

2020 Evaluation of Experiences with Self Direction in New York State

A FOCUS ON SUSTAINABILITY

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BACKGROUND INFORMATION

Self-directed supports are a program or service option in which people with disabilities, their families, and their allies directly manage their supports. In this service option, people with disabilities and their families use individually-set and -controlled budgets to select, purchase, and manage their own supports within an established framework of policy guidelines. In this model, individuals and families typically recruit, hire, and manage their own direct support workers. Fiscal intermediaries (FI) work with the individuals and their families/natural supports to complete key financial responsibilities and paperwork.

During the last 50 years, the advocacy of people with disabilities and their families have built the independent living movement that formed the foundation of self-directed supports. This movement has challenged assumptions that people with disabilities needed protection and oversight in the form of professional decision-making and management of services and supports. The theoretical foundation of self-directed supports is self-determination. Self-determination is acting as the primary contributing agent of one's life and making decisions about one's quality of life free from undue external influence. Self-direction moves control of supports and programming from the system to individuals who receive services and/or their families/natural supports, thereby providing opportunities to exercise self-determination in designing supports that are responsive to their individual needs, cultural beliefs, and personal preferences. Additionally, research has revealed increased fiscal responsibility and

cost savings with self-directed supports. Through this intersection of advocacy and research, policy innovations have emerged in which people with disabilities and their families manage their own supports and receive care in home and community settings rather than in costly institutions.

Self-direction is a Medicaid service option that has been available in New York State since 2004. The goal of self-direction is to allow people with disabilities the opportunity to choose where they live, who they hire as support staff, and overall aspects of everyday life. While self-directed supports have significantly improved the quality of life for people with disabilities and their families, questions remain about the sustainability of self-direction when the parent or natural support can no longer support the process. Thus, a primary guiding question of this project concerns the sustainability of self-direction through major life transitions, including when the primary natural support can no longer support the self-direction process. Simply stated, as people with disabilities and their families age and transition into new life phases, their services and systems, such as self-directed supports, must evolve and change as well. The current study explores both the current benefits and challenges of self-directed supports as well as the sustainability of self-directed supports when natural supports can no longer support the process. To our knowledge, this evaluation is the first to explore the sustainability of self-directed supports across major life transitions. This evaluation holds important implications for the design, implementation, and sustainability of self-directed initiatives in the future.

Purpose of the Survey

In 2020, people participating in New York State's self-direction plan were surveyed about their experiences with self-direction. The primary goal of the survey was to examine the sustainability of self-directed services: how families plan to navigate a self-directed model when the primary caregiver (typically a parent) can no longer provide support for the self-directed process. The survey asked respondents to answer questions from the perspective of the natural support.

For the purpose of the survey, the **natural support** was defined as the lead, unpaid person who provides support to a person who is self-directing services. The natural support is often a parent or guardian, but could also be a sibling, other relative, or another relationship to the person who is self-directing.

Additionally, information was gathered to better understand self-direction in New York State and to learn more about the benefits and challenges around self-direction. Individual experiences with self-direction are important and will help people make policy decisions about services for individuals with intellectual and developmental disabilities, as well as to help inform planning tools to support the sustainability of self-direction.

Sample and Response Rate

Survey respondents were recruited from the fiscal intermediary, Independent Support Services (ISS), which supports 1,700 self-direction respondents. ISS shared the survey link with the people they serve and an unknown number of other people who self-direct. This report reflects the responses of the 413 individuals who answered at least one question in the survey.

DEMOGRAPHICS

Respondents were asked to provide background information about the person who is self-directing and their natural support. The characteristics of the people who self-direct and the natural supports who participated in the survey are described below.

Respondents were asked to identify their role in self-direction, indicating whether they were a person with a disability who self-directs, a natural support person who is not paid and supports a person with a disability who self-directs, or neither of these roles. Most people who completed the survey identified as natural supports to a person who self-directs. Figure 1 displays the results.

Respondents were asked whether the person who self-directs have ever had a natural support help direct services before. Most people who completed the survey had not experienced a change in natural supports before. Figure 2 displays the results.

Respondents were asked the current age of the person who self-directs and the current

Figure 1. Role of the Respondents in Self-Direction

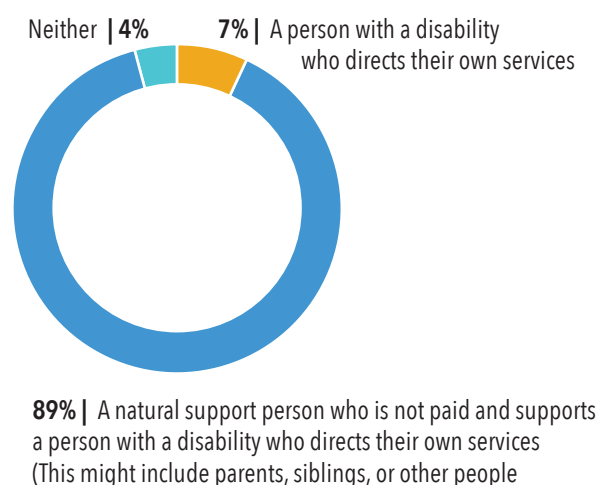


Figure 2. Natural Support Help Direct Services

92% | People Self-Directing have had a Natural Support Help Direct Services

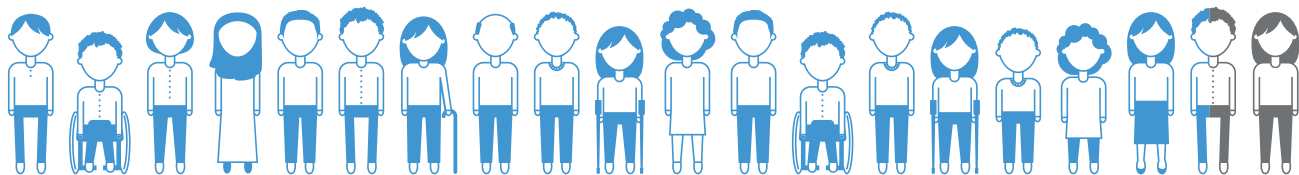


Figure 3. Average Age, in Years, of Person who is Self-Directing and Natural Support

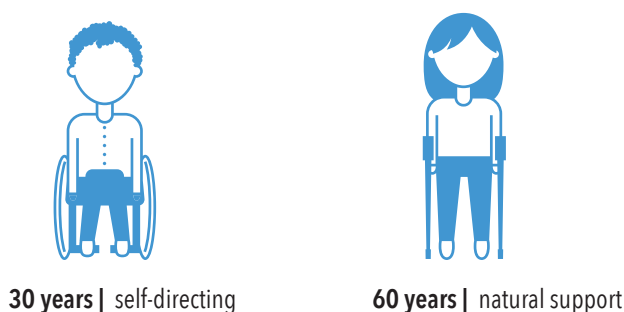
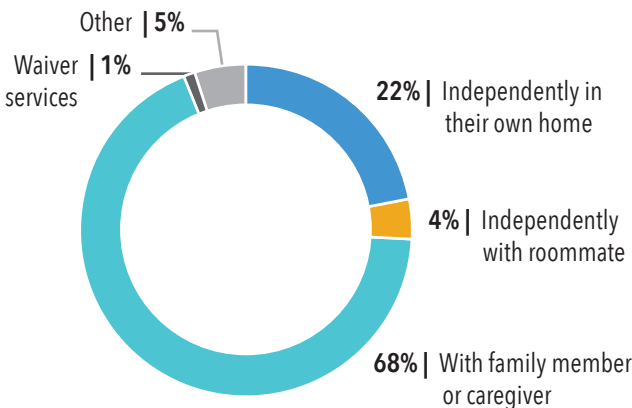


Figure 4. Gender of Person who Self-Directs



Figure 5. Living Situation of the Person who Self-Directs



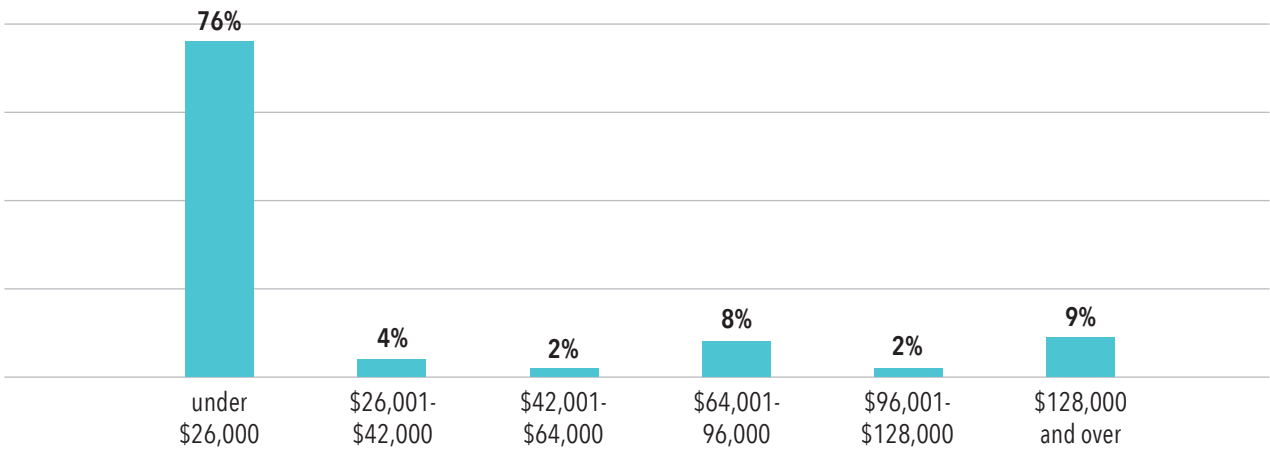
age of the natural support. The average age of the person self-directing was 30 years old, and the average age of their natural supports was 60 years old. Figure 3 displays the results.

Respondents were asked the gender of the person who self-directs. More people who self-direct were male than female in this sample (see Figure 4).

Respondents were asked the racial background of the person who self-directs. Of the 264 individuals who answered the question, 91% were White, 5% were Multiracial, 2% were Asian, 2% were Black or African American, and none were American Indian/Alaska Native or Native Hawaiian/Other Pacific Islander. Thirty-one of the respondents preferred not to answer. Of the 259 individuals who answered the question, 7% were of Hispanic or Latino descent. Thirty-four of the respondents preferred not to answer. Of the 298 individuals who answered the question about the main language spoken in the home of the person who self-directs, 97% spoke English, 1% spoke Spanish, and 2% spoke another language not listed.

Respondents were asked where the person who is self-directing lives. As Figure 5 shows, most people lived with a family member or caregiver in the family home or residence.

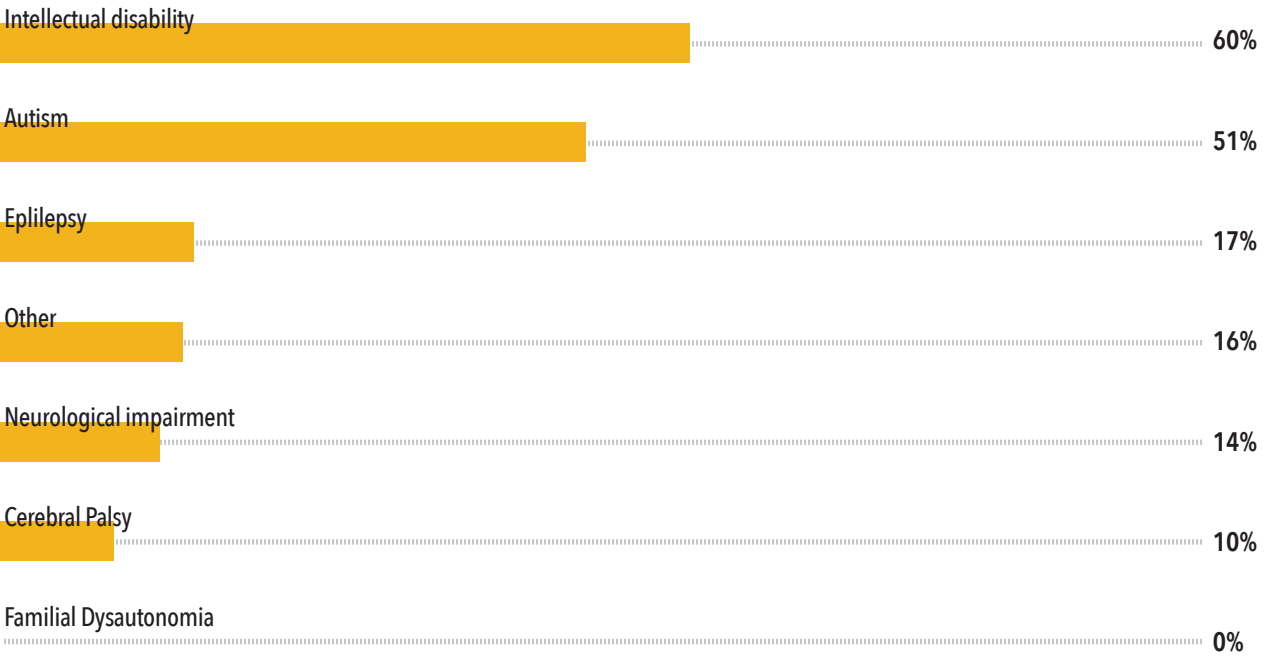
Figure 6. Household Income of Person who Self-Directs



Respondents were asked about the total household income of the person who self-directs. The survey did not distinguish whether the question referred to the income of other family members, or just the person who is self-directing. As seen in Figure 6, most respondents in this survey reported a household income under \$26,000 per year.

Respondents were asked about how the Office for People with Developmental Disabilities (OPWDD) classified the disability of the person who self-directs. Respondents could select all categories that apply. Figure 7 displays the results.

Figure 7. Disability of the Person who Self-Directs



Note: Percentages add to more than 100% as participants could check all that applied.

RESULTS

Respondents were asked to answer quantitative numerical questions and qualitative open-ended questions. This multi-method approach provides both broad quantitative trends in self-directed supports and more qualitative in-depth responses to reflect individual lived experiences. The results are reported below. None of the information provided by respondents identifies individuals. Results are presented in aggregate form.

Self-Directed Services vs. Traditional Services

Respondents were asked to comment on using self-directed services compared to traditional services. The people who answered this question were using self-directed supports at that time. Their perspective may be different than people who were using traditional services or who had tried self-directed services but were no longer using those services.

Of the 308 respondents who responded to the question, 22 respondents stated that they had no experience with traditional services. As one person stated, "It's hard for me to compare because I've never used traditional services." For some, "traditional services were never an option for the participant." Most of those people could not answer the question, but some

compared self-direction to their perception of traditional services or what they have heard from others about traditional services.

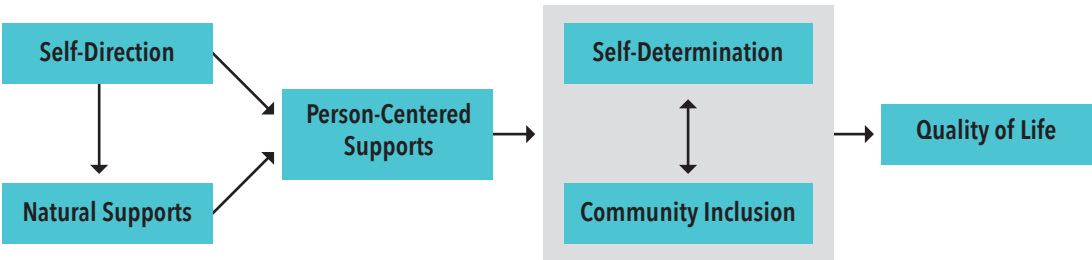
When comparing self-directed services to traditional services, respondents described the benefits, the challenges, and the give and take they experienced using self-direction.

