not take a job because they could not access reliable transportation, or the job was not close to public transportation.

3. Financing direct care support

Respondents used four types of sources to pay or supplement pay for direct care services.

CDC+ waiver. Caregivers whose loved ones received waiver services highlighted that this support was crucial to receiving and paying for the majority of direct care services.

Personal finances. Many respondents, especially those whose loved one was not receiving waiver services, used their personal funds to finance direct care. This funding came from their own savings, pension or retirement funds, or loans. Some respondents also received occasional financial support from family and friends to pay for direct care services.

Community supports. Regardless of waiver status, many caregivers leaned on community resources for services and forms of respite. Local or national nonprofits, such as Special Olympics and Rotary Youth, or local companies provided free or low-cost activities or services. State or local grants and scholarships enabled some people with IDD to access camps, work opportunities, or transportation supports.

Government benefits. Respondents relied on a range of government benefits to finance direct care support. The most commonly used benefits were Supplemental Security Income and Social Security Disability Insurance. Respondents who were connected to the military through current or past service received a wealth of support through military benefits and insurance. Military-connected caregivers noted that they had not sought out waiver supports because the military-financed supports were superior and easier to get.

> "The state better pick up on this because if these things don't get addressed, you're going to get families who burn out and then [the person with IDD] is going to be the state's problem. They're going to go into guardianship."
>
> Caregiver

4. Direct care support effects on quality of life

The well-being, comfort, and satisfaction of caregivers varied substantively depending on access to paid direct care supports.

Community integration. Having direct care support allowed people with IDD to have regular trips outside of the home. Caregivers stressed the importance of having relationships outside of the family because it promoted a sense of independence. Those who did not have direct care support described how not having trips outside of the home was a notable pain point.

Physical, emotional, and psychological well-being. Access to direct care services improved wellbeing for caregivers and their loved ones. The services provided essential breaks or respite and more flexibility, allowing the caregivers to spend more quality time with others. Caregivers who did not have direct care support were usually under extreme stress from the inability to get a break or assistance. This stress adversely affected the health of all family members, including the person with IDD.

Career and income. Having access to direct care support allowed caregivers more opportunities to contribute financially to the household. Those without access to direct care support spoke about their financial fears, inability to work due to caregiving demands, or how their careers were adversely affected.

5. Thoughts about the future (caregivers only)

When asked about the future, respondents had a general feeling of despair due to uncertainty and a lack of control.

Quality of life. Many caregivers were concerned about their loved one’s ability to have the best life possible, one with dignity and meaning, and how their lives would look as they aged.

Guardianship. Caregivers worried about their ability to continue caring for their loved one as the caregiver aged. They were also concerned about who would eventually fill their caregiving role. Because of the requirements, the caregivers sometimes felt guilt about asking others to take on the lifelong caregiving responsibility. These fears often led to concern that the person with IDD would end up as a ward of the state. Only a few caregivers had legal guardianship or proxy agreements set up for the future.

> “I really spend a lot of time trying to not think about [the future] too much, because it is terrifying… as parents, [the future] is our worst nightmare. Because we know darn well that our kids are not going to be cared for. There's not a doubt in my mind. My kids are going to be abused. There is a really good likelihood that my daughter's going to be raped. And there's nothing I can do about it.”
>
> Caregiver

Living situation. During the interviews, most of the people with IDD stated they were unable to live on their own and therefore required supervised living, such as a group home, if they were unable to live with a family member. Only one caregiver had a formal plan to meet this need in the future. Caregivers were concerned about how their loved one would pay for community living and worried that their loved one would become homeless if they could not pay.

Safety. Caregivers, especially for people with IDD who were nonverbal, were concerned about their loved one’s safety. They felt there were few safeguards in place to protect their loved ones from abuse.

Lack of services. For people with IDD younger than age 22 who received services from the Florida Department of Education or local education agencies, caregivers expressed concerns about how their loved one would get comparable services once they aged out of the educational system.

Finances. Most caregivers had some financial arrangements in place to support their loved one. Some common examples were a trust, will, or an Achieving a Better Life Experience (ABLE) account. However, even with these arrangements in place, some caregivers were not confident they were enough to meet all key needs.

6. How to improve access to direct care support

When asked what could be done to improve access to direct care services, respondents focused primarily on the APD and its waiver processes.

Adjust waiver qualifications. Many respondents had not applied for waiver services. Some were unlikely to qualify for various reasons, such as high income or having a disability that did not qualify. Community advocates noted that many immigrant families do not qualify for waiver services because they lack a Social Security number, are an undocumented immigrant, or have an immigration or residency status that does not meet the eligibility criteria.

Improve the waiver application process. Caregivers and community advocates shared that the waiver application process is complicated, confusing, and inefficient. The current application is paper-based, prohibiting features that could minimize applicant confusion and mistakes. The process could also benefit from a step-by-step guide about how to apply and a tracker that provided application status updates. Finally, community advocates shared that providing the APD website, links, information, and resources in multiple languages would enable non-English speakers to access information.

All respondents noted that Florida is a "crisis state," meaning that those deemed in crisis by the state can get quicker access to direct care services. However, there was a lack of understanding about what a crisis entailed because its definition is subject to APD's interpretation. Caregivers and community advocates felt that the crisis application process, which is different from the standard iBudget waiver application process, was dehumanizing and ambiguous. Crisis applicants must provide ample documentation and undergo intense scrutiny to prove their situation is a crisis.

> "Don't read the words so literally. It says you can't get this because of [Florida] being a crisis state. That could mean a lot of different things, so don't take it literally. You have to read between the lines. What we think might be a crisis and what you think might be a crisis are two different things."
>
> Caregiver's reference to a conversation with Florida's APD Ombudsman

Increase funding. The most common answer about how to improve direct care services was to increase funding for IDD supports and services across the state. By increasing waiver funding, DCW hourly rates could increase, and more residents could receive waiver services. The waiver program's indefinite waitlist was a key reason people did not apply. The state could invest more in other IDD support programs, such as those provided by the Florida Department of Education, so that they can expand, reach underserved areas, and reduce strain on waiver supports.

Improve resource dissemination. All respondents believed APD and other resources did not provide good program information. Several caregivers described situations in which they received no information about programs they may qualify for. There is no central source to find information about available programs and resources. Consequently, information is scattered, programs are underutilized, and people are reliant on word of mouth to find out about resources.

> "Many are not aware [the waiver] exists… But when they hear about the waitlist and years of waiting, they're like, 'why do this when you just wind up on a waitlist forever.'"
>
> Community advocate

C. Workgroup perspectives

The workgroup members provided additional context to supplement the survey and interviews. We organized their feedback into four topics.

Challenges finding and hiring paid DCWs. Workgroup members discussed the challenges to recruit DCWs including low wages, few benefits, and limited to no opportunities for paid time off. Currently, DCWs can find hospital or retail jobs with a higher hourly wage and more benefits. Age is also a limitation—workgroup members stated it is more difficult to find DCWs for older people than children. Location is another factor. Major cities have a large pool of potential DCWs whereas workgroup members living in rural parts of the state find it very challenging to find and retain direct care support.

Successes recruiting and retaining DCWs. The workgroup members shared their more successful methods for recruiting DCWs, including engaging college students as a nontraditional form of direct care support. Some students seeking health care degrees or certifications become a DCW to attain their required direct patient care hours and gain confidence caring for others. Workgroup members used community events that support people with disabilities, friends, family, and neighbors to find DCWs. Some also called local non-profit organizations and checked social media to network and find available DCWs.

Challenges faced when experiencing limited direct care support. People with IDD and caregivers face substantive challenges when DCW availability is limited, especially single parents and caregivers with their own health concerns. They spend significant time and energy to find DCWs and other resources. Workgroup members explained the difficulties experienced when a DCW misses work or quits on short notice. If the DCW is unable to provide the agreed upon care, the family will need to juggle working to find a new DCW on top of their usual commitments. Older parents with adult children with disabilities are worried about who will care for their children when they are no longer able to provide care.

Waiver challenges and suggested changes for consideration. Workgroup members shared—sometime from direct experience—the difficulty with obtaining and using waiver services. Applying for a waiver can be daunting. Families are challenged by completing the waiver forms and timely processing once paperwork is submitted to the agency. When completing the application, families struggled with the documentation required to establish needs for care. The workgroup called for changes to the application process and more waiver support coordinators. Low Medicaid reimbursement rates exacerbate the lack of providers by not providing enough money to pay both agencies and DCWs. Some workgroup members also suggested changes to waiver processes for hiring and reporting hours worked.

IV. Implications for policy and practice

The activities for the RPS project identified several needs and issues for the IDD community as its members seek to obtain and retain paid direct care support. In this chapter, we provide recommendations regarding how FDDC, the state of Florida, the IDD community, and other interested groups might work in tandem to improve direct care supports for Floridians with IDD.

A. Supporting DCWs

Respondents and participants across analyses shared that more resources are needed to pay and support DCWs. Members of the IDD community will continue struggling to secure direct care support when DCWs receive relatively low compensation for challenging work. Florida could consider the following options for increasing resources for paid direct care support. The state could expand pay and benefits for DCWs who provide services under waiver programs. This change would help people with IDD retain their current direct care support and increase the DCW labor force. Another way to expand resources would be to increase program funding so that more people with IDD receive waiver services. There are also opportunities to expand resources for direct care support outside of the waiver programs. Our research revealed that many people in the IDD community partially rely on education and community programs for direct care support. Increasing the size and scope of those programs could provide more services without requiring people with IDD and their families to enter a waiver program or directly recruit DCWs.

Mann and Nath (2023) provide other recommendations for strengthening the direct care labor force. Key recommendations include providing additional training opportunities for DCWs, creating community and mentoring supports for DCWs, and developing online direct care job registries. That report contains a more complete description of these recommendations.

B. Supporting caregivers

Family members—usually parents and siblings—have a critical role in providing direct care services in the IDD community. In most cases, family caregivers provide the primary support to people with IDD, even when paid direct care support is available. These family members often struggle to juggle their caregiving responsibilities along with other family roles, job responsibilities, and outside interests.

Better compensating and supporting the paid direct care workforce will help family member caregivers. Though most caregivers shared that caring for a loved one with an IDD was difficult, caregivers without paid direct care support reported the highest levels of caregiving-related stress and personal health difficulties. Hence, efforts to expand access to paid direct care support will likely help most unpaid caregivers, providing them with respite and time to pursue other interests, and could be lifechanging for caregivers who get assistance after having none.

The state could continue investigating the potential of compensating family members who provide direct care support. Though having paid direct care support from outside the home provides family members with time to pursue other interests and opportunities, sometimes finding such direct care support is difficult. In these situations, paying family members who provide direct care support might decrease financial stress and lessen the need to work outside the home to support the household. Florida legislators are already exploring the potential benefits of paying family members who provide direct care support in Florida House Bill 391. We encourage the state and FDDC to continue investigating this idea, possibly by documenting what other states are doing to compensate caregivers and incorporating those ideas into future policy.

C. Connecting families to DCW candidates

FDDC or the state could highlight existing or pilot new platforms that help people with IDD find paid direct care support. The interviews revealed that finding strong DCW candidates was difficult, and people had more success using informal networks to find potential DCWs. However, the size and quality of informal networks varies across individuals, so other sources could be used to identify DCW candidates. Some existing online platforms can connect people to direct care assistance. For example, Hope Florida, a new initiative in the state that connects people with various types of needs to private and public resources, could help people with IDD obtain direct care support. However, because Hope Florida is new, we do not have evidence about whether the initiative will effectively help the IDD community meet direct care needs. Findings from the analyses also suggest that large, existing care provider platforms such as Care.com have had limited success at connecting people with IDD to strong DCW candidates.

For these reasons, FDDC and the state could consider other, new initiatives to improve recruiting for paid DCWs. Mann and Nath (2023) mention that some states have developed online platforms to connect people with disabilities to DCW candidates. FDDC or the state could develop and pilot test a DCW networking platform specific to the IDD community. The pilot could be small, working in one or two locations to identify pools of DCW candidates and then develop a platform that connects those candidates to potential local job opportunities. If the pilot test is successful, FDDC or the state could expand use of the platform to other areas.

D. Community resources

FDDC might consider how it could increase the visibility of resources already available to the IDD community. The interviews revealed that some people believed the information and resources available to the IDD community were limited. We initially believed that the participants were identifying gaps in existing resources. However, we quickly found several helpful resources, including community directories, navigator services, resource lists, and help lines, through some targeted searches. This suggests that the existing resources are either not tailored to the IDD community or unknown to the IDD community. Additional data collection and analysis would clarify the extent to which each factor contributes to the interview responses we received. However, FDDC does not need additional research to take actions that could improve how the IDD community accesses existing information and resources. FDDC could use its various platforms—websites, social media, email lists, and networks—to promote what is currently available. In addition, FDDC could assess existing resources to understand if they are written in plain language, 508 compliant, and relevant to the IDD community. Resources with limited relevancy to the IDD community could then be revised or improved upon.

In addition to reviewing existing resources, FDDC might create additional information and resources for the IDD community. The set of existing resources has key information gaps. Such gaps can be filled through FDDC-sponsored initiatives. For example, few caregivers have strong plans for how to support their loved ones with IDD in the future. FDDC could commission journey maps, checklists, and other planning resources that families could use to identify and plan for future care needs. If existing resource lists do not meet the needs of the IDD community, FDDC could develop and administer a list of community resources for the IDD community. Such a list could be helpful to the IDD community, but it would need to be administered so that community members can submit resource summaries and identify outdated information. Finally, the FDDC could better promote how to apply for waiver services. Several members of the Unknown to APD group did not apply for waiver services because they did not know how. By explaining the application process in outreach materials, FDDC and APD might help some people with IDD take action to apply for and access waiver services.

