An Evaluation of Community Capacity Barriers and Opportunities for Expansion in Illinois for Adult DD Waiver Services

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List of Abbreviations

ASD Autism spectrum disorder

CILA Community Integrated Living Arrangement

DDD Division of Developmental Disabilities

DSP Direct support professional

HCBS Home and community-based services

ICF/DD Intermediate Care Facility for Developmental Disabilities

ISC Independent Service Coordination

SODC State-operated developmental center

SSH Short-Term Stabilization Home

SST Support Services Team

Executive Summary

Background

In the spring of 2021, the Division of Developmental Disabilities within the Illinois Department of Human Services contracted with the Institute on Disability and Human Development (IDHD) at the University of Illinois Chicago to evaluate the personcentered planning process and make recommendations to improve the process for all stakeholders. As part of the larger person-centered planning project, the Division tasked UIC with better understanding how the State may better support the seven different groups of people with IDD with additional support needs. The intent of this evaluation is to understand the supports necessarily to adequately support these groups, identify providers who could serve as models in supporting these groups, and identify ways to expand the capacity of the State to serve these groups of people with DD. The groups identified include 1) people with complex medical support needs; 2) people who are insulin-dependent diabetics; 3) people with high behavioral support needs; 4) people with autism spectrum disorder or other sensory support needs; 5) people who are deaf/Deaf/hard-of-hearing; 6) people who are blind/have a visual impairment; and 7) people who have physical accessibility support needs.

Methods

Two primary data collection methods were used in this evaluation to better understand community capacity for the seven groups of people with DD: 1) individual interviews and 2) an online survey of DD community residential providers. Individual interviews were conducted to better understand the barriers to serving particular groups of people with DD, to develop the survey, and to identify strategies to increase provider capacity. Prior to survey development, the Division identified provider experts to help identify supports that were considered to be good practice to include on the online survey of a larger number of community providers. Once survey results were analyzed, the PI followed-up with specific providers that were identified as experienced to better understand how they support these seven distinct populations.

Recommendations

Recommendations are organized by the seven target populations and the entity who would be responsible for carrying out the recommendation. The specific recommendations are too numerous to list here, but recommendations that apply to multiple groups include specialized training of direct support professionals (DSPs), premium pay for DSPs who support these different groups, employment of certain professionals on staff rather than on a contractual basis (such as nurses and counselors), increase salaries for certain professionals to address the staffing shortage (e.g., nurses), and implement environmental adaptations to address physical and sensory needs. General recommendations include:

- Ensure that ISCs are assisting individuals in accessing non-waiver services that they
 may be eligible for, such as Medicaid state plan home health, SNAP benefits, etc.
- Address provider liability concerns by supporting provider executives to better understand and problem solve dignity of risk situations
- Allow for more flexibility in the rate structure system for individuals with more support needs and to address person-centeredness (please note that implementation of Guidehouse Rate Study recommendations at least partially fulfills this recommendation)

Introduction

The Division identified seven groups of people with intellectual and developmental disabilities in Illinois that they felt might need more support and community options under the Adult DD HCBS Waiver to be the focus of this evaluation. These groups include the following people with DD in Illinois: 1) people with complex medical support needs; 2) people who are insulin-dependent diabetics; 3) people with high behavioral support needs; 4) people with autism spectrum disorder or other sensory support needs; 5) people who are deaf/Deaf/hard-of-hearing; 6) people who are blind/have a visual impairment; and 7) people who have physical accessibility support needs. The seven categories of support needs are not the only categories that were raised as needing additional support. Those groups are described in more detail in the results section.

In the spring of 2021, the Division of Developmental Disabilities within the Illinois Department of Human Services contracted with the Institute on Disability and Human Development (IDHD) at the University of Illinois Chicago to evaluate the personcentered planning process and make recommendations to improve the process for all stakeholders.

The following questions guided the evaluation process:

- 1. What are the barriers to supporting these seven groups of people with DD in Illinois?
- 2. What providers are supporting these specific groups well and how are they doing it? What are the characteristics and supports provided of these experienced providers?
- 3. What can we learn from these experienced providers to expand capacity of smaller or newer providers or those that don't feel as confident supporting these particular groups of people with DD?

Methods

Data Sources

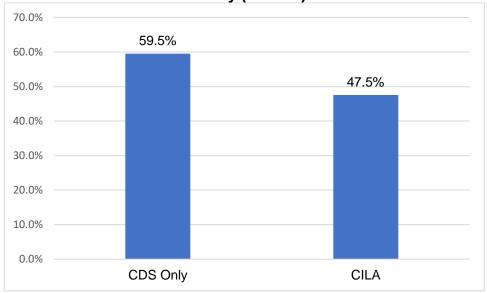
Provider Capacity Survey

The Division was interested in understanding, of the approximately 305 providers serving individuals with intellectual and developmental disabilities (I/DD) across Illinois in Community Integrated Living Arrangements (CILAs) and Community Day Services (CDS), which providers had deeper experience and demonstrated expertise in working with individuals with I/DD with additional, specific support needs. Additional support needs included 1) complex medical support needs; 2) insulin-dependent diabetes; 3) high behavioral support needs; 4) autism spectrum disorder or other sensory support needs; 5) deafness or hearing loss; 6) blindness or visual impairment; and 7) physical accessibility support needs. We also surveyed providers' desire for continuing to provide these specific support needs as well as interest in expanding to provide them if they were not currently offered.

UIC created an online survey, through the secure UIC Qualtrics platform, that was distributed initially on October 1, 2021 via a Division of Developmental Disabilities listserv targeted at community residential and day providers. Reminder e-mails were sent three more times throughout October. Responses were downloaded on November 1, 2021, with a total of 150 valid responses (49.2% response rate) collected after removing partial responses, blank responses, and non-community providers (such as Intermediate Care Facility for Developmental Disabilities (ICF/DDs) which are not considered part of the community-based service system).

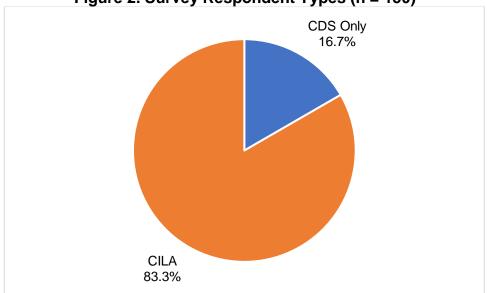
Of all CDS-only providers, about 60% responded to the survey (n = 25) compared to 47.5% of CILA providers (n = 125), see Figure 1.

Figure 1. Percentage of Total CILA and CDS Providers Who Responded to the Survey (n = 305)



Of the 150 valid responses, 16.7% were from CDS-only providers (n = 25), and the remainder were residential providers who may also provide CDS (n = 125), see Figure 2.

Figure 2. Survey Respondent Types (n = 150)



The survey contained eight sections of information, one section with agency information and the remaining seven reflected each identified support need as outlined above. Each of the seven group-specific sections included the following questions, and display logic, if applicable, is identified for each:

Survey Question	Possible Responses
Q1. How experienced is your agency in	Extremely experienced
supporting people with DD with [support	Somewhat experienced
need]?	Neither experienced nor unexperienced
	Somewhat unexperienced
	Extremely unexperienced
Does your agency provide these [specific supports]?	
	Yes
Display Logic: If Q1 = "Extremely	No
experienced" OR Q1 = "Somewhat	
experienced"	
Does your agency have continued interest	
in supporting [support need]? If no, why	
not?	Yes
	No
Display Logic: If Q1 = "Extremely	
experienced" OR Q1 = "Somewhat	
experienced"	
Does your agency have a desire to expand	
services to include [support need]? If no,	
why not?	
	Yes
Display Logic: If Q1 = "Neither experienced	No
nor unexperienced" OR Q1 = "Somewhat	
unexperienced" OR Q1 = "Extremely	
unexperienced"	

Individual Interviews

In total, 41 interviews were conducted, along with feedback elicited from two DDD-ISC meetings. These interviews represented 13 DDD staff (including 1 former staff member), all 8 ISCs, 16 provider organizations, and 4 family members. Based on the provider capacity survey, provider organizations that were identified as excelling in supporting the seven different populations were identified and the PI reached out to schedule an interview. In total, 11 experienced provider interviews were conducted with the following organizations:

- CILA Corporation (Medical)
- Trinity (Medical)
- Bridgeway, Inc. (Diabetes)
- Glenkirk (Behavioral, Autism)

- Envision (Behavioral)
- IAG (Behavioral)
- Little Friends (Autism)
- Anixter (Deafness, Blindness)
- Tazewell County Resource Centers, Inc. (Blindness)
- Cerebral Palsy of Southwestern Illinois (Physical Accessibility)
- Clearbrook (Physical Accessibility)

Data Analysis

Provider Capacity Survey

Descriptive frequencies were conducted on the survey results using SPSS software. The number responding to the specific question and broken down by each response choice were reported, along with the percentage.

Individual Interviews

Thematic analysis is a method used to organize and analyze patterns within qualitative data (Braun & Clarke, 2006) and was used within this evaluation. Survey results were analyzed by using open coding to create a list of codes. Codes were compiled into a larger list to identify themes. Themes were then sorted.

Results

Provider Capacity Survey

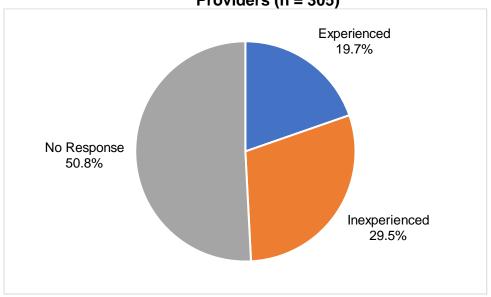
The analysis below has results broken down by provider experience, which was condensed from the five response categories to two: **experienced** providers which include providers who reported that they were *somewhat* or *extremely experienced* supporting people with DD in the specific group and **inexperienced** providers which include providers who reported that they were *neither experienced nor unexperienced* (neutral), *somewhat inexperienced*, or *extremely inexperienced* in supporting people with DD in the specific group.