Benefits of Using Self-Directed Services

Self-Directed Services. Self-directed services offered a wide variety of benefits to individuals who self-direct and their families. The benefits of using self-directed services are illustrated in Figure 8. As illustrated in Figure 8, the structure of self-directed services impacts both the natural supports and the delivery of person-centered supports. The natural supports, who are mostly parents or other family members, also impact the use of person-centered supports. Person-centered supports in turn impact the development of the person who is self-directing and use of self-determination skills and inclusion in the community. Self-determination and community inclusion enhance each other and both lead to a greater quality of life for people with disabilities and their families.

Respondents consistently indicated that self-directed services are structured in a way that is "easy to work with" for many respondents. They found the fiscal intermediary they worked with to be

Figure 8. Benefits of Self-Directed Services Flowchart



responsive, prompt, and easy to reach. The fiscal intermediary was “organized and supportive.” The paperwork was easy to follow and going more online, which was preferred. A benefit of self-directed services was finding and hiring trustworthy staff as well as keeping them because the staff were able to receive a more competitive wage: “We are able to pay staff a living wage and retain them for much longer.” Having consistency with staff develops trust and the ability to problem-solve when situations arise. Self-directed services were seen as better than other traditional programs. For some respondents, traditional services could not accommodate the person. For example, one parent shared that the person “has health problems that traditional services could not or would not accommodate.” Another person with a disability would not willingly attend an overly-structured day program. Though there are challenges with self-directed services, many respondents “would never choose any of the other options.”

Natural Supports. Natural supports experienced benefits of having increased control, choice, and personal support. Self-directed services allows the natural support to “run the show,” which provides a world of difference for them. As stated by one natural support, “hiring and training staff is important to me so that I have control over what my son does.”

Self-directed services also provide support to families “to live more normal and not feel alone in caring.” Parents take comfort in knowing what is happening in their adult child’s life and benefit from respite: “It allows me some free time when she has staff.” Having staff assistance has also allowed parents to hold full-time jobs instead of taking time off to care for their adult child.

Person-Centered Supports. Person-centered supports are more common in self-directed services and provide respondents with the flexibility and customization to meet their needs. With supports that are more person-centered, people can participate in activities that align with their interests, bring them joy, are fulfilling, and include people they enjoy. Self-directed services are “primarily about the person” and “allow the person and the supports to decide how to live their life.” For example, one man had the ability to live in his own apartment with staff who were trained to meet his specific needs and had “a schedule and supports designed around his preferences, goals, and needs.”

The flexibility of self-directed services allows the supports to be tailored to the changing needs of the person. Respondents have flexibility with scheduling, training their own staff, and accessing more opportunities and programs. This flexibility allows people to thrive. For example, one person “does best when his environment is engineered to meet his needs and preferences.” Another respondent shared, “I really value having staff that understand my cultural values. Personally training staff also allows me to have my individual needs met.” Supports are also tailored on an “individual basis according to what [the person] may need at any given time.” Respondents were able to receive nontraditional services like therapeutic horseback riding and music therapy. They were also able to have transportation covered (e.g., Uber) when their plans changed. As summarized by one parent, “There is more freedom to create what is better for my son.” For many families, self-directed services were a good fit for their needs and preferences. Further, the structure of self-directed services aligned with the key tenets of person-centered supports and thinking.

Self-Determination. The alignment of self-directed services with self-determination was another key theme that emerged from the data. As one respondent shared, self-directed supports are “all about choices.” Respondents made choices about their activities, housing, staff, environment, schedule, what to learn, and how to spend their time. As one parent explained, “Being an adult is all about gaining the freedom to make choices. With its great flexibility in choice of activity, timing, and staffing, SDS allows my adult child with autism to be more fully adult. This is so critical to her quality of life.” It was important for respondents to have some control over their life. Being a part of planning and overseeing staff was important to one respondent: “They are mine. They work for me. I am a part of the plan.” Decision-making opportunities were also important to respondents: “I love having the power to make the decisions.”

Many respondents highlighted the goal setting and attainment aspect of self-determination. For one person, it was “easier to accomplish goals” using self-directed services. For another person, she was able to “do everything she dreamed to do and then some.”

Self-directed services also promoted independence for people with disabilities. Many respondents felt independent because of the opportunities and supports offered under self-directed services. Staff were important for independent living: “She enjoys living independently and can only do so with the support of staff.” As one parent shared, “Having staff to work with him gives him a level of independence that I did not think he would ever be able to experience.”

Community Inclusion. Community inclusion was essential for respondents to experience a full life. Self-directed services “increase the opportunities they will have to be included in their community.” People have become a part of their community, known within their community, and have developed friendships in the community. Being a part of the community decreased the isolation some people had experienced. For example, one man who self-directs his services is “known throughout the community and warmly welcomed in so many places.” Another person socializes with people she enjoys and has become “a valued member of our community.” People were able to participate in age-appropriate activities, work, and go to college with supports. They were not confined to programs designed specifically for people with disabilities. Rather, they interacted with people who did and did not have disabilities. Experiencing a typical life with people of all abilities was important for many respondents. As one parent confirmed, “this is the best option for my child...to participate in community activities like his siblings do.” To be a productive member of society, people need to experience typical life experiences and situations: “Self-direction gives her the opportunity to live the life she wants and do what she enjoys as a productive member of society.”

Respondents were also asked to rate the ways self-directed services benefit the person who self-directs with respect to community living. Ninety-seven percent get to go out in the community more, 96% have more independence, and 90% spend time with people who do not have a developmental disability. Figure 9 displays their responses.

Figure 9. Agreement about Benefits of Self-Direction on Community Living



Quality of Life. Quality of life was seen as a key outcome of self-directed services through the use of person-centered supports and increased self-determination and community inclusion. Dimensions of quality of life include “emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights” (Wehmeyer, 2020). Respondents illustrated these dimensions of quality of life as they described the benefits of self-directed services.

Self-directed services supported people to reach their potential, have a full and rich life with the support of staff, and generally live their best life. A key theme that emerged from the data was how the flexibility of self-direction facilitated a match to the unique needs of individuals. For a woman with a significant physical disability and no cognitive disability, the parent found that self-directed services were “the ONLY option that gives my daughter the support she needs in order to have a good quality of life in the community.” Respondents felt happier, had lower stress, and had more self-esteem and self-confidence. One parent said her adult child had better emotional health: “I’ve seen a definite positive change in her attitude since she began self-direction.” Another parent liked being able to safeguard the adult

child’s physical health through more direct oversight. For some families, the person who is self-directing “has become a bigger part of the family unit.” The support of staff throughout the day enhanced the relationship between the person and his parents: “He even enjoys being with us more after being with his staff.”

The funding of self-directed services provided people with the basic necessities and experiences needed for an enhanced quality of life. The reimbursements allowed one woman to live in her own apartment because her rent, phone, and other utilities were covered. For two brothers, the “internet and phone reimbursement is essential for them to communicate with friends from where we lived previously.” Mileage reimbursement for staff was also essential because both men enjoyed exploring parks, historical sites, and trips back home to see their friends.

Many respondents were able to be life-long learners with the supports from self-directed services. They joined classes in the community, attended college, learned about food choices and preparation, and developed better communication and interpersonal skills. One person found he was able to learn more quickly than in site-based settings.

Figure 10. Agreement about Benefits of Self-Direction on Quality of Life



People with disabilities and their families are empowered when they have a voice. With self-directed services, people with disabilities felt like they had a greater say in what goes on, they were treated with respect, and they had the dignity of living independently. As one natural support put it, self-direction “gives families and individuals a significant voice in how the individual will live his life, increases the opportunities they will have to be included in their community, and can help the person to reach their potential.”

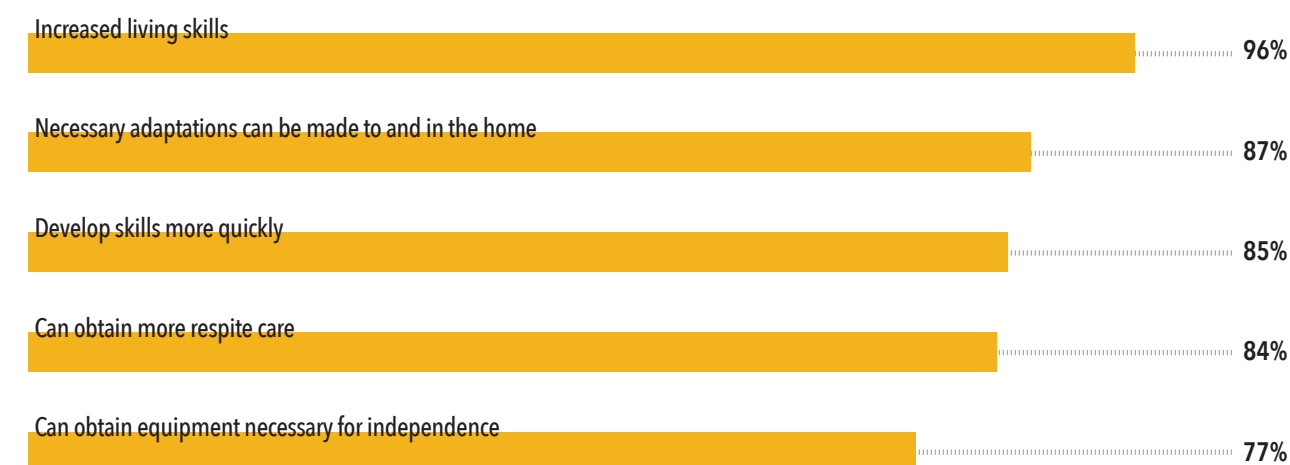
Respondents were asked to rate the ways self-directed services benefit the person who self-directs with respect to their quality of life. Overall, having a better quality of life was rated highest, but all areas were ranked highly by respondents as being key benefits of self-direction. Figure 10 shows their responses.

Respondents were also asked to rate whether, in their experience, self-direction provided benefits in other aspects of life. Of those who answered the question, 96% increased their living skills, 87% said necessary adaptations can be made to and in the home, 85% developed skills more quickly, 84% can obtain more respite care, and 77% can obtain equipment necessary for independence. Figure 11 displays their responses.

Challenges of Using Self-Directed Services

The current data also revealed familiar challenges with self-direction. The challenges of using self-directed services include processes that can be time-consuming and confusing, budget and reimbursements difficulties, lack of funding for specific services, and managing staff. Respondents were asked to rate whether they experienced

Figure 11. Agreement about Other Benefits of Self-Direction



the following challenges related to self-direction: paperwork, staffing, changes in self-directed services rules, individual goods/services considered disallowable, budget issues, complicated reimbursement process, need more case manager support, and not enough money in the self-direction budget to hire or reach goals (see Figure 12).

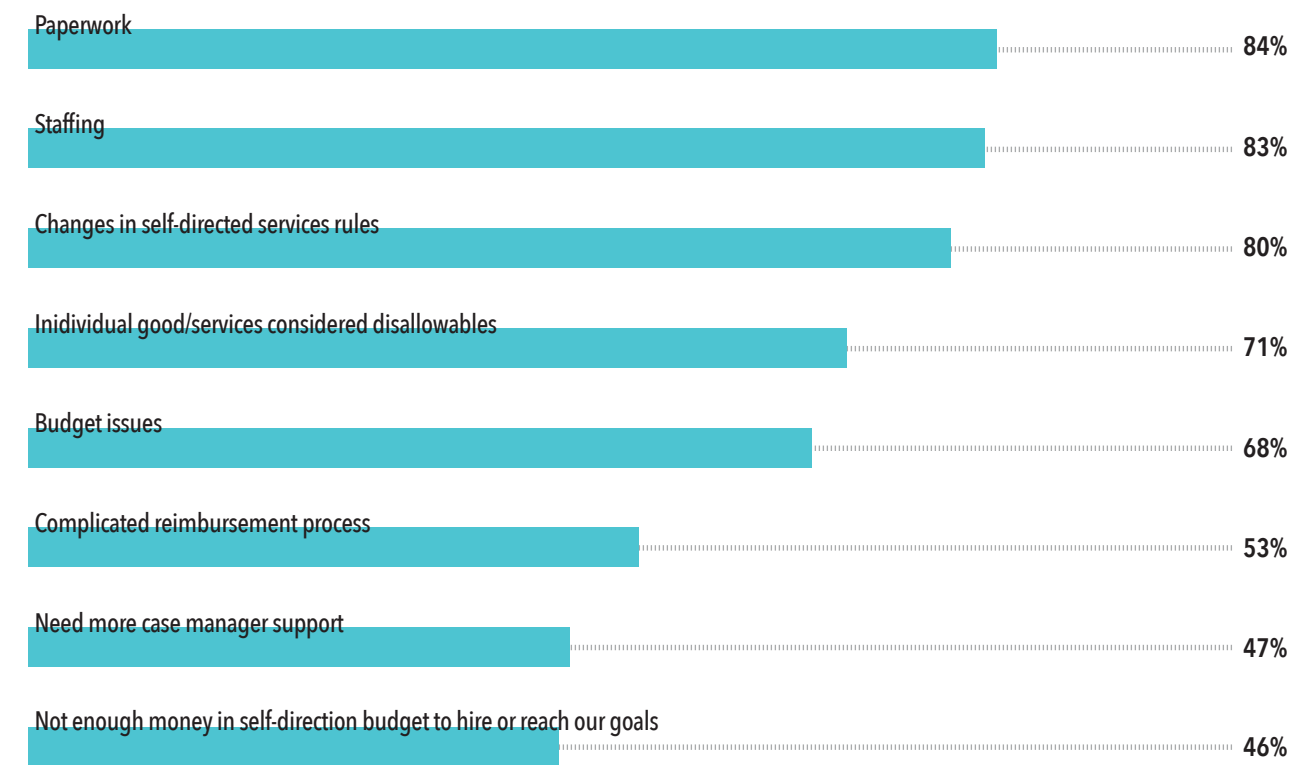
Time-Consuming and Confusing Processes.

Time-consuming and confusing processes are a challenge for many people who use self-directed services. Creating schedules for staff, learning about the budget, and completing the paperwork were all time-consuming for respondents. Many families acknowledged there was a steep learning curve when beginning self-directed services, and one respondent shared that “it took about a year to get staff and the budget all in sync.” Respondents found the paperwork overwhelming; there was too much, the budget was cumbersome, and not all forms were online. One respondent suggested, “It would be helpful if all forms could be filled out on the website and submitted, instead of filling out and mailing which delays information from being received timely.”

The process confused many respondents because of their lack of experience and understanding of the rules, the unclear reimbursement guidelines, how aspects kept changing, and the overwhelming amount of information. Because of this, most people needed a natural support for self-directed services to work. As one respondent summarized, “The amount of information is overwhelming. I do wish there was a resource guide to help or provide suggestions to families.” Some of the confusion came from a lack of communication about the rules and regulations. Regarding reimbursements, the fiscal intermediaries’ “differences in interpretation of the guidelines is frustrating.” It would be helpful for them to speak to an actual person when they have questions and have better, more transparent communication with their broker and fiscal intermediary.

Funding Structure and Services. The funding structure and services available through self-directed services did not meet everyone’s needs and preferences. Some expenses were not covered within a budget and the process did not allow for

Figure 12. Agreement about Challenges of Self-Direction



adjustments in line items. It was difficult for some families to find housing for the person because the “budget does not cover housing in certain areas.” Another respondent was “not receiving full rent because of the terms in the deed.” Respondents were also concerned about affording housing in the future.