E. Waiver processes and policies

APD could consider improving both the application and payroll processes for its waiver programs. Several interview participants explained that existing application and payroll processes are outdated and slow. Because of this, sometimes: (1) DCW candidates do not complete their applications, (2) DCWs refuse to be paid under the waiver, and (3) waiver participants pay their DCWs directly when payroll delays payment. Finding paid direct care support is difficult enough without the added burden of poor application and payroll processes. APD could update its technology and processes to quickly provide application materials, application processing, and payroll set up. Updated technology can be used to assist people with fully completing DCW applications and providing real time updates about a DCW's application or payroll status. APD could look to vendors who provide similar services for programs in other states for technology solutions.

The IDD community could also encourage APD to clarify what the threshold is to establish a crisis level of need for direct care services. The iBudget waitlist places applicants into various priority categories, with applications in certain categories receiving a higher priority for services (Fla. Stat. § 393.065(5)). People who can demonstrate a crisis level of need are placed in the highest priority category and typically start receiving services quickly. Many interview participants shared that it is unclear what APD requires to establish a crisis level of need. This lack of clarity has resulted in a confusing crisis assessment process that many interview participants characterized as demeaning. The complexity and opaqueness of the process also promotes inequity because people with more training, time, and resources are better equipped to understand what they need to establish a crisis level of need. By clarifying what is needed, APD will help people in great need obtain the direct care services they urgently require.

F. Reaching underserved communities

FDDC and APD could work to ensure that non-English speakers can access IDD community resources and waiver information and services. Non-English speakers comprise a substantial portion of Floridians, with 11.8 percent speaking English less than very well. About 22.1 percent of Floridians speak Spanish, the primary non-English language in the state (U.S. Census Bureau, n.d.). Our difficulty in finding non-English speaking survey respondents and interview participants suggests that existing networks and resources for the IDD community are not readily accessible to non-English communities in Florida. Websites, application materials, and information hot lines for IDD-related resources and programs could be accessible in English, Spanish, and Haitian Creole.

Organizations that serve the IDD community could also develop resources to better meet the needs of rural communities. In 2020, 1.82 million people—about 8.5 percent of the state population—lived in rural areas according to the U.S. Census Bureau (2022, 2023). The survey results suggest that people with IDD in rural areas are less likely to receive waiver services or even be on the Waitlist. This suggests that people with IDD in rural communities have very limited knowledge of resources that might help them. Organizations such as FDDC could create tailored resource guides for rural communities focused on describing APD programs and how to apply for them. In addition, developing county level resource lists and distributing them to people with IDD in rural communities could raise awareness of non-APD direct care supports available to the community.

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Appendix A: Survey Instrument

Mathematica®
Progress Together

How Do People with Intellectual and Developmental Disabilities Receive Support Services?:
Direct Care Services and Support Needs for People with Intellectual and Developmental Disabilities

April 18, 2023

Introduction

The Florida Developmental Disabilities Council, Inc., (FDDC) helps people with intellectual and developmental disabilities (I/DD) participate in all aspects of life. The Council focuses on education, advocacy, and building partnerships that will support its goals.

This survey is for people with I/DD who live in the state of Florida and their family and caregivers. The survey is designed to help the FDDC understand how you receive the care you need to participate in community life. Your answers will help the FDDC advocate for changes that may need to be made.

Your participation is voluntary, which means you do not have to take part. There are no risks, costs, or benefits related to this survey. It is free to fill out this survey, and it should take about 15 - 40 minutes to finish. When you fill out this survey, your answers will remain private. By finishing this survey, you are consenting to participation.

It is fine to have someone help you fill out the survey, but the answers should be your own. You must be at least 18-years old to complete the survey.

If you have questions, please write to FLProviderSolutions@mathematica-mpr.com.

A. Primary Screening

A1. What best describes you?

- 1 ○ I am a person with an I/DD completing this survey on my own → GO TO A1a
- 2 ○ I am a person with an I/DD completing this survey with someone else's help → GO TO A1a
- 3 ○ I am a parent of a person with I/DD → GO TO A2
- 4 ○ I am a sibling of a person with I/DD → GO TO A2
- 5 ○ I am a spouse or partner of a person with I/DD → GO TO A2
- 6 ○ I am another family member of a person with I/DD → GO TO A2
- 7 ○ I am a caregiver (not in the family) of a person with I/DD → GO TO A2
- 8 ○ I am a guardian (not in the family) of a person with I/DD → GO TO A2
- 9 ○ I am a representative payee (not in the family) of a person with I/DD → GO TO A2
- 10 ○ None of the above → GO TO THANK YOU
- d ○ I don't know → GO TO THANK YOU

A1a. Do you have a guardian, conservator, or a representative payee (sometimes also known as a rep payee)? [individual only]

- 1 ○ Yes → GO TO THANK YOU
- 2 ○ No → GO TO A2
- d ○ I don't know → GO TO THANK YOU

A2. How old are YOU?

[DROPDOWN: 17 OR YOUNGER - 110]

A3. [F] Does the person you care for/support live in the state of Florida?
[I] Do you live in the state of Florida?

- 1 ○ Yes → GO TO A4
- 2 ○ No → GO TO THANK YOU
- d ○ I don't know → GO TO THANK YOU

A4. **[F] What best describes the place where they live?**
[I] What best describes the place where you live?

1 ○ In the family home, or the home of another family member
2 ○ In an apartment or house that [they/you] OWN and not receiving supported living services
3 ○ In an apartment or house that [they/you] OWN and receive supported living services
4 ○ In an apartment or house that [they/you] RENT and not receiving supported living services
5 ○ In an apartment or house that [they/you] RENT and receive supported living services
6 ○ In a boarding home
→ **GO TO B1**

7 ○ In a group home with 3 or fewer other people with disabilities that [they/you] are not related to
8 ○ In a group home with 4 to 6 other people with disabilities that [they/you] are not related to
9 ○ In a residence that has 7 to 15 other people with disabilities that [they/you] are not related to
10 ○ In a residence that has more than 15 other people with disabilities that [they/you] are not related to
→ **GO TO THANK YOU**

11 ○ In an apartment building or planned community that includes only people with disabilities
12 ○ Homeless or crisis bed placement
→ **GO TO B1**

13 ○ In an Intermediate Care Facility (ICF)
14 ○ In a nursing home
15 ○ In an institution
16 ○ In an assisted living facility (ALF)
→ **GO TO THANK YOU**

17 ○ Other *(specify)* ______________________________
d ○ I don't know
r ○ Prefer not to disclose
→ **GO TO B1**

B. DIRECT CARE WAIVER SERVICES

[F] **This survey is for family members and other people that support or care for a person with an intellectual or developmental disability (I/DD). Recognizing the diverse types of relationships, we refer to family members and other caregivers as "caregivers." We use the phrase "person you care for/support" throughout the survey to refer to the person with I/DD. When answering these questions, please only include your experiences from the state of Florida.**

We would like to know about what types of government funded direct care waiver services the person you care for/support receives. Many people apply for these services through the Agency for Persons with Disabilities (APD).

[I] **Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.**

This group of questions is about what kinds of government funded direct care waiver services you receive. TIP: You may have applied for these types of services through the Agency for Persons with Disabilities (APD).

B1. **[F] Does the person you care for/support currently have government funded direct care waiver services?**
[I] Do you have government funded direct care waiver services?

1 ○ [They/I] have been approved for waiver services, but [they are/I am] not receiving them → **GO TO B2a**
2 ○ [They/I] have been approved for waiver services and [they are/I am] receiving them → **GO TO B2a**
3 ○ [They/I] have applied for waiver services, but [they are/I am] on a waiting list → **GO TO B3a**
4 ○ [They/I] have not applied for waiver services → **GO TO B4a**
d ○ I don't know → **GO TO B4a**

B2a. **[F] Which direct care waiver are they approved for?**
[I] Which direct care waiver do you have?

MARK ALL THAT APPLY

1 ☐ iBudget Waiver
2 ☐ CDC+ Waiver
3 ☐ Other *(specify)* ______________________________
d ○ I don't know

→ **GO TO B2b**

B2b. **[F] How long has the person you care for/support been approved for their direct care waiver?**
[I] How long have you been approved for your direct care waiver?

[DROPDOWN]

d ○ I don't know

B2c. **[F/I] Direct care waiver services usually have a support plan that can include personal support, respite, companion, and behavioral services.**

In [their/your] support plan, how many hours PER WEEK are [they/you] approved for <u>paid</u> direct care services?
[DROPDOWN]

1 ○ [They/I] don't have a support plan
d ○ I don't know

B2d. [F] Have you or the person you care for/support had any of the following problems with their direct care waiver services?
[I] Have you had any of the following problems with your direct care waiver services?

MARK ONE RESPONSE PER ROW

	YES	NO	DON'T KNOW/ NOT APPLICABLE
a. Services are not available in the area	1 ○	2 ○	d ○
b. [They/I] don't know where to find the needed services	1 ○	2 ○	d ○
c. [They/I] don't know what service providers [we/I] can trust	1 ○	2 ○	d ○
d. There are not enough qualified service providers at the local agency/in the area	1 ○	2 ○	d ○
e. There are not enough service provider options	1 ○	2 ○	d ○
f. It is hard to finding services that match [our/my] needs	1 ○	2 ○	d ○
g. Services are not available during times when they are needed the most	1 ○	2 ○	d ○
h. The quality of available services is poor	1 ○	2 ○	d ○
i. There is not enough funding for the services [we/I] need	1 ○	2 ○	d ○

B3a. [F] How long has the person you care for/support been waiting for their direct care waiver approval?
[I] How long have you been waiting for a direct care waiver approval?

[DROPDOWN: 0 – 30 OR MORE]

d ○ I don't know

B3b. [F] How has the wait affected the person you care for/support?
[I] How has the wait affected you?

1 ○ It has had an extremely serious effect
2 ○ It has had a very serious effect
3 ○ It has had a somewhat serious effect
4 ○ It has had a slightly serious effect
5 ○ It has not affected [them/me] at all
d ○ I don't know

B3c. **[F] Have you or the person you care for/support had any of the following problems with care services?**
[I] Have you had any of the following problems with care services?

MARK ONE RESPONSE PER ROW

	YES	NO	DON'T KNOW/ NOT APPLICABLE
a. Services are not available in the area	1 ○	2 ○	d ○
b. [They/I] don't know where to find the needed services	1 ○	2 ○	d ○
c. [They/I] don't know what service providers [we/I] can trust	1 ○	2 ○	d ○
d. There are not enough qualified service providers at the local agency/in the area	1 ○	2 ○	d ○
e. There are not enough service provider options	1 ○	2 ○	d ○
f. It is hard to finding services that match [our/my] needs	1 ○	2 ○	d ○
g. Services are not available during times when they are needed the most	1 ○	2 ○	d ○
h. The quality of available services is poor	1 ○	2 ○	d ○
i. [We/I] cannot afford the services	1 ○	2 ○	d ○
j. Waiting for a diagnosis to qualify for services	1 ○	2 ○	d ○

B4a. **[F] What are some of the reasons why you or the person you care for/support have not applied for government funded direct care waiver services?**

[I] Why haven't you applied for government funded direct care waiver services?
MARK ALL THAT APPLY

1 ☐ Do not know how or where to apply
2 ☐ Afraid to apply
3 ☐ Unsure who can apply
4 ☐ Hard to find translators
5 ☐ Not worth the hassle
6 ☐ It is hard to get the papers to apply
7 ☐ The application is long and complicated
8 ☐ Not eligible for services
9 ☐ Don't have enough time to apply
10 ☐ Afraid [they/I] will lose resources like Social Security or Medicaid
11 ☐ Other *(specify)* ____________________
d ○ I don't know

B4b. [F] Have you or the person you care for/support had any of the following problems with care services?
[I] Have you had any of the following problems with care services?

MARK ONE RESPONSE PER ROW

	YES	NO	DON'T KNOW/ NOT APPLICABLE
a. Services are not available in the area	1 ○	2 ○	d ○
b. [They/I] don't know where to find the needed services	1 ○	2 ○	d ○
c. [They/I] don't know what service providers [we/I] can trust	1 ○	2 ○	d ○
d. There are not enough qualified service providers at the local agency/in the area	1 ○	2 ○	d ○
e. There are not enough service provider options	1 ○	2 ○	d ○
f. It is hard to finding services that match [our/my] needs	1 ○	2 ○	d ○
g. Services are not available during times when they are needed the most	1 ○	2 ○	d ○
h. The quality of available services is poor	1 ○	2 ○	d ○
i. [We/I] cannot afford the services	1 ○	2 ○	d ○
j. Waiting for a diagnosis to qualify for services	1 ○	2 ○	d ○

C. PAID DIRECT CARE SUPPORT

[F] The next questions are about Direct Care Support Professionals. Direct care workers are hired and paid to work directly with people who have I/DD. Depending on the person's needs, the direct care worker may help with life's essential activities. These include getting out of bed, getting dressed, going to the bathroom, finding a job, getting to work.