For each of the seven supports for people with DD, a lack of availability of direct support professionals (DSPs) and a lack of staff with specialized training or background specific to the identified need were identified as barriers to experienced providers continuing to support the specific group and of inexperienced providers expanding to support the specific group. It is clear that a lack of direct care staff is an overall system barrier to community-based service delivery. Therefore, in the sections below, barriers to continued support and expansion will only include those identified by providers besides staffing as to reduce redundancy. Additionally, throughout the survey, some CDS-only providers indicated that they didn't feel it was their responsibility to provide highly intensive medical support at the CDS because it was the responsibility of the residential providers.

Complex Medical Support Needs

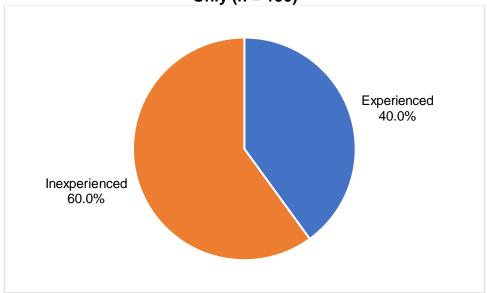
Of all 305 community providers in Illinois, including those who did not respond to the survey or the specific question (50.8%), 19.7% reported that they were somewhat or extremely *experienced* and 29.5% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and complex medical support needs (Figure 3).

Figure 3. Experience with Complex Medical Support Needs – All Community Providers (n = 305)



When only considering community providers who responded to the survey and the specific question (n = 150), 40.0% reported that they were somewhat or extremely *experienced* and 60.0% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and complex medical support needs (Figure 4).

Figure 4. Experience with Complex Medical Support Needs – Survey Respondents Only (n = 150)



Of the providers who felt extremely or somewhat experienced supporting people with DD and complex medical support needs (n = 60), Table 1 shows a list of eight complex medical supports and the percentage of these providers who did or did not

provide each support. On average, responding providers provided 5.3 of the 8 possible supports. All respondents indicated that DSPs were trained on special diets. The next most frequently provided complex medical support was access to on-call nurses and backup nursing support for consultation and guidance on healthcare issues (85%) followed closely by providers having nurses or other trained healthcare professionals on staff (83.1%). The least frequently reported complex medical support provided was the use of any add-on features of the HRST (36.8%). Other specific supports providers indicated that they provided included end-of-life and hospice care; care for specific medical conditions like wounds and cancer; and supporting the use of specific medical devices such as catheters, feeding tubes, nebulizers, CPAPs, and suctioning devices.

Table 1. Complex Medical Supports

Support	Yes	Total	%
Provider has nurses or other trained healthcare professionals	46	60	76.7
on staff (either employed or contract) that can support			
oversight of a feeding tube			
DSPs are trained to support management of a feeding tube on	30	60	50.0
a daily basis			
Provider has nurses or other trained healthcare professionals	49	59	83.1
on staff (either employed or contract) that can support			
oversight of complex medical needs			
DSPs are trained on special diets (e.g., mechanical soft diets,	60	60	100.
pureed, low sugar, etc.)			0
Provider uses any of the add-on features of the HRST to	21	57	36.8
support an individual with more complex medical needs			
Provider has access to on-call nurses and back up nurse	51	60	85.0
support for consultation and guidance on healthcare issues			
and support (not just medication administration)			
Provider has existing relationships with community healthcare	48	60	0.08
providers who can provide support for individuals with			
complex medical needs			
Provider offers these others specific supports	11	26	42.3

Of the providers who were extremely or somewhat experienced supporting people with DD and complex medical support needs (n = 58) and responded to the question, Figure 5 shows that the majority (67.2%) of these providers were interested in continuing to support individuals with complex medical support needs. Several experienced providers (n = 4) noted a shortage of nursing hours or reliance on contract nursing as challenges to continued support of people with complex medical support needs.

Figure 5. Continued Interest in Supporting Complex Medical Support Needs (n = 58)

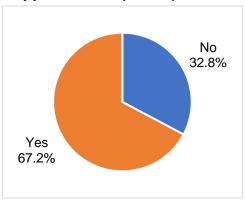
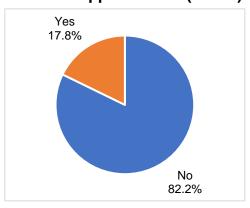


Figure 6. Desire to Expand Services to Include Complex Medical Support Needs (n = 90)



Of the providers who were neutral or somewhat/extremely inexperienced supporting people with DD and complex medical support needs and who responded to the question (n = 90), 82.2% said they did not want to expand their services to include these individuals (Figure 6). Providers cited the following for a lack of continued interest in supporting people with DD and complex medical support needs: lack of space (n = 3), liability concerns (n = 6), CDS providers not interested in or

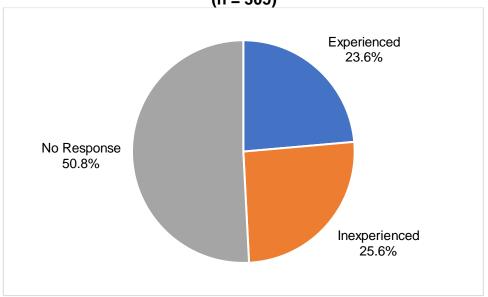
able to support complex medical support needs (n = 7), funding (n = 15), DSPs uncomfortable administering medical care (n = 1), CILA nursing guidelines difficult to navigate (n = 1), lack of resources in a rural area (n = 2), perceived lack of need (n = 1), lack of expertise (n = 1), limited in what medical help they are willing provide (n = 1), and preference to focus on other support needs, such as high behavioral support needs (n = 2). Many CDS respondents felt that supporting this population did not align with the purpose of day services (n = 15).

Insulin-Dependent Diabetes

Of all 305 community providers in Illinois, including those who did not respond to the survey or the specific question (50.8%), 23.6% reported that they were somewhat or

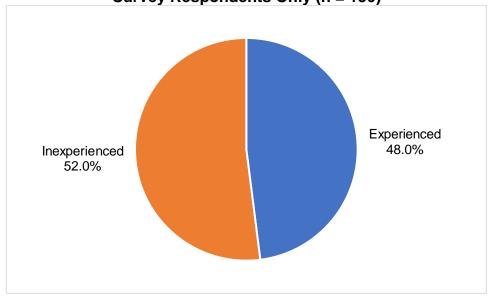
extremely *experienced* and 25.6% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and insulin-dependent diabetes (Figure 7).

Figure 7. Experience with Insulin-Dependent Diabetes – All Community Providers (n = 305)



When only considering community providers who responded to the survey and the specific question (n = 150), 48.0% reported that they were somewhat or extremely *experienced* and 52.0% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and insulin-dependent diabetes (Figure 8).

Figure 8. Experience with Insulin-Dependent Diabetes – Survey Respondents Only (n = 150)



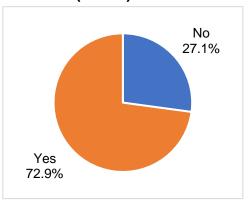
On average, somewhat and extremely experienced providers (n = 72) provided 4.8 out of 7 possible insulin-dependent diabetes supports. As shown in Table 2, the most frequently provided support was training DSPs on diabetes diets and diet accommodations (91.7%) followed by existing relationships with healthcare specialists who can support people with diabetes (88.6%). The least frequently provided support besides other specific supports (40.6%) was training and approving DSPs to administer insulin (45.8%). Other specific supports that providers indicated that they provided included dietician services and supporting people to administer their own diabetes medications.

Table 2. Insulin-Dependent Diabetes Supports

Support	Yes	Total	%
Provider has nurses or other trained healthcare professionals	58	72	80.6
on staff (either employed or contract) that can administer			
insulin			
DSPs are trained and approved to administer insulin	33	72	45.8
Provider has nurses or other trained healthcare professionals	53	72	73.6
on staff (either employed or contract) that can support an			
individual that self-administers their insulin			
Provider has policies and procedures for caring for and	59	70	84.3
monitoring diabetes			
DSPs are trained on diabetes diets and diet accommodations	66	72	91.7
Provider has existing relationships with healthcare specialists	62	70	88.6
who can provide support for individuals with diabetes			
Provider offers these others specific supports	13	32	40.6

Of the providers who were extremely or somewhat experienced supporting people with DD and insulin-dependent diabetes and who responded to the question (n = 70), almost three quarters (72.9%) said they would be interested in continuing to support individuals who are insulindependent (Figure 9). Reasons for a lack of continued interest in supporting people with DD and insulin-dependent diabetes included liability (n = 1), administrative rules (n = 4), lack of funding (n = 3),

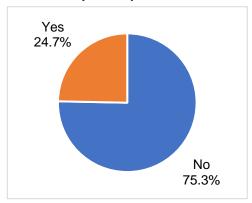
Figure 9. Continued Interest in Supporting Insulin-Dependent Diabetes (n = 70)



and nurse hesitancy to delegate insulin administration to DSPs (n = 2). One of the

providers who noted a lack of funding said, "Our primary reason is related to the lack of reimbursement for appropriate oversight." Four providers cited issues related to the administrative rules, like Rule 116. The following are provider perceptions of Rule requirements and are not necessarily accurate, which may point to a potential need for better information dissemination of Rule requirements. One of these providers said, "Inconsistent Rule 116 ovesight [sic] on requirement of being independent." Another one of these four providers said that LPN staff are not recognized through Rule 116. And another said they do not have continued interest because "of the requirement for DSP to be employed for 6months [sic]".

