

Concerns about the Sustainability of Self-Direction

Self-direction is a Medicaid service option in which people with disabilities, commonly with the support of their families, use individually-set budgets to select, purchase, and manage their own supports. They typically recruit, hire, train, and supervise their own staff. While self-directed services are based on the individual's needs and preferences, a key ingredient of this approach is often a strong natural support (e.g., parent, sibling, other relative, friend). Thus, an important question remains about the sustainability of self-direction when the primary natural support is no longer able to help support the person who is self-directing.

The purpose of this study was to better understand what concerns natural supports the most about directing supports in the future, specifically when the primary natural support can no longer provide support. In 2020, people in New York State were surveyed about their experiences with self-direction. One of the goals of the survey was to learn about the concerns people have about using self-directed services after the primary natural support (e.g., parent, sibling, other relative, friend) can no longer provide assistance. Respondents who had not yet experienced a change in the person who provides natural supports were asked to share what concerned them the most about directing supports in the future. Those who had already had a significant change in natural supports were asked what concerned them the most before the major life change. There were 413 respondents who answered quantitative survey questions about the sustainability of self-direction and 335 respondents who shared their concerns about the change to a new primary natural support in the future.

Sustainability Plans

Respondents were asked whether they had experienced a major change in their natural supports. Most of the people in this sample who self-direct (86%) had not yet experienced this change. Those who had not 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. Figure 1 shows their agreement that self-direction would be maintained in key areas. This includes 63% of respondents for health, 62% for emotional support, 62% for fiscal, 59% for community inclusion, 57% for staffing, 56% for housing, and 55% for legal issues. Overall, 55% agreed or strongly agreed that self-direction would continue after the major transition of natural supports and 45% disagreed or strongly disagreed that they could continue self-directed services, as seen in Figure 2.

Seventy-four percent of respondents who experienced a major change in natural supports in the past agreed or strongly agreed that self-direction had continued since the transition of

natural supports and 26% disagreed or strongly disagreed, as shown in Figure 3. Figure 4 displays the agreement that self-direction has been maintained in key areas.

Sustainability Concerns

When describing their concerns about directing supports in the future, natural supports shared the difficulties with letting go and allowing someone else to care for the person, select a replacement natural support, prepare for the transition, maintain quality of life, and sustain supports for the person.

Letting Go. Many parents were concerned about the process of letting go—allowing someone else to take over their roles. These parents put in a lot of time and often fulfill multiple complex roles within self-direction. Someone else may not take the time, effort, and care to provide the quality of supports that the individual needs, and many people with disabilities are not able to direct their own services.