[I] Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

This group of questions is about direct care workers, who are people that are paid to help you. They can help with things like getting out of bed, getting dressed, going to the bathroom, finding a job, or getting to work.

C1. [F] Does the person you care for/support currently have a paid direct care worker?
[I] Do you have a paid direct care worker right now?

1 ○ Yes → **GO TO C2**
2 ○ No
d ○ I don't know
→ **GO TO D1**

C2. [F] How many paid direct care workers regularly help the person you care for/support every week?
[I] How many paid direct care workers help you every week?

[DROPDOWN: 0 – 10 OR MORE] →
d ○ I don't know

IF 0, GO TO D1
IF 1 OR D, GO TO C3A
IF 2 OR MORE, GO TO C3B

[F] We would like to know more about the paid direct care support worker who helps the person you care for/support.

[I] We would like to know more about the paid direct care support worker who helps you.

C3a. [F] Think about how the paid direct care worker was hired. How involved were you or the person you care for/support in the process of finding and hiring their paid direct care worker?

[I] Think about how your paid direct care worker was hired. How involved were you in the process of finding and hiring your paid direct care worker?

1 ○ Not at all involved
2 ○ Slightly involved
3 ○ Somewhat involved
4 ○ Mostly involved
5 ○ Extremely involved
d ○ I don't know

C4a. **[F] Think about the place where the person you care for/support gets most of their paid direct care services. What is the place where they get most of their paid direct care services?**

[I] Think about the place where you get most of your paid direct care services. What is the place where you get most of your paid direct care services?

1 ○ Post-secondary education program
2 ○ Afterschool program
3 ○ Childcare setting
4 ○ In the home
5 ○ At a job
6 ○ Respite setting
7 ○ In the community
8 ○ A faith-based organization
9 ○ Medical center or office
10 ○ At an Adult Day Training program
11 ○ Remotely through video calls or the phone
12 ○ Other *(specify)* ____
d ○ I don't know

C5a. **[F] How many hours PER WEEK does the paid direct care worker spend with the person you care for/support?**

[I] How many hours PER WEEK does your paid direct care worker spend with you?

[DROPDOWN: 0 – 168]

d ○ I don't know

C6a. **[F] How long has their paid direct care worker worked for the person you care for/support?**

[I] How long has your paid direct care worker worked for you?

1 ○ Fewer than 90 days
2 ○ Less than 1 year
3 ○ 1 year
4 ○ 2 years
5 ○ 3 - 4 years
6 ○ 5 - 9 years
7 ○ 10 or more years
d ○ I don't know

C7a. **[F] Are you or the person you care for/support able to schedule their paid direct care worker when they need them the most?**

[I] Are you able to schedule your paid direct care worker when you need them the most?

1 ○ Yes
2 ○ No
d ○ I don't know

C8a. [F] How often does their paid direct care worker…

[I]How often does your paid direct care worker…

MARK ONE RESPONSE PER ROW

	NEVER	SOMETIMES	USUALLY	ALWAYS	DON'T KNOW
a. Come to work on time..	1 ○	2 ○	3 ○	4 ○	d ○
b. Leave work early..	1 ○	2 ○	3 ○	4 ○	d ○
c. Call out sick or say they are unable to come to work for another reason.....................................	1 ○	2 ○	3 ○	4 ○	d ○
d. Tell you they are running late	1 ○	2 ○	3 ○	4 ○	d ○

C9a. [F] Do you expect their paid direct care worker to leave in the next 6 months?

[I] Do you expect your paid direct care worker to leave in the next 6 months?

1 ○ Yes
2 ○ No
d ○ I don't know

C10a. [F] Who pays for their direct care worker?
[I] Who pays for your direct care worker?

MARK ALL THAT APPLY

1 ☐ [The person with I/DD/ Me]
2 ☐ [Me/ A family member, friend, or caregiver]
3 ☐ Private health insurance
4 ☐ Medicare
5 ☐ Medicaid
6 ☐ Medicaid - CDC+ Waiver
7 ☐ Medicaid - iBudget Waiver
8 ☐ Another government program, including state health programs
9 ☐ A special needs trust
10 ☐ Scholarships/grants
11 ☐ A church or other religious organization
12 ☐ Other *(specify)* ____
d ○ I don't know

C11a. [F] Do you or the person you care for/support personally give their paid direct care worker any of the following…
[I] Do you or someone else give your paid direct care worker any of the following…
MARK ALL THAT APPLY

1 ☐ Higher wages (above minimum wage or in addition to what the state, agency, or insurance pays)
2 ☐ Bonuses
3 ☐ Paid vacation time
4 ☐ Paid sick time
5 ☐ Additional training
6 ☐ Unpaid time off without penalty
7 ☐ Flexible work hours
8 ☐ Other *(specify)* ______________________________
d ○ I don't know

C12a. [F] How would you rate the quality of care their paid direct care worker provides?
[I] How would you rate the quality of care your paid direct care worker gives you?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
d ○ I don't know

C13a. [F] How would you rate the overall experience with their paid direct care worker?
[I] How would you rate your overall experience with your paid direct care worker?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
d ○ I don't know
→ **GO TO C14**

[F] We would like to know more about the paid direct care workers who helps the person you care for/support. We are going to ask questions about each paid direct care support worker. The first set of questions will focus on the paid direct care worker who provides the most care to the person you care for/support. We will refer to this person as the primary direct care worker. Once you complete the questions about the primary, we will ask the same questions about the secondary direct care worker.

Please answer the next questions while thinking about the person you care for/support's PRIMARY paid direct care worker.

[I] Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

This group of questions is about the paid direct care workers who help you. We will ask you about two kinds of direct care workers:

PRIMARY direct care worker – the person who helps you most often

SECONDARY direct care worker – the person who helps you the second-most often

[F] We would like to know more about the paid direct care workers who helps the person you care for/support. We are going to ask questions about the two paid direct care workers that help the person you care for/support the most often. The first set of questions will focus on the paid direct care worker who provides the most care to the person you care for/support. We will refer to this person as the primary direct care worker. Once you complete the questions about the primary, we will ask the same questions about the secondary direct care worker.

Please answer the next questions while thinking about the person you care for/support's PRIMARY paid direct care worker.

[I] Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

This group of questions is about the direct care workers who help you. We will ask you about two kinds of direct care workers:

PRIMARY direct care worker – the person who helps you most often

SECONDARY direct care worker – the person who helps you the second-most often

C3b. **[F] Think about how the PRIMARY paid direct care worker was hired. How involved were you or the person you care for/support in the process of finding and hiring their PRIMARY direct care worker?**

[I] Think about how your PRIMARY paid direct care worker was hired. How involved were you in the process of finding and hiring your PRIMARY direct care worker?

1 ○ Not at all involved
2 ○ Slightly involved
3 ○ Somewhat involved
4 ○ Mostly involved
5 ○ Extremely involved
d ○ I don't know

C4b. **[F] Think about the place where the person you care for/support gets their services from their PRIMARY paid direct care worker. What is the place where they get most of their PRIMARY paid direct care services?**

[I] Think about the place where you get your services from your primary paid direct care worker. What is the place where you get most of your PRIMARY paid direct care services?

1 ○ Post-secondary education program
2 ○ Afterschool program
3 ○ Childcare setting
4 ○ In the home
5 ○ At a job
6 ○ Respite setting
7 ○ In the community
8 ○ Faith-based organization
9 ○ Medical center or office
10 ○ At an Adult Day Training program
11 ○ Remotely through video calls or the phone
12 ○ Other *(specify)* ______________________________
d ○ I don't know

C5b. [F] How many hours PER WEEK does their PRIMARY paid direct care worker spend with the person you care for/support?
[I] How many hours PER WEEK does your PRIMARY paid direct care worker spend with you?

[DROPDOWN: 0 – 168]

d ○ I don’t know

C6b. [F] How long has their PRIMARY paid direct care worker worked for the person you care for/support?

[I] How long has your PRIMARY paid direct care worker worked for you?

1 ○ Fewer than 90 days
2 ○ Less than 1 year
3 ○ 1 year
4 ○ 2 years
5 ○ 3 - 4 years
6 ○ 5 - 9 years
7 ○ 10 or more years
d ○ I don’t know

C7b. [F] Are you or the person you care for/support able to schedule their PRIMARY paid direct care worker when they need them the most?

[I] Are you able to schedule your PRIMARY paid direct care worker when you need them the most?

1 ○ Yes
2 ○ No
d ○ I don’t know

C8b. [F] How often does their PRIMARY paid direct care worker…

[I] How often does your PRIMARY paid direct care worker…

MARK ONE RESPONSE PER ROW

	NEVER	SOMETIMES	USUALLY	ALWAYS	DON’T KNOW
a. Come to work on time..	1 ○	2 ○	3 ○	4 ○	d ○
b. Leave work early..	1 ○	2 ○	3 ○	4 ○	d ○
c. Call out sick or say they are unable to come to work for another reason....................................	1 ○	2 ○	3 ○	4 ○	d ○
d. Tell you they are running late	1 ○	2 ○	3 ○	4 ○	d ○

C9b. [F] Do you expect their PRIMARY paid direct care worker to leave in the next 6 months?

[I] Do you expect your PRIMARY paid direct care worker to leave in the next 6 months?

1 ○ Yes
2 ○ No
d ○ I don’t know

C10b. [F] Who pays for their PRIMARY direct care worker ?
[I] Who pays for your PRIMARY direct care worker?

MARK ALL THAT APPLY

1 ☐ [The person with I/DD/ Me]
2 ☐ [Me/ A family member, friend, or caregiver]
3 ☐ Private health insurance
4 ☐ Medicare
5 ☐ Medicaid
6 ☐ Medicaid - CDC+ Waiver
7 ☐ Medicaid - iBudget Waiver
8 ☐ Another government program, including state health programs
9 ☐ A special needs trust
10 ☐ Scholarships/grants
11 ☐ A church or other religious organization
12 ☐ Other *(specify)* ________________________________
d ○ I don't know

C11b. [F] Do you or the person you care for/support personally give their PRIMARY paid direct care worker any of the following…
[I] Do you or someone else give your PRIMARY paid direct care worker any of the following…
MARK ALL THAT APPLY

1 ☐ Higher wages (above minimum wage or in addition to what the state, agency, or insurance pays)
2 ☐ Bonuses
3 ☐ Paid vacation time
4 ☐ Paid sick time
5 ☐ Additional training
6 ☐ Unpaid time off without penalty
7 ☐ Flexible work hours
8 ☐ Other *(specify)* ________________________________
d ○ I don't know

C12b. [F] How would you rate the quality of care their PRIMARY paid direct care worker provides?
[I] How would you rate the quality of care your PRIMARY paid direct care worker gives?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
d ○ I don't know

C13b. [F] How would you rate the overall experience with their PRIMARY paid direct care worker?
[I] How would you rate your overall experience with your PRIMARY paid direct care worker?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
d ○ I don't know

→ **GO TO C3C**

[F] Please answer the next questions while thinking about the person you care for/support's SECONDARY paid direct care worker.

[I] Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

This group of questions is about your SECONDARY direct care worker – the person who helps you the second-most often.

C3c. [F] Think about how the SECONDARY paid direct care worker was hired. How involved were you or the person you care for/support in the process of finding and hiring their SECONDARY paid direct care worker?

[I] Think about how your SECONDARY paid direct care worker was hired. How involved were you in the process of finding and hiring your SECONDARY paid direct care worker?

1 ○ Not at all involved
2 ○ Slightly involved
3 ○ Somewhat involved
4 ○ Mostly involved
5 ○ Extremely involved
d ○ I don't know

C4c. [F] Think about the place where the person you care for/support gets their services from their SECONDARY paid direct care worker. What is the place where they get most of their SECONDARY paid direct care services?

[I] Think about the place where you get your services from your SECONDARY paid direct care worker. What is the place where you get most of your SECONDARY paid direct care services?

1 ○ Post-secondary education program
2 ○ Afterschool program
3 ○ Childcare setting
4 ○ In the home
5 ○ At a job
6 ○ Respite setting
7 ○ In the community
8 ○ Faith-based organization
9 ○ Medical center or office
10 ○ At an Adult Day Training program
11 ○ Remotely through video calls or the phone
12 ○ Other *(specify)* ______________________________
d ○ I don't know

C5c. [F] How many hours PER WEEK does their SECONDARY paid direct care worker spend with the person you care for/support?
[I] How many hours PER WEEK does your SECONDARY paid direct care worker spend with you?

[DROPDOWN: 0 – 168]

d ○ I don't know

C6c. [F] How long has their SECONDARY paid direct care worker worked for the person you care for/support?

[I] How long has your SECONDARY paid direct care worker worked for you?

1 ○ Fewer than 90 days
2 ○ Less than 1 year
3 ○ 1 year
4 ○ 2 years
5 ○ 3 - 4 years
6 ○ 5 - 9 years
7 ○ 10 or more years
d ○ I don't know

C7c. [F] Are you or the person you care for/support able to schedule their SECONDARY paid direct care worker when they need them the most?

[I] Are you able to schedule your SECONDARY paid direct care worker when you need them the most?