The lack of funding for specific activities means that families need to pay out of pocket or the person is not able to participate. The budget and funding guidelines do not allow for activities designed for people with disabilities; “classes are not covered if geared to people with disabilities.” Even though one woman is “happy in a group setting,” the day activities with other people who have disabilities are not available to her.

Crisis intervention was not available for times of need. During the COVID-19 pandemic, there was a lack of direction from self-directed services.

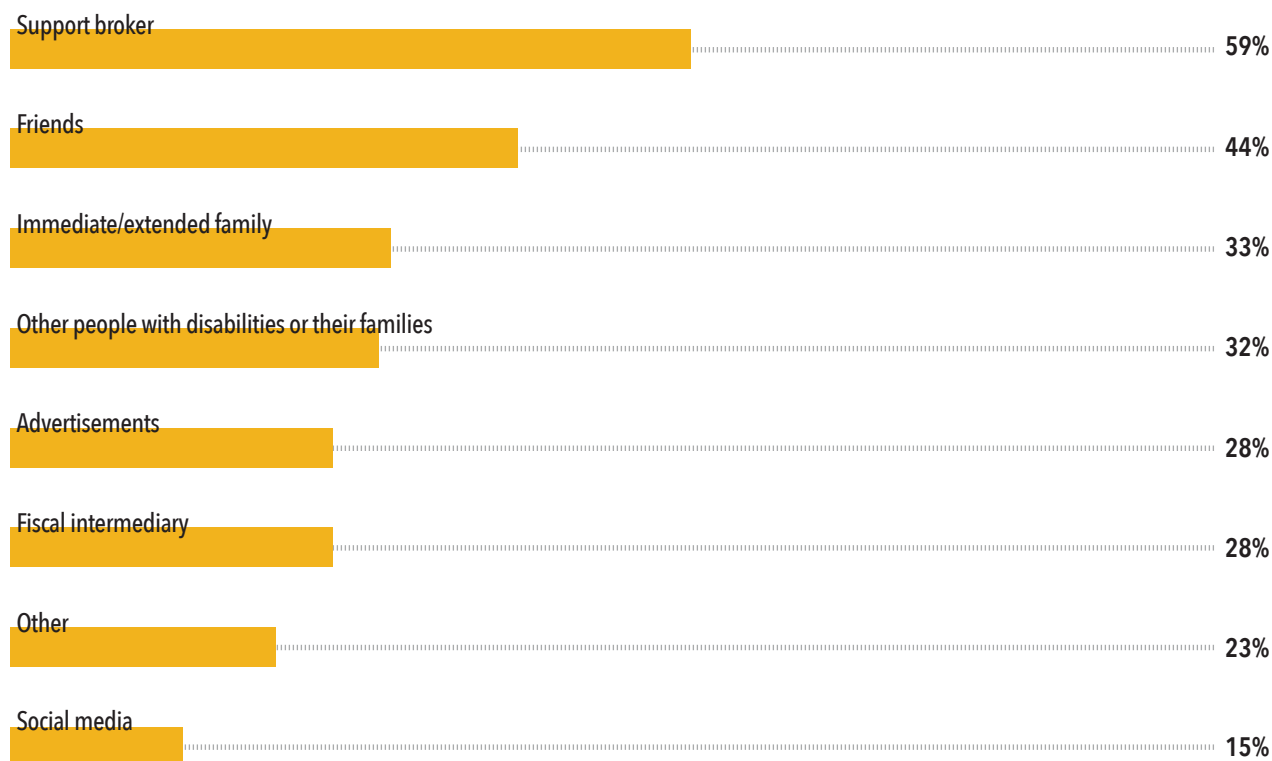
Reimbursements included extra paperwork and took a long time. For one family, the time it took the fiscal intermediary to pay vendors limited the person’s activities because they “could not pay out of pocket so son spent most days home alone.” Regarding the reimbursement challenges, respondents wished for self-directed services to pay the bills directly or that “there can be EBT cards for spending our money and more freedom.” As one respondent summarized, self-direction “needs to have a greater role in some of these areas while allowing families and individuals to maintain hiring and activities and employment power. I believe it has to be more of a hybrid approach to insure sustainability.”

Managing Staff. Managing staff is a challenge for many families. The specific challenges include finding, hiring, training, and keeping trustworthy staff as well as not having back-up staff when needed. Many found that hiring the right staff was difficult and that turnover was a problem, sometimes due to low pay or challenging behaviors of the person. In self-directed services, there were no back-up staff if people were sick or if staff left. As described by one parent, “When staff cancels, there is no back-up plan other than natural supports. My son misses the activity that he looked forward to.” Training staff is challenging because it is not available through an agency and parents, other natural supports, or the person receiving supports are in charge of delivering the training. Not all families have the time and resources to conduct training: “training is difficult because

participant can’t be left alone.” Others may not have the knowledge and skills to conduct the training on their own. One respondent was frustrated that staff was “not trained to work with married couples,” but it is her responsibility to train her own staff.

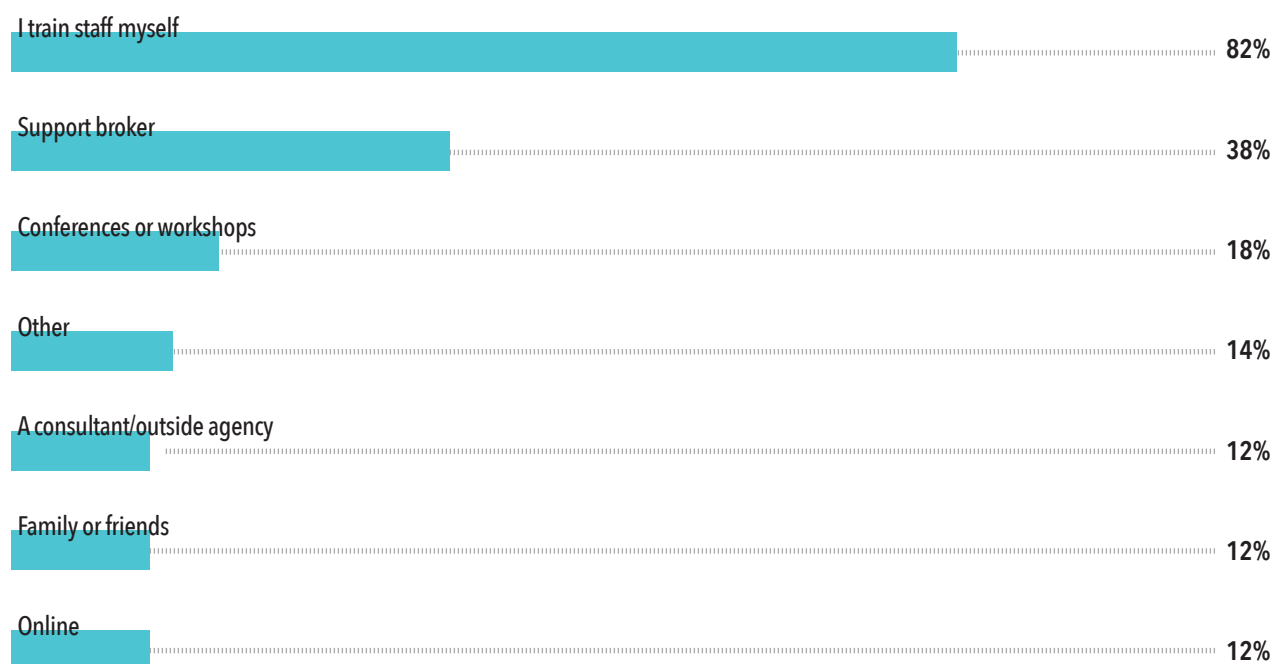
Respondents were asked where the person who self-directs finds new staff. Overall, support brokers, followed by friends, were reported as the primary ways respondents most often found new staff. Other sources for new hires that respondents listed included job websites, agencies, camp, care provider’s place of employment, church/faith community, college students, community groups, coworkers, parenting networks, support networks, current staff/other staff, email, family members, school programs, and meeting new people in public (see Figure 13).

Figure 13. Where People who Self-Direct find New Staff



Note: Percentages add to more than 100% as participants could check all that applied.

Figure 14. Delivery of Staff Training



Note: Percentages add to more than 100% as participants could check all that applied.

Respondents were asked how they delivered training to staff. Overall, respondents reported that they provided the majority of training for support staff, followed by training by a support broker. Other training sources included advocacy and medical agencies, agency training, current staff train new staff, fiscal intermediary, lots of on-the-job training, and school guidance. Some said no training had been done. Figure 14 displays the results.

Unpaid Time Spent Supporting People who are Self-Directing

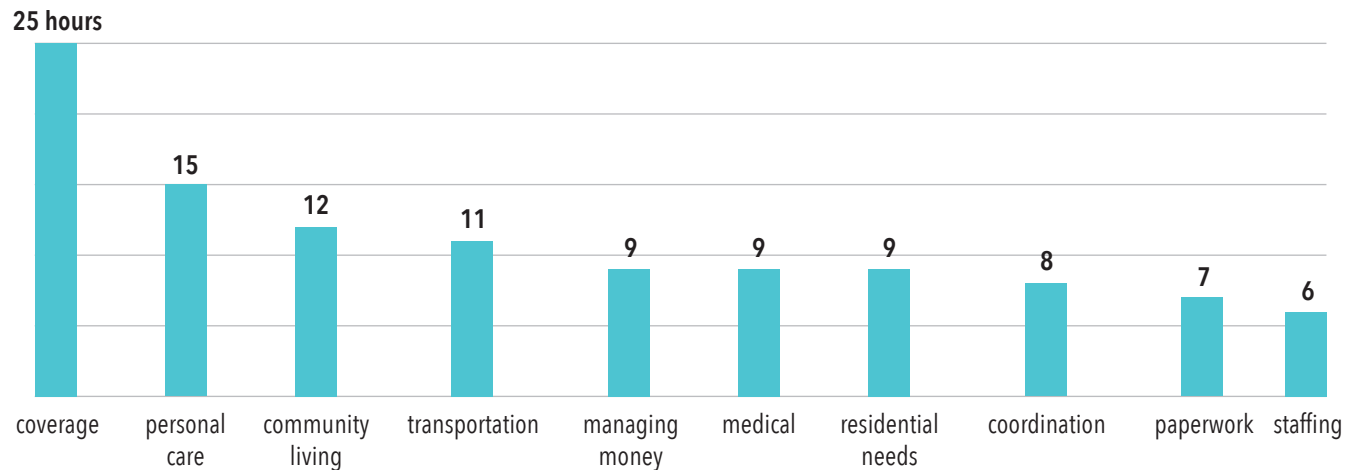
Respondents were asked about unpaid time spent supporting the person who self-directs. They were asked to report how much time the natural support spends per week on different areas of support. If the amount of time the natural support spent supporting the person who is self-directing changed substantially due to COVID-19, they were asked to recall what a typical week was like before the pandemic.

During a week, natural supports provide an average of 25 hours on coverage, 15 hours on personal care, 12 hours on community living, and 11 hours on transportation. They spent 9 hours each on managing money, medication, and residential needs. On average, they spent 8 hours on coordination, 7 hours on paperwork, and 6 hours on staffing (see Figure 15).

Three broad themes emerged to summarize how natural supports spent time supporting people who self-direct: (a) the logistics and systemic issues around supporting self-direction, (b) specific areas they were providing support in, and (c) staffing.

Respondents spoke about coordinating and planning for self-direction. They also spoke about issues that current policy for self-direction does not adequately address. The hours that respondents reported allowed self-direction to operate, but were not always hours spent directly supporting the person

Figure 15. Average Hours Spent Each Week by Natural Supports



Note: Participants could respond to as many or as few categories as applied, so hours across categories should not necessarily be totaled.

who is self-directing. A considerable number of hours were spent managing the self-direction plan.

Gaps. Gaps in the self-direction program were described in various ways. Self-direction was “like running your own business” that “provides very little safety net for these individuals, and zero community opportunities” unless natural supports are providing a lot of programmatic oversight and coordination. One respondent described their role as being like “an on-site service manager.” The unpaid commitment to implementing self-direction was reported as being a full-time job, or more, even when the person self-directing had quality staff. One respondent noted, “I am not able to work full time due to this...it is ME who arranges and schedules, trains staff and makes all of this happen.”

Running self-direction required a full understanding of the support needs of the person who is self-directing, day-to-day planning to schedule staff, activities in the community, and developing social connections. Respondents also spoke

about the need to be an expert on self-direction rules, that it takes “time and knowledge” to keep “abreast of all the latest twists and turns the state decides to implement.” One respondent noted that the “bureaucracy of the systems in place (OPWDD, Social Security, the fiduciaries) make it so much harder.”

24/7/365. The general daily oversight of running a self-direction plan was described as a job, yet for many respondents, “it is all day, every day, the very first thing on my mind.” One respondent said, “As the parent of a person who self-directs, there is no one else who would have the same commitment and do it for free.” In some cases, this was because of the lack of staff, which could have been due to unfilled positions or not enough funding to cover the number of hours needed. Several respondents reported the need for 24/7 care, but that “I’m on with her whenever her staff is not, so that’s about 128 hours a week.” One respondent shared, “It is physically impossible to care for my child around the clock, yet I am doing it often. It is wearing me out.”

Unpaid support didn't stop at being physically present. One respondent asked, "How do you measure hours upon hours of mental energy?" Others described the unpaid support as "always being there and being ready." It did not matter if they had staff scheduled, because even "with staff, we are still on call." One respondent said, "I oversee [her] life on a day-to-day basis."

Flexibility. Flexibility was a key aspect of the unpaid time that natural supports reported in supporting the person who is self-directing. It was reported as being "a full-time job" yet the hours are not routine: "the reality is that it changes day to day and week to week." This is partially because the "amount of time devoted to covering for staff absences is variable and unpredictable." The impact of staff missing a day of work on the person who is self-directing was significant, with one parent saying, "If staff calls in sick, it is generally me who covers and my son does not typically go to scheduled activities." If staff leaves their position, the impact on natural supports was also significant, not only in coverage, but in "the amount of time spent on paperwork, phone calls, interviewing, and scheduling."

Rules. Expertise in understanding the latest self-direction rules was important in managing self-direction, especially given the frequent changes in OPWDD rules. One respondent said it required "MANY hours spent keeping abreast of OPWDD" in order to understand the current rules, as well as planning for any upcoming changes that might be taking place. However, this was only one aspect of the expertise respondents reported needing.

Respondents were overwhelmed by the amount and nature of the paperwork. One respondent said, "The mechanics

and paperwork involved in Self-Direction are unnecessarily complicated," that "A lot of it is redundant," and that "even WITH staff, it's a full-time job to do this well." As one respondent described, "The paperwork is daunting and hard to explain to anyone who wants to step in and help the natural supports."

Other areas where respondents reported being overwhelmed by the expertise needed were related to the payment of staff, needing to "make sure their time sheets are correct and approved within the FI computer system so they get paid," and in finding things for the person who is self-directing to do in the community that were reimbursable under the self-direction program, including "collecting the required bills and proof of payment and proof of attendance, researching classes and activities for the individual to take and then making sure they are reimbursable."

Areas of Support. The areas of support are specific categories where natural supports spent unpaid time providing support. These hours were directed at the person who is self-directing. Respondents described providing support to people who are self-directing in several areas of life, including day-to-day activities, wellbeing, communication, and health.