Figure 1. Agreement about having a plan to sustain self-direction in key areas

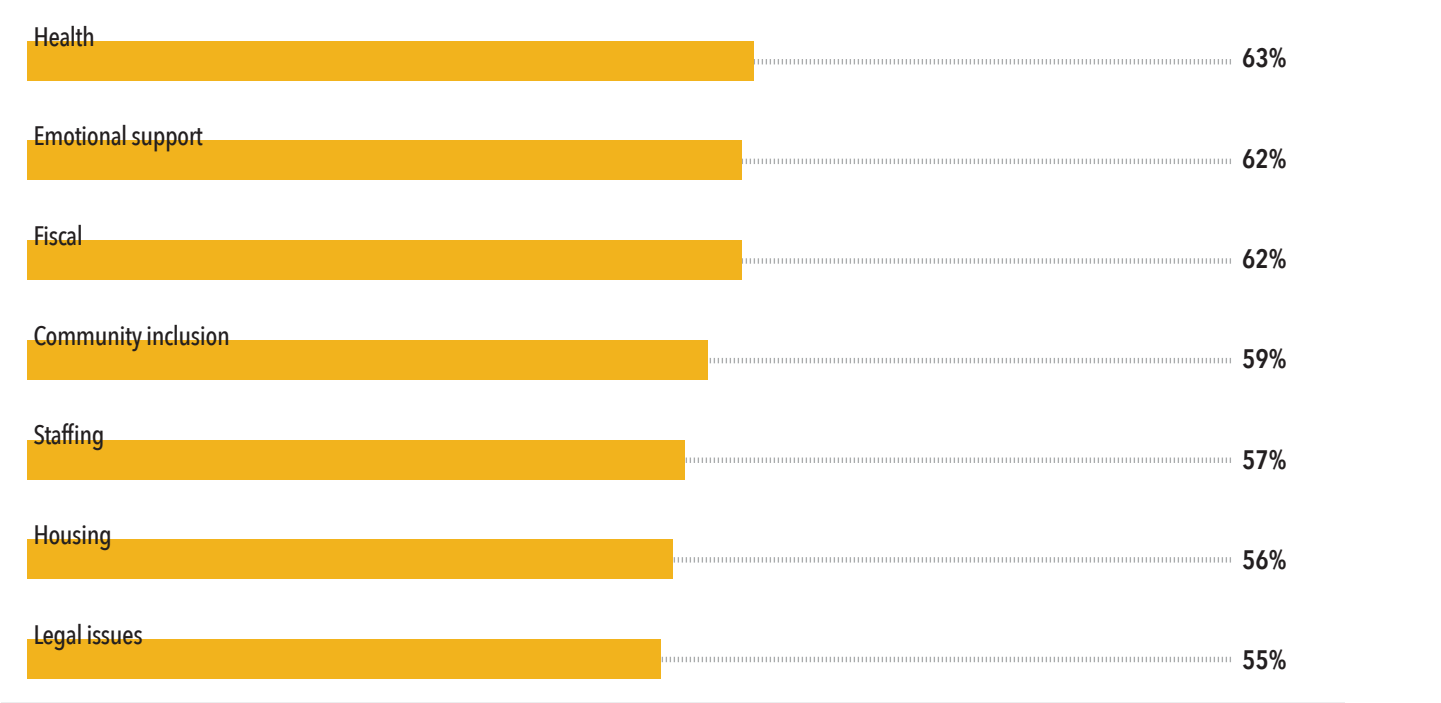


Figure 2. Agreement about whether self-direction will be sustained in the future after transition of natural supports

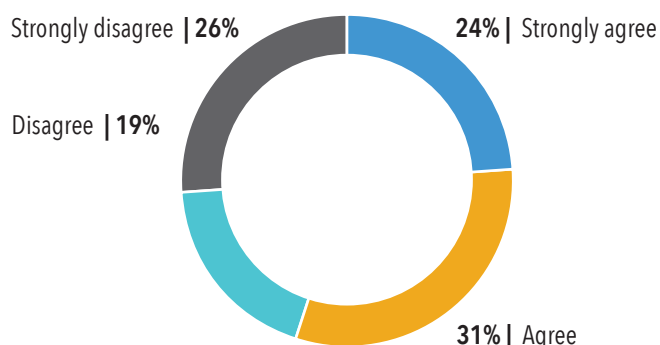
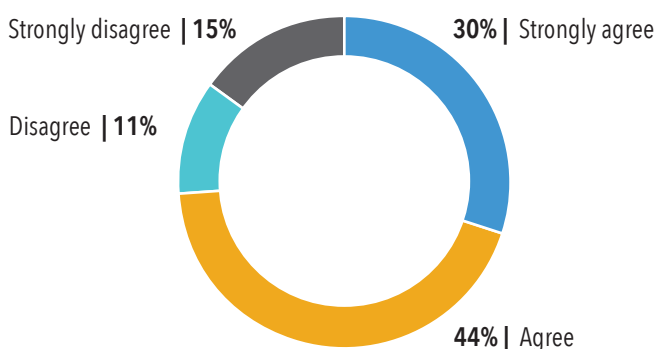


Figure 3. Agreement about whether self-direction was sustained after a past transition of natural supports



"I am concerned that the people who will take on our responsibilities will not do it with the same care and concern."

- parent

Selecting the Next Natural Support(s).

Directing supports can be complex with a steep learning curve. It would be difficult for other family members, let alone people unrelated, to take over. For this reason, many respondents said that a team is needed to complete all of the responsibilities. Some people look to their "Circle of Support" for help.

