
2022-2023 STATEWIDE ASSESSMENT OF NEED FOR IDAHOANS WITH DISABILITIES

July 1, 2023

Idaho State Independent Living Council



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EXECUTIVE SUMMARY

The 2022 statewide assessment of need and the resulting 2023 report contained herein represents the work of many during the last two years. As the executive director of the Idaho State Independent Living Council, I have the good fortune to work with the three Idaho Centers for Independent Living, the Idaho Commission for the Blind and Visually Impaired, the Division of Vocational Rehabilitation and many other state, private and local partners, including the Idaho Council on Developmental Disabilities, several divisions within the Department of Health and Welfare, the Community Council of Idaho and the Intermountain Fair Housing Council to name just a few. Additionally, I get to work for a volunteer Council of Idahoans, most of whom have a disability, who repeatedly step up to serve, even when some of them can't find help to get out of bed.

Beyond the above, we have the opportunity to travel our state, and the honor of meeting with people with disabilities, family members and service providers across Idaho. Idahoans with disabilities are a resilient bunch, though the Public Health Emergency, aka: COVID, has clearly taken a toll. Indeed, some who have helped in previous assessments were noticeably absent from their communities during our visits. Yet others stepped forward and shared their hopes, fears, losses and dreams.

By no means is this assessment scientific nor were our community visits as consistently conducted as has been the case in years' past. In some communities we had surprisingly high attendance and in others where we'd previously expected at least a handful of people, no one attended. This is likely reflective of multiple factors, including that these were some of the first large gatherings held for a population which remains at risk, transportation services for people who don't drive are sorely lacking since the public health emergency began, many don't have direct support professionals who once helped them get out and about, and our logistics teams were at times, a bit rusty. That said, our many partners helped us disseminate surveys and the results show in the number of responses received.

While much of our state appears to have bounced back from the recent public health emergency, many people with disabilities and seniors are struggling to remain in their homes with the supports and services they need, especially those on low or fixed incomes. This report reflects the strength and depth of the disability community and some portion of that need.

Statewide Assessment and State Plan for Independent Living (SPIL) Planning Committee Members 2020 - 2023

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Recognition and gratitude to the following:

The many staff at the Centers for Independent Living who coordinated community meetings, interviews, and interpreters while also helping disseminate surveys.

Boise State University, Center for the Study of Aging, College of Health Sciences for working with us in coordination with graduate student, Domini Baker-Strayer, who provided qualitative analysis, professional insight and literature review as we worked to finalize this report.

PURPOSE

The Idaho State Independent Living Council (SILC) actively engages in statewide activities that assist in providing Idahoans with disabilities a greater voice in obtaining services that are participant-directed, cost-effective and community based. The Council often partners with national, state and local agencies, advocacy organizations and nonprofits to effect positive systems change.

Every three years, the Idaho SILC collaborates with the Centers for Independent Living (CILs), the Division of Vocational Rehabilitation and the Idaho Commission for the Blind and Visually Impaired to conduct a statewide needs assessment collecting input from constituents for review, revision and development of the three-year State Plan for Independent Living (SPIL).

The core functions of the Idaho SILC are specific to the federal mandates in Title VII Part B of the Rehabilitation Act of 1973, as amended, and Idaho Statute, Title 56, Chapter 12; and provide the authority and rationale behind the SPIL. The SILC serves people with disabilities across lifespan in all 44 Idaho counties, working with and amplifying the voices of Idahoans with disabilities. The SILC does not provide any direct services.

PLANNING

The State Independent Living Council SPIL planning committee includes members of the SILC executive committee, the three Center Directors and representatives from the Idaho Commission for the Blind and Visually Impaired and the Division of Vocational Rehabilitation, as well as the SILC executive director and program specialist. The committee began development of the most recent assessment in July 2021, participated in events and followed progress throughout the 2022 assessment and review process culminating with this report.

Idaho's three Centers for Independent Living, Disability Action Center-Northwest (DAC-NW), LIFE, A Center for Independent Living (LIFE), and Living Independence Network Corporation (LINC) serve all 44 counties across Idaho. Center service areas are defined by county as follows:

DAC-NW: Benewah, Boundary, Bonner, Clearwater, Idaho, Kootenai, Latah, Lewis, Nez Perce and Shoshone, counties and includes three of five Idaho Native American Indian Reservations. This service area covers ten counties across more than 21,000 square miles. DAC-NW's main office is in Moscow with

two field offices: one in Post Falls to the north and one in Lewiston to the south.

LIFE: Bannock, Bear Lake, Bingham, Bonneville, Butte, Caribou, Cassia, Clark, Custer, Franklin, Fremont, Jefferson, Lemhi, Madison, Minidoka, Oneida, Power, and Teton counties, and includes the Fort Hall Reservation. This 18-county service area covers nearly 33,000 square miles. LIFE's main office is in Pocatello with field offices in Idaho Falls, Burley and Blackfoot.

LINC: Ada, Adams, Blaine, Boise, Camas, Canyon, Elmore, Gem, Gooding, Jerome, Lincoln, Owyhee, Payette, Twin Falls, Valley and Washington counties, and includes a large portion of the Duck Valley Reservation. This service area of 16 counties covers nearly 9,000 square miles. LINC's main office is in Boise with field offices in Twin Falls and Caldwell. While LINC's service area is geographically the smallest of the three Centers, the region is home to approximately half of the state's population of 1,939,092 people¹.

As previously mentioned, the assessment and planning process includes the Commission for the Blind and Visually Impaired (ICBVI). ICBVI serves people in all 44 counties in Idaho. ICBVI's main office is in Boise with field offices in southeastern, northern and southcentral Idaho.

OVERVIEW OF ASSESSMENT PROCESS:

Survey Dissemination, Responses and Community Meetings

The Idaho SILC in partnership with the three CILs, the Commission for the Blind and Visually Impaired and the Division of Vocational Rehabilitation conducted a statewide survey of the needs of people with disabilities January 25 - September 16, 2022. Surveys were available in various formats, including electronic surveys in English and Spanish, hard-copy surveys, available in English, Spanish, large print, and Braille. Additionally, the SILC staff read surveys to several people upon request. No other language requests were made, though the SILC prepared to provide translation services should the need arise. One person completed an electronic survey in Spanish.

Idahoans with disabilities and other stakeholders participated in the surveys via the SILC, CIL and partner agency websites. Additionally, the SILC distributed surveys through email, newsletters through the Department of Health and Welfare and other partner agencies, community meetings, and outreach events. These efforts led to the return of

658 surveys, a 205% increase in responses from the 2018 assessment survey. Much of this increase can be attributed to increased partnerships with a variety of disability and non-disability specific organizations and state agencies. Additionally, through 29 events coordinated by the CILs, SILC and Center staff met with community members across Idaho from April 21 through August 24, 2022. The SILC held two additional sharing events via virtual format that included people from northern, eastern, central and western Idaho. In all, 213 people provided input and shared concerns about the state of services, support, community access and local challenges as well as successes through a variety of opportunities, including formal meetings, personal interviews and follow-up conversations.

Survey Respondents

Of the six-hundred-fifty-eight survey respondents, 38% identified as people with disabilities, 60% identified as people without a disability, and 0.3% of respondents did not answer the question. Twenty-three percent of those identifying as a person with a disability were also a family member of a person with a disability, a service provider/agency owner, or a direct care or community support worker. For those without a disability, 41% identified as a family member of a person with a disability, 10% identified as a service provider/agency owner, and 5% indicated that they were either a direct care or community support worker. Further breakdown revealed that 16 of those who identified as a person with a disability also worked as a service provider or agency owner.

Six-hundred-thirty-five respondents included their location. Of those, 19% reside in the DAC-NW service area; 52% live in the LINC service area; and the remaining 29% live in the LIFE Service area.

Four-hundred-sixteen respondents shared their race and ethnicity: 87.5% identified as white, 7.69% as Hispanic or Latino, 5.0% as Native American, 1.68% as Black or African American, 0.72% as Native Alaskan, 0.24% as Pacific Islander, and 4.81% as other.

The age distribution of respondents follows: 0.5% of respondents are 0-11, 13% are 12-20, 18% are 21-30, 14% are 31-40, 14% are 41-50, 21% are 51-60, and 20% of respondents are 60 or older.

ISSUE AREAS

Housing

Five-hundred-seventy-four respondents answered the survey questions about housing. A statewide analysis found that 289 own their own homes, while the rest either rent, live in a group setting, with friends or family, shelter or other temporary housing or are homeless. Group settings may include residential habilitation (Res-Hab) where individuals and their roommates are on the lease, pay rent and receive services through developmental disability agency (DDA) and those who live in Residential Assisted Living Facilities (RALFs). People who live in RALFs are renters who may also pay for a variety of services through the facility as well as for services outside of the facility.

The highest-ranking concerns for respondents providing information about housing across service areas are affordability, property taxes, need help with daily activities, maintenance, transportation, and accessibility. (Figure 1)

What issues, barriers, or worries do you face related to your housing?