Figure 10. Desire to Expand Services to Insulin-Dependent Diabetes (n = 77)



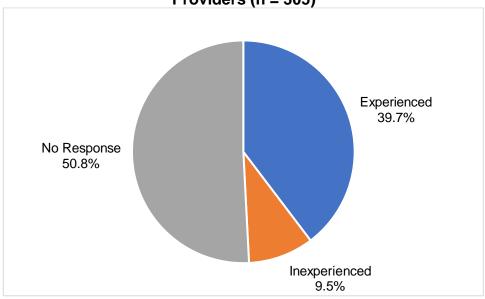
Of providers who were neutral or somewhat or extremely inexperienced supporting people with DD and insulin-dependent diabetes and who responded to the question (n = 77), three-quarters said they would not be interested in expanding to support these individuals (Figure 10). Barriers included liability (n = 4), lack of funding (n = 8), a perceived lack of need (n = 1), lack of resources in rural communities (n = 1), and nurses hesitant to delegate insulin administration to DSPs (n = 2). One

provider who noted nurse hesitancy to delegate insulin administration to DSPs said, "[If] the people we serve would qualify for all the new ways to test and know how much insulin it would be different but Medicaid does not cover such supplies. the [sic] nurse is uneasy with DSPs measuring the insulin." Additionally, one provider said that because their program is CDS only, they have chosen not to train their staff to support insulin administration.

High Behavioral Support Needs

Of all 305 community providers in Illinois, including those who did not respond to the survey or the specific question (50.8%), 39.7% reported that they were somewhat or extremely *experienced* and 9.5% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and high behavioral support needs (Figure 11).

Figure 11. Experience with High Behavioral Support Needs – All Community Providers (n = 305)



When only considering community providers who responded to the survey and the specific question (n = 150), 80.7% reported that they were somewhat or extremely *experienced* and 19.3% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and high behavioral support needs (Figure 12).

Figure 12. Experience with High Behavioral Support Needs – Survey Respondents Only (n = 150)

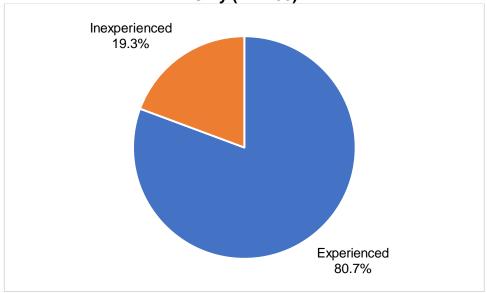


Table 3 shows 20 possible supports (including other) providers could provide to support individuals with high behavioral support needs. On average, experienced providers (n = 121) provided 9.6 behavioral supports. One provider provided 18 of the

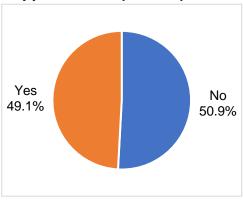
20 possible supports, which was the maximum number of supports provided of the experienced survey respondents. The most frequently reported behavioral supports provided were involving DSPs in the Behavior Support Plan process (91.6%), policies and procedures in place to use individualized behavioral interventions prior to calling 911 to stabilize someone experiencing a behavioral health crisis (88.1%), and DSPs are certified in de-escalation training (86.4%). The least frequently reported supports were requiring higher education levels for staff working in homes with higher behavioral support needs (6.7%) and employing Registered Behavior Techs, or RBTs (9.3%). Other specific supports that providers indicated that they provided to people with high behavioral support needs included contracting with BCBAs (not employing them directly), occupational therapy, speech therapy, in-house CPI training, skills training, and medical care coordination.

Table 3. High Behavioral Supports

Support Provider has experience supporting people with suicidal behaviors Provider has experience supporting sex offenders 37 116 31.9
Dehaviors Provider has experience supporting sex offenders 37 116 31.9
Provider has experience supporting sex offenders DSPs are certified in Safety Care, Crisis Prevention Training, or other de-escalation training DSPs are certified in Safety Care, Crisis Prevention Training, or other method that teaches physical management DSPs are involved in the Behavior Support Plan process to plan for and create address support needs DSPs are offered premium pay to work in homes with higher behavioral support needs Provider requires a higher education level expectation for DSPs working in homes with higher behavioral support needs Provider requires certified DD aides or higher (or commensurate experience of at least three years) working in homes with higher behavioral support needs Provider employs BCBAs or BCABAs Provider employs Registered Behavior Techs (RBTs) Provider employs staff that specialize in trauma-informed 32 119 26.9 care and support
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i i origo: has access to a poychiathot with admitting 1 00 110 TLiT
privileges in a hospital system
Provider provides environmental modifications to prevent 87 119 73.1
elopement and/or property damage (e.g., reinforced walls,
bells on doors, sensory modifications)
Provider provides higher staffing ratios in homes with higher 79 118 66.9
behavioral support needs
Provider has, or is willing, to develop one or two-person 41 117 35.0
CILAs to support individuals with higher behavioral support
needs
Provider has policies and procedures that encourage 104 118 88.1
individualized behavioral interventions prior to using 911 to
stabilize an individual experiencing a behavioral health crisis
Provider has policies and procedures in place that ensure 97 117 82.9
exhaustive behavioral interventions are used to avoid issuing
discharge notices for higher behavioral health support needs
Provider has existing relationships with community mental 78 118 66.1
health or behavioral health providers who can provide
support for individuals with high behavioral needs
Provider offers these others specific supports 19 47 40.4

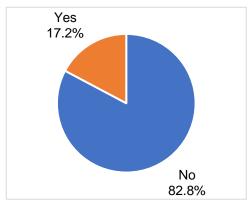
Continued interest of experienced providers who responded to the question (n = 116) in supporting high behavioral support needs was nearly evenly split: 49.1% indicated they would like to continue supporting individuals with high behavioral support needs while 50.9% said they would not be interested in continuing to support these individuals (Figure 13). Reasons for lack of continued interest in supporting people with DD and high behavioral support needs included lack of funding (n = 7), lack

Figure 13. Continued Interest in Supporting High Behavioral Support Needs (n = 116)



of community resources such as appropriate psychiatric care (n=7), liability (n=2), a difficult discharge process leaving providers feeling "stuck" (n=4), lack of specific behavioral supports for sex offenders and those with suicidal ideations (n=1), burden on direct care staff in terms of time and energy (n=3), lack of resources in rural areas (n=2), potential and actual negative impacts on other housemates and staff (n=3), and low success rate or not enough support provided by existing community supports like SSTs, psychiatric hospitals in the area, SSHs, and the Illinois Crisis Prevention Network consultations (n=3). One provider explained a barrier as the following: "Our agency is a work center where all individuals work among regular employees and perform the same work tasks. Our agency is also located within a store where customers are present."

Figure 14. Desire to Expand Services to Include High Behavioral Support Needs (n = 29)



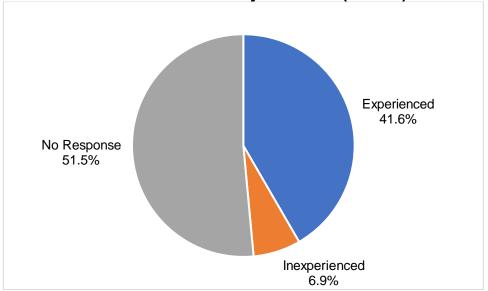
Of providers who were neutral or inexperienced serving people with DD and high behavioral support needs and who responded to the question (n = 29), 82.8% indicated that they do not wish to expand to include these individuals (Figure 14). Barriers included the perceived negative impact on other housemates (n = 4), liability concerns (n = 2), lack of funding (n = 4), lack of community supports (n = 1), and lack of expertise (n = 2). One provider who noted a lack of qualified staff said

"...the risk of being hit drives employees away." Another provider said that there was a limited number of staff who not only have the ability to support these individuals, but also the desire to support these individuals. One of the four providers who had concerns about how supporting people with DD and high behavioral support needs would impact housemates said, "Current residents came from a home with high behavioral [support needs] and were terrified to the point of emotional trauma. They have recouped and blossomed in a quiet and stable environment."

Autism Spectrum Disorder or Other Sensory Support Needs

Of all 305 community providers in Illinois, including those who did not respond to the survey or the specific question (51.5%), 41.6% reported that they were somewhat or extremely *experienced* and 6.9% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and autism spectrum disorder or other sensory support needs (Figure 15).





When only considering community providers who responded to the survey and the specific question (n = 148), 85.8% reported that they were somewhat or extremely *experienced* and 14.2% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and autism spectrum disorder or other sensory support needs (Figure 16).



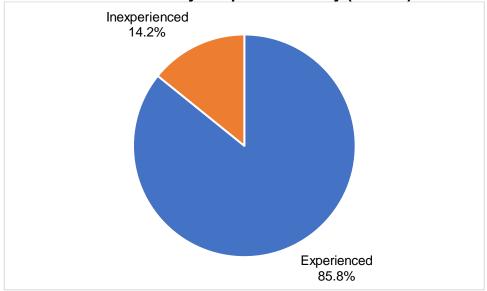


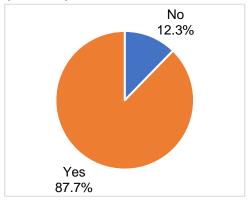
Table 4 shows a list of 11 possible supports experienced providers (n = 127) could provide for people with autism or other sensory support needs. On average, providers experienced in supporting people with autism or other sensory support needs provided 6.9 supports related to this population. Almost all of these experienced providers indicated that DSPs were trained to support this population to keep their routines (99.2%). Additionally, 95.2% of providers indicated that DSPs were trained to communicate with individuals using adaptive equipment. The least frequently reported supports provided besides other (32.1%) were homes that are "sensory sensitive" (45.1%) and policies and procedures to recognize and reduce sensory issues (43.8%). Other supports that providers indicated that they provided for people with autism or other sensory support needs related to professionals such as an autism programming specialist, communication experts, BCBAs, a team trained to work with people with autism, speech therapists, and occupational therapists. One provider indicated that they employed occupational therapy and speech professionals on staff to support and develop sensory diets. Another provider has a behavior clinic that is focused on providing autism support.