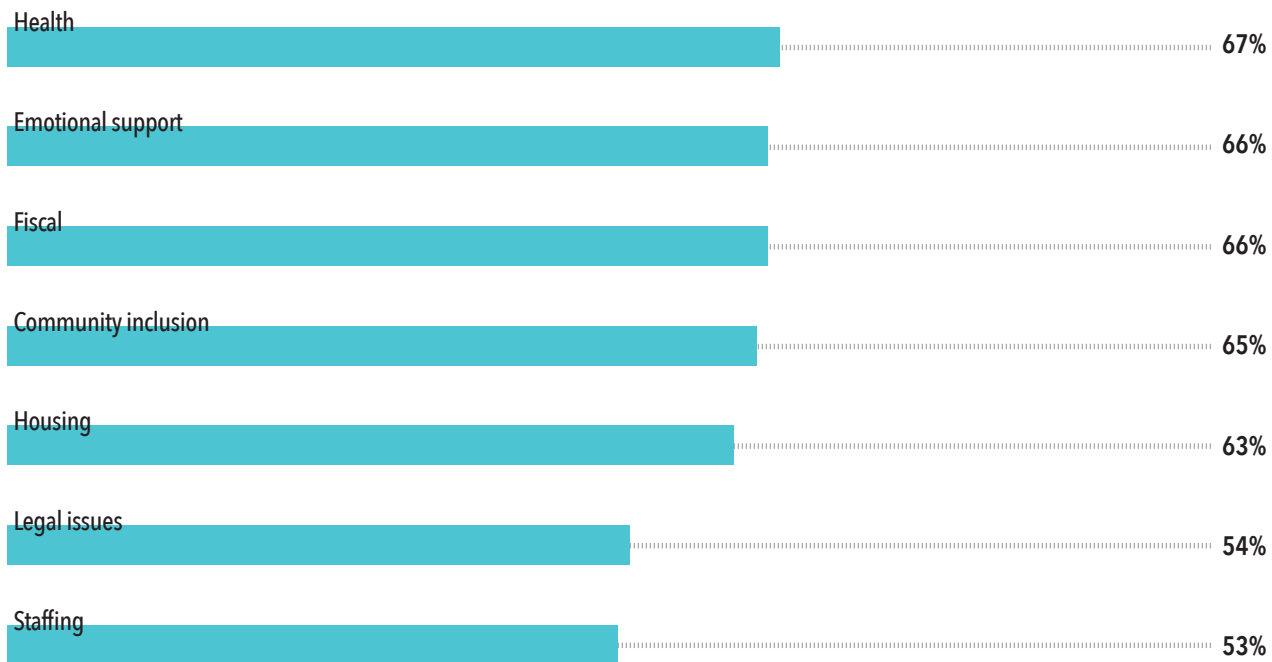
When selecting the next natural support to support their child after a transition, parents often consider the burden of time, energy, and finances on the person's siblings. When siblings lived far away, or their parents thought they may move out of state, they were not selected to be the next natural support. Parents were concerned "that the siblings do not live close enough to give the day-to-day support" and their adult child would be all alone.

Preparation for the Transition. Many parents were concerned about the actual transition to the next natural support with so many unknowns about what will happen. Many did not feel like they or the replacement natural support were prepared for the shift in responsibilities.

"I worry about what will happen to my son when I am no longer here."

Some families had plans in place, but nobody to implement them. Others had ideas about who may be the next natural support but had not confirmed or even began the discussion with them. Many parents hoped, prayed, or assumed that another sibling would become the next natural support, but it was difficult to anticipate the siblings' future circumstances. Other parents had selected their replacement natural support, but that person was not prepared to take on the role. With so many unknowns, parents were sometimes left without concrete plans.

Figure 4. Agreement about previous preparedness in sustaining self-direction in key areas



Quality of Life. Losing a natural support can have a great emotional impact on a person and can significantly influence their quality of life. Whether the natural support moves, dies, or is just unable to provide support anymore, it is a great personal loss. Since other family members may live far away, some worried about the availability of short-term and long-term emotional support for the person. Respondents also had concerns about people getting the support they need to reach their goals, become more independent, and continue to be an active member of their community.

“When my mom passed away, it was and still is very hard for me.”

Sustaining Supports. When natural supports or life situations change, it was important for people who self-direct to have a continuation

of supports to live a full life. It was also important that their supports were flexible to meet their needs at different times in their lives. Natural supports also provide a lot of day-to-day natural support for the person who self-directs. Day-to-day assistance from a natural support was essential for many people who self-direct because this is not provided in self-directed services.

Text box: 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.”

Respondents shared financial and personnel capacity barriers for independent living. Parents were concerned about where, with whom, and how their adult children would live without them. Finding, hiring, training, scheduling, supervising, mentoring, filling in, and firing staff is challenging for many natural supports.

“Staffing is often difficult to find and keep.”

Funding for self-direction was a concern for many respondents. People were concerned about losing some or all services because of budget cuts. Since not all services were 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. Self-direction was too complicated for most people who received supports. The amount of paperwork was daunting and the reimbursement guidelines were confusing. 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.

special needs trusts, and ABLE accounts. In some situations, a team may be needed to replace the current natural support because of the significant time, effort, and expertise needed. Ultimately, incorporating intentional futures planning into the self-direction process could help strengthen the sustainability of self-direction across the lifespan.

Conclusion

Self-directed services are essential for people with disabilities and their families who would like more choice and control over their services. Natural supports provided a significant amount of unpaid work and personal care to support the person who self-directs. They had many concerns about the future, such as trusting someone else to care for the person, selecting the next natural support, preparing for the transition to the next natural support, maintaining the person's quality of life, and sustaining supports. To strengthen the sustainability of self-direction, additional planning and support is needed for the transition to the next primary natural support. Families could better plan and prepare for the future with the support of additional information, resources, and guidance from self-directed services. This could include training about documentation, financial planning, wills, housing options,