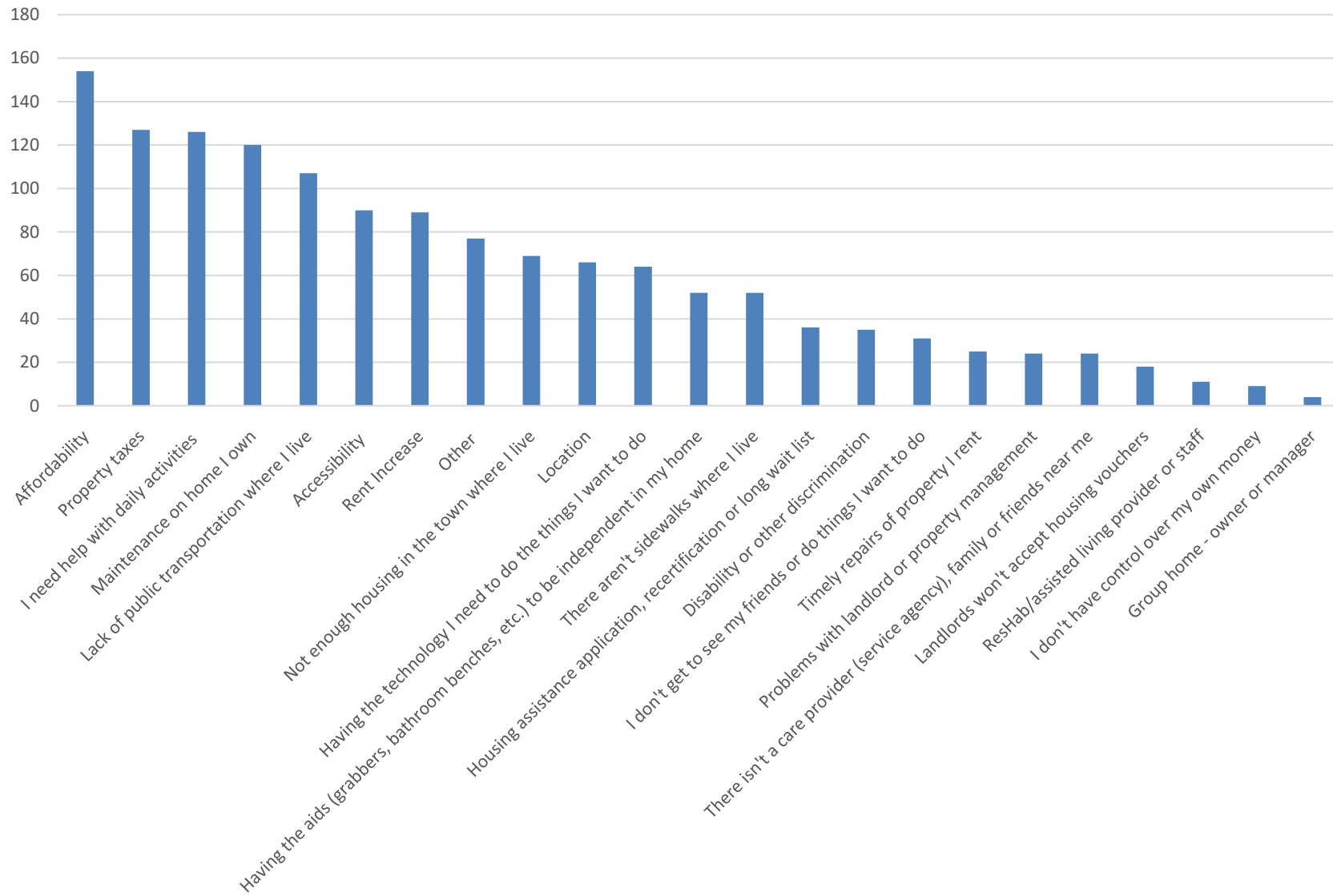


Figure 1

Affordability/Property Taxes

The U.S. Department of Housing and Urban Development (2011) defines affordable housing as that for which the occupant pays no more than 30% of their total gross income for housing costs, including utilities. In Idaho, the average income is climbing slower than housing costs. Over the course of the last six years, Idaho's housing prices increased by 150%, while income rose only by 26% (Russell, 2022).

Twenty-seven percent of respondents indicated that affordability is a housing barrier, while 23% cited property taxes. Another 16% of survey participants relayed that rent increases are creating a housing barrier.

During a meeting in Idaho Falls/Ammon (LIFE service area), an attendee noted that rent has increased by \$400-\$900 monthly, forcing many people to leave their homes. Another noted the difficulties in securing public housing, "you have to wait for someone to die to get into one of the two senior living housing complexes." Participants in several meetings across southern Idaho service areas noted that local hotels are full of people who can't find housing.

Attendees across meetings in the LINC service area also discussed the impact of the rising costs of rent and property taxes. People in this area also cited a two-year waiting list for low-income housing. In Gooding, a participant shared that multiple families often live in a single home to make ends meet.

The concerns of those that attended the community meetings held in DAC-NW's service area noted similar struggles. Meeting participants in Lewiston relayed that an estimated 150 people were unhoused or precariously housed. Those in this region must also compete with the tourism industry and its impact on housing access not only for people with disabilities but also for those who provide needed services, such as medical providers and direct support professionals.

In an open-ended comment, one survey respondent shared, "My landlord last year doubled my rent at the end of my lease.... I was homeless for three months this winter; I have autism and can't talk...I couch surfed at my res-hab agency, thankfully but would have been institutionalized at the height of COVID otherwise."

Help Needed with Daily Activities

The National Institute of Health defines daily living activities as those required to manage one's most basic needs in order to maintain health (Edemekong et al., 2022).

Activities of daily living (ADLs) include ambulating, feeding, dressing, personal hygiene, and toileting.

Twenty-two percent of respondents relayed that they need help with daily activities such as cooking, showering, getting out of bed, cleaning, getting and taking medication, getting dressed, shopping, etc. A deeper dive into where respondents live based on service area provides further insight into what Independent Living training may be helpful regionally with 17% of respondents living within the DAC-NW region, 57% residing in the LINC service area and 25% living within the region served by LIFE.

It's noteworthy that 72% of respondents who indicated that they need help with activities of daily living are under the age of 60. This is significant in that many in the general public, including policy makers and funders often appear more willing to direct resources for in-home supports toward people identified as seniors than for people who are younger or considered "working age."

In open-ended questions, survey respondents elaborated on the difficulties they face while completing daily activities. One respondent noted that they are entirely dependent on family members for help getting dressed, eating and getting out of bed. Several shared that they need assistance in all categories and have (or need) 24-hour support. At a community meeting in Pocatello/Chubbuck (LIFE service area) an attendee shared that when their Community Support Worker (CSW) doesn't show up in the morning, they are stuck in bed and need to use a bedpan instead of getting to the bathroom. Many people across meeting locations and regions shared that they're unable to find workers for the wages Medicaid allows them to pay. Those not using a self-directed model also report being unable to find home care agencies with enough workers to take on another client.

Assistance with Maintenance

Twenty-one percent of respondents conveyed that maintenance on a home they own is an issue, barrier or worry. Additionally, 4% of participants cited that timely repair on their rentals is a barrier to living independently. There is a noted crossover between affordability, accessibility and home adaptations needed for activities of daily living embedded in maintenance assistance.

Observationally, during several community visits across regions, we noted that people in smaller, rural communities weren't aware of programs to help with repairs or the installation of accessibility features like ramps to doorways or grab bars in bathrooms.

Transportation

Transportation remains a barrier in several areas of respondents' lives. Heaps et al. (2021) note that the lack of public transport increases social isolation, which impacts overall health.

Open-ended responses in the survey elaborated on the impact of poor public transportation on peoples' daily lives. One respondent noted that "lack of transportation in my semi-rural area forced me to resign from my job this year." Another stated, "A service should be provided for the disabled and/or visually impaired to help them transport themselves where they need to go. The bus system is too unreliable."

During community meetings, attendees often spoke at length about their reduced ability to navigate their communities. One participant stated, "Rexburg doesn't have public transport. Walmart has a ride program for students. It isn't wheelchair accessible." A resident of Challis shared that, "If you don't drive around here, you're going nowhere." A community member from Twin Falls stated that public transportation can be challenging to understand and that many are unaware of how to get assistance to access buses." Most communities fell short in regard to accessible routes of travel, i.e.: sidewalks and curb-cuts. In Sandpoint, we heard complaints that people don't use free and accessible bus system. Yet during our brief review of several bus stops we noted that many stops are in places without access via sidewalks, curb-cuts or both.

MTM is Idaho's non-emergency medical transportation broker through a managed care contract with Medicaid. Respondents relayed that the MTM system is challenging to navigate; they often miss appointments or are left at doctor's offices because no one comes to get them. Others noted that MTM often leaves users at incorrect locations. Several people shared that they or a loved one had been left in the wrong place; one person sharing that their elderly parent was left in a parking lot for several hours in temperatures nearing 100 degrees (summer 2022).

Accessibility

The survey asked participants if they had issues with accessibility in their homes. Nearly 16% of survey respondents relayed that their homes need modifications such as ramps, wider doorways, showers, toilets, accessible pathways and appliances they could reach or otherwise use due to visual impairments. Another 9% shared that their homes lack grab bars, bathroom benches, lifts, magnifiers, or bump dots that would allow for

greater independence at home. Many cited a need for sidewalks or voiced that their sidewalks are in disrepair, thus limiting their ability to get out into the community.

A few respondents expanded on their concerns. One stated, “My home needs modifications, or I need a different home better suited to our needs, but the market is not ok right now.” Another shared that public housing is not accessible for those using a wheelchair, “spend one week in a wheelchair, try putting trash in an apartment complex dumpster, getting through your front door, access to your vehicle, or doing laundry in a top load washer.” A person with a visual impairment shared that they cannot ascertain whether the burners on their stove are hot or cold without touching them and as a result had been burned several times.

Life Skills

The survey asked respondents, “What things do you struggle with or need help doing?” Of the 658 respondents 497 reported needing help in at least one of the life skills areas listed. Respondents were able to select multiple options within this question.

The top 5 life skills that respondents struggled with or need help doing in order of greatest to least were: cleaning, cooking, budgeting, wellness, and self-care (bathing, hygiene, washing clothes), and medication management. (Figure 2)

What things do you struggle with or need help doing?