Table 4. Autism or Other Sensory Support Needs

Support	Yes	Total	%
Provider offers homes with yards with fences	80	123	65.0
Provider offers homes with door and window alarms	76	123	61.8
Provider offers homes that are "sensory sensitive"	55	122	45.1
Provider offers home that allows space for pacing	97	123	78.9
Provider has policies and procedures in place that recognize and reduce sensory issues related to textures of food, clothing, light levels, and noise	53	121	43.8
DSPs are trained in the use of sequencing methods (e.g., First Then cards, Social Stories)	91	124	73.4
DSP are trained to communicate with individuals with adaptive equipment (e.g., pictures, visual cues)	119	125	95.2
DSPs are trained on supporting individuals to keep to routines	124	125	99.2
DSPs participate in formal training on communication strategies for individuals with autism (for example, use less words and be concrete)	93	125	74.4
Provider has existing relationships with community providers who can provide ancillary support for individuals with autism/sensory needs	62	122	50.8
Provider offers these others specific supports	17	53	32.1

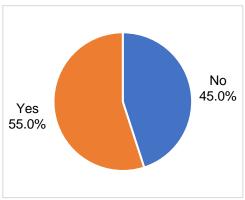
Of those providers already experienced in serving people with autism or other sensory support needs and who responded to the question (n = 122), 87.7% indicated they would like to continue serving this population (Figure 17). Of those providers who did not wish to continue supporting this population, barriers included no openings (n = 1), lack of community supports (n = 1), and lack of funding (n = 1). The provider who noted lack of funding said that they would be open

Figure 17. Continued Interest in Supporting Autism or Other Sensory Support Needs (n = 122)



to continuing to support these individuals if "funding was available to adapt physical plants and increase staffing levels." Another provider said that they currently have therapeutic day schools and are hoping to build their post-transition programming for young adults with autism. One provider indicated that they don't have enough qualified staff and that they are a day provider, not a residential provider.

Figure 18. Desire to Expand Services to Include Autism or Other Sensory Support Needs (n = 20)

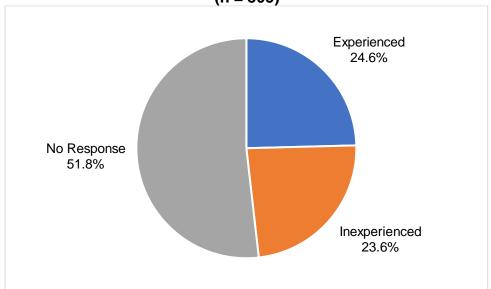


Of providers who were neutral or inexperienced supporting people with autism or other sensory support needs and who responded to the question (n = 20), slightly less than half (45.0%) said they did not wish to expand their services to support this population (Figure 18). One provider felt they would need to learn more in this area in order to expand to include people with DD and autism or other sensory support needs.

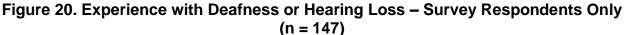
Deafness or Hearing Loss

Of all 305 community providers in Illinois, including those who did not respond to the survey or the specific question (51.8%), 24.6% reported that they were somewhat or extremely *experienced* and 23.6% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and deafness or hearing loss (Figure 19).

Figure 19. Experience with Deafness or Hearing Loss – All Community Providers (n = 305)



When only considering community providers who responded to the survey and the specific question (n = 147), 51.0% reported that they were somewhat or extremely experienced and 49.0% reported that they were neutral or somewhat or extremely inexperienced serving people with DD and deafness or hearing loss (Figure 20).



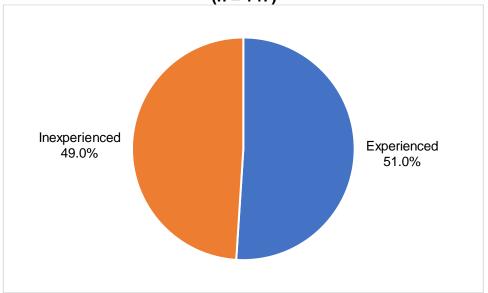


Table 5 shows a list of seven possible supports experienced providers (n = 75) could provide for people with deafness or hearing loss. Of the seven possible supports related to deafness or hearing loss, experienced providers provided an average of 2.9 of these supports. About two-thirds of providers indicated they offered homes with visual emergency systems (68.9%), trained DSPs in basic American Sign Language (ASL) or to communicate using adaptive communication devices (68.9%), and/or had established relationships with community providers to provide medical care for this population (65.3%). The least frequently provided support, besides other (11.5%), was employing DSPs that are proficient in ASL (23.0%). One other specific support that a provider indicated they provided to this population was the provision of an on-site communications team.

Table 5. Deafness or Hearing Loss Supports

Support	Yes	Total	%
Provider offers homes that has visual cues for sounds (e.g.,	30	75	40.0
visual doorbells, visual phone ringing)			
Provider offers home with visual emergency systems	51	74	68.9
Provider can provide beds that shake to signal an emergency	20	73	27.4
alarm			
Provider employs DSPs that are proficient in ASL	17	74	23.0
DSP are trained in basic ASL and/or trained to communicate	51	74	68.9
with individuals with adaptive communication devices and			
equipment, including pictures (e.g., PECs system, Dynavox,			
etc.)			
Provider has established relationships with community	49	75	65.3
providers (doctors, specialists, community resources) who are			
able to provide medical care to people who are deaf/hard-of-			
hearing			
Provider offers these others specific supports	3	26	11.5

Over 90% of experienced providers who responded to the question (n = 71) had continued interest in supporting people with DD and deafness/hearing loss (Figure 21).

Figure 22. Desire to Expand Services to Include Deafness or Hearing Loss (n = 72)

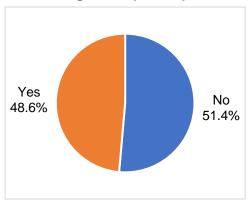
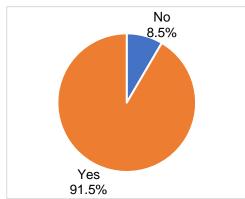


Figure 21. Continued Interest in Supporting Deafness or Hearing Loss (n = 71)



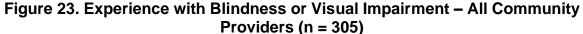
Inexperienced providers who responded to the question (n = 72) were almost evenly split on their desire to expand services to support people with DD and deafness/hearing loss, though a slight

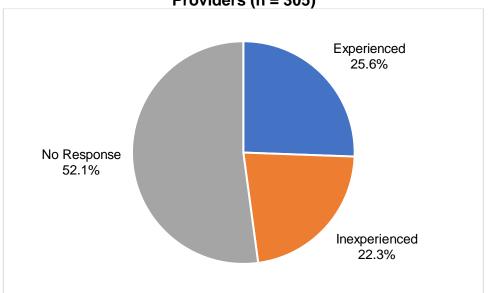
majority (51.4%) indicated they did *not* want to expand to provide services for this population (Figure 22). Barriers to expansion included lack of funding (n = 4), availability of interpreters (n = 1), perceived lack of need in this area (n = 1), and lack of expertise (n = 3). One provider who noted a lack of funding expressed that cost of time of DSPs to learn sign language is high and "not reimbursed by anyone". Another provider who cited

a lack of funding said that there is "not sufficient support from the Division to pay for interpretation and specialized trainings."

Blindness or Visual Impairment

Of all 305 community providers in Illinois, including those who did not respond to the survey or the specific question (52.1%), 25.6% reported that they were somewhat or extremely *experienced* and 22.3% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and blindness or visual impairment (Figure 23).





When only considering community providers who responded to the survey and the specific question (n = 146), 53.4% reported that they were somewhat or extremely experienced and 46.6% reported that they were neutral or somewhat or extremely inexperienced serving people with DD and blindness or visual impairment (Figure 24).

Figure 24. Experience with Blindness or Visual Impairment – Survey Respondents Only (n = 146)

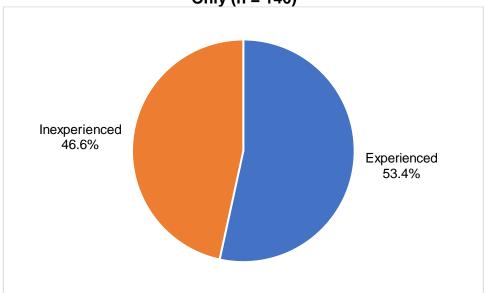


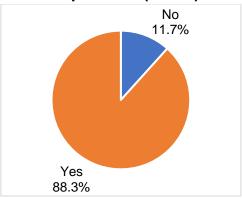
Table 6 shows a list of eight possible supports experienced providers (n = 78) could provide for people with blindness or a visual impairment. On average, experienced providers provided 3.9 of these supports. Nearly 85% of providers had DSPs trained to keep items in the same place to better support individuals. The least frequently provided support, besides other (18.5%), was offering homes that provide tactile signage to identify rooms or to indicate if the lights or an appliance is on or off (29.5%). Other specific supports that providers indicated that they provided included an on-site communications team, Braille, and assistive technology for communication purposes. One provider indicated that they have a staff member with low vision who acts as a resource and guide for developing care plans.