1 ○ Yes
2 ○ No
d ○ I don't know

C8c. [F] How often does their SECONDARY paid direct care worker…

[I] How often does your SECONDARY paid direct care worker…

MARK ONE RESPONSE PER ROW

	NEVER	SOMETIMES	USUALLY	ALWAYS	DON'T KNOW
a. Come to work on time..	1 ○	2 ○	3 ○	4 ○	d ○
b. Leave work early..	1 ○	2 ○	3 ○	4 ○	d ○
c. Call out sick or say they are unable to come to work for another reason....................................	1 ○	2 ○	3 ○	4 ○	d ○
d. Tell you they are running late	1 ○	2 ○	3 ○	4 ○	d ○

C9c. [F] Do you expect their SECONDARY paid direct care worker to leave in the next 6 months?

[I] Do you expect your SECONDARY paid direct care worker to leave in the next 6 months?

1 ○ Yes
2 ○ No
d ○ I don't know

C10c. [F] Who pays for their SECONDARY direct care worker?
[I] Who pays for your SECONDARY direct care worker?

MARK ALL THAT APPLY

1 ☐ [The person with I/DD/ Me]
2 ☐ [Me/ A family member, friend, or caregiver]
3 ☐ Private health insurance
4 ☐ Medicare
5 ☐ Medicaid
6 ☐ Medicaid - CDC+ Waiver
7 ☐ Medicaid - iBudget Waiver
8 ☐ Another government program, including state health programs
9 ☐ A special needs trust
10 ☐ Scholarships/grants
11 ☐ A church or other religious organization
12 ☐ Other *(specify)* ____________________
d ○ I don’t know

C11c. [F] Do you or the person you care for/support personally give their SECONDARY paid direct care worker any of the following…
[I] Do you or someone else give your SECONDARY paid direct care worker any of the following…
MARK ALL THAT APPLY

1 ☐ Higher wages (above minimum wage or in addition to what the state, agency, or insurance pays)
2 ☐ Bonuses
3 ☐ Paid vacation time
4 ☐ Paid sick time
5 ☐ Additional training
6 ☐ Unpaid time off without penalty
7 ☐ Flexible work hours
8 ☐ Other *(specify)* ____________________
d ○ I don’t know

C12c. [F] How would you rate the quality of care their SECONDARY paid direct care worker provides?
[I] How would you rate the quality of care your SECONDARY paid direct care worker gives?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
d ○ I don’t know

C13c. [F] How would you rate the overall experience with their SECONDARY paid direct care worker?
[I] How would you rate your overall experience with your SECONDARY paid direct care worker?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
d ○ I don't know

C14. [F] In an average month, how much <u>additional</u> money is spent on ALL paid direct care services for the person you care for/support? [iBudget and CDC+ Waiver only]
[I] In an average month, how much <u>additional</u> money is spent on ALL paid direct care services for you? [iBudget and CDC+ Waiver only]

[F] In an average month, how much money is spent on ALL paid direct care services for the person you care for/support? [iBudget Waiver waitlist and unknown to APD only]
[I] In an average month, how much money is spent on ALL paid direct care services for you? [iBudget Waiver waitlist and unknown to APD only]

1 ○ None
2 ○ Less than $100 per month
3 ○ $100 - $249 per month
4 ○ $250 - $499 per month
5 ○ $500 - $999 per month
6 ○ $1000 - $1499 per month
7 ○ $1500 - $1999 per month
8 ○ $2000 - $2499 per month
9 ○ $2500 - $2900 per month
10 ○ $3000 or more per month
d ○ I don't know

→ **IF INDIVIDUAL, GO TO D1**
IF FAMILY/CAREGIVER, GO TO C15

C15. As a result of having paid direct care support, do you… [family/caregiver only]

MARK ALL THAT APPLY

1 ☐ Have more time for personal activities
2 ☐ Have the ability to maintain a job
3 ☐ Feel less stress
4 ☐ Better understand how to get the services for the person you care for/support
5 ☐ Know more about the person you care for/support's condition
6 ☐ Feel more confident in providing care to the person you care for/support
7 ☐ Feel that the person you care for/support needs are being fully met
8 ☐ Other *(specify)* ______________________________
d ○ I don't know

D. ACCESS – PAID

[F] Think about ALL the paid direct care workers who have helped the person you care for/support in the last 12 months. Please include all direct care workers who are currently employed, are no longer employed by the person you care for/support, and agency provided personnel.

[I] Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

This group of questions is about ALL the direct care workers who have helped you in the last 12 months. Please include those who work with you now and those who no longer work with you.

D1. **[F] In the past 12 months, how many paid direct care workers have helped the person you care for/support?**
[I] In the past 12 months, how many paid direct care workers have helped you?

[DROPDOWN: 0 – 20 OR MORE] → **IF 0 OR D, GO TO D2**

d ○ I don't know **IF 1 OR MORE, GO TO D1A**

D1a. **[F] Do you feel that their paid direct care worker changes too often?**
[I] Do you feel that your paid direct care worker changes too often?

1 ○ Yes
2 ○ No
d ○ I don't know

D1b. **[F] How often do you or the person you care for/support need to find a <u>new</u> paid direct care worker?**
[I] How often do you need to find a <u>new</u> paid direct care worker?

1 ○ Very often
2 ○ Often
3 ○ Sometimes
4 ○ Rarely
5 ○ Very rarely
6 ○ Never
d ○ I don't know

D2. **[F] In the last 6 months, have you or the person you care for/support searched for a <u>new</u> paid direct care worker?**
[I] In the last 6 months, have you searched for a <u>new</u> paid direct care worker?

1 ○ Yes → **GO TO D2A**
2 ○ No → **GO TO D3**
d ○ I don't know → **GO TO D3**

D2a. **[F] Did you or the person you care for/support find and hire a <u>new</u> paid direct care worker?**
[I] Did you find and hire a <u>new</u> paid direct care worker?

1 ○ Yes
2 ○ No
d ○ I don't know

D2b. [F] How hard is it to find a paid direct care worker that you or the person you care for/support are satisfied with?
[I] How hard is it to find a paid direct care worker that you are satisfied with?

1 ○ Very hard
2 ○ Somewhat hard
3 ○ Not very hard
d ○ I don't know

D3. [F] Are any of the following a problem for you or the person you care for/support?

[I] Are any of the following a problem for you?

MARK ONE RESPONSE PER ROW

	MAJOR PROBLEM	SOME PROBLEM	NOT A PROBLEM	DON'T KNOW/ NOT APPLICABLE
a. Finding <u>trained</u> paid direct care workers....................	1 ○	2 ○	3 ○	d ○
b. Finding <u>dependable</u> paid direct care workers............	1 ○	2 ○	3 ○	d ○
c. Finding <u>stable</u> paid direct care workers	1 ○	2 ○	3 ○	d ○

E. UNPAID CAREGIVERS

[F] These next questions are about unpaid caregivers. An unpaid caregiver helps the person with I/DD with activities. This person is NOT a paid helper. If you regularly help the person that you care for/support, make sure to include yourself in the questions below.

[I] Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

This group of questions is about unpaid caregivers. This includes people who help you with activities but are NOT paid for their help.

E1. [F] How many unpaid caregivers regularly help the person you care for/support?
[I] How many unpaid caregivers regularly help you?

[DROPDOWN: 0 – 20 or more] → **IF 0 OR D, GO TO F1**

d ○ I don't know **IF 1 OR MORE, GO TO E2**

E2. [F] Who are their regular unpaid caregivers?
[I] Who are your regular unpaid caregivers?

MARK ALL THAT APPLY

1 ☐ Parent or parents
2 ☐ Brother or sister
3 ☐ Grandparent
4 ☐ Aunt or uncle
5 ☐ Spouse, partner, boyfriend, or girlfriend
6 ☐ Child
7 ☐ Another family member
8 ☐ Friend
9 ☐ A neighbor
10 ☐ Faith-based community members
11 ☐ Other *(specify)* ____________________
12 ○ Do not need any help
0 ○ No one
d ○ I don't know

E3. **[F] Think about the place where the person you care for/support gets most of their unpaid caregiver support. Where do they get most of their <u>unpaid</u> caregiver support?**

[I] Think about the place where you get most of your <u>unpaid</u> caregiver support. Where do you get most of your unpaid caregiver support?

1 ○ Post-secondary education program
2 ○ Afterschool program
3 ○ Childcare setting
4 ○ In the home
5 ○ At a job
6 ○ Respite setting
7 ○ In the community
8 ○ Faith-based organization
9 ○ Medical center or office
10 ○ At an Adult Day Training program
11 ○ Remotely through video calls or the phone
12 ○ Other *(specify)* ________________________________
d ○ I don’t know

F. SUPPORT NEEDS

[F] We would like to know about what types of help the person you care for/support needs. For this section, please think about both paid and unpaid support.

[I] Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

This group of questions is about the types of help you need.

F1. [F] Which activities does the person you care for/support need regular assistance, supervision, or reminders for?
[I] Which activities do you need regular help or reminders for?

MARK ALL THAT APPLY

Around the home

1 ☐ Cooking or preparing meals
2 ☐ Doing light work around the house (for example, laundry, doing dishes, straightening up, light cleaning, or taking out the trash)
3 ☐ Doing heavy work around the house (for example, scrubbing floors, washing windows, and doing heavy yard work)
4 ☐ Home maintenance

In the community

5 ☐ Shopping
6 ☐ Managing communication (for example, the telephone, mail, texting)
7 ☐ Providing sign language interpretation
8 ☐ Emotional support
9 ☐ Visiting friends or other social arrangements
10 ☐ Support at recreational activities

Daily life

11 ☐ Personal care (for example, bathing, feeding, dressing, grooming, toileting, etc.)
12 ☐ Walking (for example, getting around inside or outside the home)
13 ☐ Managing money (for example, keeping track of expenses or paying bills)
14 ☐ Managing medications
15 ☐ Managing transportation (for example, either via driving or by organizing other means of transport)
16 ☐ Arranging and monitoring outside help or services
17 ☐ Coordinating community services – or services with a local religious institution
18 ☐ School responsibilities (for example, homework, reading, writing)
19 ☐ Other *(specify)* ______________________________
d ○ I don't know

F2. **[F] In the past 12 months, did the person you care for/support <u>receive</u> the help they needed?**
[I] In the past 12 months, did you <u>receive</u> the help you needed?

1 ○ Yes

2 ○ No

d ○ I don’t know

F3. **[F] In the past 12 months, did the person you care for/support ever <u>go without</u> help when they needed it?**
[I] In the past 12 months, did you ever <u>go without</u> help when you needed it?

1 ○ Yes

2 ○ No

d ○ I don’t know

→ **IF INDIVIDUAL, GO TO I1**

IF FAMILY/CAREGIVER, GO TO G1

G. FAMILY/CAREGIVERS - FAMILY/CAREGIVER ONLY

We would like to know more about your caregiving experience. Please complete this section from YOUR OWN POINT OF VIEW.

G1. Are any of the following a problem for you as a caregiver of a person with a disability?

MARK ONE RESPONSE PER ROW

	MAJOR PROBLEM	SOME PROBLEM	NOT A PROBLEM	DON'T KNOW/ NOT APPLICABLE
a. Respite care – for when I need time to take care of my own needs	1 ○	2 ○	3 ○	d ○
b. Day care – for when I work	1 ○	2 ○	3 ○	d ○
c. Night care – for when I work overnight shifts	1 ○	2 ○	3 ○	d ○
d. Emergency Care – for when I need to care for another family member or myself	1 ○	2 ○	3 ○	d ○
e. After school or summer care	1 ○	2 ○	3 ○	d ○
f. Finding care substitutes – for when I need temporary care	1 ○	2 ○	3 ○	d ○
g. Dealing with break downs in care arrangements	1 ○	2 ○	3 ○	d ○
h. Having enough money to pay for direct care support	1 ○	2 ○	3 ○	d ○
i. Ensuring the safety of the person you care for/support	1 ○	2 ○	3 ○	d ○

G2. In the past 12 months, how often do you feel that caregiving interferes with your day-to-day life?

1 ○ Always
2 ○ Usually
3 ○ Sometimes
4 ○ Rarely
5 ○ Never
r ○ Prefer not to disclose

G3. Have you ever…

MARK ONE RESPONSE PER ROW

	YES	NO	DON'T KNOW
a. Received money from government programs for your caregiving duties	1 ○	2 ○	d ○
b. Received any Federal caregiver tax credits (e.g., caregiver tax credit, infirm dependent tax credit, medical expense tax credit)	1 ○	2 ○	d ○
c. Requested information about how to get financial help for the person you care for/support	1 ○	2 ○	d ○
d. Received services or supports that have reduced your out-of-pocket expenses for the person you care for/support	1 ○	2 ○	d ○

G4. If there was a government program that paid you for some of your current unpaid caregiving responsibilities, would you apply?

1 ○ Yes
2 ○ No
d ○ I don't know

G5. What types of long-term planning have you done to prepare for the person you care for/support's future?

MARK ALL THAT APPLY

1 ☐ Housing or living arrangements
2 ☐ Caregiving
3 ☐ Medical support and decisions
4 ☐ Decision-making support (daily and major life decisions)
5 ☐ Financial
6 ☐ Guardianship, Guardian Advocacy, or Supported Decision-Making
7 ☐ Vocational (e.g., employment, postsecondary education)
8 ☐ Other *(specify)* ______________________________
9 ○ None
d ○ I don't know

G6. In the past 12 months, how stressful have your caregiver responsibilities been?

1 ○ Extremely stressful
2 ○ Very stressful
3 ○ Moderately stressful
4 ○ Mildly stressful
5 ○ Not at all stressful
r ○ Prefer not to disclose

→ **GO TO H1**

H. ABOUT THE PERSON YOU CARE FOR/SUPPORT DEMOGRAPHICS – FAMILY/CAREGIVER ONLY

These questions ask for some general information about the person you care for/support.