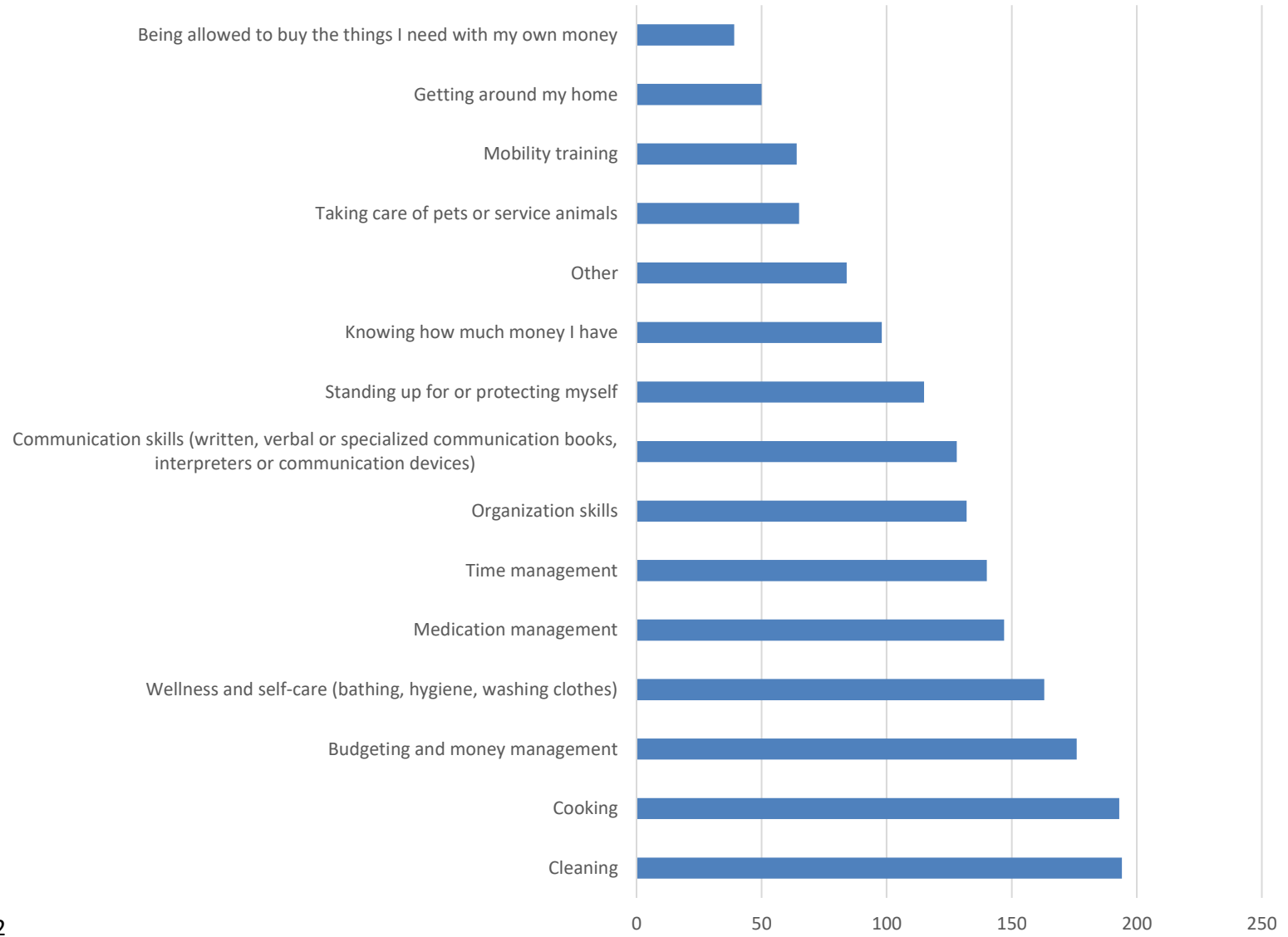


Figure 2

Cooking and Cleaning

Taking an in-depth look at cooking and cleaning, more than 190 respondents shared that they need assistance with cleaning, more than 190 need assistance with cooking and 163 of those individuals indicated that they need help with both cooking and cleaning, accounting for nearly 25% of the total responses to this question.

Further analysis indicates that of those who need help with cooking and cleaning, 22% live within the DAC-NW service area, 26% live in the region served by LIFE, and 23% of those residing in the LINC service area.

Of the 163 respondents in need of assistance with cooking and cleaning, 137 included their age. Of those that indicated they need help, again, notably, 80% are under the age of 60.

One respondent stated that they are unable to make food and must rely on their spouse for cooking. When their spouse is unavailable, they use food delivery which is incredibly expensive.

Assistance with Budgeting or Money Management

A total of 177 respondents shared that they are either struggling or need assistance with budgeting or money management. Eighty-eight people reported they need help to know how much money they have and 27 shared that they struggle to be allowed to buy the things they need with their own money.

The above provides further insight into opportunities for Independent Living training and support related to financial management. Analyzing by service area: 24% of survey respondents to this question reside in the region served by DAC-NW, 25% of survey respondents live in the LIFE service area and 24% of respondents living in the LINC service area report that they need help with budgeting or money management.

Assistance with Wellness and Self-Care (bathing, hygiene, washing clothes)

Over 160 respondents reported needing assistance with wellness or self-care (bathing, hygiene, and washing clothes). Eighty-six percent of the people that answered that they need help are under the age of 60.

Medication Management

A total of 148 respondents shared that they need assistance with medication management. Seventy-nine percent indicated they need help with medication management are under the age of 60.

Transportation

Heaps et al. (2021) note that lack of access to transportation increases social isolation, and negatively impacts overall health. Thus, the survey administered in 2022 took care to evaluate transportation needs on several levels.

How do you get to where you want to go?

A look at the responses reveals that 33% of respondents rely on family/friends for transportation across all service areas. Twenty-five percent report that they have a private vehicle/driver's license. Ten percent are technically pedestrians who walk, use a wheelchair or a scooter. Medicaid transportation accounts for only 7% of respondents, and 6% of those who answered the question rely on Taxi/Uber/Lyft rides. It is worth noting that during community meetings, many people who use Home and Community Based Services (HCBS) through the Aged and Disabled (A & D) waiver seemed unaware that Medicaid can pay for non-medical transportation to grocery stores, pharmacies, employment and other community destinations.

In open-ended survey comments tied to this question, respondents elaborated on the struggles of relying on others for transportation. "My parents take care of me well, but I would like others to take me places too. So it is not just with my family. How do I do that?" The family member of a person with a disability relayed the difficulties of transporting their son, reporting that they "must leave work several times a day to do so." Another respondent said, "It is hard to ask for a ride all the time. I want people to ask me if I want to go along with them for a change."

Can you get where you want to go in your community by using public transit (bus), personal vehicle, crosswalks, sidewalks, and entryways?

While 29% of respondents stated that they can always get where they want to go, the remaining 71% relayed some difficulties. Of the 71% that had difficulties, 26% said they can never get where they want to go, and 21% said they can sometimes get where they want to go.

Those over the age of 60 were the majority of respondents indicating that they are never able to go where they want by using public transit (bus), personal vehicles, crosswalks, sidewalks, and entryways. During a community meeting in Twin Falls (LINC service area), one woman commented that “we can raise money to save neglected pets, but not to help hungry seniors get to the grocery store.”

What places in your community are hard to get to?

Respondents were given the following options:

- It's easy to go where I want,
- grocery store or other shopping,
- pharmacy,
- doctor or counseling appointments,
- visit nearby friends or relatives,
- church, social, community, or other recreational activities
- other.

Ranking in the top 4 of all service areas is grocery shopping, doctor's appointments, and social, community, or recreational activities. Our survey failed to list “work” as one of the options and that answer was indicated several times under the option of “other”. (Figure 3)

What places in your community are hard to get to?

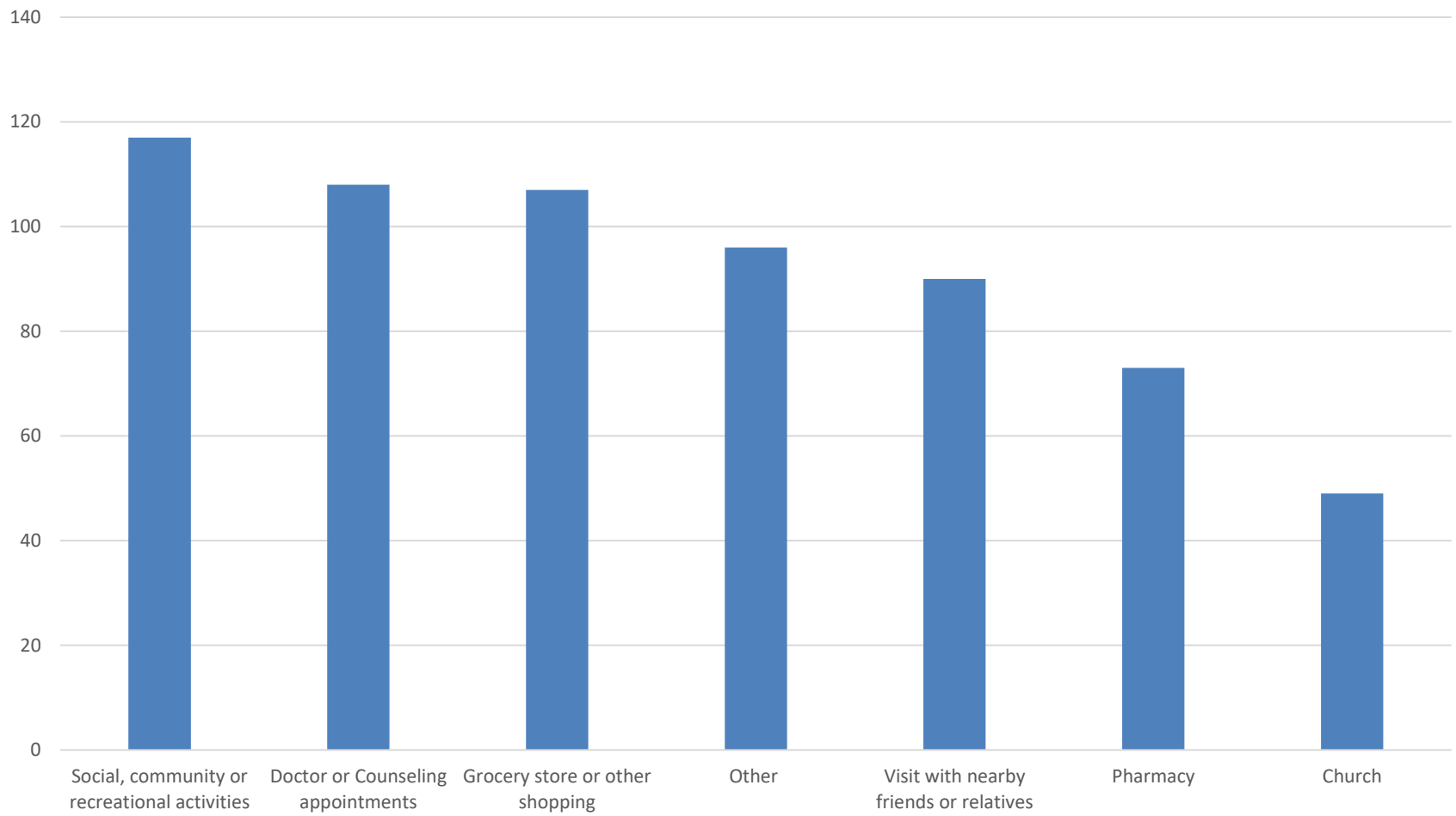


Figure 3

What would help you get to where you want to go?