Day-to-day. Respondents described how they supported day-to-day activities. Sometimes this meant "setting up the day's schedule" and "arranging daily activities" and doing tasks for the person who is self-directing around the home, including cooking, doing laundry, and organizing crafts. Respondents also supported engagement in the community by "searching for appropriate activities" and "finding social groups." They found that, ultimately, "lots of community involvement is left unpaid and in the hands of natural supports."

Respondents also spent time providing companionship to the person who is self-directing, whether it was “down time at home, playing board games, doing puzzles,” or “shopping for clothes...planning for vacations—usually with her, going out to restaurants, and doing fun things.”

Wellbeing. While companionship was part of the day-to-day support, respondents also supported overall wellbeing through “hours of phone calls weekly for reassurance, support or just chatting and sharing.” This included “doing activities that build skills and self-confidence.” As one person shared, “without this the quality of life would diminish.” Many respondents noted that “a lot of time is spent on emotional support” and that “managing anxiety is a huge component.” Another aspect of supporting wellbeing was supporting safety through “visiting and checking in on him every day.”

Communication. Respondents were the lead in communication between the person who was self-directing and others who played a role in their lives. Whether in-person, via email, or over the phone, respondents spent a significant amount of time sharing information to support the implementation of the self-direction plan. This included communication to support the daily activities of the person self-directing. One respondent explained, “when all the classes are in swing, I’m spending at least two hours a day communicating with the instructors and staff.” Another shared, “I spend time speaking to his staff and his support professionals, such as doctors [and] therapist.” Communicating with staff included training, answering questions, and problem solving as well as “anticipating HOW to prep staff to provide appropriate supports and plan appropriate activities.” Communicating with professionals who were important in the management of the self-direction plan, such

as OPWDD, the care coordinator, the fiscal intermediary, and DSS, also “eats up time and energy.” One respondent said, “When I panic, regarding plumbing issues, transportation issues, device issues, landlord issues, and electric issues, I call for help. I need help making medical appointments.”

Health. Respondents provided unpaid support for health and medical needs of the person who is self-directing. This included everything from making (often numerous) medical appointments to having specialized expertise to monitor significant medical conditions. This was an ever-present responsibility, with one respondent noting that “we are eyes on/or hearing distance and vigilant.” Managing daily health or medical activities included physical therapy, insulin monitoring, monitoring for seizures, nebulizer treatments, regular cleaning of a tracheostomy tube, and monitoring a CPAP machine.

Staff. Though respondents had “great DSPs,” (direct support professionals) there was a lot of unpaid support that contributed to their positive experiences. Substantial time was spent recruiting because “sometimes it can take months before we have the right person.” There were frustrations around who could be hired as staff. One respondent explained, “Our daughter helps out as much as possible, but we were told she cannot be paid because she resides at the same address when not in school. This seems unbelievable as she is a person whom we trust most in the world.”

Unpaid time spent training was also significant, with respondents reporting that the “largest portion of my time is spent on training,” and that “it takes about a month to train them about the specifics of our home program.” Managing staff included “supervision of the quality and type of work being done,” but also making sure

timesheets were filled out correctly so that staff would be paid. When staff were not available, many parents and caregivers reported filling in.

Though it is time-consuming, spending unpaid hours on staffing issues in self-direction was important. One respondent said that the person who is self-directing “is successful because we have trained staff together and current staff is amazing and trustworthy.”

The Give and Take of Using Self-Directed Services

Many respondents highlighted the give and take they experienced when using self-directed services. They shared the challenges and benefits, but also indicated that the challenging aspects were necessary, at that time, to get the benefits. Most of the people who pointed out the give and take they experienced shared that the larger workload was worth the effort to enhance the quality of life for the person who is self-directing. Others described a give and take with staff, the budget, and type of services.

Workload versus Quality of Life. The intense workload was a challenge for many of the natural supports, but it led to an enhanced quality of life for the people who are self-directing. Self-directed services were a lot of work, time-consuming, and overwhelming for many. As one respondent shared, “We appreciate the freedom to create a quality program, but the workload is intense.” There can be a lot of paperwork and a steep learning curve, but people who are self-directing are happier and their lives were improved: “It’s a lot of work, but it is VERY rewarding for everyone involved.” Even though self-directed services are “extremely time-consuming and can be complicated” for

many respondents, it was highly preferred over other services. Self-directed services can “enrich an individual’s life if the time is put in to explore programs, classes, and activities.” Even though it is time-consuming, it is “the best option for my child to be able to have a voice of his own, to have [the] opportunity [to] work with support as needed, to participate in community activities like his siblings do, to maintain his self-esteem, and to be as independent as possible.”

Staff. The freedom to choose one’s own staff is an advantage of self-directed services, though staff can be difficult to find. The time commitment to manage staff is countered by the choice and control families have: “Hiring staff and training staff, even though time-consuming, is more beneficial because I can have more control of my daughter’s care.” When staff were not available, there were no back-ups. As one parent pointed out, “there is no mechanism in place to cover sick calls or when a support staff member leaves.” Luckily, the person who is self-directing was able to stay at home alone while both parents worked.

Respondents were asked how much they felt they experienced the following staffing benefits through self-direction. Overall, setting pay for staff, choosing staff, and hiring people known to the natural support and person who self-directs were rated highest by respondents as benefits of self-direction, though all areas related to staffing were rated important (see Figure 16).

Respondents were asked to reflect on the ways self-directed services were challenging to the person who self-directs related to staffing. As shown in Figure 17, overall, finding new staff was reported as the top challenge related to hiring staff.

Budget. Though the budget sometimes limited what a person who is self-directing could do, they still had choices. As one natural support who experienced this stated, “It is a relief knowing we can have a choice and regulate daily life for our participant.”

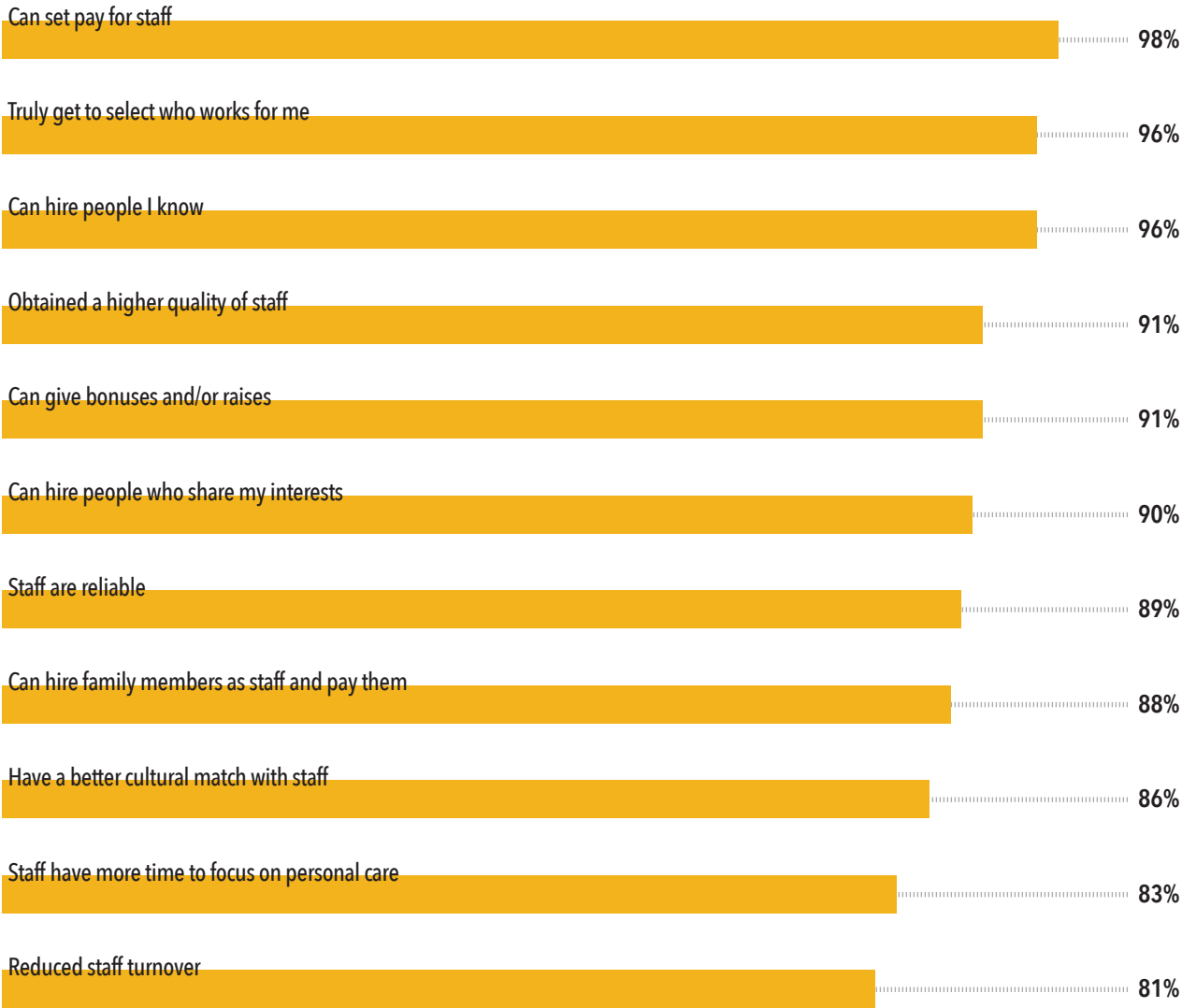
Respondents were also asked how the person who self-directs spends their budget. As shown in Figure 18, their spending categories included community habilitation (94%), brokerage (86%), respite (57%), and supported employment (25%).

Respondents were asked what kinds of things they spent their self-directed services funds on related to individual goods and services (IDGS). Figure 19 displays the results.

Respondents were asked how they spent their self-directed services money that were funded through Other Than Personal Services (100% state-funded), (see Figure 20.)

Hybrid Services. To balance the benefits of self-directed services with the benefits of traditional services, at least one family

Figure 16. Agreement about Benefits of Hiring Staff through Self-Direction



created their own hybrid model using both. The self-directed services supported the independence of the person who is self-directing, but her parents learned that she was happy in a group setting. Since they were unable to find a group setting using self-directed services, they began using a hybrid model by adding traditional day services.

Plans for Sustaining Self-Direction

Respondents were asked to share any plans they have in place for sustaining self-direction.

A Good Life. Ultimately, the purpose of planning was to ensure the highest quality of life across the lifespan of the person who is self-directing, even when the natural support could no longer support the implementation of the plan. Respondents

Figure 17. Agreement about Challenges of Staff Hiring through Self-Direction

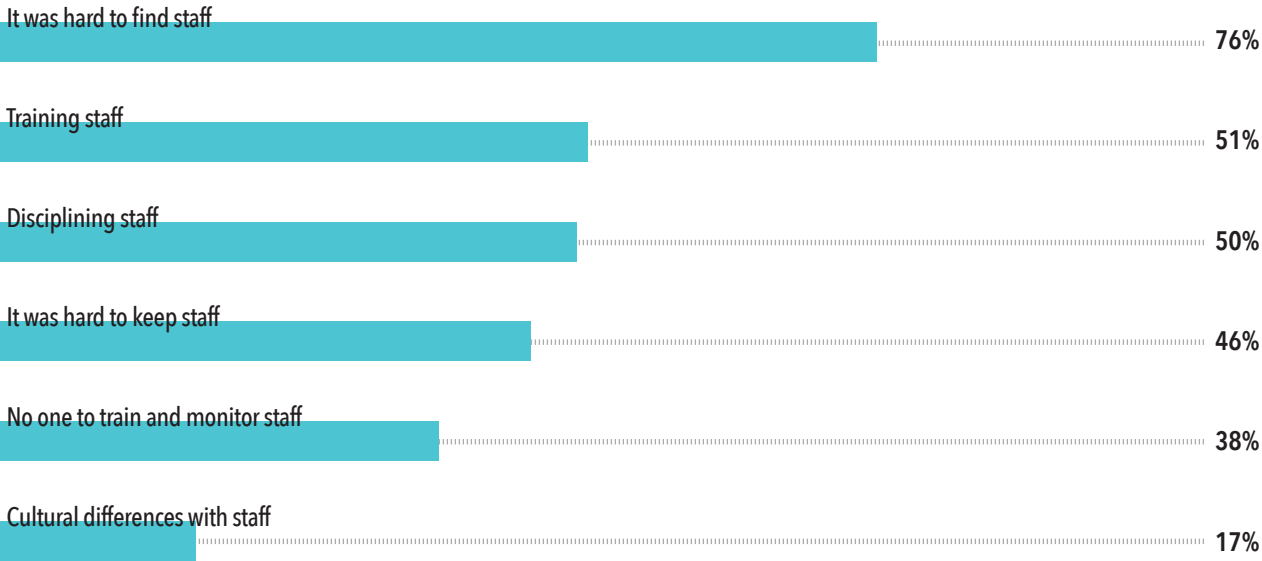
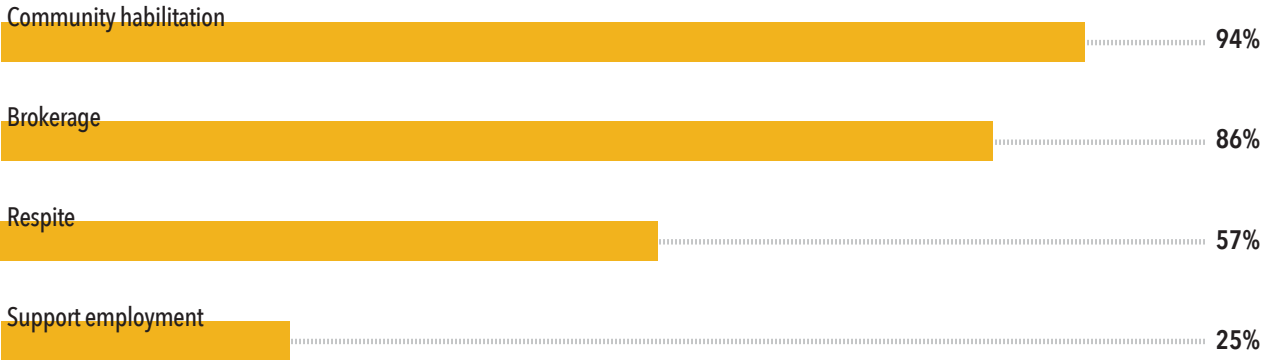
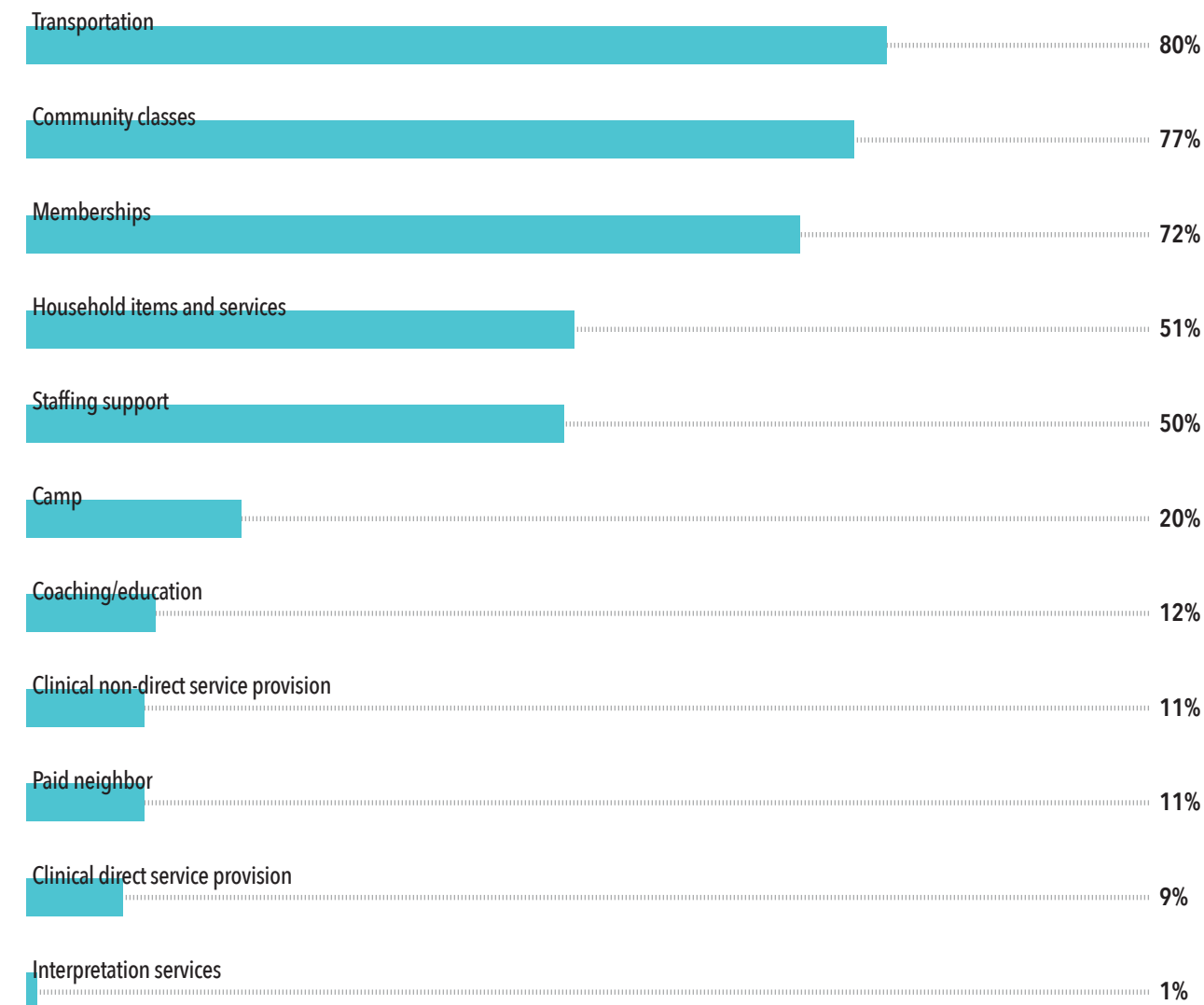