Table 6. Blindness or Visual Impairment Supports

Support	Yes	Total	%
Provider offers homes that provide tactile signage (e.g.,	23	78	29.5
identifying rooms, if lights or appliance is on/off)			
Provider offers homes that have tactile railings along hallways	30	78	38.5
to help with trailing			
Provider offers home with door alarms or other sound systems	46	77	59.0
to communicate			
DSP are trained to communicate with individuals with adaptive	59	77	76.6
equipment			
DSPs are trained to support individuals by keeping items in	65	77	84.4
the same spot (furniture, manipulatives, meals, etc.)			
DSPs are trained on the use of tactile schedules	28	78	36.4
Provider has existing relationships with community providers	50	27	64.1
(doctors, specialists, community resources) who can provide			
support for individuals who are blind/visually impaired			
Provider offers these others specific supports	5	78	18.5

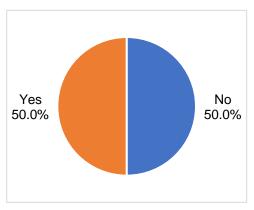
88.3% of experienced providers who responded to the question (n = 77) had continued interest in supporting people with DD and blindness/visual impairment (Figure 25). In response to why they didn't have continued interest in supporting this population, one provider said, "Our work center is integrated within a store and production area. We could offer supports for a blind/visually impaired individual but would have to make adjustments to our work center to make that

Figure 25. Continued Interest in Supporting Blindness or Visual Impairment (n = 77)



accommodation [sic]." Another provider indicated that while it isn't their area of expertise, they could help someone if needed.

Figure 26. Desire to Expand Services to Include Blindness or Visual Impairment (n = 66)



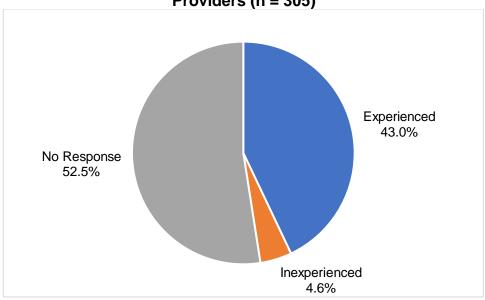
Inexperienced providers who responded to the question (n = 66) were evenly split on their desire to expand services to support people with DD and blindness/visual impairment (Figure 26). Aside from a lack of staff, providers noted a lack of resources in this area as a barrier to expansion to include people with DD and blindness/visual impairment (n = 2). One of these two providers said, "We would always be up for learning more, but currently don't have access to resources or

experience around this area of support."

Physical Accessibility Support Needs

Of all 305 community providers in Illinois, including those who did not respond to the survey or the specific question (52.5%), 43.0% reported that they were somewhat or extremely *experienced* and 4.6% reported that they were neutral or somewhat or extremely *inexperienced* serving people with DD and physical accessibility support needs (Figure 27).

Figure 27. Experience with Physical Accessibility Support Needs – All Community Providers (n = 305)



When only considering community providers who responded to the survey and the specific question (n = 145), 90.3% reported that they were somewhat or extremely experienced and 9.7% reported that they were neutral or somewhat or extremely inexperienced serving people with DD and physical accessibility support needs (Figure 28).



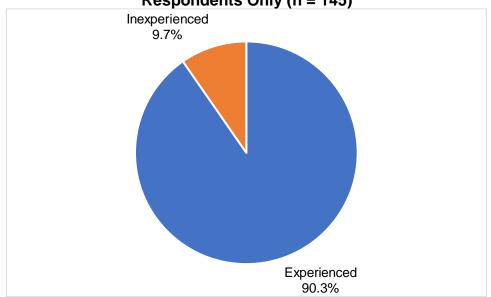
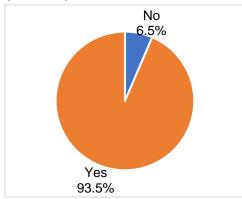


Table 7 shows a list of nine possible supports experienced providers (n = 131) could provide for people with physical accessibility support needs. Of the nine possible supports related to physical accessibility, experienced providers provided an average of 6.8 of these supports. Overall, a large majority of providers (80% or above) provided each support, with the exception of two: other (26.5%) and existing relationships with companies that service wheelchairs or scooters (76.2%). Nearly all (96.0%) of experienced providers had knowledge about universal design and an understanding of physical accessibility rules and requirements. Other specific supports that providers indicated they provided to support this population included overhead lifts such as Hoyer and Arjo lifts and one provider specified that they provide training for their staff in safe transfers and using lifts. A few providers had at least some fully accessible homes for wheelchair users, and one indicated they had a wheelchair-accessible kitchen. Also, a few providers had departments specific to this area, including an assistive technology department, physical therapy department, and a wheelchair clinic.

Table 7. Physical Accessibility Supports

Support	Yes	Total	%
Provider has knowledge about universal design and	121	126	96.0
understands physical accessibility rules and requirements			
Provider offers homes with ramps	105	126	83.3
Provider offers homes with widened doorways	107	126	84.9
Provider offers homes with walk-in/roll-in shower	105	127	83.3
Provider has wheelchair accessible vehicle(s) or access to other	117	125	92.1
accessible transportation			
Provider is knowledgeable about wheelchair/scooter funding	102	127	81.6
options and replacement			
Provider is knowledgeable about wheelchair/scooter repair and	103	126	81.1
servicing			
Provider has existing relationships with companies that service	96	49	76.2
wheelchair/scooters			
Provider offers these others specific supports	13	126	26.5

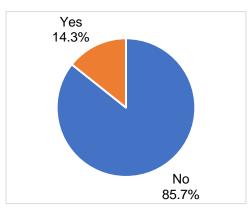
Figure 29. Continued Interest in Supporting Physical Accessibility Support Needs (n = 124)



93.5% of experienced providers who responded to the question (n = 124) had continued interest in supporting people with DD and physical accessibility support needs (Figure 29). Providers noted a lack of accessibility (n = 1), space (n = 1), and openings (n = 1) when asked about why they did not want to continue supporting people with physical accessibility support needs and DD. The same provider who noted a lack of accessibility in their homes said, "Aging care givers unable or

struggling to support people with significant physical support needs is creating high burnt out and turnover rates."

Figure 30. Desire to Expand Services to Include Physical Accessibility Support Needs



Of neutral or inexperienced providers who responded to the question (n = 14), most (85.7%) did *not* wish to expand services to support people with DD and physical accessibility support needs (Error! Reference source not found.).

Inexperienced providers noted a lack of accessible spaces (n = 3). One provider explained that a lack of direct care staff was especially problematic for people who may require two people to assist them.

Two providers did note that this need will likely

increase as the people they currently support age and recognized the need for future planning in this area.

Individual Interviews

There was a total of 435 codes from individual interviews where stakeholders discussed community capacity for people with DD in Illinois. These codes were sorted into themes and sub-themes. The themes within the interviews are 1) *Specific Support Needs* (n = 277 codes, 63.7%), 2) *General Community Capacity* (n = 85 codes, 19.5%), and 3) *Other* (n = 73 codes, 16.8%). Codes within the *Other* theme are not discussed below.

Specific Support Needs

The theme, *Specific Support Needs*, includes any challenge to supporting or recommendation to improve capacity for individuals with specific support needs, including recommended populations to focus on. In terms of challenges to supporting specific populations (n = 146 codes), the sub-themes were 1) difficulty providing supports to individuals with a dual diagnosis and/or behavioral support needs, 2) difficulty providing support to individuals with complex medical support needs and/or insulin-dependent diabetes, 3) difficulty providing support to individuals with physical accessibility support needs, 4) difficulty supporting other specific populations, 5) lack of access to or availability of specific supports, and 6) provider liability and discharge.

Stakeholders noted difficulties providing supports to individuals with a dual diagnosis and/or behavioral support needs (n = 45, 30.8%). Most significantly (n = 10, 22.2%), stakeholders felt there was a lack of resources, including staffing, and expertise of community DD providers in supporting this population. Additionally, a lack of hospitals, or inpatient/psychiatric units, with expertise in supporting individuals with a dual diagnosis or those with behavioral support needs and a DD was identified as a challenge (n = 6, 13.3%). Furthermore, some stakeholders felt that providers were resistant to SSH and SST recommendations or that providers were not held accountable for following the recommendations (n = 5, 11.1%)

Stakeholders also noted difficulties supporting individuals with complex medical support needs and/or insulin-dependent diabetes (n = 40, 27.4%). Issues with nursing, including low salaries and not enough time for nurses to provide medical care, was the most cited barrier to supporting this population (n = 17, 42.5%).

Supporting individuals with physical accessibility support needs (n = 20, 13.7%), such as someone using a wheelchair or another mobility device to navigate their environments, was identified as a challenge. Individuals using wheelchairs, both manual and power/electric wheelchairs, were specifically more difficult to support (n = 12, 60.0%) due to a lack of providers with physically accessible homes to accommodate wheelchairs.

Stakeholders described a lack of access to or availability of specific supports (n = 15, 10.3%) which included a wide variety of supports, and also described difficulties supporting other specific populations besides those seven groups that were the focus of this capacity report (n = 16, 11.0%). These other specific populations included traumatic or acquired brain injury and DD (n = 4, 25.0%), individuals with deafness/blindness (n = 4, 25.0%), and individuals aging or with dementia (n = 3, 18.8%). We also specifically asked stakeholders to identify populations of people with DD in need, those populations are listed below.

Stakeholders, particularly providers, noted provider liability in supporting specific populations and a difficult discharge process (n = 10, 6.8%). Liability was a particular issue (n = 8, 80.0%) while discharge was less of an issue (n = 2, 20.0%).

When specifically asked, stakeholders identified a number of populations of people with DD in the state that they felt were not adequately served under the DD Waiver or that continued focus should rest on to acknowledge capacity (n = 37 codes). These groups included:

- Behavioral and/or dual diagnosis support needs (n = 9, 24.3%)
- Other (n = 5, 13.5%)
- Physical accessibility support needs (n = 5, 13.5%)
- High medical support needs (n = 4, 10.8%)
- Prader-Willi (n = 4, 10.8%)
- Fewer support needs, such as those using iCILA (n = 3, 8.1%)
- Children (n = 3, 8.1%)
- Diabetes (n = 2, 5.4%)
- Aging (n = 2, 5.4%)

General recommendation areas from stakeholders related to *Specific Support*Needs include (n = 94 codes):

- High behavioral support needs (n = 40, 42.6%)
- Individuals with complex medical support needs and/or insulin-dependent diabetes (n = 23, 24.5%)
- Individuals with physical accessibility support needs (n = 19, 20.2%)
- Individuals with deafness and/or blindness (n = 12, 12.8%)

General Community Capacity

The theme, *General Community Capacity*, includes any challenge to supporting or recommendation to improve capacity within the community for the general DD population in Illinois. In terms of challenges to community capacity (n = 59 codes), the sub-themes were 1) funding, 2) general staffing issues, 3) a lack of community options and/or resources, 4) housing challenges, 5) SODCs, and 6) guardians.