When asked what resources would help respondents get to where they want to go the highest-ranking responses were public transportation or bus and help to pay for rides through public or private transportation services, followed by safe pedestrian routes like sidewalks, curb cuts, and crosswalks. (Figure 4)

One survey respondent from LINC's service area expressed a need for more public transportation throughout Ada and Canyon counties. Another respondent said that the bus system is too unreliable, while another shared that public transit needs to be available during the hours of employment. During a community meeting in Idaho Falls/Ammon (LIFE service area) a young man shared that he had to quit his job because taking Uber cost more money than he earned on the job.

Several survey participants voiced their concerns about the high cost of transportation services such as taxis, Uber and Lyft. One respondent noted that they could not afford Uber for evening events; another indicated that while the Freedom shuttle can accommodate a power chair, paying \$70 for a roundtrip is too expensive.

Survey respondents also addressed the safety of public sidewalks concerning curb cuts and crosswalks. A respondent in from LIFE's service area voiced a need for accessible pedestrian signals for street crossings. Another from LINC's service area shared, "The sidewalks are not shoveled in the winter, and not all sidewalks have curb cuts. Many sidewalks are not even or flat because of tree roots." During a community meeting in Lapwai (DAC-NW service area) a participant noted that the community would benefit from a walkable trail system in Lapwai to make it safe for those using wheelchairs. Across all regions, through surveys and community meetings, accessible routes of travel are a concern, even for those who don't have ambulatory or sensory disabilities.

What would help you get where you want to go?

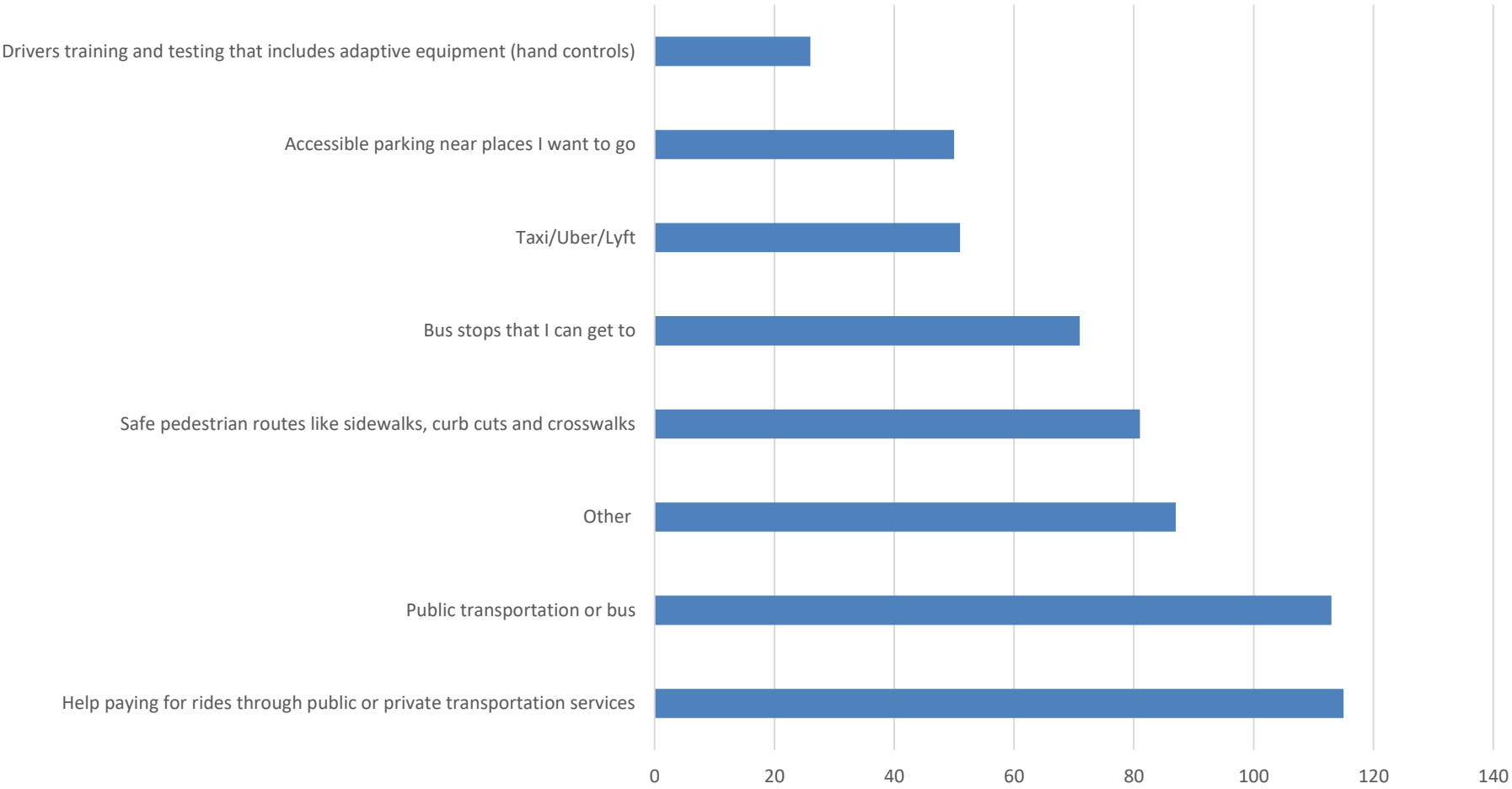


Figure 4

Independent Living Supported Services

Given the Public Health Emergency (PHE) and increasing reports of a shortage of Direct Care Professionals, the SPIL development team devoted nine questions in the survey to respondents' use of Independent Living Supported Services.

Do you have paid or unpaid support (helpers, including family members) that help you stay in your home?

Of the 445 people who answered this question, 271 responded that they have either paid or unpaid support, or both.

If you rely on friends or family for help, what things would be hard for you without their help?

Individuals answering this question were able to select multiple options. The top 5 categories are shopping, cooking, cleaning the home, going to the doctor, and picking up prescriptions. All five categories are repeatedly cited as areas of need throughout survey responses. (Figure 5)

If you rely on friends or family for help, what things would be hard for you without their help?