Figure 18. Self-Direction Spending Related to Staffing



Note: Percentages add to more than 100% as participants could check all that applied.

Figure 19. Self-Directed Spending related to Individual Goods and Services



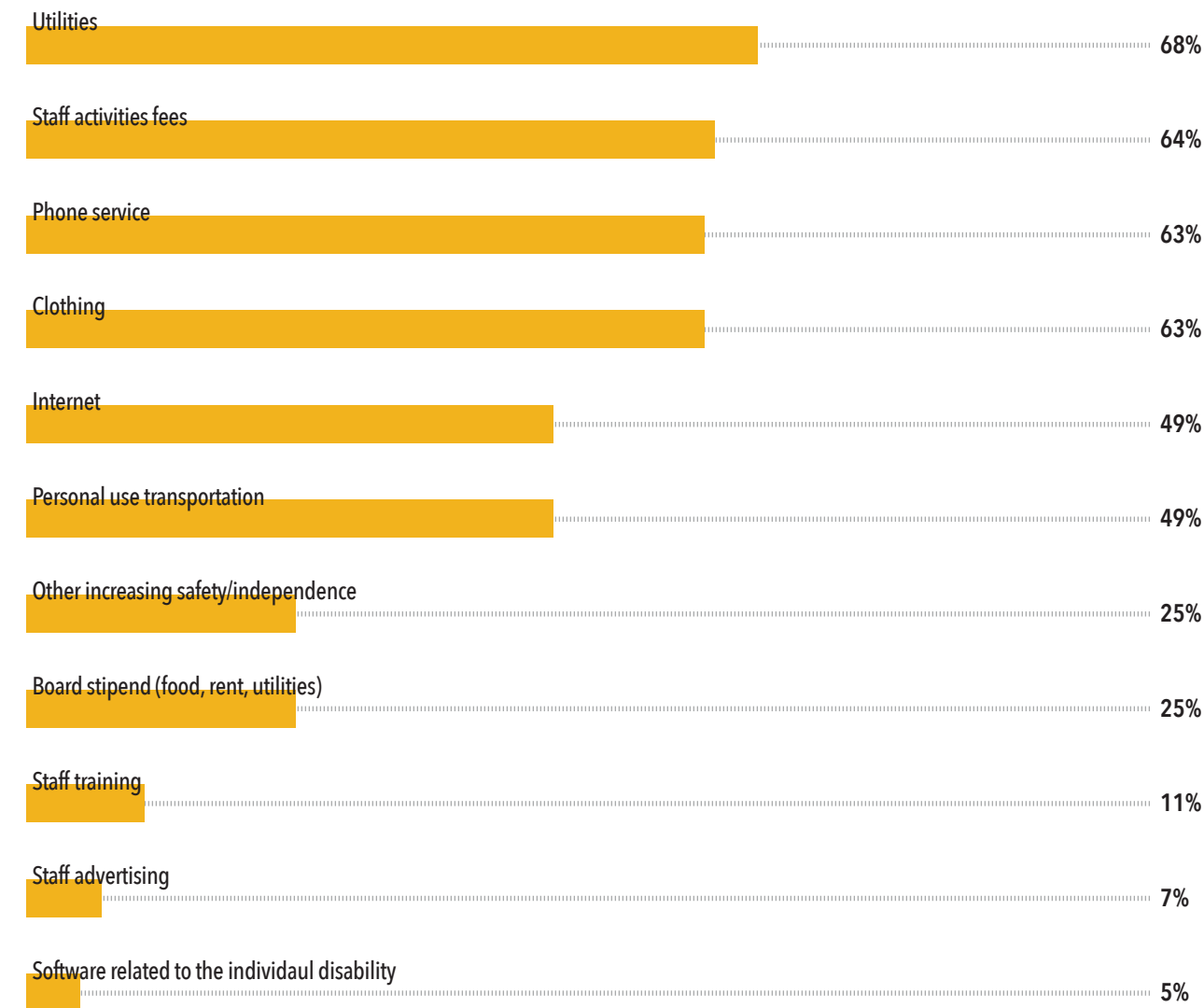
Note: Percentages add to more than 100% as participants could check all that applied.

reported positive experiences with self-direction. One respondents said, “We LOVE self-directed services.” It provides “a more independent life” and it “is far superior to any traditional agency program available.” Respondents hoped for a “life that resembles” the current carefully planned life of the person who was self-directing. The depth and quality of care that respondents described would allow the person who is self-directing to “to have a fulfilled life and

be treated with respect and care to the highest level.” One respondent said, “I want my son to live in his home, with staff to help him.” Some respondents worried that independent living would cease and that the person who was self-directing would end up in a group home.

The Plan. Respondents described elements of plans they had in place for sustaining self-direction. Sustainability was important because while self-direction “gives families

Figure 20. Self-Directed Spending funded through Other Than Personal Services (100% state-funded)



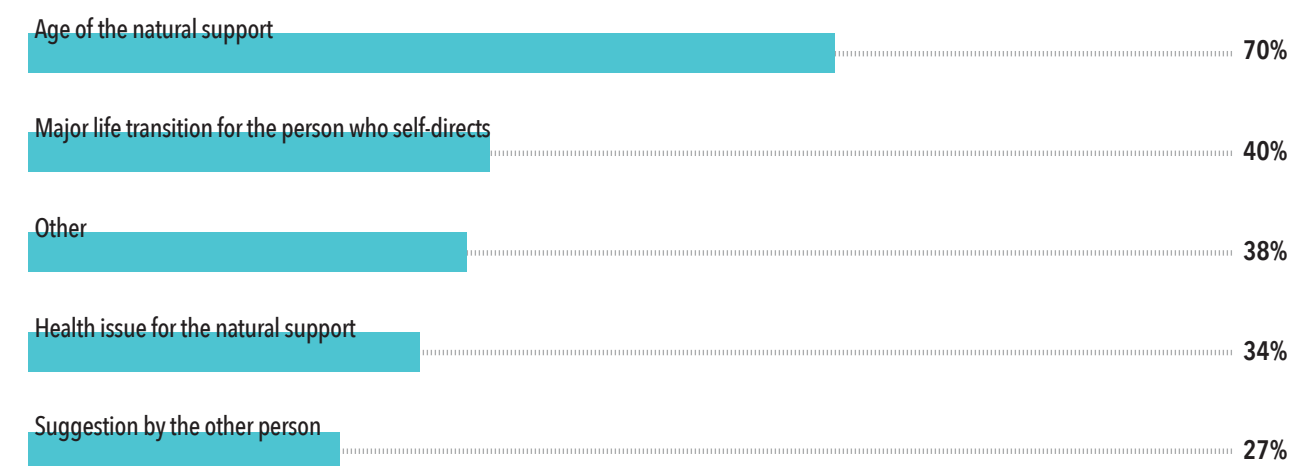
Note: Percentages add to more than 100% as participants could check all that applied.

and individuals a significant voice in how the individual will live his life,” respondents also said that “there are huge gaps” in implementing the program. They described the people in the plan, what they included in the plan, and the documentation they had in place in order to attain their hopes for the person who was self-directing to live a good life.

People. People who were crucial to carrying out the plan, and act as “keepers

of the vision,” were essential. Family members were often reported as the people who would eventually take on the role of natural support; they included siblings, aunts, uncles, and cousins. They would also fill roles such as formal guardianship and serving as trustees. Other relationships and roles were important too, including friends, brokers, care coordinators, and staff.

Figure 21. Reasons for Planning Natural Support Replacement



Note: Percentages add to more than 100% as participants could check all that applied.

Figure 22. Will Siblings Provide Natural Supports in the Future?



Natural Support Replacement.

Respondents were asked about the reason they began planning for the next natural support (see Figure 21). Overall, the age of the natural support was the primary reason respondents began planning to replace the natural support.

Sixty percent of respondents said that siblings would take on the role of the natural support in the future and 40% said they would not be a natural support (see Figure 22).

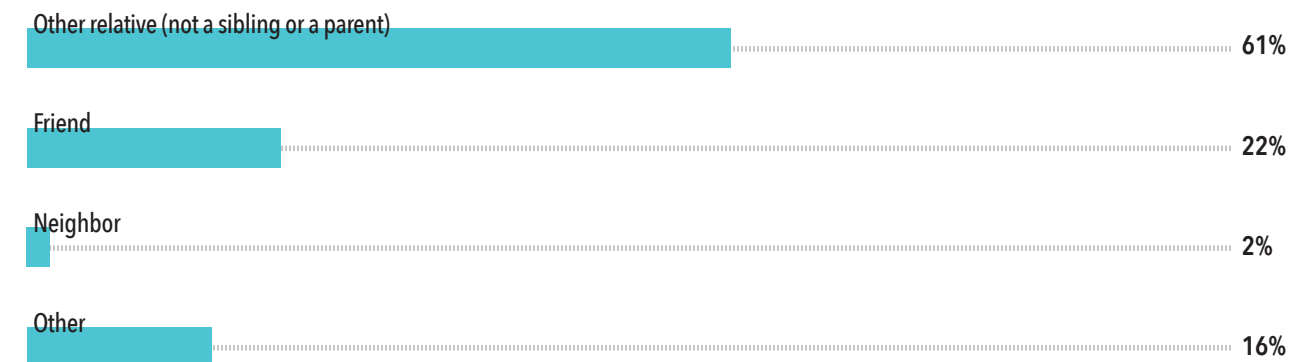
Respondents were also asked whether the person who is self-directing has a trusted, non-sibling person in their life who could take on the role of natural support in the future. Those who answered “yes” were asked to describe the relationship of the trusted person to the person who is self-

directing. Overall, most respondents said another relative was a trusted person would take on the role of natural support (see Figure 23).

Plans for identifying a **natural support replacement** ranged in levels of preparation. Some respondents were working on identifying the key person who would take on the role. There was a need for **flexibility** in selecting a natural support. In some cases, the person who was self-directing was still a minor, and respondents acknowledged that plans would change as the person grows into adulthood. Other respondents noted that while the natural support replacement may have been selected, it’s possible that the selected person will not be able to take on that role permanently. One area where this came up repeatedly was with siblings: “I have serious concerns that he will be busy with his own life and I do not want to burden him.”

Barriers to natural support selection included the complexity of implementing the plan, and time available: “[spouse] won’t be able to manage it, and one of my daughters

Figure 23. Relationship of Other Trusted Person for Natural Support



Note: Percentages do not add to 100% as participants could check all that applied.

who is a standby guardian will struggle to do it, if at all.” Several respondents noted having potential natural supports available but wished for “someone that lives closer” whether it was in the same state, or another state. Respondents also acknowledged that the potential replacement natural support “has her own family” and wouldn’t be able to devote the same time to the role.

Staffing. The topic of staffing came up repeatedly in sustainability planning. Concerns about the need for a consistent key person, such as a natural support, to help run self-direction were clear: “Self-direction is excellent for individuals who have disability as long as parent is alive.” “When staff cancels, there is no back up plan other than natural supports.” The importance of finding and maintaining reliable staff was a recurring theme. One respondent said, “I’m there already. I am an older adult with an aging parent who cannot help me much. I rely on a very good support broker and a few very good direct support staff.”

Teams. Given the effort and complexity in the natural support role, several respondents reported taking a team approach so they could “do what my

husband and I do for my son.” One approach was to “[surround] ourselves with a network of professionals and other parents who understand the process.” They took into account possible life changes for people who had agreed to part of the plan, acknowledging that an individual person might not be able to do it for the rest of their life, so respondents created a series of “backups.” They also divided various aspects of running a self-direction plan across several people, appointing specific people to carry out specific functions. In some cases, this meant hiring additional people, such as an accountant or attorney. In other cases, it meant asking for a greater role from a care coordinator or a broker. And for others, it meant shared roles across various family members. In some cases, a team had been in place but they were “re-building their Circle of Support” because life circumstances had changed for members of the Circle of Support.

Respondents shared how they were preparing natural support replacements to take the lead in the self-direction plan. Some replacement natural supports were unsure: “I live in dread of having to take it over.” Other natural supports were in the process of training

their replacements. Several respondents had “conversations with our [child’s] siblings” or other family members, and said they planned “to involve them in all aspects of her care and well-being, including in arranging services supported by self-direction.” Though much planning and training was taking place, respondents still felt that “no one is in a position to assume my responsibilities.”

Learning. Training in how to carry out aspects of the plan sometimes extended to the person who is self-directing. Respondents reported “giving more responsibility” to the person who is self-directing, such as “practicing daily living skills” or “trying to train my son now to pay bills.” However, respondents noted that these are each just one piece of self-direction, that “those are life skills and nothing about running the business of self-direction.”