Funding was the primary challenge identified within *General Community Capacity* (n = 14, 23.7%). Specifically, low provider reimbursement was noted as an issue (n = 5, 35.7%) along with inadequate funding for small CILAs (n = 4, 28.6%). General staffing issues of DSPs and ISCs was identified as a particular barrier to providing community

supports (n = 13, 22.0%). In addition to low funding and resources, there was general lack of community options and/or resources (n = 12, 20.3%). More specifically, housing challenges were identified (n = 8, 13.6%). Some stakeholders felt that having SODCs in Illinois reduced community capacity (n = 6, 10.2%). Additionally, some stakeholders felt that guardians were a barrier to community capacity, in that some preferred to keep individuals in more segregated settings, like SODCs, ICF/DDs, or nursing homes (n = 6, 10.2%) without the individual's input.

General recommendations from stakeholders related to *General Community*Capacity include (n = 26 codes):

- Data tracking considerations (n = 10, 38.5%)
- General training needed (n = 8, 30.8%)
- Funding (n = 8, 30.8%)

Recommendations

The following recommendations are broken down by target population and the entity responsible (DDD, provider, or Other). Recommendations are informed by individual interviews, survey questions (as recommended by experienced stakeholders), and survey responses.

	Complex Medical Support Needs
Responsibility	Recommendation
	Clarify the intent and responsibility of a nurse in community settings through training and
	documentation such as an Information Bulletin
	Increase nursing time (or staffing) for documentation and paperwork requirements, including
	completion of the HRST (expected to be implemented for FY23)
DDD	Increase general nursing hours (per Guidehouse recommendation #9, the nursing hours will be
	tied to an individual's HCL score beginning on January 1, 2023)
	Encourage usage of the current nursing curriculum to support individuals with IDD in Illinois
	(https://www.dhs.state.il.us/page.aspx?item=53825)
	Work with CDS providers to expand support for individuals with complex medical support
	needs. Convene a discussion with CDS providers about growing this capacity.
	Employ a full-time nurse on staff who can spend more time supporting individuals with daily or
Provider	frequent nursing needs and/or overseeing DSPs to support people.
	Use add-on features of the HRST

	Insulin-Dependent Diabetes
Responsibility	Recommendation
DDD	 Ensure provider understanding and awareness of the DDD Rule 116 training for RNTs and the DDD curriculum that providers can give DSPs (see the Information Bulletin here: https://www.dhs.state.il.us/page.aspx?item=115327) Ensure provider understanding of Rule 116 requirements, perhaps through a dedicated training targeting providers that focuses on how to problem-solve support for people with insulindependence in the community Review Rule 116 and applicable laws to consider how to expand access to DSPs being able to receive training and approval to administer insulin beyond the current allowances
Provider	 Ensure DSPs are trained on the aspects of insulin administration that they can do under current rule. DDD has a training on insulin administration (see the Information Bulletin on insulin training here: https://www.dhs.state.il.us/page.aspx?item=115327) DSPs are trained on diabetes diets and diet accommodations Maintain providers' existing relationships with healthcare specialists who can provide support for individuals with diabetes Support individuals to administer their own insulin (if appropriate). Connect with other agencies who are already doing this for support

	High Behavioral Support Needs
Responsibility	Recommendation
	Work with community hospitals to advocate for strengthening their programs for people with a dual
	diagnosis and/or behavioral support needs
	• Ensure that providers follow-through with SST and SSH recommendations prior to placement in a
	more restrictive setting or initiation of the discharge process
	 Provide mental health support for DSPs in the revised DSP training
DDD	Collaborate with DMH to identify training opportunities for mental health facility workers to
	recognize and support dual diagnosis
	• Increase annual therapy hours. Assess the need to increase annual therapy hours and if needed
	explore an appropriate maximum
	 Consider tying wage rates to increased training for DSPs that work with individuals with high
	behavioral support needs. Increase the reimbursement rate for DSPs who support individuals with
	high behavioral support needs
	Consider additional changes to reimbursements for providers to offer further support to individuals
	with high behavioral support needs in one or two-person CILAs
	Consider providing increased training and wages for DSPs working in homes with higher
Provider	behavioral support needs
	Train staffto specialize in trauma-informed care and support
	• Certify DSPs working in homes with higher behavioral support needs in de-escalation training (e.g.,
	Safety Care, Crisis Prevention Training)

High Behavioral Support Needs	
Responsibility	Recommendation
	Develop policies and procedures that encourage individualized behavioral interventions prior to
	using 911 to stabilize an individual experiencing a behavioral health crisis
	Develop policies and procedures in place that ensure exhaustive behavioral interventions are used
	to avoid issuing discharge notices for higher behavioral health support needs
	Develop relationships with community mental health or behavioral health providers who can
	provide support for individuals with high behavioral needs
	Identify support plans to address the impact of behaviors on other housemates and staff

Autism Spectrum Disorder or Other Sensory Support Needs	
Responsibility	Recommendation
DDD	Provide trainings/webinars to providers on how to design and adapt homes for individuals with
	autism or other sensory support needs
	Offer the option for individuals to live in homes with fenced yards if it improves individual safety
	Offer homes with door and window alarms if it improves individual safety
	Offer homes that are "sensory sensitive"
	Offer home that allows space for pacing
	Have policies and procedures in place that recognize and reduce sensory issues related to
	textures of food, clothing, light levels, and noise
	Provide training to DSPs in the use of sequencing methods (e.g., First Then cards, Social
Provider	Stories) through the revised DSP training
	Provide training to communicate with individuals with adaptive equipment (e.g., pictures, visual
	cues) through the revised DSP training
	Ensure DSPs are trained on supporting individuals to keep to routines through the revised DSP
	training
	Ensure DSPs are trained on communication strategies for individuals with autism (for example,
	use less words and be concrete) through the revised DSP training
	Solicit companies that modify homes to receive a presentation on new technology

	Deafness or Hearing Loss
Responsibility	Recommendation
DDD	Provide trainings/webinars providers on how to design and adapt homes for individuals with deafness or hearing loss
	Offer homes that have visual cues for sounds (e.g., visual doorbells, visual phone ringing)
	Employ DSPs that are proficient in ASL and/or trained to communicate with individuals with
	adaptive communication devices and equipment, including pictures (e.g., PECs system,
	Dynavox, etc.)
Provider	Offer homes with visual emergency systems and beds that shake to signal an emergency alarm.
	Seek out informational sessions from businesses that are able to design and adapt homes for
	individuals with deafness or hearing loss
	Form an on-site communications team to identify communication supports needed
	Solicit companies that modify homes to receive a presentation on new technology

	Blindness or Visual Impairment
Responsibility	Recommendation
DDD	Provide webinars/trainings to providers on how to design and adapt homes for individuals with blindness or visual impairment
	Offer homes that provide tactile signage (e.g., identifying rooms, if lights or appliance is on/off)
Provider	Offer homes that have tactile railings along hallways to help with trailing
Flovidei	Offer homes with door alarms or other sound systems to communicate
	Train DSPs to communicate with individuals with adaptive equipment

	Train DSPs to support individuals by keeping items in the same spot (furniture, manipulatives,
	meals, etc.)
	Train DSPs on the use of tactile schedules
	Solicit companies that modify homes to receive a presentation on new technology
	Physical Accessibility Support Needs
Responsibility	Recommendation
DDD	Provide webinars to providers on how to design and adapt homes for individuals with physical
	accessibility support needs
	Provide ramps from the outside into all homes
	Widen doorways within homes
	Expand knowledge about wheelchair/scooter funding options, replacement, and maintenance
Provider	requirements
	Develop relationships with companies that service wheelchairs/scooters or other mobility
	devices
	Solicit companies that provide adaptive equipment to receive presentations on new technology

	General
Responsibility	Recommendation
DDD	Ensure that ISCs are assisting individuals in accessing non-waiver services that they may be eligible for, such as Medicaid state plan home health, SNAP benefits, and adaptive equipment or home modifications

- Address provider liability concerns by supporting provider executives to better understand and problem-solve dignity of risk situations through DDD provided training and technical assistance
- Hold quarterly meetings with OIG to discuss situations that occur in CILAs that involve the tension between dignity of risk and risk
- Allow for more flexibility in the rate structure system for individuals with more support needs and to address person-centeredness (please note that implementation of Guidehouse Rate Study recommendations at least partially fulfills this recommendation)

Appendix A

DD Provider Capacity Survey

Introduction The Division of Developmental Disabilities (DDD) in partnership with the University of Illinois at Chicago has developed the following survey in order to better understand service provider experience and support of individuals with intellectual and/or developmental (I/DD) disabilities with co-occurring additional support needs (for example, high medical needs, accessible home or autism sensitive supports). This survey will help to inform recommendations of how to grow and expand system capacity in order to meet the diverse needs of people with I/DD and their families across Illinois. The survey hopes to capture provider experience, and continued interest, in serving individuals with specialized support needs, as well as understanding provider interest in expanding service offerings.

It is just one component of the assessment of capacity in the state of Illinois, not the only component. Your answers are intended to inform what is the system's current ability to support people with specialized support needs. It is not meant as a measure of your current, specific vacancies within your organization. We may follow up with you to better understand what we can do to support growing service capacity.

DDD is requesting each provider agency to respond to this survey by October 14. We would appreciate you taking the time to complete the following survey. Survey completion time will vary based on the answers provided. Your responses are voluntary. You can come back and finish the survey later, if you wish. Qualtrics will save your progress if you wish to finish the survey at another time. If you click on the survey link again, it will take you back to where you left off. If you wish to start the survey over completely, please copy and paste the survey into a different browser. If you have any questions or concerns, please contact Caitlin Crabb at ccrabb2@uic.edu. Thank you for your participation.