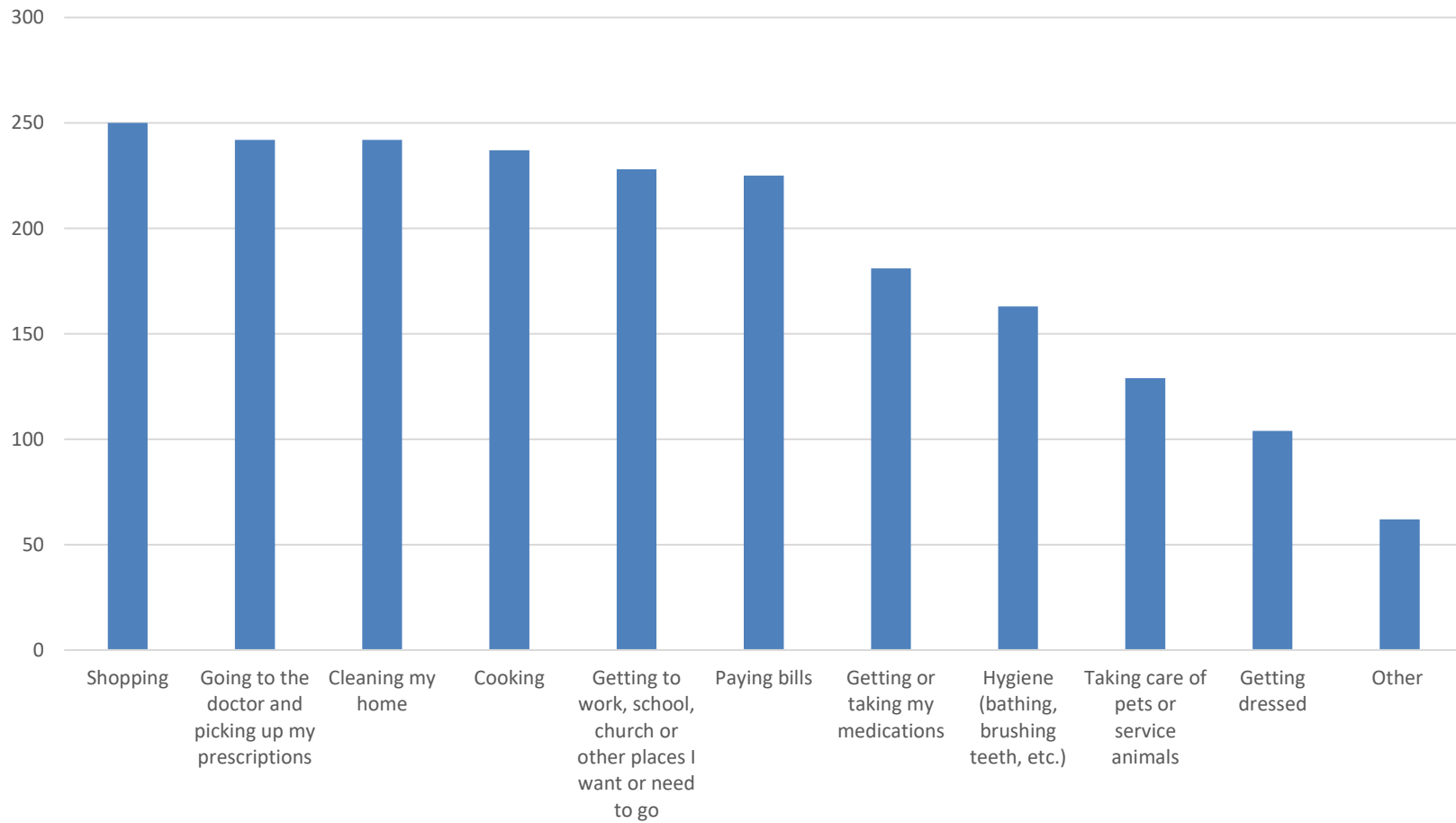


Figure 5

If you have paid support, who is the payer?

Fifty-eight percent of respondents have Medicaid as their payer, 20% access Managed Care (Medicare/Medicaid), 9% use private insurance, another 9% use private pay (out of pocket) and 21% didn't know who paid for their supports.

In the last 12 months, have you gone without staff, help or support (paid or unpaid) when you needed it?

Twenty-eight percent of individuals who answered this question indicated that they have gone without staff, help or support in the last 12 months.

If yes, how long did you go without paid direct care staff or community support workers?

Seventy-two respondents replied that they went without direct care for varying lengths of time and 34.7% of them reported that they still did not have help at home, or that they have given up getting help at home. (Figure 6)

More than 70% of the people who answered this question were under the age of 60.

Respondents' comments reflect their despair concerning the need for direct care staff or community support workers. Many shared the negative impact that the COVID-19 pandemic had on worker availability. Others discussed the barriers agencies face with staff retention. Additionally, respondents shared their concerns that Medicaid's low reimbursement rate is exacerbating the staffing crisis.

During one of our virtual townhall meetings, a participant emphatically stated, "We CANNOT keep the State [aging & disability services] going on volunteers. We have a \$2 BILLION dollar surplus; this should not be a problem!"

How long did you go without direct care staff or community support workers*?

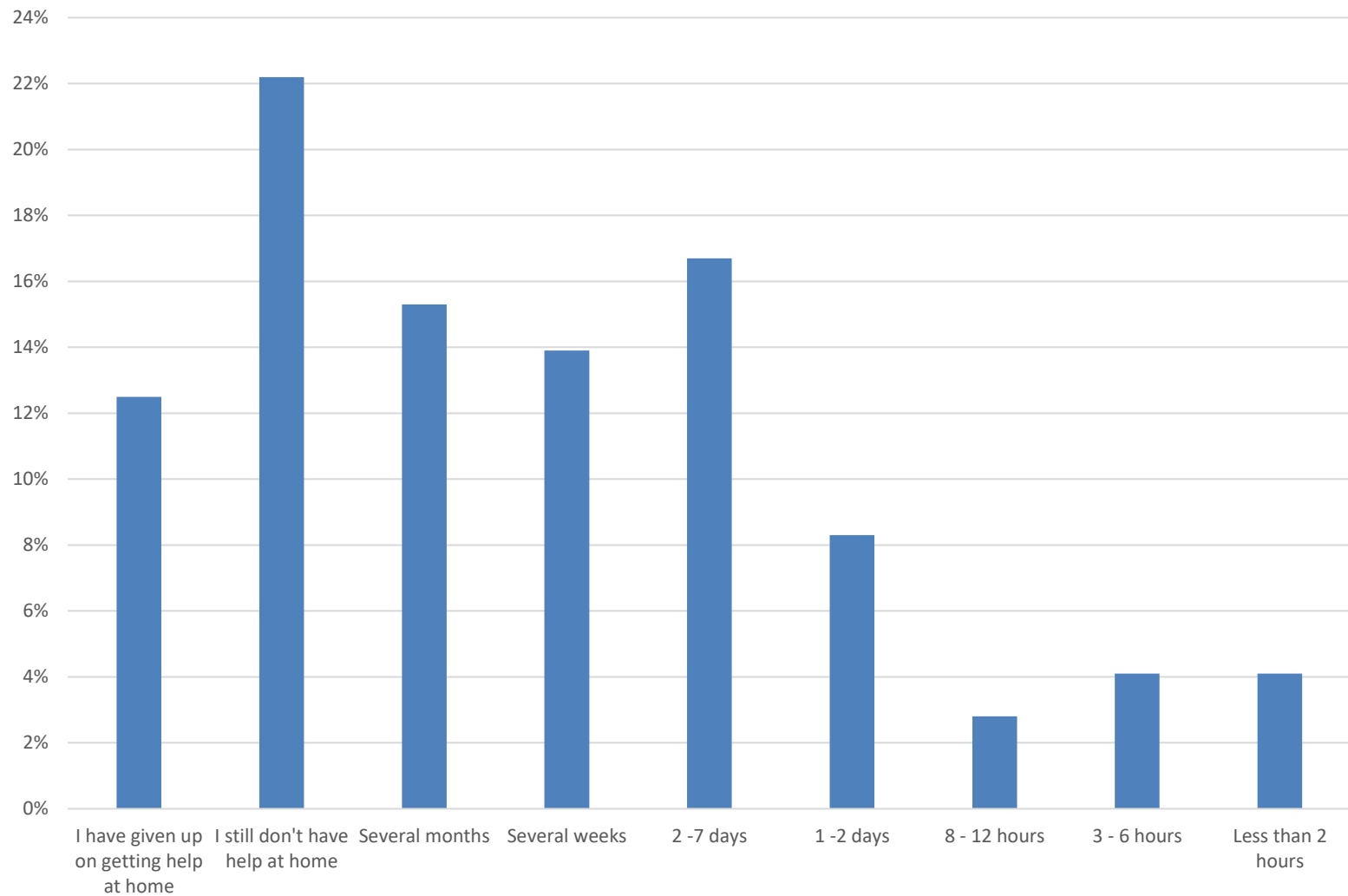


Figure 6

* Percentage indicated by responses received

In the last 12 months, what paid support or services have you had trouble getting or keeping?

One-hundred-sixty-nine people answered this question and were able to select multiple answers. (Figure 7)

One person shared, “Due to staff shortage and the current social health scares, the center doesn’t do community activities anymore.”

Another stated, “Speech and Physical and Occupational Therapies discharged me because they wanted my care provider to build a home program without being dependent on them since they said they "ran out of approved service time."”

A family member shared the following regarding their need for paid support: “He likes working with people outside the home, gets tired of just family and friends, we need respite care, we are not able to find a provider outside the home.” One person responded to the question saying, “I don’t know what case management or target service coordination is. Whatever it is, we don’t have it.”