H1. How old are they?

[DROPDOWN: 0 - 110]

d ○ I don't know
r ○ Prefer not to disclose

H2. What is their diagnosis, if they have one?

MARK ALL THAT APPLY

1 ☐ Autism
2 ☐ Cerebral palsy
3 ☐ Intellectual disability
4 ☐ Down syndrome
5 ☐ Prader-Willi syndrome
6 ☐ Phelan McDermid syndrome
7 ☐ Spina bifida
8 ☐ Other *(specify)* ______________________________
d ○ I don't know
r ○ Prefer not to disclose

H3. Which of the following best describes their disability or disabilities?

MARK ALL THAT APPLY

1 ☐ Intellectual disability
2 ☐ Learning disability
3 ☐ Neurological developmental disability
4 ☐ Mobility or physical impairment
5 ☐ Mental health, psychological, psychiatric, or emotional impairment
6 ☐ Vision impairment
7 ☐ Hearing impairment
8 ☐ Speech impairment
9 ☐ Orthopedic impairment
10 ☐ Traumatic brain injury
11 ☐Other *(specify)* ______________________________
d ○ I don't know
r ○ Prefer not to disclose

H4. Would you describe the person you care for/support as having a level of disability that is, in terms of their functioning:

1 ○ Mild
2 ○ Moderate
3 ○ Severe
d ○ I don't know
r ○ Prefer not to disclose

H5. In general, how would you rate their overall health?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
d ○ I don't know
r ○ Prefer not to disclose

H6. What kind of health insurance or health care coverage do they have?

MARK ALL THAT APPLY

1 ○ No coverage of any type
2 ☐ Private health insurance
3 ☐ Medicare
4 ☐ Medigap
5 ☐ Medicaid
6 ☐ Children's Health Insurance Program (CHIP)
7 ☐ Military related health care: TRICARE (CHAMPUS) / VA health care / CHAMPVA
8 ☐ Indian Health Service
9 ☐ Single service plan (e.g., dental, vision, prescriptions)
10 ☐ State-sponsored health plan (e.g., through a state exchange)
11 ☐ Other government program *(specify)* ______________________________
d ○ I don't know
r ○ Prefer not to disclose

H7. **What is the highest level of education they have completed?**

1 ○ Grade school
2 ○ Some high school
3 ○ Special diploma
4 ○ High school certificate of completion
5 ○ High school diploma or completed GED
6 ○ Certificate of completion from post-secondary program for persons with disabilities
7 ○ Some college or technical school
8 ○ 2-year college degree (Associate's degree)
9 ○ 4-year college degree (Bachelor's degree)
10 ○ Some post-graduate studies
11 ○ Graduate degree
12 ○ Aged out at age 22
13 ○ On alternate assessment
14 ○ Other *(specify)* ______________________________
d ○ I don't know
r ○ Prefer not to disclose

H8. **What is their current occupational status?**

MARK ALL THAT APPLY

1 ☐ Employed, full time
2 ☐ Employed, part time
3 ☐ Unemployed and looking for a job
4 ☐ Unemployed, but not looking for a job
5 ☐ Homemaker
6 ☐ Student
7 ☐ Attending vocational training program
8 ☐ Attending adult day training program
9 ☐ Retired
10 ☐ Receiving income support because of a disability
11 ☐ Other *(specify)* ______________________________
d ○ I don't know
r ○ Prefer not to disclose

H9. **Which best describes the area where they live?**

1 ○ Urban
2 ○ Suburban
3 ○ Rural
d ○ I don't know
r ○ Prefer not to disclose

H10. **Which Florida county do they live in?**

[DROPDOWN]

d ○ I don't know

r ○ Prefer not to disclose

H11. **Are they Hispanic or Latino/a?**

1 ○ Yes, Hispanic

2 ○ Yes, Latino/a

3 ○ No, not Hispanic or Latino/a

4 ○ Different ethnicity *(specify)* ____________________

d ○ I don't know

r ○ Prefer not to disclose

H12. **What is their race?**

MARK ALL THAT APPLY

1 ☐ American Indian or Alaska Native

2 ☐ Asian

3 ☐ Black or African American

4 ☐ Native Hawaiian or and Other Pacific Islander

5 ☐ White

6 ☐ Other *(specify)* ____________________

d ○ I don't know

r ○ Prefer not to disclose

H13. **What is their gender?**

MARK ALL THAT APPLY

1 ☐ Male

2 ☐ Female

3 ☐ They use a different term:__________

d ○ I don't know

r ○ Prefer not to disclose

→ **GO TO J1**

I. ABOUT YOU DEMOGRAPHICS – INDIVIDUAL ONLY

Please respond to each question. Remember that all answers should be your own, even if someone is helping you fill out the survey.

The last questions ask for information about you.

I1. What is your diagnosis, if you have one?

MARK ALL THAT APPLY

1 ☐ Autism
2 ☐ Cerebral palsy
3 ☐ Intellectual disability
4 ☐ Down syndrome
5 ☐ Prader-Willi syndrome
6 ☐ Phelan McDermid syndrome
7 ☐ Spina bifida
8 ☐ Other *(specify)* ____________________
r ○ Prefer not to disclose

I2. Which of the following best describes your disability or disabilities?

MARK ALL THAT APPLY

1 ☐ Intellectual disability
2 ☐ Learning disability
3 ☐ Neurological developmental disability
4 ☐ Mobility or physical impairment
5 ☐ Mental health, psychological, psychiatric, or emotional impairment
6 ☐ Vision impairment
7 ☐ Hearing impairment
8 ☐ Speech impairment
9 ☐ Orthopedic impairment
10 ☐ Traumatic brain injury
11 ☐ Other *(specify)* ____________________
r ○ Prefer not to disclose

I3. In general, how would you rate your overall health?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
r ○ Prefer not to disclose

I4. What kind of health insurance or health care coverage do you have?

MARK ALL THAT APPLY

1 ○ No coverage of any type
2 ☐ Private health insurance
3 ☐ Medicare
4 ☐ Medigap
5 ☐ Medicaid
6 ☐ Children's Health Insurance Program (CHIP)
7 ☐ Military related health care: TRICARE (CHAMPUS) / VA health care / CHAMPVA
8 ☐ Indian Health Service
9 ☐ Single service plan (dental, vision, prescriptions)
10 ☐ State-sponsored health plan (through a state exchange)
11 ☐ Other government program *(specify)* ______________________________
r ○ Prefer not to disclose

I5. What is the highest level of education you have completed?

1 ○ Grade school
2 ○ Some high school
3 ○ Special diploma
4 ○ High school certificate of completion
5 ○ High school diploma or completed GED
6 ○ Certificate of completion from post-secondary program for persons with disabilities
7 ○ Some college or technical school
8 ○ 2-year college degree (Associate’s degree)
9 ○ 4-year college degree (Bachelor’s degree)
10 ○ Some post-graduate studies
11 ○ Graduate degree
12 ○ Aged out at age 22
13 ○ On alternate assessment
14 ○ Other *(specify)* ______________________________
r ○ Prefer not to disclose

I6. What is your current occupational status?

MARK ALL THAT APPLY

1 ☐ Employed, full time
2 ☐ Employed, part time
3 ☐ Unemployed and looking for a job
4 ☐ Unemployed, but not looking for a job
5 ☐ Homemaker
6 ☐ Student
7 ☐ Attending vocational training program
8 ☐ Attending adult day training program
9 ☐ Retired
10 ☐ Receiving income support because of a disability
11 ☐ Other *(specify)* ______________________________
r ○ Prefer not to disclose

I7. Which best describes the area where you live?

1 ○ Urban
2 ○ Suburban
3 ○ Rural
r ○ Prefer not to disclose

I8. Which Florida county do you live in?

[DROPDOWN]

r ○ Prefer not to disclose

I9. Are you Hispanic or Latino/a?

1 ○ Yes, Hispanic
2 ○ Yes, Latino/a
3 ○ No, not Hispanic or Latino/a
4 ○ Different ethnicity *(specify)* ______________________________
r ○ Prefer not to disclose

I10. What is your race?

MARK ALL THAT APPLY

1 ☐ American Indian or Alaska Native
2 ☐ Asian
3 ☐ Black or African American
4 ☐ Native Hawaiian or and Other Pacific Islander
5 ☐ White
6 ☐ Other *(specify)* ______________________________
r ○ Prefer not to disclose

I11. **What is your gender?**

MARK ALL THAT APPLY

1 ☐ Male
2 ☐ Female
3 ☐ I use a different term:_______________
r ○ Prefer not to disclose

→ **END SURVEY, GO TO THANK YOU**

J. ABOUT YOU DEMOGRAPHICS – FAMILY/CAREGIVER ONLY

These last questions ask for some general information about you.

J1. In general, how would you rate your overall health?

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent
r ○ Prefer not to disclose

J2. What is the highest level of education you have completed?

1 ○ Grade school
2 ○ Some high school
3 ○ Special diploma
4 ○ High school certificate of completion
5 ○ High school diploma or completed GED
6 ○ Certificate of completion from post-secondary program for persons with disabilities
7 ○ Some college or technical school
8 ○ 2-year college degree (Associate’s degree)
9 ○ 4-year college degree (Bachelor’s degree)
10 ○ Some post-graduate studies
11 ○ Graduate degree
12 ○ Aged out at age 22
13 ○ On alternate assessment
14 ○ Other *(specify)* ____________________
r ○ Prefer not to disclose

J3. **What is your current occupational status?**

MARK ALL THAT APPLY

1 ☐ Employed, full time
2 ☐ Employed, part time
3 ☐ Unemployed and looking for a job
4 ☐ Unemployed, but not looking for a job
5 ☐ Homemaker
6 ☐ Student
7 ☐ Attending vocational training program
8 ☐ Attending adult day training program
9 ☐ Retired
10 ☐ Receiving income support because of a disability
11 ☐ Other *(specify)* ______________________________
r ○ Prefer not to disclose

J4. **Which Florida county do you live in?**

[DROPDOWN]

1 ○ I don’t live in the state of Florida
r ○ Prefer not to disclose

J5. **Are you Hispanic or Latino/a?**

1 ○ Yes, Hispanic
2 ○ Yes, Latino/a
3 ○ No, not Hispanic or Latino/a
4 ○ Different ethnicity *(specify)* ______________________________
r ○ Prefer not to disclose

J6. **What is your race?**

MARK ALL THAT APPLY

1 ☐ American Indian or Alaska Native
2 ☐ Asian
3 ☐ Black or African American
4 ☐ Native Hawaiian or and Other Pacific Islander
5 ☐ White
6 ☐ Other *(specify)* ______________________________
r ○ Prefer not to disclose

J7. What is your gender?

MARK ALL THAT APPLY

1 ☐ Male
2 ☐ Female
3 ☐ I use a different term:__________
r ○ Prefer not to disclose

→ **END SURVEY, GO TO THANK YOU**

THANK YOU

Thank you taking the time to complete this survey. The findings from this survey will be used to raise awareness about the challenges people with intellectual and developmental disabilities (I/DD) face when accessing direct care and support services.

Please share this survey link with your friends, family, or community: [survey link]

THANK YOU – SCREEN OUT PAGE. NOT ELIGIBLE

Thank you for your interest. This survey is for people with intellectual and developmental disabilities (I/DD) who are 18 years or older, live in the state of Florida, and can give legal consent or their family or caregivers. You are not eligible to take the survey.

If you know an adult who does meet these qualifications, please share this survey with them: [survey link]

Appendix B: Interview Guide

Direct Care Services and Support Needs Interview Protocol

Thank you for taking the time to speak with us today. My name is [name], a Researcher at Mathematica. These interviews are being conducted on behalf of the Florida Developmental Disabilities Council, Inc. (FDDC), an organization that supports people with intellectual and developmental disabilities (I/DD) through education, advocacy, and partnerships that promote meaningful participation in all aspects of life.

The purpose of our project is to learn about how people with intellectual and developmental disabilities and their family members and caregivers access the direct care they need to take part in community life.

Your answers will help inform issues related to services and supports (i.e., personal care, companion, and respite) that (**[I]** you/**[F]** the person you care for/support/**[C]** the community) has now or may need.

Today's discussion will be about ([individual interview] 60/ [focus group] 90) minutes long. Information we learn today will be handled in a confidential manner. ([focus group] Similarly, we ask that you respect the privacy of the other group members by not talking about any information shared during the study.) Lastly, Florida state law requires that we tell the authorities if we learn about possible neglect or abuse or that you might hurt yourself or someone else (§ 415.1034(1)(a)5).

To protect your privacy, only the project team will see or hear our discussion. Your responses and names will remain private (confidential). No names will be included in any reports shared with the Florida Developmental Disabilities Council.

[F] We recognize that there are different types of relationships, so we will refer to family members and other caregivers as "caregivers." We also use the phrase "person you care for/support" throughout the survey to refer to the person with intellectual and developmental disabilities.

Your participation is voluntary, which means you do not have to take part. There are no risks, costs, or benefits related to today's discussion. You can choose to keep your video on or off during the interview. If you do not feel comfortable using your real name during our conversation, you may use a fake name (pseudonym).

We would like to video, and audio record our discussion to help us with our notes. We will not share the recording with anyone outside of our team and the recording will be erased once we finish our study. Do I have your permission to continue with the interview and video and audio record this conversation?