	Provider_Name Name of provider agency:
_	
	Respondent_Name Your name and position at provider agency:
	Respondent_Email Your e-mail address:

Medical_Experience How experienced is your agency in supporting people with DD with
complex medical support needs (e.g., feeding tubes, cancer care, degenerative disease
care, individuals with chronic skin break down, etc.)?
C Extremely comfortable (5)
O Somewhat comfortable (4)
O Neither comfortable nor uncomfortable (3)
O Somewhat uncomfortable (2)
C Extremely uncomfortable (1)

Display This Question:

If How experienced is your agency in supporting people with DD with complex medical support needs (e... = Extremely comfortable

Or How experienced is your agency in supporting people with DD with complex medical support needs (e... = Somewhat comfortable

Medical_Supports Does your agency provide these complex medical supports (e.g., feeding tubes, cancer care, degenerative disease care, individuals with chronic skin break down, etc.)?

	Yes (1)	No (0)
Provider has nurses or other trained healthcare		
professionals on staff (either employed or contract) that can support oversight of a feeding tube (Medical_Supports_1)		
DSPs are trained to support management of a feeding tube on a daily basis (Medical_Supports_2)	0	
Provider has nurses or other trained healthcare professionals on staff (either employed or contract) that can support oversight of complex medical needs (Medical_Supports_3)		
DSPs are trained on special diets (e.g., mechanical soft diets, pureed, low sugar, etc.) (Medical_Supports_4)	0	0
Provider uses any of the add-on features of the HRST to support an individual with more complex medical needs (Medical_Supports_5)		0

Provider has access to on-call nurses and back up nurse support for consultation and guidance on healthcare issues and support (not just medication administration) (Medical_Supports_6) Provider has existing relationships with community healthcare providers who can provide support for individuals with complex medical needs (Medical_Supports_7) Provider offers these others specific supports (please specify): (Medical_Supports_8)

Display This Question:

If How experienced is your agency in supporting people with DD with complex medical support needs (e... = Extremely comfortable

Or How experienced is your agency in supporting people with DD with complex medical support needs (e... = Somewhat comfortable



Medical_Cont Does your agency have continued interest in supporting people
with complex medical support needs? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with complex medical support needs (e = Neither comfortable nor uncomfortable
Or How experienced is your agency in supporting people with DD with complex medical support needs (e = Somewhat uncomfortable
Or How experienced is your agency in supporting people with DD with complex medical support needs (e = Extremely uncomfortable
$X \rightarrow$
Medical_Expand Does your agency have a desire to expand services to include
individuals with complex medical support needs? If no, why not?
○ Yes (1)
○ No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with complex medical support needs (e = Extremely comfortable

Somewhat comfortable

Medical_Serve In total, how many people with comple	ex medical support needs
can you support (currently serving + current vacancies)?	
Page ————————————————————————————————————	
Break	



Diabetes_Experience How experienced is your agency in supporting people with DD with insulin-dependent diabetes?

Extremely experienced (5)
O Somewhat experienced (4)
O Neither experienced nor unexperienced (3)
O Somewhat unexperienced (2)
Extremely unexperienced (1)

Display This Question:

If How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Extremely experienced

Or How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Somewhat experienced



Diabetes_Supports Does your agency provide these supports to individuals with insulindependent diabetes?

	Yes (1)	No (0)
Provider has nurses or other trained healthcare professionals on staff (either employed or contract) that can administer insulin (Diabetes_Supports_1)	0	
DSPs are trained and approved to administer insulin (Diabetes_Supports_2)	0	
Provider has nurses or other trained healthcare professionals on staff (either employed or contract) that can support an individual that self-administers their insulin (Diabetes_Supports_3)		
Provider has policies and procedures for caring for and monitoring diabetes (Diabetes_Supports_4)		
DSPs are trained on diabetes diets and diet accommodations (Diabetes_Supports_5)		0
Provider has existing relationships with healthcare specialists who can provide support for individuals with diabetes (Diabetes_Supports_6)		

Provider offers these
others specific supports
(please specify):
(Diabetes_Supports_7)

Display This Question:

If How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Extremely experienced

Or How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Somewhat experienced



Diabetes_Cont Does your agency have continued interest in supporting people with insulin-dependent diabetes? If no, why not?

- O Yes (1)
- O No (please elaborate): (0)

Display This Question:

If How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Neither experienced nor unexperienced

Or How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Somewhat unexperienced

Or How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Extremely unexperienced



Diabetes_Expand Does your agency have a desire to expand services to include
individuals with insulin-dependent diabetes? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Extremely experienced
Or How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Somewhat experienced
Diabetes_Serve In total, how many people with insulin-dependent diabetes can you support (currently serving + current vacancies)?
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Behavior_Experience How experienced is your agency in supporting people with DD with high behavioral support needs?

Extremely experienced (5)
O Somewhat experienced (4)
O Neither experienced nor unexperienced (3)
O Somewhat unexperienced (2)
Extremely unexperienced (1)

Display This Question:

If How experienced is your agency in supporting people with DD with high behavioral support needs? = Extremely experienced

Or How experienced is your agency in supporting people with DD with high behavioral support needs? = Somewhat experienced



Behavior_Supports Does your agency provide these behavioral supports?

	Yes (1)	No (0)
Provider has		
experience supporting people		
with suicidal behaviors	O	O
(Behavior_Supports_1)		
Provider has		
experience supporting sex		
offenders	O	\bigcirc
(Behavior_Supports_2)		
DSPs are certified in		
Safety Care, Crisis Prevention		
Training, or other de-	\circ	\circ
escalation training		
(Behavior_Supports_3)		
DSPs are certified in		
Safety Care, Crisis Prevention		
Training, or other method that		
teaches physical	O	O
management		
(Behavior_Supports_4)		
DSPs are involved in		
the Behavior Support Plan		
process to plan for and create	\circ	
address support needs		
(Behavior_Supports_5)		
DSPs are offered		
premium pay to work in		
homes with higher behavioral	0	\circ
support needs		
(Behavior_Supports_6)		

Provider requires a higher education level expectation for DSPs working in homes with higher behavioral support needs (Behavior_Supports_7)		0
Provider requires certified DD aides or higher (or commensurate experience of at least three years) working in homes with higher behavioral support needs (Behavior_Supports_8)		0
Provider employs BCBAs or BCABAs (Behavior_Supports_9)		0
Provider employs Registered Behavior Techs (RBTs) (Behavior_Supports_10)		0
Provider employs Counselors/Therapists/Social Workers (Behavior_Supports_11)		0
Provider employs staff that specialize in trauma- informed care and support (Behavior_Supports_12)	0	0

Provider has access		
to a psychiatrist with admitting		
privileges in a hospital system	\circ	
(Behavior_Supports_13)		
Provider provides		
environmental modifications		
to prevent elopement and/or		
property damage (e.g.,	\circ	\circ
reinforced walls, bells on		
doors, sensory modifications)		
(Behavior_Supports_14)		
Provider provides		
higher staffing ratios in homes		
with higher behavioral support	0	0
needs		
(Behavior_Supports_15)		
Provider has, or is		
willing, to develop one or two-		
person CILAs to support		
individuals with higher	0	0
behavioral support needs		
(Behavior_Supports_16)		
Provider has policies		
and procedures that		
encourage individualized		
behavioral interventions prior		
to using 911 to stabilize an	0	\circ
individual experiencing a		
behavioral health crisis		
(Behavior_Supports_17)		

Provider has policies and procedures in place that ensure exhaustive behavioral interventions are used to avoid issuing discharge notices for higher behavioral health support needs (Behavior_Supports_18) Provider has existing relationships with community mental health or behavioral health providers who can provide support for individuals with high behavioral needs (Behavior_Supports_19) Provider offers these others specific supports (please specify): (Behavior_Supports_20)

Display This Question:

If How experienced is your agency in supporting people with DD with high behavioral support needs? = Extremely experienced

Or How experienced is your agency in supporting people with DD with high behavioral support needs? = Somewhat experienced



Behavior_Cont Does your agency have continued interest in supporting people
with high behavioral support needs? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with high behavioral support needs? = Neither experienced nor unexperienced
Or How experienced is your agency in supporting people with DD with high behavioral support needs? = Somewhat unexperienced
Or How experienced is your agency in supporting people with DD with high behavioral support needs? = Extremely unexperienced
X÷
Pohavior Expand Doos your agancy have a desire to expand convices to include
Behavior_Expand Does your agency have a desire to expand services to include
individuals with high behavioral support needs? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with high behavioral support needs? =
Extremely experienced
Or How experienced is your agency in supporting people with DD with high behavioral support needs? =

69

Somewhat experienced

Behavior_Serve In total, how many people with high behavioral support needs
can you support (currently serving + current vacancies)?
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Break



ASD_Experience How experienced is your agency in supporting people with DD with autism spectrum disorder or other sensory support needs?

Extremely experienced (5)
O Somewhat experienced (4)
O Neither experienced nor unexperienced (3)
O Somewhat unexperienced (2)
Extremely unexperienced (1)

Display This Question:

If How experienced is your agency in supporting people with DD with autism spectrum disorder or othe... = Extremely experienced

Or How experienced is your agency in supporting people with DD with autism spectrum disorder or othe... = Somewhat experienced



ASD_Supports Does your agency provide these autism or sensory supports?