Breakdown of paid supports or services you had trouble getting or keeping

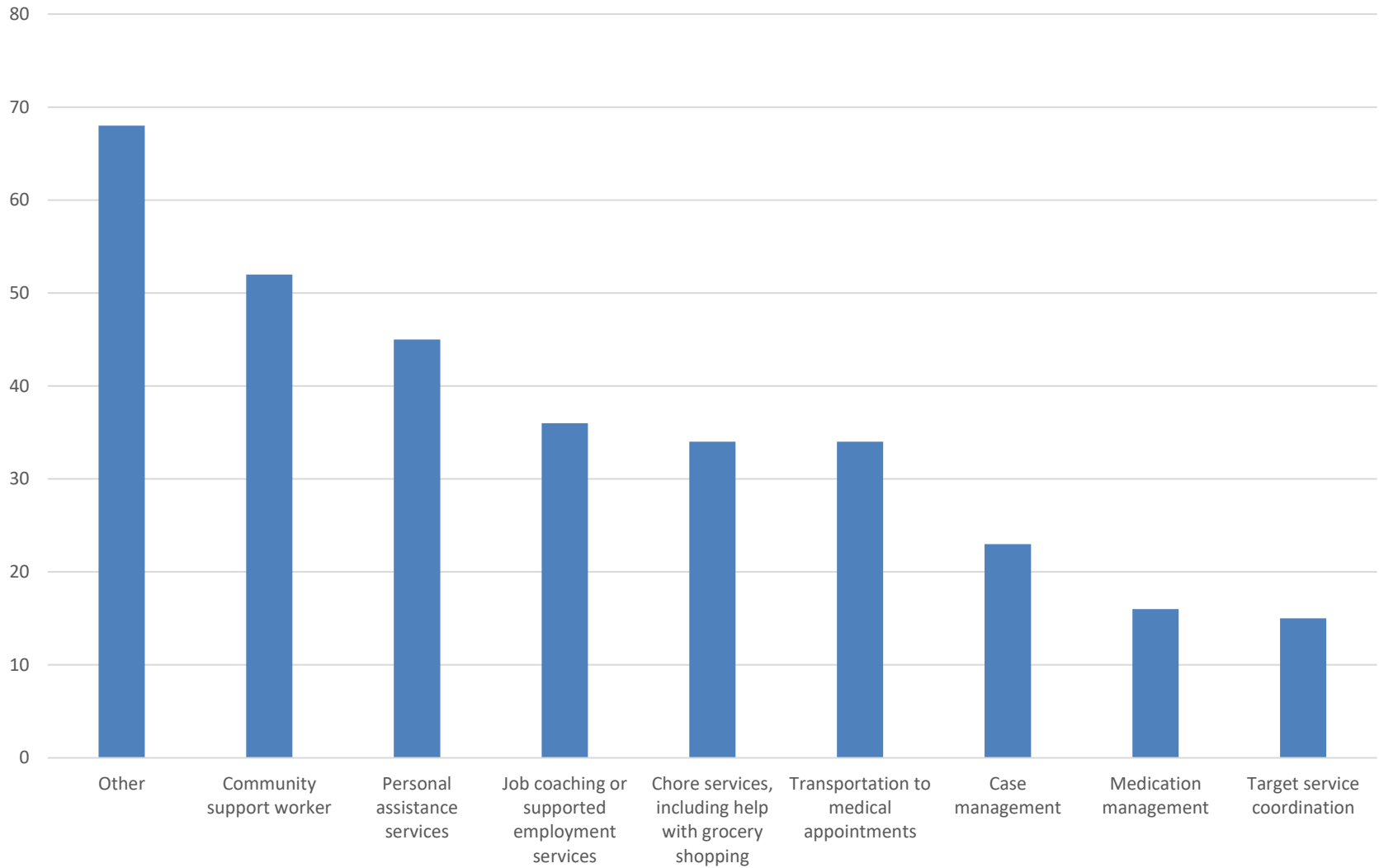


Figure 7

What things would you like to do, but can't because you don't have help (paid or unpaid)?

Two -hundred-eighty people answered this question and were able to select multiple answers.

Across service areas, the top responses were as follows: go out to community activities, have a cleaner home, go shopping for groceries, clothes, or other things and get a job. (Figure 8)

Participants that provided additional comments regarding the need for support largely cited budget constraints and the need to pay direct care workers more. One respondent expanded on the difficulties of paying for services privately, "I pay out-of-pocket since Medicare won't pay and I don't qualify for Medicaid. I can't afford to pay a Caregiver \$30-\$40 per hour!"

What things would you like to do, but can't because you don't have help (paid or unpaid)?

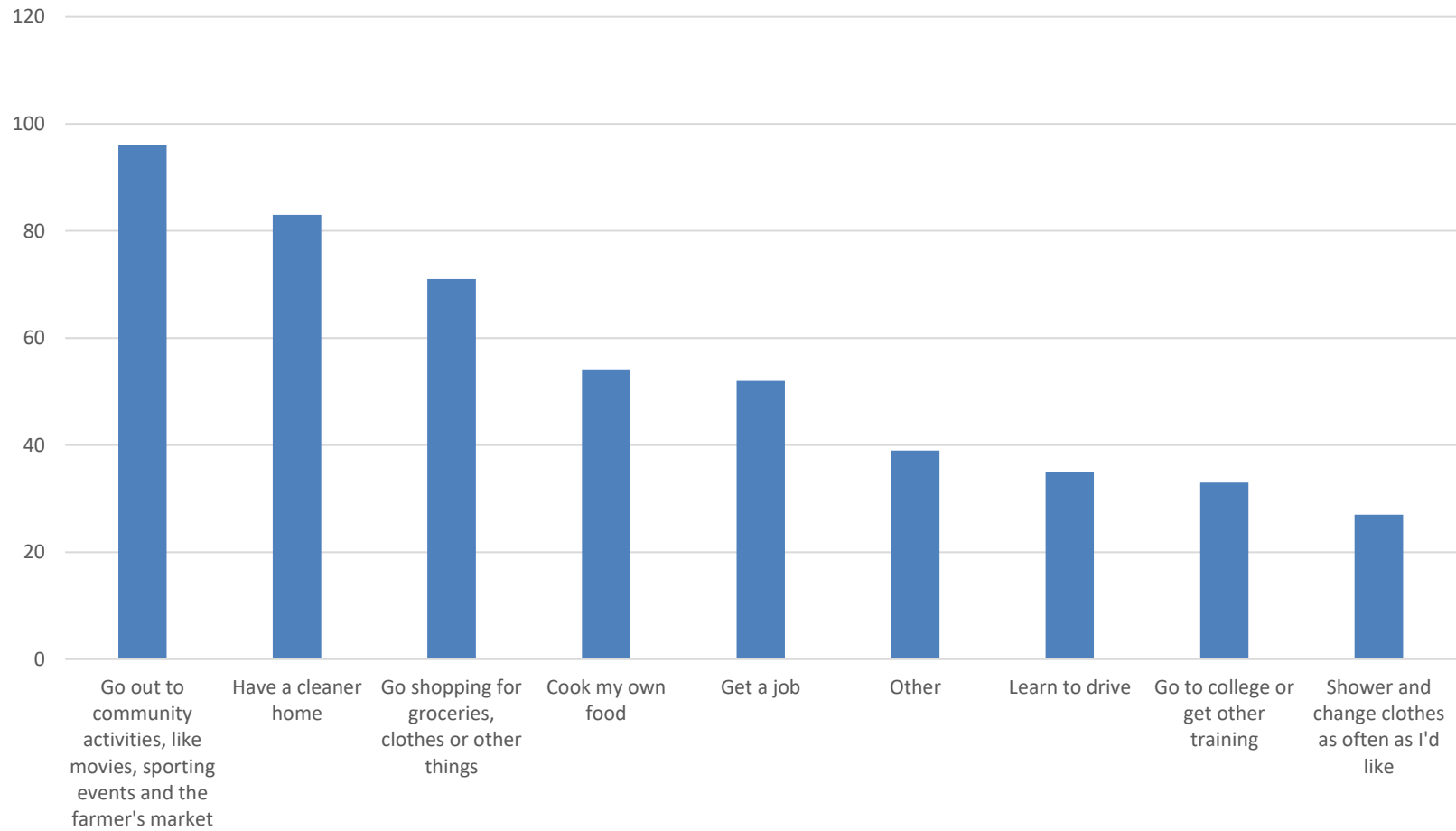


Figure 8

What things make it difficult to get the support you need?

Two-hundred-fourteen respondents shared what made it difficult to get the support they needed and many selected multiple concerns. (Figure 9)

The top concerns cited: “my support workers need better pay and benefits”, “I don’t know what to ask for” and “it is hard for people who don’t know me to understand me”. The choice of “other” was the third highest with many of the comments surrounding lack of direct care workers. Seventy comments were made on this question.

“I rely on the people that know me because of my communication skills. So, you can see why I feel that my csw needs better pay and benefits. that I cannot afford in my [Medicaid] budget. I need the time for my support and the money to pay for that support.” *

“I get the support I need from mom and sometimes sisters. I need a CSW to take me out giving me a break from mom and mom a break from me.” *

“It’s not covered by the insurance or the state. I’d have to pay out of pocket and be sure they are qualified/certified to care for my client. Don’t know where to even hire such person.”

“The businesses say they have no staff to provide him services.”

“Shortage of providers in my town, complicated mess of red tape in application process, not enough energy or executive functioning to keep up with the fight for services.”

* CSW: Community Support Worker

What things make it difficult to get the support you need?

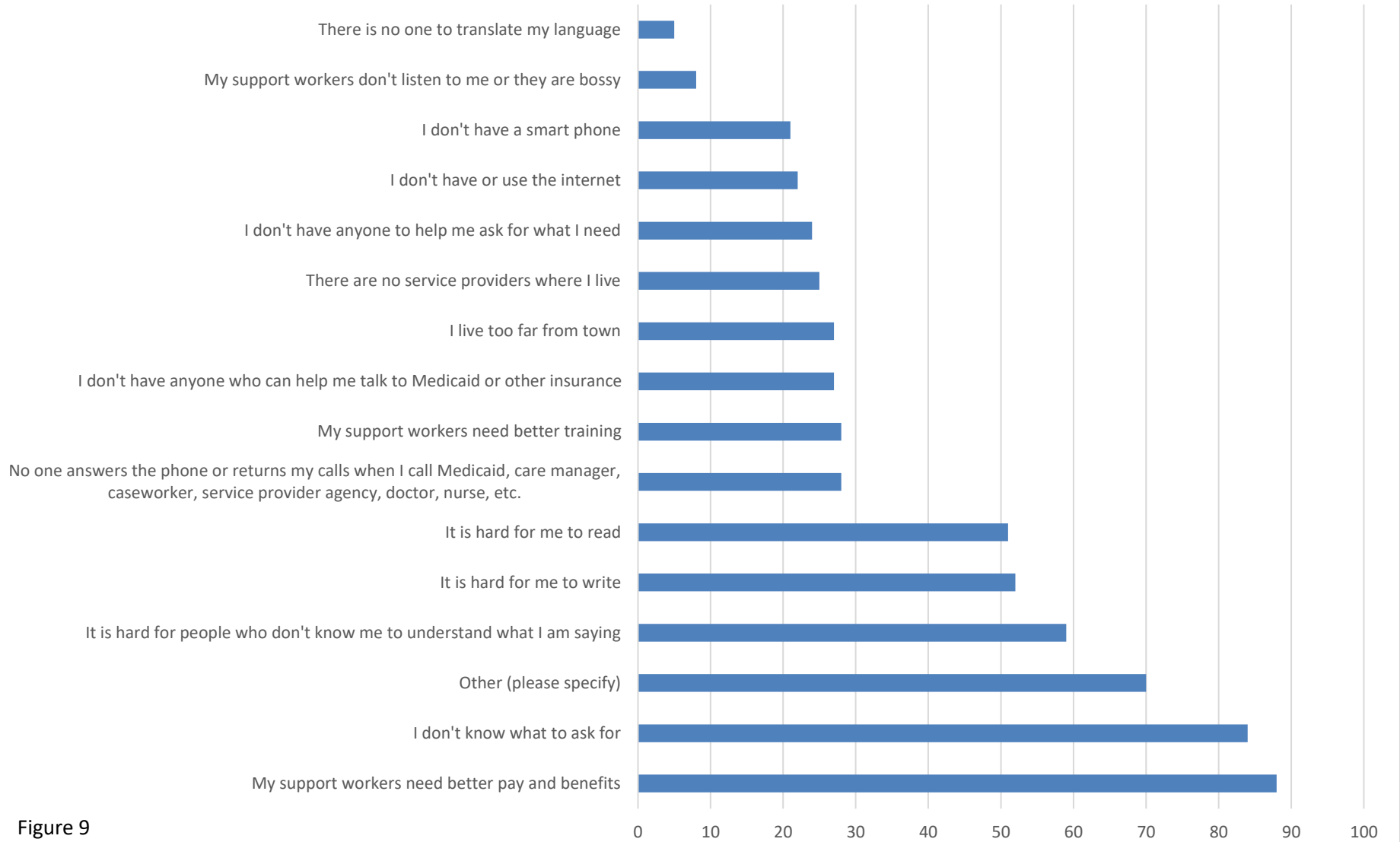


Figure 9

Would you like to know more about training and working with your staff/in-home helpers?