Documentation. Documentation was another part of creating a plan for the sustainability of self-direction. The amount of documentation was substantial, with one respondent noting, “I have a file cabinet of plans” and another respondent described it covering both the “macro” and the “micro” of self-direction, and the person’s life. Sometimes the documentation was informal, though important, including contact information of the broker, care coordinator, fiscal intermediary, and staff. It included the typical daily routine (including activities) for the person who is self-directing, as well as what needs to take place on a daily, weekly, and monthly basis. Plans also included other information about the person who is self-directing, such as diagnoses, therapies, medical information, and food restrictions. Many formal documents had been put into place as well, including a special needs trust, a pooled income trust, guardianship, Power of Attorney, a will, living wills, and ABLE accounts.

Housing. Plans to ensure the person who is self-directing will continue to have “a safe place to live,” were described. Many approaches were shared, including purchasing a home, willing the family home to the person who is self-directing, and even altering the existing home to “make a separate part of the house for him.” One respondent reported plans to “build a uncertified residence with 12 apartments” specifically for people who are self-directing. In some cases, the decision had been made to place the person who is self-directing in a residential home.

Day-to-Day. Support needs for the daily oversight of specific aspects of the plan were described. There was a desire for a “service to pay all the bills out of budget.” Some respondents hired an accountant to manage this. Another area was in finding things for the person who is self-directing to do every day and the logistics around making the activities happen, from finding staffing to support the person in the activity to learning whether fees associated with the activity were reimbursable under the self-direction plan.

Work in Progress. Some respondents described their plans for sustainability as a work in progress, with parts of the plan in place. Others felt like they had no options. And some were hopeful that it would all work out even with no plan in place.

Developing. Respondents were developing the plans for sustainability. They had “loose plans but nothing solid” and were in the process of “identifying the needs of the [person who is self-directing] and building a team.” Plans would continue developing as life changed. One parent noted that “if one of us dies, the other will have to set more concrete plans.” Developing plans ranged from focusing on the individual, “trying to improve our child’s plan with goals and

objectives,” to the structural components, such as putting “guardianship in place, broker in place, working on housing.”

Plan – No People. Some respondents had elements of a plan in place, but no people to take the lead on running the self-direction plan. Respondents had put a trust in place, arranged housing for the long-term, or put other legal documentation into place, but they didn’t feel they had anyone who could oversee the plan and ensure it continued to operate in a way that benefitted the person who is self-directing.

People – No Plan. Other respondents had people identified, often selecting a guardian or other family members who they hoped would take the lead. They noted the complexity and time-consuming nature of taking on the role of natural support, and worried that nobody else would be able to take on the role. They also worried about the “burden” the role of natural support replacement would place on others, especially siblings of people who are self-directing. Even with people identified, many respondents noted that they did not have concrete written plans in place for the people to work from.

No Options. Some respondents felt that they had no options for putting a plan into place. They described the complexity of implementing self-direction, and how hard it would be for another person to take on their role in directing it. Some felt defeated, one respondent stating, “I don’t think about it since I don’t have a sustainable plan to put in place.” Another respondent said, “We have no plans in place. We are screwed.”

Uncertainty. Respondents were unsure of how pieces of the plan would be carried out, once they no longer played a role in managing it. Many respondents reported lots of time spent on finding things to

do every day and the coordination that went into making those things happen, from determining if activity fees were reimbursable under self-direction to finding staff to support the person who is self-directing during the activity. One respondent said, “the hardest thing about self-direction is creating meaningful activities each day and then coordinating and finding the staff to meet those hours. When staff cancels, there is no back up plan other than natural supports. My son misses the activity that he looked forward to. Supervision-wise this works fine when it’s me but if I were out of the picture, what would happen?”

Hope. Some respondents were hopeful that self-direction would continue, whether or not a concrete plan was in place. Some had a developed plan in place and hoped that it would be carried out the way they had planned. Others hoped that another person would take on the responsibility, sometimes a family member and other times a broker or someone in another role. One respondent said, “I feel this program will be helpful in the future when I am unable. I hope the supports I put in place will provide enough care for sustainability.”

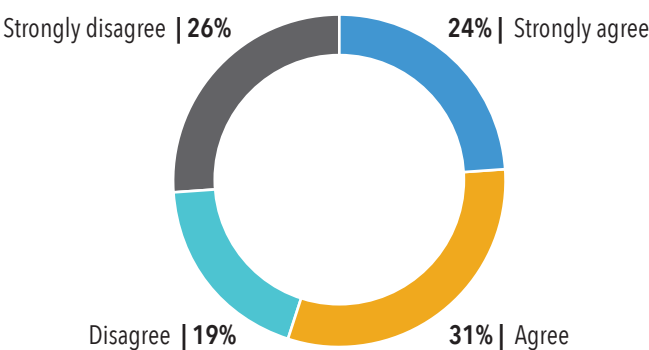
Concerns about the Sustainability of Self-Direction

Respondents were asked whether the person who self-directs had ever had a major change in natural supports before. As seen in Figure 24, most respondents (86%) had not experienced a major change in their natural supports.

Figure 24. Percent of Respondents who had Experienced a Change in Natural Support



Figure 25. Agreement that Self-Direction will be Sustained after Change in Natural Supports



Respondents who had never had a major change in natural supports were asked whether the person who self-directs had a plan in place for key areas of life, including housing, staffing, health, community inclusion, fiscal, legal issues, emotional support, and whether they generally felt prepared to sustain self-direction. Figure 25 displays the results of general

agreement of whether self-direction would be continued after the transition of natural supports. Figure 26 displays the results of agreement that self-direction would be maintained in key areas.

Respondents who had experienced a major change in natural supports were asked whether the person who self-directs was well-prepared to sustain self-direction in different areas of life during the transition of natural supports. Figure 27 displays the results of general agreement of whether self-direction has continued since the transition of natural supports. Figure 28 displays the results of agreement that self-direction has been maintained in key areas.

Respondents shared their concerns about using self-directed services in the future. Those who have not experienced a transition in who provides natural supports were asked to share what concerned them the most about directing supports in the future. Respondents

Figure 26. Agreement about Having a Plan to Sustain Self-Direction in Key Areas

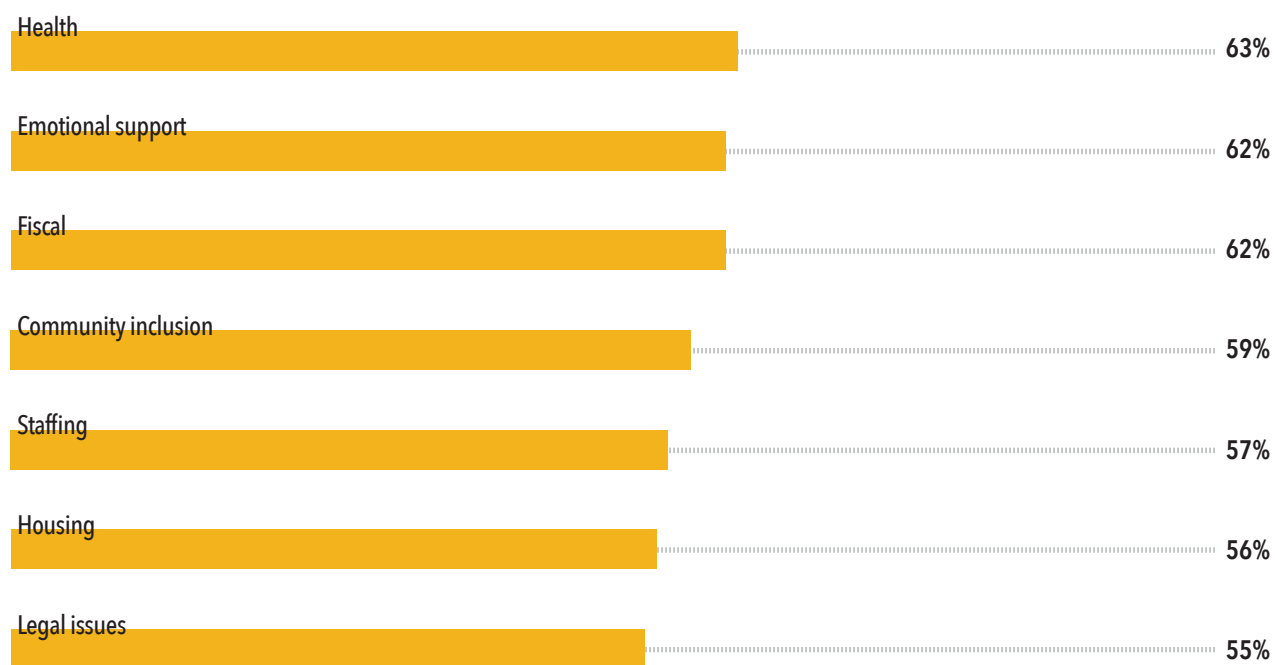
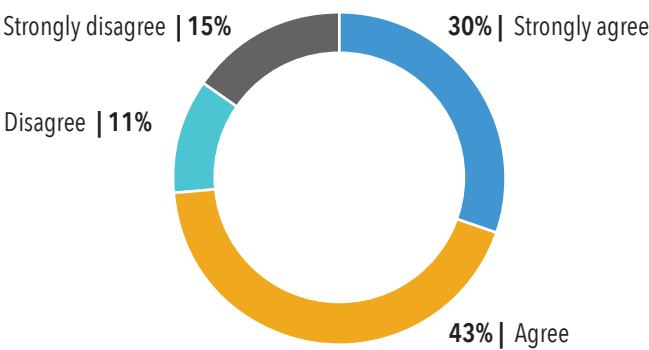


Figure 27. Agreement that Self-Direction has Continued Since Transition of Natural Supports



who had a transition in who provided natural supports were asked to think about the time before the major life change and share one thing that concerned them the most about directing supports then.

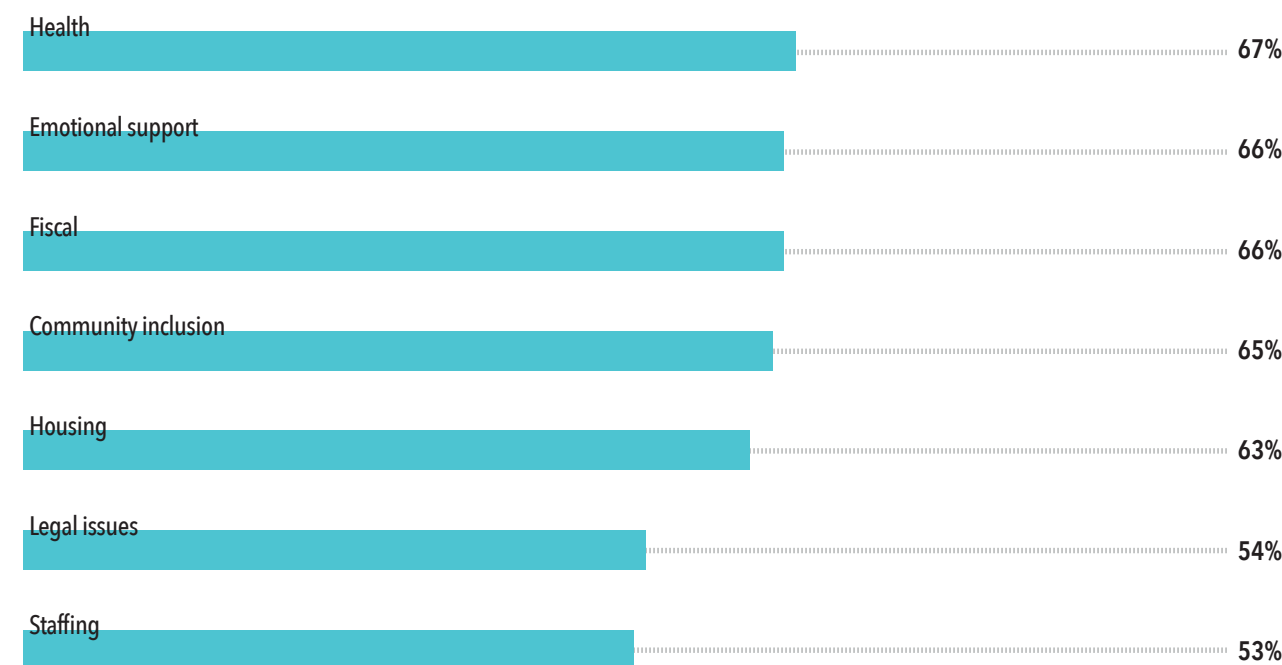
When describing their concerns about directing supports in the future, natural

supports shared their difficulty of letting go and having someone else care for the person, selecting a replacement natural support, preparing for the transition, maintaining quality of life, and sustaining supports for the person.

Letting Go. Many of the parents were concerned about letting go—allowing someone else to take over their roles—and for good reasons. These parents put in a lot of time, fulfill multiple complex roles, and focus on the best interests of their adult children. Someone else may not take the time, effort, and care to provide the quality of supports that the individual needs. Also, many people who receive supports are not able to direct their own services.

Respondents were concerned about the person’s quality of supports after the current natural support is no longer able to provide assistance. Parents were concerned that the next natural support would not provide the

Figure 28. Agreement about Previous Preparedness in Sustaining Self-Direction in Key Areas



same commitment, care, and love as they do. One parent was unsure if the next natural support would “take the time and care to provide an optimal life experience” for her son. A person receiving supports was concerned about sustaining the quality of attention they received: “What concerns me the most is getting the quality of attention and dedication my current natural support provides. My natural support looks out for me. Devotes a lot of time helping me be the best I can be. She cooks for me. Hires staff and is an advocate for me with my education and daily activities.”

Many parents, mostly mothers, could not see someone else taking on their multiple roles. Parents worried about others not being as involved or keeping the best interest of the person in mind. As one mother said, “If something happens to me, it all falls apart.” Parents worried that the next natural support would “not be as on top of things” and that they would not take care of the person like they do. One parent explained that it is “too complicated to have someone step in.” The paperwork alone is overwhelming and it’s a full-time job. As another parent summarized, “I am concerned that the people who will take on our responsibilities will not do it with the same care and concern.”

Directing supports takes a lot of time and effort. As one parent explained, “The support I give our daughter exceeds the work of a full-time job.” They are concerned others will not put forth the effort or even have the time to dedicate to directing supports: “Although a family member would take over the natural support role, the level of involvement would not be as much as I have.”

Selecting the Next Natural Support(s).

The person receiving supports is dependent on the current natural support for so many complex tasks that a team may be needed

to cover everything. Considerations and hesitations in identifying a succeeding (replacement) natural support include the burden of care and the physical distance of the potential succeeding natural support.

Directing supports can be very complex and there is a steep learning curve for many people. It would be difficult for other family members, let alone natural supports who are not related, to take over. According to one natural support, “The process is very complex and difficult to understand. It has taken years to learn the ins and outs of the system, which periodically changes.” Families have found that not many people are able to take on the work: “Aside from a parent, it’s hard to put all the responsibility on one person.” For this reason, many respondents shared that they need to have a team to carry out all of the responsibilities. Some people look to their Circle of Support for help, but the workload is too much for many people. Even when siblings will be involved, more outsiders will need to provide assistance. Some parents even wanted to find “a group of families that were interested in working together to coordinate homes, work, leisure, and learning opportunities for our children.”

It is difficult for parents to envision their adult child continuing self-direction without them because of the amount of responsibilities. One mother illustrated this point well:

Trying to explain to spouse what is completed every month in terms of forms, copies, change of addresses, legal documents, lawyers, paying bills, rent, shop food, food stamp recertification, job searches and contacts with job coach, ACCESS-VR, coordinate appts, interviews, sometimes transportation, fixing mistakes, filing forms, sending work gross income

to social security, arranging meetings and coordinating schedules broker, care manager, fiscal intermediary, job coach, agency hired community habilitation, the Circle of Support (2 brothers and husband), making corrections to life plan, lost wallets, lost bus cards, arranging paratransit, following up with bloodwork, making sure Medical reports and bloodwork are sent in a timely way to necessary doctors, trying to find time for self to walk or use indoor bike for 20 minutes after shop, clean, cook, put away dishes, pots, laundry. Only depends on me!