	Yes (1)	No (0)
Provider offers homes with yards with fences (ASD_Supports_1)	0	0
Provider offers homes with door and window alarms (ASD_Supports_2)		0
Provider offers homes that are "sensory sensitive" (ASD_Supports_3)	0	0
Provider offers home that allows space for pacing (ASD_Supports_4)		0
Provider has policies and procedures in place that recognize and reduce sensory issues related to textures of food, clothing, light levels, and noise (ASD_Supports_5)		
DSPs are trained in the use of sequencing methods (e.g., First Then cards, Social Stories) (ASD_Supports_6)		
DSP are trained to communicate with individuals with adaptive equipment (e.g., pictures, visual cues) (ASD_Supports_7)		

DSPs are trained on		
supporting individuals to keep		
to routines	O	O
(ASD_Supports_8)		
DSPs participate in		
formal training on		
communication strategies for		
individuals with autism (for	\circ	
example, use less words and		
be concrete)		
(ASD_Supports_9)		
Provider has existing		
relationships with community		
providers who can provide		
ancillary support for	\circ	
individuals with		
autism/sensory needs		
(ASD_Supports_10)		
Provider offers these		
others specific supports		
(please specify):	0	\bigcirc
(ASD_Supports_11)		

Display This Question:

If How experienced is your agency in supporting people with DD with autism spectrum disorder or othe... = Extremely experienced

Or How experienced is your agency in supporting people with DD with autism spectrum disorder or othe... = Somewhat experienced



ASD_Cont Does your agency have continued interest in supporting people with
autism spectrum disorder or other sensory support needs? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with autism spectrum disorder or othe = Neither experienced nor unexperienced
Or How experienced is your agency in supporting people with DD with autism spectrum disorder or othe = Somewhat unexperienced
Or How experienced is your agency in supporting people with DD with autism spectrum disorder or othe = Extremely unexperienced
$X \rightarrow$
ASD_Expand Does your agency have a desire to expand services to include
individuals with autism or other sensory support needs? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with autism spectrum disorder or othe = Extremely experienced
Or How experienced is your agency in supporting people with DD with autism spectrum disorder or othe = Somewhat experienced

	ASD_Serve In total, how many people with autism or other sensory support
needs can you support (currently serving + current vacancies)?	
	Page —
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Deaf_Experience How experienced is your agency in supporting people with DD who are deaf/Deaf/hard-of-hearing?

Extremely experienced (5)	
O Somewhat experienced (4)	
O Neither experienced nor unexperienced (3)	
O Somewhat unexperienced (2)	
O Extremely unexperienced (1)	

Display This Question:

If How experienced is your agency in supporting people with DD who are deaf/Deaf/hard-of-hearing? = Extremely experienced

Or How experienced is your agency in supporting people with DD who are deaf/Deaf/hard-of-hearing? = Somewhat experienced



Deaf_Supports Does your agency provide these supports for individuals who are deaf/Deaf/hard-of-hearing?

	Yes (1)	No (0)
Provider offers homes that has visual cues for sounds (e.g., visual door bells, visual phone ringing) (Deaf_Supports_1)	0	0
Provider offers home with visual emergency systems (Deaf_Supports_2)		
Provider can provide beds that shake to signal an emergency alarm (Deaf_Supports_3)		0
Provider employs DSPs that are proficient in ASL (Deaf_Supports_4)		0
DSP are trained in basic ASL and/or trained to communicate with individuals with adaptive communication devices and equipment, including pictures (e.g., PECs system, Dynavox, etc.) (Deaf_Supports_5)		

Provider has established relationships with community providers (doctors, specialists, community resources) who are able to provide medical care to people who are deaf/Deaf/hard-of-hearing (Deaf_Supports_6)		
Provider offers these		
others specific supports		
(please specify): (Deaf_Supports_7)	O	O
Display This Question:		
If How experienced is your agency i	in supporting people with DD who are dec	of/Deaf/hard-of-hearing? =
Extremely experienced Or How experienced is your agency	in supporting people with DD who are de	eaf/Deaf/hard-of-hearing? =
Somewhat experienced		
X→		
Deaf_Cont Does your a are deaf/Deaf/hard-of-hearing?	gency have continued interest i ? If no, why not?	n supporting people who
○ Yes (1)		
O No (please elaborate):	(0)	

Display This Question:
If How experienced is your agency in supporting people with DD who are deaf/Deaf/hard-of-hearing? = Neither experienced nor unexperienced
Or How experienced is your agency in supporting people with DD who are deaf/Deaf/hard-of-hearing? = Somewhat unexperienced
Or How experienced is your agency in supporting people with DD who are deaf/Deaf/hard-of-hearing? = Extremely unexperienced
$X \rightarrow$
Deaf_Expand Does your agency have a desire to expand services to include
individuals who are deaf/Deaf/hard-of-hearing? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Extremely experienced
Or How experienced is your agency in supporting people with DD with insulin-dependent diabetes? = Somewhat experienced

Break



Blind_Experience How experienced is your agency in supporting people with DD who are blind/visually impaired?

Extremely experienced (5)
O Somewhat experienced (4)
O Neither experienced nor unexperienced (3)
O Somewhat unexperienced (2)

O Extremely unexperienced (1)

Display This Question:

If How experienced is your agency in supporting people with DD who are blind/visually impaired? = Extremely experienced

Or How experienced is your agency in supporting people with DD who are blind/visually impaired? = Somewhat experienced



Blind_Supports Does your agency provide these supports for individuals who are blind/visually impaired?

	Yes (1)	No (0)
Provider offers homes that provide tactile signage (e.g., identifying rooms, if lights or appliance is on/off) (Blind_Supports_1)	0	0
Provider offers homes that have tactile railings along hallways to help with trailing (Blind_Supports_2)		0
Provider offers home with door alarms or other sound systems to communicate (Blind_Supports_3)		0
DSP are trained to communicate with individuals with adaptive equipment (Blind_Supports_4)	0	
DSPs are trained to support individuals by keeping items in the same spot (furniture, manipulatives, meals, etc.) (Blind_Supports_5)	0	
DSPs are trained on the use of tactile schedules (Blind_Supports_6)	0	

Provider has existing relationships with community providers (doctors, specialists, community resources) who can provide support for individuals who are blind/visually impaired (Blind_Supports_7)		
Provider offers these others specific supports (please specify): (Blind_Supports_8)		
experienced	supporting people with DD who are bling supporting people with DD who are bli	
Blind_Cont Does your agare blind/visually impaired? If no	gency have continued interest i o, why not?	n supporting people who
O Yes (1) O No (please elaborate): (0)	

Display This Question:
If How experienced is your agency in supporting people with DD who are blind/visually impaired? = Neither experienced nor unexperienced
Or How experienced is your agency in supporting people with DD who are blind/visually impaired? = Somewhat unexperienced
Or How experienced is your agency in supporting people with DD who are blind/visually impaired? = Extremely unexperienced
$X \rightarrow$
Blind_Expand Does your agency have a desire to expand services to include
individuals who are blind/visually impaired? If no, why not?
○ Yes (1)
O No (please elaborate): (0)
Display This Question:
If How experienced is your agency in supporting people with DD who are blind/visually impaired? = Extremely experienced

Or How experienced is your agency in supporting people with DD who are blind/visually impaired? = Somewhat experienced

Blind_Serve In total, how many people who are blind/visually impaired can you
support (currently serving + current vacancies)?

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Physical_Experience How experienced is your agency in supporting people with DD who have physical accessibility support needs (e.g., individuals using wheelchairs, walkers, and/or scooters)?

Extremely experienced (5)
O Somewhat experienced (4)
O Neither experienced nor unexperienced (3)
O Somewhat unexperienced (2)
O Extremely unexperienced (1)

Display This Question:

If How experienced is your agency in supporting people with DD who have physical accessibility suppo... = Extremely experienced

Or How experienced is your agency in supporting people with DD who have physical accessibility suppo... = Somewhat experienced



Physical_Supports Does your agency provide these supports for individuals with physical accessibility support needs (e.g., individuals using wheelchairs, walkers, and/or scooters)?

	Yes (1)	No (0)
Provider has knowledge about universal design and understands physical accessibility rules and requirements (Physical_Supports _1)	0	
Provider offers homes with ramps (Physical_Supports _2)		
Provider offers homes with widened doorways (Physical_Supports _3)		
Provider offers homes with walk-in/roll-in shower (Physical_Supports _4)		
Provider has wheelchair accessible vehicle(s) or access to other accessible transportation (Physical_Supports _5)	0	
Provider is knowledgeable about wheelchair/scooter funding options and replacement (Physical_Supports _6)		

Provider is				
knowledgeable about				
wheelchair/scooter repair and	\bigcirc	\bigcirc		
servicing (Physical_Supports				
_7)				
Provider has existing				
relationships with companies				
that service	\bigcirc	\circ		
wheelchair/scooters				
(Physical_Supports _8)				
Provider offers these				
others specific supports				
(please specify):		\bigcirc		
(Physical_Supports _9)				
Display This Question:	s cupporting poople with DD who have n	husical accessibility suppo		
Extremely experienced	supporting people with DD who have p	nysicai accessibility suppo =		
Or How experienced is your agency i Somewhat experienced	in supporting people with DD who have _l	physical accessibility suppo =		
$X \rightarrow$				
Physical_Cont Does you	r agency have continued intere	est in supporting people		
who have physical accessibility support needs? If no, why not?				
○ Yes (1)				
O No (please elaborate): (0)			

Display This Question: If How experienced is your agency in supporting people with DD who have physical accessibility suppo... = Neither experienced nor unexperienced Or How experienced is your agency in supporting people with DD who have physical accessibility suppo... = Somewhat unexperienced Or How experienced is your agency in supporting people with DD who have physical accessibility suppo... = Extremely unexperienced Physical_Expand Does your agency have a desire to expand services to include individuals with physical accessibility support needs? If no, why not? Yes (1) O No (please elaborate): (0) Display This Question: If How experienced is your agency in supporting people with DD who have physical accessibility suppo... = Extremely experienced Or How experienced is your agency in supporting people with DD who have physical accessibility suppo... = Somewhat experienced

Physical_Serve In total, how many people with physical accessibility support needs can you support (currently serving + current vacancies)?

End of Block: Default Question Block