One-hundred-twenty respondents answered that they would or may like more information about training and working with staff/in-home helpers.

I would like to know more about the following

Top 5 responses to this question in order from greatest to least: Focus on my well-being (health, nutrition, fitness, wellness), The Americans with Disabilities Act (ADA) and other disability rights laws, Budgeting or Money Management, Skills training to increase my independence (cooking, budgeting, shopping, etc.) and Service or emotional support animals. (Figure 10)

Other topics suggested by respondents were driving, assistance for adult children in crisis/substance abuse, legal help, orientation, or mobility for the blind.

I would like to learn more about the following

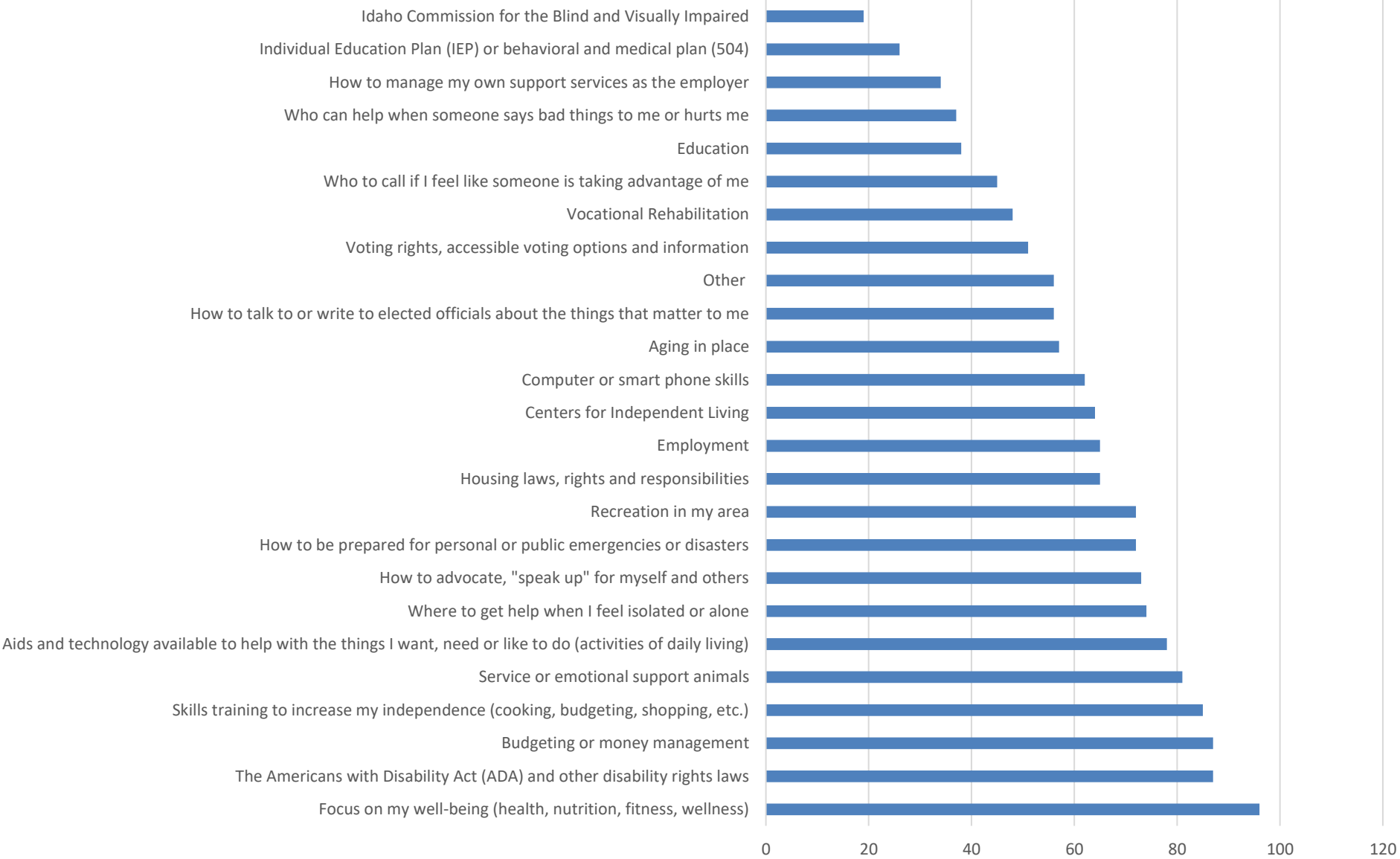


Figure 10

If you could educate (teach) people (businesses, government, family, friends, other people with disabilities) on ONE topic, what would it be?

This survey question was interpreted in many ways by respondents. A standout aspect of this question is that it implies the potential for action on the part of the respondent to engage with their communities.

Qualitative coding divided the answers to this question into 18 categories which are as follows: Dignity, Transportation, Care Partners**, Visibility, Finances, Population Specific Education, Access, Employment, Hobbies, Communication, "I don't know," Services, Peer Education, Housing, Barriers, System Frustrations, and Help Needed.

The top five categories in order of greatest to least are Dignity, Population specific education, Peer education, Caregivers and Hobbies/interests. (Figure 11)

**Care partners are identified as paid direct support professionals, community support workers, job coaches, service coordinators, and may also include unpaid family supports.

What would you teach

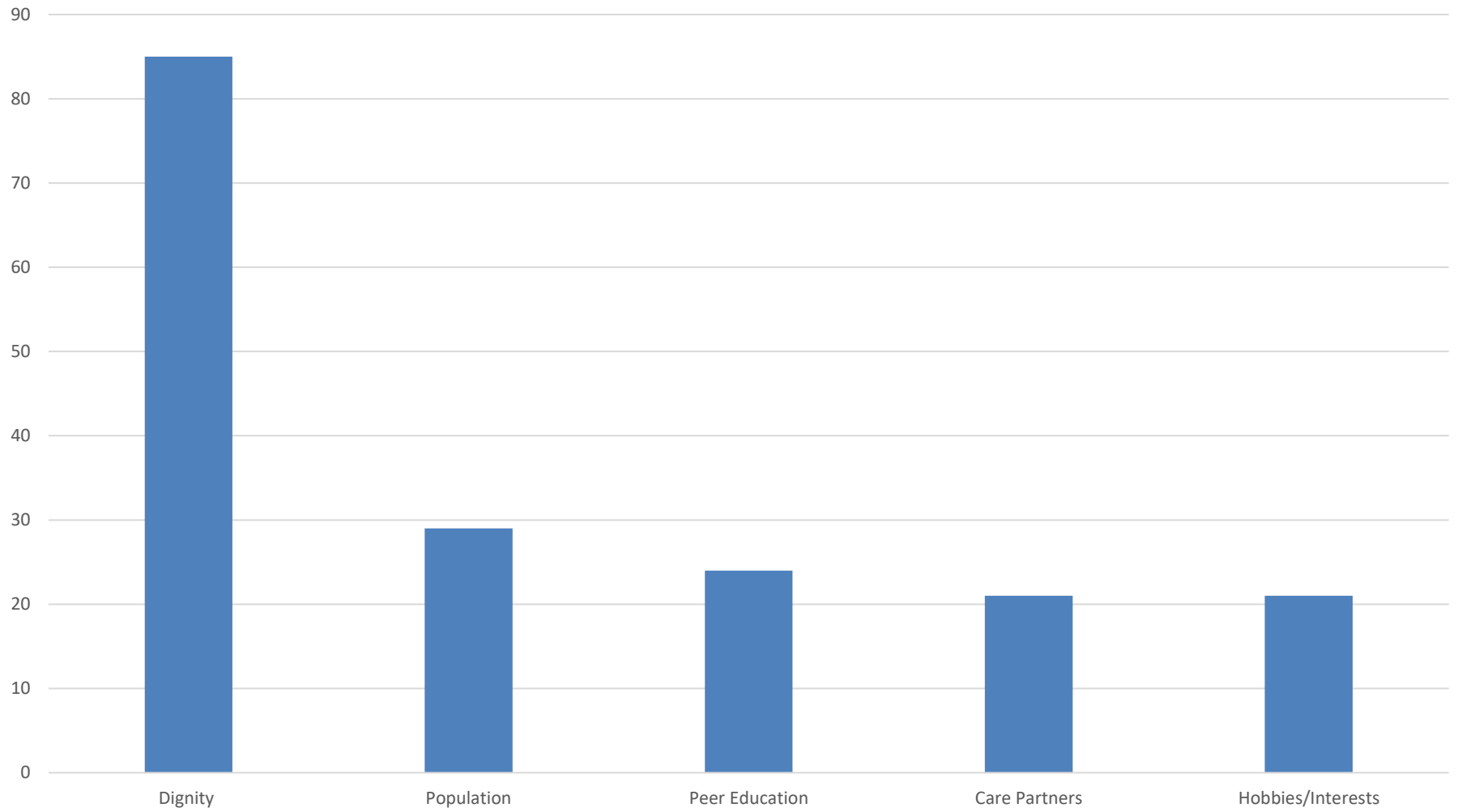


Figure 11

Dignity

Thirty-two percent of the responses to “What would you teach?” were coded into the category of dignity. These answers reflect a bid for kindness, and, in some instances, are an offer of connection. These respondents want others to know that they are intelligent, talented and share the same hopes for their lives as anyone else.