When selecting the next natural support, parents often consider the burden of self-direction on the person's siblings. As one parent explained, "It is a huge amount of work that I don't want to fall on my two other daughters." Another parent worried about the toll it would take on the older brother's life if he was responsible for "the day-to-day details to help to run my daughter's life." The burden of time, energy, and finances are considerations parents take when selecting natural supports. For some families, the financial burden on a sibling to support housing options that allow the person to live independently would be too great.

Even when siblings agree to help, parents are still hesitant: "Their intentions are true and good but I don't think they understand the full complexity of caring for their brother who needs assistance in all areas. They now have families of their own with young children. I'm not so sure how their spouses feel either."

For future natural supports who are not family members, "finding support people who can make a long-term commitment seems we are asking people who are not relatives to make a tremendous sacrifice." Even with a Circle of Support, friends and

family members may not have the time because they also have to work and take care of their own families.

When siblings lived far away, or their parents thought they may move out of state at some point, they were not selected to be future natural supports. Parents were concerned "that the siblings do not live close enough to give the day-to-day support." They also feared that their adult child would be all alone because other family members lived far away. Many parents had questions about moving across state lines. Would their daughter be able to get similar resources in another state? Would it be beneficial to move the person to the state where his siblings lived?

The Unknown. Many parents voiced that they were concerned about the actual transition to the next natural support. There are many unknowns about what will happen, and many do not feel like they or the next natural support is prepared for the shift in responsibilities.

"What will happen to my daughter when I die?" Many parents have this exact question. Some families have plans in place, but nobody to implement the plans. It is difficult to predict or see into the future. As one parent explained, "I don't know what my daughter will do if I can no longer support her—I do have a person who has told me that they will take over for me but how can I know how things will unfold?" Other parents have thought of who may be the next natural support but have not confirmed or even begun the discussion with them. For example, one parent believes a sister may be able to take over, but "there is no guarantee that this will be the case." Many parents hope, pray, or assume that another sibling will become the next natural support, but it is difficult to anticipate those siblings' future

circumstances. With so many unknowns, parents are left without concrete plans: “I worry about what will happen to my son when I am no longer here.”

Families often do not feel prepared to switch responsibilities to the next natural support. Some families do not have anyone in line: “When I die, my daughter has no family who can take over for me.” As one parent suggested, the intense responsibilities of a natural support can make it more difficult to select and prepare a back-up: “I have future guardianship set up but being the natural support person is more involved and hands-on and I haven't really thought that through yet.”

Other parents have their succeeding natural support selected, but that person is not prepared to take on the role. Though family members may be great supports in certain areas, they may not know anything about the self-direction process. Parents rely on the person's siblings but wonder if it is too much for them or if they will know how to do the work. There is no “useful guidebook” for being a natural support, so families wonder how the next in line will receive the training and resources they need.

Personal Impact. Losing a natural support can have a deep emotional impact on a person and significantly influence their quality of life.

The emotional impact of losing a natural support cannot be overlooked. Natural supports are often parents but they can be siblings, other family members, or close friends and allies. Whether the natural support moves, dies, or is just unable to provide support anymore, it is a great personal loss. As one respondent shared, “When my mom passed away, it was and still is very hard for me.” This is a great

concern for parents: “What concerns me most is leaving my child alone in this world.” Their adult children also have this on their minds. As one person who self-directs shared, “when my mom dies, I will be lost.” Family is so important for emotional support during these times. Since other family members may live far away, some worry about the availability of short-term and long-term emotional support for the person.

Respondents were concerned about the quality of life of the person receiving services when they lose their natural support. Like many respondents, the natural support of one man wondered “whether his Circle of Support will be able to help him have the same quality of life as his natural supports.” Respondents had concerns about people getting the support they need to reach their goals, become more independent, and stay an active member of the community. This can be difficult for new natural supports because, as one person shared, “not very many people understand her medical needs, emotional needs, personality, kindness, vulnerability, etc.”

Sustaining Supports. When thinking about the future, respondents had concerns about the continuation of supports. It was important that the people receiving services were able to both keep the supports they had during the transition to the next natural support and to have supports that were flexible enough to meet their needs at different times in their lives.

When life situations or natural supports change, it is important for people to have a continuation of supports that allow them to live a full life. To make a smooth transition from one natural support to another, respondents want to ensure that “all services are continued.” As one family explained,

"our hope is that everything would continue as it has, but it will be in others' hands." Respondents were also concerned with keeping the person's Circle of Support active: "People go on with their lives and Circles change. We are in the process of a major change where Circle members have moved and passed away. We are in the process of re-building the Circles."

Day-to-day supports were important for many people who use self-direction. Natural supports may provide that assistance on a daily basis. For one man, "his needs are such that he requires almost daily intervention from his natural supports." Respondents were concerned that people would not get the support they needed without their natural supports: "He has competent broker and care coordinator, but they won't be there for the mundane, day-to-day." Some people need "24-hour support in all areas" and others need support and reminders on an occasional basis. Without a natural support, one parent wondered: "Who will nag my daughter to get exercise?" Parents realize that, even with a wonderful support system, people will not have the same support without their natural supports. As one family shared, self-directed services "do not provide the day-to-day assistance that we parents provide. Our daughter will not have a person that can take care of her needs at a moment's notice."

"Where will she live?" Future housing was a great concern for many respondents. Parents were concerned about where, with whom, and how their adult children will live without the natural support. The cost of living independently was a concern: "As costs rise, I am concerned that the housing allowance will not be able to bridge that gap of his rent and his income." Some people would like to maintain independent living and stay out

of a group home. They fear that the person receiving supports would have to live in a group home if the natural support is not able to hire, train, and keep staff. Because of the amount of work to manage staff, others would like the option to live in a group home. There seems to be both financial and personnel capacity barriers for independent living. As one parent explained,

an ideal situation would be for my son to live with his friends with full time support. But how do you supply that support when staff turnover is so high? Who has to manage the finances of the home, the hiring and firing of staff, the training, the scheduling and on and on? The parents, and after them, the siblings.

"Staffing is often difficult to find and keep." Finding, hiring, training, scheduling, supervising, mentoring, filling in, and firing staff is challenging for many natural supports. It is important to find qualified and trustworthy staff that will keep the best interest of the person in mind. Some people have "difficulty finding staff members as self-direction is not easily understood in the general population." This makes it even more difficult when there is high staff turnover. The natural support needs to fill in for staff when there are vacancies or staff are on personal time off or sick leave. Even when people have had good experiences in the past, managing staff is not always sustainable: "We have been fortunate to cultivate both natural supports and sincere, committed, direct staff. We put a great deal of energy into maintaining those relationships. But, the older we get, the harder it is to mentor staff."

Funding for self-direction was a concern for many respondents. As one respondent explained, "The biggest concern is a decrease or change of funds available for self-

directing programs. Self-directing individuals will require lifelong assistance and that is only possible with government-provided programs.” People were concerned about losing some or all services because of budget cuts. One natural support was afraid that budget cuts will affect the person’s “ability to have a fulfilled life.” Another natural support communicated concerns about the future, which were shared by many: “I am concerned there will not be enough funds to support my participant after I am no longer able to assist him.” Since not all services are covered, some families were already paying out of pocket for needed supports.

The system for self-direction can be confusing and time-consuming, particularly for people new to the process. As one natural support explained, “I barely understand the system. I barely remember all the abbreviations.” Self-direction was too complicated for most people who were receiving supports: “I cannot imagine an individual with a developmental disability being able to manage a self-direction program effectively on their own. There are very rigorous lists of requirements for receiving reimbursement.” Respondents were daunted by the amount of paperwork and confused by the reimbursement guidelines. The lack of appropriate programs (e.g., housing and medical care) was limiting for some respondents. Overall, the respondents preferred self-direction, but were concerned it would not be available to people without their current natural support because there was no succession plan built in. They also feared that self-direction would be discontinued and people would have to live in more restrictive environments.

What Worked and What Didn't Work

Respondents who had been through the

process of transitioning from one natural support to another were asked to share what worked during the transition process and what didn't work. Themes around preparation, support, services, emotion, and independence emerged.

Preparation. Respondents spoke about parts of preparation and how they functioned through the transition of natural supports. Meetings with members of the Circle of Support, including the person who is self-directing, parents, care coordinator, broker, and other staff, helped to educate everyone on the various aspects of the plan and how to keep it running. Documenting contact information for staff, healthcare providers, and all others involved in the self-direction plan and keeping the contact information updated also helped the plan work through the transition. When the natural support replacement was not included in the day-to-day aspects of the plan, the transition didn't go smoothly. One respondent said, “When my wife passed, it was chaos. It wasn't easy.” Another respondent said, “I wasn't really prepared to take this over.”

Support. Many respondents described how teams came together to support the transition of natural supports. This was sometimes a formal team, such as the Circle of Support, but it was also sometimes informal, such as family or staff “stepping in,” a relative living close by, or a broker checking in with the person who was self-directing. Other respondents had a different experience, where people did not step in and supports did not go as planned. Sometimes a family member did not want to take on the support role and/or there was “no one to help when staff was ill or away.” Even well-thought-out plans did not always work out and some pieces “fell

apart almost immediately.” Respondents worried that without careful oversight of the self-direction plan, eventually, the life of the person who is self-directing would not “be any different, at that point, from a group home.”

Services. Some respondents were not able to access services during the transition of natural supports because they were not able to access reimbursement forms, or they just didn’t understand the self-direction process. Sometimes respondents “paid for whatever [the] person needed and just didn’t submit.” For others, due to miscommunication, “money went unused.” Processes broke down without the oversight of a natural support, and there was confusion about who had authority to carry things out. For example, “The care coordinator recommended that we get a home health aide through the county, but the nurse who evaluated [his] case told us that because [he] is relatively high functioning and needs no hands-on assistance with personal care... they could not approve services.” For other respondents, self-directed services became their supports when the fiscal intermediary staff “brought [the person self-directing] through this hard time and still is sensitive to his needs” and “the caregivers in the house gave a lot to the situation, their commitment, and the broker and Medicaid service coordinator got involved to try and help support the continuation.”

Emotion. The emotional aspects around the transition of a natural support also had elements of working or not working. Simply being “able to have a proper funeral [and] mourning period” helped with the grieving process, and sometimes support came from various people in the lives of the person who was self-directing. In one case, the fiscal intermediary staff “worker was great

in helping [him] to better understand the death of his brother.” But the grieving process was difficult too, with one respondent sharing that the person who was self-directing “had an anxiety attack and was unable to function in the community.”

Independence. Respondents spoke about the independence of the person who was self-directing. Some respondents felt that without natural supports, the self-direction plan could not function, that the person who is self-directing “can’t do it on his own.” Other respondents were working with the person who is self-directing to become more involved in the plan, “to get [the person who is self-directing] to take additional responsibility, piece by piece.” One respondent pursued their own independence, saying, “I took a chance and walked to the stores by myself.”

Training Topics for Self-Directed Services

Respondents were asked to share one or two training topics, which were not already required, that they would like to have presented by their fiscal intermediary. Respondents described training ideas in five areas: person-centered thinking, support skills, community living, health and wellness, and self-direction procedures. Most of the training topics were shared without a specific audience directly identified (e.g., natural support, staff, person receiving supports). Though some training topics may be specific to staff (e.g., staff professionalism) or natural supports (e.g., self-direction procedures), other training topics may be open to whomever would benefit from the information.

Person-Centered Thinking

Respondents wanted to learn about specific disabilities, common supports, and how to focus on the individual’s personal interests

and goals.

Disability Awareness Goal: Understand the characteristics of specific disabilities, how people may be affected, and common supports people may receive. Respondents wanted training about “understanding people with specific disabilities” such as intellectual and developmental disabilities (IDD), traumatic brain injury (TBI), visual impairment, epilepsy, autism, physical disabilities, and deaf-blindness. They would like to know the criteria for diagnosis as well as the behavior, learning, socialization, and language/communication characteristics for each disability.

Individuality Goal: Use person-centered thinking and planning to learn about the individual’s strengths, interests, and personal goals to better support the individual. Respondents would like trainings on how to assess and respond to the individual’s unique interests and goals, the importance of goal attainment, and how individuals may live independently with more services.

Support Skills

Respondents identified training topics to develop skills to support people with specific disabilities, encourage positive behaviors, and manage crises. They also wanted staff to have access to training in ethics and competencies for direct support professionals.

Disability Supports Goal: Develop knowledge and skills to support people with a particular disability or support need. In general, people would like training about how to work with people who have specific disabilities (e.g., IDD, TBI, visual impairment, physical disabilities, Deaf-Blind), while keeping in mind that everyone’s needs are

different and that people should “meet them at their point of need.” This would include “how to fully respect an individual while allowing a person with disability to have independence.”

Specifically, learning how to support people with autism was important (e.g., sensory processing disorder, motivation, dealing with stress and anxiety, supporting health and wellness, and the importance of routines). For people who use wheelchairs, natural or paid support need to know how to safely move a person and what adaptive methods there are for physical activities. It is important for many people to learn nonverbal communication strategies as well as working with people who are labeled as high functioning. Others would like training related to seizures. Teaching strategies, such as applied behavior analysis, were requested to help individuals develop independence.

Behavioral Supports Goal: Use positive behavior supports to decrease negative behavior, increase positive behavior, and increase communication. Respondents would like to understand why behaviors occur and learn how to work with people who have challenging behaviors (e.g., outbursts, head banging and other self-injurious behaviors, outwardly aggressive behaviors) and need support with anxiety and anger management. They wanted to learn about specific behavior techniques to ease anxiety, handle aggressive behavior, redirect behaviors, and de-escalate situations. Behavioral supports that enhance social interactions were also identified as important to learn.

Staff Professionalism Goal: Staff learn about competencies and ethics of direct support professionals to better support the people they serve. Natural supports would like training for themselves on using best practices

for managing staff. They want to know how to keep staff motivated, what to do if staff get injured, effective communication strategies, and how to help facilitate the relationship between staff and the individual.

Like other professions, staff would benefit from training about professionalism and how it applies to their job. Professionalism would include the importance of being honest, respectful, reliable, taking notes, showing up on time, and not missing work. They should understand that in some situations, “unreliable attendance on the part of staff undermines the individual’s confidence—they think they are not liked by staff—and this impacts their ability to function.” Since they do not have coworkers working alongside them, staff need training on how to be self-reliant. They should know how to budget weekly expenses with the individual, “create and implement a weekly schedule,” and identify potential activities that fit the individual’s interests. Staff need to know how to support the family’s way of living. In some situations, they will need to learn how to work with married couples with disabilities. Staff should also learn strategies to become active advocates for the people they support.

Staff need the knowledge and skills to develop a respectful relationship with the individual receiving support. This may include learning their preferences and needs, how to speak to them, being consistent, how to be a mentor, and how to best communicate with the individual’s natural supports. Staff also need training in supporting individuals to work on and accomplish their goals. In addition to initial training, staff would also benefit from on-call support when they have difficulties working with people who are self-directing or their families. As one respondent shared, “It’s one thing to have an overview of the

characteristics of some people with ASD, for example. It is quite another thing to be faced with your first meltdown in Home Depot.” Staff need to be active advocates.