We know your time is valuable, so we appreciate you taking the time to talk with us today. If you do not have any questions, we are ready to start!

1. **Icebreaker** [All groups]

   To start off, I would like to begin with introductions.

   a. **[F]** Could you please tell us your name and briefly about the individual with intellectual and developmental disabilities you care for/support, including your relationship. /**[I]** Could you please tell us your name and briefly about yourself./**[C]** Could you please tell us your name and briefly about your role within the intellectual and developmental disability community.

2. **Support general** [All groups]

   [F] *First, let's talk about all the people in the person you care for/support's life who help them.* /**[I]** *First, let's talk about all the people in your life who help you.*/**[C]** *First, we are going to talk about supports in general.*

   a. **[F]** Who are the main people that help the person you care for/support and what are their roles? / **[I]** Who are the main people who help you and what are their roles?
      i. Probe: People inside or outside the home (e.g., sisters or brothers, grandparents, other family members and friends)
      ii. Probe: Formal or informal support individuals (e.g., people who are hired or paid to provide assistance versus someone who helps out occasionally, or isn't paid to help)
      iii. Probe: Paid or unpaid?

 iv. Probe: **[F]** Who primarily helps them with their day-to-day activities?/ **[I]** Who primarily helps you with your day-to-day activities?

b. **[C]** What are the various types of supports available to the Florida IDD community?
   - i. **[C]** Probe: How does the community find out about these supports?
   - ii. **[C]** Probe: What are the most common barriers caregivers and individuals with IDD experience either finding or applying for these supports?
   - iii. **[C]** Probe: What are the barriers for non-English speaking communities in receiving or finding these supports?

c. **[C]** Do support needs differ between communities? For example, are support needs different the English- versus the Spanish-speaking communities?

d. How has support and support services changed over time?
   - i. Probe: **[F]** How have these changes affected your ability to provide care? [Family/caregiver only]
   - ii. Probe: How have these changes affected your family?
   - iii. Probe: How have these changes affected the person you care for/support? / **[I]** How have these changes affected you?
   - iv. **[C]** Probe: Do supports differ across the state? Availability?

3. Paid support [Has regular paid direct care support only]

[F] *You said that the person you care for/support currently has or had regular paid direct care support services in the past 12 months. I would like to ask a few questions about this or these individuals. /* **[I]** *You that you currently have or had a regular paid direct care support services in the past 12 months. I would like to ask a few questions about this or these individuals./* **[C]** *Let's talk about paid supports. By that I mean direct care workers that are either paid for by the Waiver or through personal funds.*

a. **[F]** What types of paid direct care support services does the person you care for/support currently receive? / **[I]** What types of paid direct care support services do you currently have?
   - i. Probe: **[F]** How often do they or you use these services? / **[I]** How often do you use these services?
   - ii. Probe: **[F]** Are these services meeting their needs? / **[I]** Are these services meeting your needs?

b. **[C]** In your opinion, what makes a high quality or even good direct care provider?

4. Hiring

[F] *Think about how their paid direct care worker was hired or the times you have tried to find a paid direct care worker. /* **[I]** *Think about how you hired or the times you have tried to find a paid direct care worker.*

a. What are the common barriers to finding paid direct care workers?
   - i. Probe: Is it hard to find qualified direct care workers?
   - ii. Probe: Is it hard to figure out how to pay for care?
   - iii. **[F] [I]** Probe: Are there issues with providers understanding the needs of the person they are hired to support?
   - iv. **[C]** Probe: What are the barriers for non-English speaking communities?

b. **[F] [I]** Where and how do you or others look for direct care workers to hire? / **[C]** Where do people look for direct care workers to hire?
   - i. Probe: Online? Places in the community? Agencies? Other families?
   - ii. Probe: Is there a preferred method?
   - iii. **[C]** Probe: What you've heard from the community about using an agency for direct care support services?
   - iv. **[C]** Probe: If any, are there any differences in staff from agencies versus those who are hired as individuals? (e.g., reliable, shows up when promised and on time, training, skills, back-up care)
   - v. **[C]** Probe: If any, are there any differences in staff from agencies versus those who are hired as individuals? (e.g., reliable, shows up when promised and on time, training, skills, back-up care)

b. How could the hiring process be improved?
c. **[F] [I]** Based on your experience, what advice would you give to someone brand new to the hiring/selection process?
   i. Probe: What methods have you used that were successful?
   ii. Probe: What methods have you used that were unsuccessful?
   iii. Probe: Anything that wasn't worth the effort?

5. Turnover [Has regular paid direct care support only]

We know that turnover can be a problem.

a. **[F] [I]** What are the common barriers to keeping a paid direct care worker?
b. **[F] [I]** Based on your experience and others you know, what helps keep paid direct care workers?
   i. Probe: What methods have you used that were successful?
   ii. Probe: What methods have you used that were unsuccessful?
   iii. Probe: Anything that wasn't worth the effort?
c. **[F] [I]** What is your experience using an agency for direct care support services?
   i. Probe: If any, are there any differences in staff from agencies versus those who are hired as individuals? (e.g., reliable, shows up when promised and on time, training, skills, back-up care)
d. **[F] [I]** What do you do when there are gaps or breaks in service or support?
   i. Probe: Who stepped in?
   ii. Probe: What balls get dropped/what doesn't get done?
   iii. Probe: What are the temporary solutions you usually use?
   iv. Probe: What hardships does this create?

6. Financial

[CDC+ Waiver only]

Let's talk about your experience with identifying and utilizing different funding sources for support services. **[F]** *First, I would like to know more about the services and supports the person you care for/support receives from the CDC+ Waiver.* / **[I]** *First, I would like to know more about the services and supports you receive from the CDC+ Waiver.*

a. **[F]** Tell me about direct care support services that the person you care for/support currently uses that are paid for by the CDC+ Waiver. / **[I]** Tell me about direct care support services that you currently use and are paid for by the CDC+ Waiver. [Has regular paid direct care support only]
   i. Probe: Is the CDC+ Waiver payment amount enough? Does it cover all the costs?
   ii. Probe: If no, how much does it fall short? Who covers these additional costs?
   iii. Probe: Have any of these support services ever been reduced or changed?
   iv. Probe: If yes, which supports (e.g., approved direct care support services hours, CDC+ Waiver payment amount)? Was this change planned? Who made this decision? Did you agree with this decision?
b. **[F] [I]** Do you personally contribute any supplemental compensation, additional funds, or other benefits on top of those provided by the CDC+ Waiver? [Has regular paid direct care support only]
   i. Probe: For example, higher wages (above minimum wage or in addition to what the state, agency, or insurance pays), bonuses, paid vacation time, paid sick time, unpaid time off without penalty, flexible work hours
c. **[F]** Are there any CDC+ Waiver qualified support services that the person you care for/support needs and doesn't currently have? / **[I]** Are there any CDC+ Waiver qualified support services that you need, but currently don't have?
   i. Probe: If yes, which services?
   ii. Probe: What are the barriers to obtaining these services?

d. **[F]** What other activities does the person you care for/support engage in that are not related to or paid for by the CDC+ Waiver? / **[I]** What other activities do you engage in that are not related to or paid for by the CDC+ Waiver?
   i. Probe: Who pays for these services or activities (e.g., the person with intellectual and developmental disabilities, caregiver, Medicaid, or insurance)?
   ii. Probe: Why haven't you sought out these services?

e. **[F] [I]** Are there other financial supports that you have used or know about that we have not covered?
   i. Probe: How often have you used these resources or financial supports? And for what services?
   ii. Probe: How have they been helpful to you?

[iBudget Waiver waitlist and unknown to APD only]

Let's talk about your experiences with identifying and using different funding sources for support services.

a. **[F] [I]** What types of assistance help or have helped you provide direct care support?
   i. Probe: Methods that provide support, not necessarily paid (e.g., charities, non-profit care, faith-based organizations)
   ii. Probe: Methods to pay for (e.g., Health savings accounts, state programs (non-Medicaid))

b. **[F] [I]** Is it hard to figure out how to pay for paid direct care support?

c. **[F]** What types of compensation, funds, or benefits do you or the person you care for/support provide to their paid direct care support worker? / **[I]** What types of compensation, funds, or benefits do you provide to your paid direct care support worker? [Has regular paid direct care support only]
   i. Probe: For example, higher wages (above minimum wage or in addition to what the state, agency, or insurance pays), bonuses, paid vacation time, paid sick time, unpaid time off without penalty, flexible work hours

d. **[F]** Are there any support services that the person you care for/support needs and doesn't currently have? / **[I]** Are there any support services that you need, but currently don't have?
   i. Probe: If yes, which services?
   ii. Probe: What are the barriers to obtaining these services?

e. **[F] [I]** Are there other financial supports that you have used or know about that we have not covered?
   i. Probe: How often have you used these resources or financial supports? And for what services?
   ii. Probe: How have they been helpful to you?

7. Waiver program

[CDC+ Waiver only]

a. **[F] [I]** Why did you choose to access CDC+ Waiver services as opposed to the iBudget Waiver?

b. **[F] [I]** Can you describe the experiences you went through to qualify for iBudget/CDC+ Waiver services?

c. **[F] [I]** If you had to choose again, would you make the same choice?
   i. Probe: Why?

[unknown to APD only]

a. **[F] [I]** Why haven't you applied for a Waiver program?

[Community advocate only]

a. **[C]** Why do some people with IDD or their caregivers apply for the iBudget Waiver and others don't?
   i. Probe: What are the barriers to applying?
   ii. Probe: What are the barriers for non-English speaking communities? (e.g., documents in multiple languages, available translators)

   iii. Probe: In a perfect world, what things could we do to increase non-English application rates?
   iv. Probe: What is the non-English speaking community's perception of these Waivers?

b. **[C]** For the clients you work with who are on the iBudget/CDC+ Waiver, what has been their experience?
   i. Probe: Overall, which Waiver has your clients had a better experience with, iBudget or CDC+? And why?
   ii. Probe: What are the barriers once a client has a Waiver?
   iii. Probe: What are the barriers for non-English speaking communities? (e.g., documents in multiple languages, available translators, multilingual service providers)
   iv. Probe: Is the budget enough?
   v. Probe: How long were they on the waitlist?
   vi. Probe: How did most of them get off the waitlist?

c. **[C]** What advice would you give to someone brand new to Florida and was considering applying to a Waiver program?

8. Quality of Life and health impacts [This section will be included if there is time]

[Has regular paid direct care support only]

[F] *We would like to know how having paid direct care support services has impacted both your life and that of the person you care for/support.* / **[I]** *We would like to know how having paid direct care support services has impacted your life.*

a. **[F]** How has having paid support services helped the person you care for/support? / **[I]** How has having paid support services helped you?/ **[C]** For clients who do have external paid supports, what has their experience been like?
   i. Probe: **[F] [I]** Improved health? Happiness? More independence?/ **[C]** How has this helped them?
   ii. Probe: How has their quality of life been affected?

b. **[F]** How has the paid support services affected your ability to help the person you care for/support?
   i. Probe: Helped you personally? Your well-being? Day-to-day life? Work arrangements?

c. **[F] [I]** Have there been any changes in your family or social life with paid support services?
   i. Probe: Have your relationships improved or strengthened?

d. **[F]** What do you feel has been the main benefit of paid support services for you and the person you care for/support? / **[I]** What do you feel has been the main benefit of paid support services?

e. **[C]** For clients who do have paid supports for the caregiver's time, what has their experience been like?
   i. Probe: How has this helped them?
   ii. Probe: What needs are still unfulfilled?

[Does NOT have regular paid direct care support only]

[F] *We would like to know how not having paid direct care support services has impacted both your life and that of the person you care for/support.* / **[I]** *We would like to know how not having paid direct care support services has impacted both your life.*

a. **[F]** How has not having paid support services affected the person you care for/support? / **[I]** How has not having paid support services affected you?/ **[C]** For those who do not have paid supports, how has this effected them and their families?
   i. Probe: Health? Independence?
   ii. Probe: How has their quality of life been affected?

b. **[F]** How has not having paid support services affected your ability to help the person you care for/support? [Family/caregiver only]
   i. Probe: Your well-being? Day-to-day life? Work arrangements?

c. **[F] [I]** Have there been any changes in your family or social life without paid supports?
   i. Probe: Have your relationships been negatively affected?

   d. **[F]** What do you feel has been the main burden of not having paid support services for you and the person you care for/support? / **[I]** What do you feel has been the main burden of not having paid support services?

9. **Future family caregiving arrangement/planning** [Family/caregiver only]

   We've been discussing a lot of the issues that you have handled or are currently handling. Let's switch and think about the future.

   a. **[F]** Based on the current care needs of the person you care for/support, what concerns do you have about their future care?
   b. **[F]** What supports will you need?
   c. **[F]** What plans do you have to continue to provide care for them?
   d. **[F]** What plans do you have to achieve/implement your plans for their continued care from now until later life?

10. **Improvements in access** [All groups - Closing]

    As we wrap up our discussion, I have one final question.

    a. **[F] [I]** Based on the information you provided in the survey, and what you also are telling me today, what do you think could be done to help improve access to the kind of qualified and reliable direct care support services needed for the IDD community? / **[C]** Based on the information you are telling me today, what do you think could be done to help improve access to the kind of qualified and reliable direct care support services needed for the non-English speaking IDD community?

Conclusion

Thank you again for your time. Your input has been invaluable.