The Oxford Dictionary defines dignity as “being given honor and respect by people,” as well as “a sense of your own importance and value” (Oxford American Dictionary, n.d.). Deliverance or denial of dignity is, in part, a social contract between individuals, communities and the governmental entities that serve them. Giselsso (2018) maintains that dignity must stand on a foundation of equality.

Examples of responses that were coded under the category of dignity are: “Stop making laws for disabled people without consulting disabled people,” “Be kind, encouraging, and helpful,” and “I can’t speak but I have a voice.”

Population Specific

Eleven percent of the respondents that answered the “What would you teach” question wanted to educate others on topics specific to different disabilities or diagnoses. Topics such as autism awareness, Tourette’s syndrome, and visual impairment were suggested.

Peer Education

Nine percent of the respondents want to educate other people with disabilities. The proposed topics were centered on encouragement and support. An example of a response coded into this category is “How to make it through college and thrive being dual diagnosis.” Another respondent wanted to stress the importance of being with family.

Care Partners

Eight percent of the answers to “What would you teach?” fell into the category of care partners. Notably, out of the 23 responses, four identified as a person with a disability, two of those four identified as both people with a disability and a care partner, and 19 identified as people without a disability. Thirty percent of these respondents emphasized the importance of Care Partners, while another 30% expressed concerns about Care Partner wages.

Examples of comments are as follows: “If my paid help does not get a wage increase to match the massive increase in the cost of living, there will be a lot of homeless people with disabilities,” “Support workers need a raise,” “Raise salaries and improve screening and training of support staff.”

Hobbies

Eight percent of the respondents wanted to share their interests or hobbies. Examples of these responses are “sports,” “Broadway,” “forensics,” and “bowling.” Forty-five percent of these respondents fell into the 12-20 age category. Though purely speculative, could this be reflective of a new generation of people with disabilities who clearly do not identify first with having a disability but as people with much to share with the community and the world around them?

Do you have any additional comments?

Eighty-nine respondents took the time to add additional comments to the survey. These responses were coded into the following categories: Transportation, Help Needed, Care Partners, Access, Housing, Appreciation, Survey Dissatisfaction, Finances, Employment, Dignity, System Frustrations, and Miscellaneous,

The top five topics from greatest to least are Care Partners, Appreciation, System Frustrations, Access, and Housing. (Figure 12)

Additional Comments - Top 5 Topics

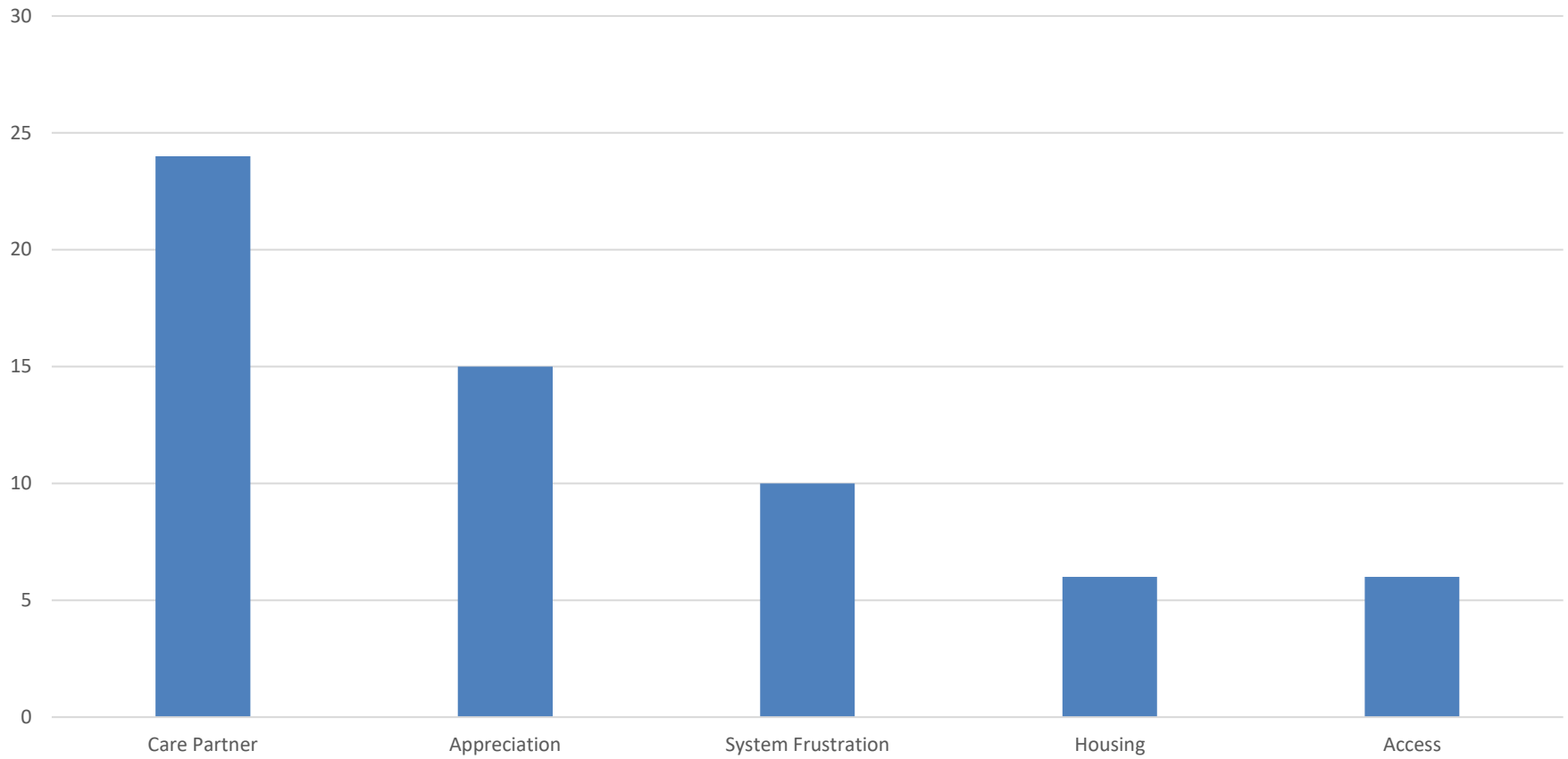


Figure 12

Care Partners (paid or unpaid community support)

Twenty-seven percent of the respondents provided additional information on Care Partners. Of these 25% identified themselves as a person with a disability. An example of a response from a person with a disability is, “I have been needing help with daily living. For a few years. Just when I think my life can be better, something or someone makes things difficult.” An example of a comment from a person without a disability is, “I would like to figure out, as a caregiver of my daughter with disabilities, how to have enough income to support us as I cannot work outside of the home due to her needed level of care.”

Appreciation

Seventeen percent of the respondents voiced appreciation. Seven of these comments were directed at the survey itself. An example of a comment expressing survey appreciation is, “If you are reading this, thank you for the time and patience.”

Another statement of appreciation from a person without a disability who is caring for a person with a disability is, “I very much appreciate being able to care for my family member at home by the monetary assistance provided by her MMCP [Medicare Medicaid Coordinated Plan]. I am a senior citizen myself. Unsure how long my own health will hold out. Thanks for listening.”

System Frustrations

Eleven percent of respondents made comments indicating frustrations with bureaucracy. Examples of statements categorized as frustration are “you need to let the people that know us best help us” and “government forms and hoops are extremely frustrating and confusing to get through.”

Housing

Seven percent of the respondents discussed housing. Comments ranged from frustrations with Section 8 housing as a barrier to independent living, and another was concerned with affordability.

CONCLUSION

The SILC reviews progress on the current State Plan for Independent Living (SPIL) at least quarterly. Through this process the Council and our partners are aware of on-going and emerging issues within the disability community. The statewide assessment allows a deeper dive into the issues we may anticipate, typically issues around housing access and affordability, physical access to public spaces, transportation, access to home and community supports, employment, education/training and healthcare rise to the top as well as those of which we may have little prior knowledge. It is no surprise that these concerns have grown given the recent pandemic, resulting isolation and loss of once relied upon resources, i.e.: volunteer driver programs which remain virtually non-existent across Idaho. The loss of affordable housing due to our state's phenomenal growth is perhaps the most pronounced concern, impacting people with disabilities and the direct support professionals who help them stay in their homes. As people move further from resources to maintain affordability, they lose connections, transportation and lifesaving services.

The assessment voices pleas for help while also demonstrating the depth and resilience of the disability community.

The State Plan for Independent Living can be a meaningful piece of how we connect Independent Living services to the people who need them. The Plan can be a roadmap, guiding us to meet people where they are. We can use the information from people who took time to offer it through surveys, interviews and meetings during the 2022 assessment. When drafting the Plan, we can correlate the information gathered with other significant reports that include county demographics, about housing, transition youth, Medicaid Home and Community Based Services, public access and transportation.

The loss of connection remains overwhelming for many. Independent Living is about connecting to people with disabilities to each other via peer to peer support, including teaching each other how to cook, shop, find support workers, voice our needs to policy makers AND fly fishing, "facts about cats" and basic car repair. It's about helping each other get the services and supports we need in a way that works for us in communities of our choosing.

The State Plan is our opportunity to demonstrate that we heard and are willing to act. Independent Living is not about who saves the day – it is about how we save the moment with and for each other.

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¹ U.S. Census Bureau, July 2022 estimate