Staff would benefit from training about how to support community inclusion for people with disabilities. They need to know about activities in the community, travel training, budgeting, and facilitating relationships with people in the community. The importance of fun, social interactions and social inclusion in the community should be emphasized.

Community Living

Respondents wanted to learn more about how to find employment, housing, and community participation opportunities. Natural supports and staff should develop skills to support the individual to select and access opportunities. They also need to know how to teach the individual skills for work, travel, daily living, communication, and social interactions.

Employment Goal: Know “how to find and keep a job” that is a good fit for the person. Staff and natural supports should learn how to find a job that meets the interests and abilities of the person, identify work-related supports, opportunities for advancement, and ways to sustain employment.

Housing Goals: Know current housing options, funding supports, and how to prepare for the future to maintain or change housing. Understand safety issues and responsibilities of living independently. Natural supports would like training on housing options and financial planning including subsidy, trust, and will information as it changes over time. They want to learn how to prepare for the future, especially if the individual needs to move

or if a roommate leaves. Respondents also want training on the person's rights and responsibilities, safety concerns, and supports to help the individual live as independently as possible.

Daily Living Goal: Develop skills to teach and support activities of daily living. Respondents would like training and tips about how to teach the person independent living and self-help skills. This includes "how to do personal hygiene care for an individual, showing patience and respect." Some would also like training about "communication with an AAC device." For others, how to support the appearance of the person when leaving the house is important, making sure "shoes are tied, shirt buttoned, blouse closed, looking presentable."

Community Access Goal: Develop knowledge and skills to facilitate relationships and access community resources and activities. Natural supports and staff should have training about developing "innovative community connections," "being a liaison with community members," "developing support networks," and using social media for connections. They also need to learn how to conduct travel training to support the individual's access to the community.

Many respondents shared that training is needed to learn "how to find interesting and appropriate activities and social opportunities for respondents." They thought that fiscal intermediaries should share community resources that are approved for reimbursement and clearly explain the regulations on which services, classes, and activities are covered through self-direction and what documentation is required. Natural supports and staff would benefit from suggestions of activities or how to find them.

Specifically, one respondent asked, "What are all the recreational, cultural, and volunteer opportunities available in our community?" Natural supports also want to know "how to find buddy programs or support groups that include typical peers" and how to connect with other people who have disabilities.

Health and Wellness

Respondents want to learn how to support the health and wellness of the person receiving services. This includes providing direct support and teaching the individual skills to support their emotional health, diet and exercise, medical needs, and safety concerns.

Emotional Goal: Know how to find or provide emotional support for people with disabilities. People who are self-directing need to know "how to handle emotional issues" and find professional emotional support when needed. Since people with disabilities may feel lonely more often, "they need to feel there are people who can empathize with them. I'm not sure if staff know how to do that."

Food and Exercise Goal: Develop the knowledge and skills to support a healthy diet and exercise habits for people with disabilities. Respondents wanted training on selecting and preparing healthy meals and snacks, as well as information about the exercise people with disabilities need to be healthy.

Medical Goal: Develop the skills to manage medications, perform first aid and cardiopulmonary resuscitation (CPR), handle specific medical needs of the individual, and support people in managing their own healthcare. Natural supports and staff need training on first

aid, CPR, and medical issues of the people they support (e.g., what to do during a seizure, using an epi-pen). They need to know “how to support respondents in managing their own health care” and how to get support through telehealth.

Safety Goal: Understand safety concerns and measures in the home and community, as well as “what happens in an emergency.” This includes knowing “what is considered a reportable incident” for documentation. During an emergency, they need to know what to do and how to “work constructively during high stress situations.”

Self-Direction Procedures

Natural supports want additional training on the rules, procedures, and any changes in managing self-directed services. This includes onboarding natural supports, understanding the budget and reimbursement process, completing timesheets, planning for the future, and staying up-to-date with changes and updates to the rules and procedures.

Onboarding Goal: Learn the rules and procedures of self-direction, related information, and ideas for successful self-direction. The natural supports and/or person who is self-directing need training about how to use self-directed services and all areas that “pertain to filling out forms.” They need to know compliance requirements, timesheet entry, mileage entry, reimbursement, and “other potential programs or resources available” to the person self-directing. People new to the program would also benefit from general tips and getting ideas from stories of successful self-direction experiences.

Budget and Reimbursement Goal: Understand the budget, allowable expenses,

“how the pay system works,” and how to request reimbursements. Natural supports need additional training to understand how the budget works, including allowable expenses (e.g., equipment, activities), staff activity fees, and unpaid items. Providing “money management tips” would also be helpful. Natural supports want to make sure they know “how to accurately document services provided” and the “procedures for submission of paperwork.” As suggested by one respondent, it would be helpful to have a “detailed handbook for online reimbursement” procedures.

Timesheet Goal: Understand how to complete timesheets accurately. Respondents want additional training on how to complete timesheets, including how many hours staff have earned in personal time off (PTO) or sick time, in a timely manner, as well as how to submit timesheets using the online system.

Future Planning Goal: Learn how to prepare for the future, including options available, steps to take, and considerations for planning. Natural supports would like training in financial planning, including wills, health proxies, special needs trusts, and ABLE accounts. It is also important to stay aware of “trust and will information, as it changes over time.” Housing options and funding is a concern for many natural supports (e.g., moving from home to independent living, moving in or out of state, changes in roommates). Natural supports were also concerned about how the person will use self-direction if there are budget cuts that affect services.

Understanding Changes Goal: Keep updated on any changes to self-directed services. People who self-direct and their natural supports would like training on the changes to self-direction that may affect them.

Figure 29. Agreement about Aspects of Coordinating Self-Direction



This includes budget cuts, support for new electronic systems, changes in procedures, and updates to the rules and regulations. They would like formal training with written resources for reference and a contact person for questions. They want to know the reasons for the changes and future impacts to their program. Semi-annual updates on the status of self-direction, any challenges or threats to the program, and efforts happening behind the scenes would be appreciated.

Experiences with Coordination of Self-Direction

Respondents were asked to rate various experiences with self-direction. As seen in Figure 29, respondents had high agreement in many areas of coordination of self-direction. They most agreed that if they do not know something about the budget, they know where to learn more about it and that they have working knowledge of the budget lines currently in the Self-Direction Plan. Respondents could select all that applied.

CONCLUSION

Services and supports for people with disabilities have been transformed in the past 50 years. The momentum for this systems change has been fueled by changing societal views of people with disabilities and advocacy by people with disabilities and their families. These policy and systems changes have reformed the way in which supports are provided and funded to promote increased choice and control for people with disabilities and their families. Research reveals that self-directed supports both enhanced quality of life for people with disabilities and are a cost-effective and efficient way to deliver support services.

Self-directed supports are an essential component of the disability services landscape. As people with disabilities and their families age and transition into new life phases, the services and systems that support them must evolve and change as well. The results of this study illuminate the successes and challenges of self-directed

service implementation for persons with disabilities from the perspectives of both individuals who self-direct and natural supports who are responsible for the direct management of programs. A key area of focus of this study is the sustainability of self-direction when natural supports can no longer support the process. Overall, the majority of families and people with disabilities in this study emphasized the importance of continuation of self-directed supports through the lifespan.

As in previous research on self-directed supports, key benefits emerged around enhanced quality of life, increased self-determination, and increased quality and availability of staff and services. In the current study, several families spoke to the increased quality and availability of services under the self-directed option. Previous research found that individuals with disabilities were significantly more satisfied with their services when they were enrolled in self-directed option compared with traditional services. The flexibility afforded allowed individuals who self-direct to achieve a quality of life and individual choice not possible in traditional services. Both natural supports and people with disabilities often shared that self-directed supports allowed them to also demonstrate autonomy and help direct/manage services in a way that worked well for both the individual and their family. Supports from staff, support brokers, and fiscal intermediaries were consistently listed as key ingredients for successful implementation of self-directed supports.

Challenges with current implementation also emerged in the data. Consistent with previous research, one of the most significant challenges of self-direction has been that of program implementation and program complexity. The stated challenges of using

self-directed services include processes that can be time-consuming and confusing, budget and reimbursement difficulties, lack of funding for specific services, and managing staff. Rule and program changes were also an ongoing concern of respondents, as these ongoing changes added further complexity to implementation.

Challenges can provide insight into program improvement and policy innovation. In looking closely at self-directed supports in this sample, the results of the current study reveal that the following would improve program implementation:

- Simplified processes for administrative aspects of managing self-direction
- More flexibility in who can be hired as staff
- More support for natural supports (possibly including being paid as staff)
- Reliable staff with more training on disability and inclusion
- Tools to help with the sustainability of self-direction, including developing individual pieces of the plan, identifying the people who need to be involved, and information about self-direction programs in other states

The central role of natural supports represents both a benefit and a challenge to self-direction. While natural supports (often parents) play a key leadership role that enables autonomy and enhances quality of life, it also presents a challenge in that the system relies on natural supports to devote a significant amount of time to support the process. This challenge becomes particularly pertinent when the natural support can no longer provide coordination support. A key question of this study was the sustainability of self-direction when a natural support can no longer help manage or support the process. Given the significant time

commitment parents and natural supports provide to manage self-directed services, this is an essential question for the sustainability of self-directed supports.

Looking at the survey sample, the majority of respondents in this study had yet to experience a transition in natural supports. Of these respondents, the majority (55%) felt that self-directed supports could be sustained after transition. Approximately 45% had concerns about the sustainability of self-direction after the natural support. While most felt it could be maintained, a sizable group had significant concerns about the future sustainability of self-direction, including the time, effort, and care needed to provide quality supports to the individual. Health, emotional support, and fiscal support were the areas the group felt most prepared and confident would continue. Staffing, community inclusion, and legalities were areas of most concern for sustainability. For those who experienced a transition or planned for a transition, the age of the natural support was the primary reason. About 60% of respondents planned for a sibling to take on the lead coordinating role.

The current data reveals that natural supports, who are typically parents, are doing a significant amount of unpaid work and additional hours to support self-direction. Natural supports put in a lot of time, fulfill multiple complex roles, and focus on the best interests of their adult children. Additional natural supports revealed that it would be challenging to replicate the commitment and dedication a parent has for supporting their child's success. For many, the success of the program relies on a natural support managing all aspects of the program. Families in this study revealed that they want to ensure that self-direction continues throughout the lifetime of the

person who is self-directing, even when the natural support can no longer take the lead in managing the plan. Thus, a key finding of this evaluation is understanding the key components needed to maintain self-directed supports when natural supports change.

Families said that continuing the self-direction plan depended on "keepers of the vision." Siblings were often chosen as the keepers of the vision, but there were also frequently-expressed concerns about siblings having their own lives and responsibilities. Thus, additional strategies for continuing were intentionally building robust Circles of Support with a clear focus on transition and sustainability. Further, the sheer amount of unpaid time that natural supports typically provide may need to integrate into transition budgets. For many respondents, a combination of family and community supports and paid staff was a common arrangement. Also, the complexity of managing self-directed services should be a gradual learning process that is incorporated into transition roles and the Circle of Support.

Another common content denominator was the need to provide emotional and mental health supports to the people with disabilities during this time of transition and potential emotional distress. The emotional impact of losing a natural support for a person with a disability cannot be overlooked or minimized as a critical aspect of this transition. Natural supports are often parents but they can be siblings, other family members, or close friends and allies. Whether the natural support moves, dies, or is just unable to provide support anymore, it is a great personal loss. Transition plans must incorporate emotional health supports into the plan and budget.

Key **practical implications** for supporting the sustainability of self-directed supports across

transition were:

- Early and intentional planning integrated into the self-directed supports model from the beginning. This needs to be a regular component of program planning within self-directed supports.
- A guidebook for natural supports to help support transitions. A realistic preview of the role with essential duties and skills would be beneficial for transitions.
- Intentional strengthening of the Circle of Support with a focus on supporting future transitions. Families found success with a combination of natural supports and committed direct support staff.
- Regular meetings with members of the Circle of Support, including the person who is self-directing, parents, care coordinator, broker, and other staff, can educate the team on the various aspects of the plan and how to keep it running.
- Documenting basic information, such as contact information for staff, healthcare providers, and all others involved in the self-direction plan and keeping the contact information updated also help the plan work through a transition.
- Provide ongoing transition training to families, including how to prepare for the future, options available, steps to take, and planning considerations.
- Natural supports need training in future financial planning, including wills, health proxies, special needs trusts, housing options, and ABLE accounts.
- Losing a natural support can have a great emotional impact on a person and significantly influence their quality of life. The emotional impact of losing a natural support cannot be overlooked. Consider the emotional and mental health needs of person with a disability when a natural

support can no longer provide supports. Supports need to be integrated into the plan.

- Due to the large number of hours most natural supports put into self-directed supports, the role of the natural supports may need to be replaced by a team to carry out all of the responsibilities. Accounting for the large number of unpaid hours that natural supports (often parents) provide to manage self-directed supports and the additional staff needed must be included in self-directed budgets when there is a transition.
- Budget allocations to support the transition process include funds devoted to supporting transition needs, increases in hours, and mental health supports.

In conclusion, this is the first study to examine the sustainability of self-directed supports across major life transitions. As the success and sustainability of self-directed programs are closely related to the natural support's role, this research may hold important implications for the design, implementation, and sustainability of self-directed initiatives in the future. As people with disabilities and their families age and transition into new life phases, the services and systems that support them must evolve and change as well. The long-term viability and expansion of self-directed programs require an intentional transition plan across the lifespan to accommodate life transitions and changes in natural supports. Thus, this study provides recommendations from families as well as future policy innovations to accommodate sustainability and improve the systems that serve people with disabilities and their families across the lifespan.

REFERENCES

- Bogenschutz, M., Hewitt, A., Hall-Lande, J., & LaLiberte, T. (2010). Status and trends in the direct support workforce in self-directed supports. *Intellectual and Developmental Disabilities, 48*(5), 345–360.
- Bogenschutz, M. D., DeCarlo, M., Hall-Lande, J., & Hewitt, A. (2019). Fiscal stewardship, choice, and control: The context of self-directed services for people with intellectual and developmental disabilities (IDD) in the United States. *Intellectual and Developmental Disabilities, 57*(2), 158–171.
- DeCarlo, M. P., Bogenschutz, M. D., Hall-Lande, J. A., & Hewitt, A. S. (2019). Implementation of self-directed supports for people with intellectual and developmental disabilities in the United States. *Journal of Disability Policy Studies, 30*(1), 11–21.
- DeCarlo, M. (2016). *Implementation of self-directed supports for individuals with intellectual and developmental disabilities: A political economy analysis*. Virginia Commonwealth University.
- Hall-Lande, J., Hewitt, A., Bogenschutz, M., & LaLiberte, T. (2012). County administrator perspectives on the implementation of self-directed supports. *Journal of Disability Policy Studies, 22*(4), 247–256.
- Heller, T., Schindler, A., Palmer, S. B., Wehmeyer, M. L., Parent, W., Jenson, R., Abery, B. H., Geringer, W., Bacon, A., & O'Hara, D. M. (2011). Self-determination across the life span: Issues and gaps. *Exceptionality, 19*(1), 31–45.
- Office for People with Developmental Disabilities. (n.d.). Self-direction: Making your own decisions. Retrieved December 12, 2020 from <https://opwdd.ny.gov/types-services/self-direction>
- Wehmeyer, M. L. (2020). The importance of self-determination to the quality of life of people with intellectual disability: A perspective. *International Journal of Environmental Research and Public Health, 17*, 1–7.
- Wehmeyer, M. L., & Schalock, R. L. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children, 33*(8), 1–16.

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