Appendix C: Additional Survey Results

Appendix C presents the results of the project-administered survey on direct care support needs and services provided by direct care workers (DCWs) for people with intellectual and developmental disabilities in Florida. The survey responses are divided into three groups based on respondents' experiences. People with IDD and caregivers reported experiences enrolled in the Consumer-Directed Care Plus (CDC+) waiver, being on Medicaid Home- and Community-Based Services iBudget waiver waitlist, or have not applied for waiver services and therefore are unknown to the Agency for Persons with Disabilities (APD).

Appendix Exhibit C.1. Characteristics of survey respondents

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**20**	**23**	**26**
Description of survey respondent			
Parent of a person with an IDD	85%	87%	85%
Person with an IDD	10%	13%	12%
Sibling of a person with an IDD	5%	0%	0%
Another family member of a person with an IDD	0%	0%	3%
Age of survey respondent			
18-30	5%	17%	0%
31-45	25%	4%	35%
46-60	20%	39%	46%
61-75	50%	40%	19%
Waiver status (either self or person respondent is caring for)			
Approved for waiver services and receiving them	75%	0%	0%
Approved for waiver services and not receiving them	20%	0%	0%
Applied for waiver services, but on a waiting list	0%	100%	0%
Have not applied for waiver services	0%	0%	88%
Unsure	5%	0%	12%
Residence of person with an IDD (either self or person respondent is caring for)			
Family home	65%	96%	65%
Home the person <u>rents and receiving</u> supported living services	20%	0%	0%
Home the person <u>owns and receiving</u> supported living services	10%	0%	0%
Home the person <u>rents and not receiving</u> supported living services	0%	4%	19%
Home the person <u>owns and not receiving</u> supported living services	5%	0%	8%
Other (in a boarding home or crisis bed placement/homeless)	0%	0%	8%

Source: Project-administered survey

Notes: Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.2. Characteristics of respondents with IDD

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**2**	**1**	**3**
Diagnosis (Choose all that apply)			
Cerebral palsy	1	0	0
Intellectual disability	0	1	1
Spina bifida	1	0	0
Other	0	1	2
Description of disability of person with an IDD (Choose all that apply)			
Intellectual disability	0	1	1
Neurological developmental disability	1	0	2
Mobility or physical impairment	1	1	3
Mental health, psychological, psychiatric, or emotional impairment	1	0	2
Vision impairment	0	1	0
Hearing impairment	0	0	1
Speech impairment	0	1	0
Orthopedic impairment	1	0	1
Other	1	0	0
Health rating			
Poor	50%	0%	33%
Fair	50%	0%	33%
Good	0%	0%	33%
Very good	0%	0%	0%
Excellent	0%	100%	0%
Health insurance/coverage (Choose all that apply)			
Private health insurance	0	0	1
Medicare	1	0	2
Medigap	0	0	1
Medicaid	2	1	1
Highest level of education completed by person with an IDD			
High school certificate of completion	0%	0%	33%
2-year college degree (associate's degree)	100%	0%	0%
Some post-graduate studies	0%	0%	33%
Graduate degree	0%	0%	33%
Other	0%	100%	0%
Current occupational status (Choose all that apply)			
Employed, full time			
Employed, part time	1	0	0
Unemployed and looking for a job	0	1	1
Unemployed, but not looking for a job	0	0	1

	CDC+ waiver	Waitlist	Unknown to APD
Student	0	1	1
Retired	0	0	1
Receiving income support because of a disability	1	0	0
Description of area living in			
Urban	0%	100%	33%
Suburban	100%	0%	33%
Rural	0%	0%	33%
Race (Choose all that apply)			
American Indian or Alaska Native	0	0	0
Asian	0	1	0
Black or African American	0	0	0
Native Hawaiian or and Other Pacific Islander	0	0	0
White	2	1	3
Ethnicity			
Hispanic	100%	0%	33%
Latino/a	0%	0%	0%
Not Hispanic or Latino/a	0%	100%	67%
Gender (Choose all that apply)			
Male	0	0	1
Female	2	1	2
Different term	0	0	0

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.3. Characteristics of people with IDD according to caregivers

	CDC+ waiver	Waitlist	Unknown to APD
Age of person with an IDD (N)	**12**	**13**	**18**
0-17	17%	15%	56%
18-30	17%	54%	33%
31-45	50%	23%	11%
46-60	17%	8%	0%
Diagnosis (Choose all that apply) (N)	**13**	**15**	**18**
Autism	3	7	15
Cerebral palsy	2	4	0
Intellectual disability	8	8	4
Down syndrome	2	3	0
Spina bifida	0	0	1
Other	7	5	4
Description of disability (Choose all that apply) (N)	**13**	**15**	**18**
Intellectual disability	11	14	8
Learning disability	11	9	11
Neurological developmental disability	6	9	12
Mobility or physical impairment	5	7	3
Mental health, psychological, psychiatric, or emotional impairment	5	2	10
Vision impairment	4	4	1
Hearing impairment	0	1	3
Speech impairment	10	12	7
Orthopedic impairment	4	2	2
Traumatic brain injury	2	0	2
Other	0	1	0
Prefer not to disclose	0	1	0
Description of level of disability (N)	**13**	**15**	**18**
Mild	0%	7%	17%
Moderate	38%	60%	44%
Severe	46%	33%	28%
Unsure	8%	0%	11%
Prefer not to disclose	8%	0%	0%
Health rating (N)	**13**	**15**	**18**
Poor	0%	0%	22%
Fair	23%	0%	6%
Good	54%	53%	61%
Very good	15%	33%	11%
Excellent	8%	13%	0%

	CDC+ waiver	Waitlist	Unknown to APD
Health insurance/coverage (Choose all that apply) (N)	**13**	**15**	**18**
Private health insurance	6	6	8
Medicare	8	4	2
Medicaid	10	10	8
Children's Health Insurance Program (CHIP)	0	0	1
Military related health care: TRICARE (CHAMPUS) / VA health care / CHAMPVA	1	0	0
State-sponsored health plan (e.g., through a state exchange)	0	1	1
Unsure	0	0	1
Highest level of education completed (N)	**13**	**15**	**18**
Grade school	0%	7%	28%
Some high school	0%	20%	17%
Special diploma	46%	20%	0%
High school certificate of completion	15%	27%	6%
High school diploma or completed GED	0%	7%	6%
Certificate of completion from post-secondary program for persons with disabilities	23%	7%	6%
Some college or technical school	0%	7%	11%
2-year college degree (Associate's degree)	8%	0%	6%
Other	8%	7%	22%
Current occupational status (Choose all that apply) (N)	**13**	**15**	**18**
Employed, full time	1	0	1
Employed, part time	2	7	1
Unemployed and looking for a job	1	1	0
Unemployed, but not looking for a job	1	2	4
Homemaker	0	1	0
Student	0	4	10
Attending vocational training program	1	1	2
Attending adult day training program	5	1	0
Receiving income support because of a disability	1	1	2
Other	2	1	1
Description of area living in (N)	**13**	**15**	**18**
Urban	15%	33%	28%
Suburban	77%	67%	50%
Rural	8%	0%	17%
I don't know	0%	0%	6%
Race (Choose all that apply) (N)	**13**	**15**	**18**
American Indian or Alaska Native	0	0	0
Asian	0	2	0

	CDC+ waiver	Waitlist	Unknown to APD
Black or African American	0	0	0
Native Hawaiian or/and Other Pacific Islander	0	1	0
White	13	15	17
Ethnicity (N)	**13**	**15**	**18**
Hispanic	23%	20%	22%
Latino/a	0%	7%	11%
Not Hispanic or Latino/a	77%	73%	67%
Gender (Choose all that apply) (N)	**13**	**16**	**18**
Male	7	5	14
Female	6	11	4
Different term	0	0	0

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.4. Characteristics of caregivers

	CDC+ waiver	Waitlist	Unknown to APD
Health rating (N)	**13**	**16**	**17**
Poor	0%	0%	29%
Fair	38%	13%	18%
Good	31%	44%	29%
Very good	31%	25%	6%
Excellent	0%	19%	18%
Highest level of education completed (N)	**13**	**16**	**17**
Grade school	0%	6%	6%
Special diploma	0%	0%	6%
High school certificate of completion	15%	0%	0%
High school diploma or completed GED	15%	6%	6%
Some college or technical school	15%	13%	24%
2-year college degree (associate’s degree)	8%	6%	6%
4-year college degree (bachelor’s degree)	23%	44%	12%
Some post-graduate studies	15%	0%	0%
Graduate degree	0%	25%	35%
Other	0%	0%	6%
Prefer not to disclose	8%	0%	0%
Gender (Choose all that apply) (N)	**13**	**16**	**17**
Male	4	4	2
Female	9	12	15

	CDC+ waiver	Waitlist	Unknown to APD
Current occupational status (Choose all that apply) (N)	**13**	**16**	**17**
Employed, full time	5	7	2
Employed, part time	1	3	4
Unemployed and looking for a job	1	0	1
Unemployed, but not looking for a job	1	0	1
Homemaker	2	2	4
Student	0	0	1
Retired	5	6	2
Receiving income support because of a disability	0	0	3
Other	0	1	1
Race (Choose all that apply) (N)	**13**	**16**	**16**
American Indian or Alaska Native	0	0	0
Asian	0	2	0
Black or African American	0	0	0
Native Hawaiian or and Other Pacific Islander	0	1	0
White	13	14	16
Other	0	1	0
Ethnicity (N)	**13**	**16**	**15**
Hispanic	31%	25%	33%
Latino/a	8%	6%	13%
Not Hispanic or Latino/a	54%	69%	53%
Prefer not to disclose	8%	0%	0%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.5. Number of years approved for CDC+ waiver

	CDC+ waiver
Number of respondents (N)	**18**
0-5	39%
6-10	11%
11-20	44%
21+	6%

Source: Project-administered survey

Note: Not all respondents answered the question described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. This question is applicable only for people responding to the survey about their experiences with the CDC+ waiver. People responding to the survey about experiences on the waitlist and unknown to APD do not have access to waiver services and were not asked this question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.6. Number of hours per week approved for paid direct care services in CDC+ waiver support plan

	CDC+ waiver
Number of respondents (N)	**17**
0-20	35%
21-40	41%
41-59	0%
60+	24%

Source: Project-administered survey

Note: Not all respondents answered the question described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. This question is applicable only for people responding to the survey about their experiences with the CDC+ waiver. People responding to the survey about experiences on the waitlist and unknown to APD do not have access to waiver services and were not asked this question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.7. Reasons why people with IDD or caregivers have not applied for a direct care waiver

	Unknown to APD
Number of respondents (N) (Choose all that apply)	**26**
Do not know how or where to apply	11
Afraid to apply	3
Unsure who can apply	5
Hard to find translators	1
Not worth the hassle	1
It is hard to get the papers to apply	2
The application is long and complicated	4
Not eligible for services	5
Recently moved to Florida	2
Afraid to lose resources like Social Security or Medicaid	3

Source: Project-administered survey

Note: Not all respondents answered the question described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. This question is applicable only for people responding to the survey who were unknown to APD. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.8. Currently has a paid DCW to provide support

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**20**	**23**	**26**
Yes	90%	9%	12%
No	10%	91%	85%
Unsure	0%	0%	4%

Source: Project-administered survey

Note: Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.9. Number of paid DCWs providing support per week

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**18**	**2**	**2**
1	39%	50%	50%
2	22%	0%	50%
3-5	28%	0%	0%
6 or more	11%	50%	0%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. This question is applicable only for people responding to the survey who currently has a paid DCW to provide support. In the exhibit, we only present the answers of those who replied to the question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.10. Experiences with utilizing paid direct care services

	Only one paid DCW	More than one paid DCW	
	Only paid DCW	Primary paid DCW	Secondary paid DCW
	CDC+ waiver	CDC+ waiver	CDC+ waiver
Number of respondents (N)	**7**	**11**	**11**
Involvement with finding and hiring the direct care worker			
Not at all involved	29%	0%	0%
Slightly involved	14%	9%	0%
Somewhat involved	0%	9%	0%
Mostly involved	14%	9%	18%
Extremely involved	43%	73%	82%
I don’t know	0%	0%	0%
Location where receiving paid direct care support			
In the home	71%	73%	64%
In the community	14%	9%	36%
At an adult day training program	14%	9%	0%
At a job	0%	9%	0%
Post-secondary education program	0%	0%	0%
Hours per week of paid direct care support			
1-10	14%	9%	60%
11-20	14%	9%	10%
21-30	14%	27%	20%
31-40	57%	27%	0%
More than 40	0%	27%	10%
Length of employment of DCW			
Less than 1 year	14%	9%	45%
1-2 years	0%	9%	27%
3-4 years	57%	36%	0%
5-9 years	0%	9%	18%
10 or more years	29%	27%	9%
Able to schedule DCW when needed most			
Yes	71%	73%	82%

	Only one paid DCW	More than one paid DCW	
	Only paid DCW	Primary paid DCW	Secondary paid DCW
	CDC+ waiver	CDC+ waiver	CDC+ waiver
No	29%	27%	18%
Expect DCW to leave in next 6 months			
Yes	14%	18%	27%
No	71%	73%	55%
I don't know	14%	9%	18%
Who pays DCW? (Choose all that apply)			
Individual with IDD themselves	0	0	1
Family member, friend, or caregiver	0	0	0
Private health insurance	0	0	1
Medicare	2	0	0
Medicaid	1	0	0
Medicaid - CDC+ Waiver	7	1	1
Another government program, including state health programs	0	1	0
Benefits given to DCW by the individual or family (Choose all that apply)			
Higher wages (above minimum wage or in addition to what the state, agency, or insurance pays)	2	4	2
Bonuses	1	2	1
Paid vacation time	0	3	2
Paid sick time	0	2	0
Additional training	1	1	1
Unpaid time off without penalty	2	3	3
Flexible work hours	2	4	5
Other	0	1	0
Unsure	2	0	1
Quality of care by DCW			
Poor	0%	0%	0%
Fair	0%	9%	9%
Good	14%	27%	27%
Very good	29%	27%	18%
Excellent	57%	36%	45%
Overall experience with DCW			
Poor	0%	0%	0%
Fair	0%	0%	10%
Good	14%	27%	20%
Very good	43%	45%	20%
Excellent	43%	27%	50%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. This question is applicable only for people responding to the survey who currently have at least one paid DCW to provide support. In the exhibit, we only present the answers of those who replied to the question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.11. Frequency experiencing issues with DCW's timeliness or absence

	Only one paid DCW	More than one paid DCW	
	Only paid DCW	Primary paid DCW	Secondary paid DCW
	CDC+	CDC+	CDC+
Number of respondents (N)	**7**	**11**	**11**
How often does your DCW…			
Come to work on time			
Never	9%	9%	18%
Sometimes	0%	0%	9%
Usually	27%	27%	9%
Always	64%	64%	64%
Unsure	0%	0%	0%
Leave work early			
Never	64%	64%	64%
Sometimes	27%	27%	18%
Usually	9%	9%	9%
Always	0%	0%	0%
Unsure	0%	0%	9%
Call out sick or say they are unable to come to work for another reason			
Never	45%	45%	55%
Sometimes	45%	45%	36%
Usually	9%	9%	9%
Always	0%	0%	0%
Unsure	0%	0%	0%
Tell you they are running late			
Never	36%	36%	64%
Sometimes	45%	45%	27%
Usually	9%	9%	0%
Always	9%	9%	9%
Unsure	0%	0%	0%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. This question is applicable only for people responding to the survey who currently has a paid DCW to provide support. In the exhibit, we only present the answers of those who replied to the question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.12. Respondents who have experienced issues with direct care services

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**17**	**23**	**24**
Services are not available in the area	24%	57%	46%
Don’t know where to find the needed services	39%	61%	75%
Don’t know what service providers they can trust	58%	61%	71%
There are not enough qualified service providers at the local agency/in the area	72%	74%	58%
There are not enough service provider options	83%	74%	56%
It is hard to finding services that match their needs	82%	87%	75%
Services are not available during times when they are needed the most	53%	74%	50%
The quality of available services is poor	59%	57%	42%
Not enough funding for the services needed/Cannot afford services	65%	35%	50%
Waiting for a diagnosis to qualify for services	N/A	14%	4%

Source: Project-administered survey

Note: Each percentage indicates the proportion of respondents who selected "yes" to the statement. The percentages do not include those who said no, unsure, or skipped question. Not all respondents answered the questions described in this exhibit. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.13. Personal funds used to pay for direct care services in addition to waiver funds

	CDC+ waiver
Number of respondents (N)	**15**
None	7%
Less than $100 per month	0%
$101 - $249 per month	27%
$250 - $499 per month	13%
$500 - $999 per month	7%
$1000 - $1499 per month	7%
$1500 - $1999 per month	0%
$2000 - $2499 per month	7%
$2500 - $2999 per month	13%
$3000 or more per month	0%
Unsure	19%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the questions. This question is applicable only for people responding to the survey about their experiences with the CDC+ waiver. People responding to the survey about experiences on the waitlist and unknown to APD do not have access to waiver services and were not asked this question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.14. Past-year experiences with DCWs

	CDC+ waiver	Waitlist	Unknown to APD
Number of paid DCWs in past 12 months (N)	**18**	**23**	**26**
0	6%	83%	85%
1-2	50%	9%	16%
3-5	28%	4%	0%
6 or more	17%	4%	0%
How often need to find and hire new paid DCW (N)	**17**	**4**	**4**
Very often	0%	25%	0%
Often	18%	25%	0%
Sometimes	12%	25%	0%
Rarely	35%	0%	50%
Very rarely	24%	0%	25%
Never	12%	25%	25%
Searched for a new paid DCW in last 6 months (N)	**18**	**23**	**26**
Yes	44%	17%	8%
No	56%	70%	92%
Unsure	0%	13%	0%
Hired a new paid DCW (N)	**8**	**4**	**2**
Yes	50%	0%	50%
No	50%	100%	50%
Feeling that paid DCW changes too often (N)	**17**	**4**	**4**
Yes	29%	0%	0%
No	71%	75%	100%
Unsure	0%	25%	0%
Difficulty finding paid DCW that is satisfactory (N)	**8**	**4**	**2**
Very hard	63%	75%	50%
Somewhat hard	25%	0%	50%
Not very hard	13%	0%	0%
Unsure	0%	25%	0%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.15. Challenges experienced when finding DCWs

	CDC+ waiver	Waitlist	Unknown to APD
Finding trained paid DCW (N)	**18**	**22**	**26**
Major problem	61%	64%	42%
Some problem	22%	9%	12%
Not a problem	11%	0%	0%
Don’t know/Not applicable	6%	27%	46%
Finding dependable paid DCW (N)	**18**	**23**	**26**
Major problem	44%	48%	38%
Some problem	28%	17%	4%
Not a problem	17%	0%	4%
Don’t know/Not applicable	11%	35%	54%
Finding stable paid DCW (N)	**18**	**23**	**26**
Major problem	39%	57%	35%
Some problem	28%	9%	8%
Not a problem	17%	0%	8%
Don’t know/Not applicable	17%	35%	50%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.16. Support needs for help in home, community, and daily life

	CDC+ waiver	Waitlist	Unknown to APD
Activities need regular help with around the home (Choose all that apply) (N)	**20**	**23**	**26**
Cooking or preparing meals	15	16	21
Doing light work around the house (for example, laundry, doing dishes, straightening up, light cleaning, or taking out the trash)	16	12	18
Doing heavy work around the house (for example, scrubbing floors, washing windows, and doing heavy yard work)	11	10	13
Home maintenance	7	13	11
Activities need regular help within the community (Choose all that apply) (N)	**20**	**23**	**26**
Shopping	16	20	16
Managing communication (for example, the telephone, mail, texting)	12	14	12
Providing sign language interpretation	2	1	2
Emotional support	9	13	20
Visiting friends or other social arrangements	14	15	15
Support at recreational activities	16	16	19

	CDC+ waiver	Waitlist	Unknown to APD
Activities need regular help within daily life (Choose all that apply) (N)	**20**	**23**	**26**
Personal care (such as bathing, feeding, dressing, grooming, and toileting)	15	10	17
Walking (for example, getting around inside or outside the home)	8	6	6
Managing money (for example, keeping track of expenses or paying bills)	12	17	16
Managing medications	14	16	12
Managing transportation (for example, either via driving or by organizing other means of transport)	16	18	15
Arranging and monitoring outside help or services	12	17	12
Coordinating community services – or services with a local religious institution	12	10	8
School responsibilities (for example, homework, reading, writing)	4	6	16
Receiving the help needed in past 12 months? (N)	**17**	**19**	**23**
Yes	88%	74%	35%
No	12%	26%	65%
Went without the help needed in past 12 months? (N)	**17**	**20**	**24**
Yes	53%	30%	63%
No	47%	60%	33%
Unsure	0%	10%	4%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.17. Characteristics of unpaid caregiving

	CDC+ waiver	Waitlist	Unknown to APD
Number of unpaid caregivers providing support (N)	**18**	**23**	**26**
0	11%	13%	27%
1-2	72%	39%	58%
3-5	11%	17%	15%
6 or more	6%	26%	0%
Unsure	0%	4%	0%
Relationship with unpaid caregivers (Choose all that apply) (N)	**20**	**23**	**26**
Parent or parents	14	20	17
Brother or sister	7	9	3
Grandparent	1	0	2
Aunt or uncle	1	3	1
Spouse, partner, boyfriend, or girlfriend	0	0	2
Child	0	0	1
Friend	1	1	2
Location receiving most unpaid caregiver support (N)	**15**	**20**	**19**
Post-secondary education program	0%	5%	5%
In the home	80%	85%	89%
Respite setting	7%	0%	5%
In the community	0%	5%	0%
At an Adult Day Training program	7%	0%	0%
Unsure	7%	5%	0%

Source: Project-administered survey

Note: Not all respondents answered all the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.18. Caregiver challenges and level of severity

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**13**	**16**	**19**
Respite care – for when I need time to take care of my own needs			
Major problem	38%	31%	47%
Some problem	46%	50%	32%
Not a problem	8%	6%	11%
Don’t know/Not applicable	8%	13%	11%
Day care – for when I work			
Major problem	14%	19%	32%
Some problem	7%	31%	21%
Not a problem	43%	19%	26%
Don’t know/Not applicable	36%	31%	21%
Night care – for when I work overnight shifts			
Major problem	15%	0%	21%
Some problem	23%	19%	0%
Not a problem	46%	31%	37%
Don’t know/Not applicable	15%	50%	42%
Emergency care – for when I need to care of another family member or myself			
Major problem	31%	25%	47%
Some problem	23%	44%	21%
Not a problem	38%	13%	21%
Don’t know/Not applicable	8%	19%	11%
After school or summer care			
Major problem	14%	25%	26%
Some problem	7%	25%	26%
Not a problem	36%	19%	11%
Don’t know/Not applicable	43%	31%	37%
Finding care substitutes – for when I need temporary care			
Major problem	36%	33%	50%
Some problem	29%	33%	33%
Not a problem	7%	7%	6%
Don’t know/Not applicable	29%	27%	11%
Dealing with break downs in care arrangements			
Major problem	31%	13%	37%
Some problem	46%	44%	5%
Not a problem	8%	13%	21%
Don’t know/Not applicable	15%	31%	37%
Having enough money to pay for direct care support			
Major problem	36%	44%	68%
Some problem	21%	38%	11%
Not a problem	36%	6%	16%
Don’t know/Not applicable	7%	13%	5%

	CDC+ waiver	Waitlist	Unknown to APD
Ensuring the safety of the person you care for/support			
Major problem	33%	25%	47%
Some problem	8%	44%	21%
Not a problem	50%	19%	21%
Don’t know/Not applicable	8%	13%	11%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.19. Frequency caregiving interferes with day-to-day life in the past 12 months

	CDC+ waiver	Waitlist	Unknown to APD
Number of respondents (N)	**14**	**16**	**18**
Always	29%	25%	50%
Usually	43%	31%	28%
Sometimes	7%	31%	11%
Rarely	21%	6%	11%
Never	0%	6%	0%

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.20. Caregiver experiences, sources of support, and plans for the future

	CDC+ waiver	Waitlist	Unknown to APD
Sources of financial support and information* (N)	**12**	**16**	**18**
Received money from government programs for your caregiving duties	31%	0%	5%
Received any Federal caregiver tax credits (e.g., caregiver tax credit, infirm dependent tax credit, medical expense tax credit)	54%	13%	11%
Requested information about how to get financial help for the person you care for/support	54%	50%	39%
Received services or supports that have reduced your out-of-pocket expenses for the person you care for/support	58%	31%	39%
Would apply if government program paid for some of current unpaid caregiving responsibilities (N)	**14**	**16**	**19**
Yes	79%	81%	74%
No	14%	0%	26%
Unsure	7%	19%	0%
Level of stress of caregiver responsibilities (N)	**14**	**16**	**19**
Extremely stressful	29%	13%	41%
Very stressful	7%	37%	32%
Moderately stressful	21%	37%	11%
Mildly stressful	36%	13%	16%
Not at all stressful	7%	0%	0%
Types of long-term planning caregivers have done (Choose all that apply) (N)	**14**	**16**	**18**
Housing or living arrangements	7	7	5
Caregiving	5	6	8
Medical support and decisions	7	10	7
Decision-making support (daily and major life decisions)	10	12	7
Financial	6	11	8
Guardianship, Guardian Advocacy, or Supported Decision-Making	8	15	8
Vocational (e.g., employment, postsecondary education)	1	6	6
Other	2	1	1
None	0	0	6

Source: Project-administered survey

Note: In the section marked with *, each percentage indicates the proportion of respondents who selected "yes" to the statement. Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. The number of respondents varies by survey question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

Appendix Exhibit C.21. Benefits caregiver experiencing with having paid direct care support

	CDC+ waiver	Waitlist	Unknown to APD
As a result of having paid direct care support, do you… (Choose all that apply) (N)	**14**	**16**	**18**
Have more time for personal activities	5	1	2
Have the ability to maintain a job	7	1	1
Feel less stress	8	2	1
Better understand how to get the services for the person you care for/support	8	0	0
Know more about the person you care for/support's condition	1	1	0
Feel more confident in providing care to the person you care for/support	6	1	0
Feel that the person you care for/support needs are being fully met	8	0	0
Other	3	0	0

Source: Project-administered survey

Note: Not all respondents answered the questions described in this exhibit. In the exhibit, we only present the answers of those who replied to the question. We present counts, rather than percentages, for survey questions in which respondents could select all that apply. Rows containing respondent counts for answers are noted with (N).

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