

Plans for Sustaining Self-Direction

Self-direction is a Medicaid service option in which people with disabilities directly manage their supports. In this service option, people with disabilities are often supported by a primary natural support, such as a parent, sibling, other relative, or friend. People who self-direct their services typically recruit, hire, train, and supervise their own staff. While self-directed services have significantly enhanced the quality of life of people with disabilities and their families, little is known about the plans that families make to sustain self-direction throughout an individual's lifespan.

The purpose of this study was to understand (a) the plans for sustaining self-direction for people who have not transitioned from one primary natural support to another, and (b) what worked and did not work for those who have already made that transition. In 2020, 1,700 people participating in New York State's self-direction plan were surveyed about their experiences with self-direction, including questions about the sustainability of self-directed services. People with disabilities and their primary natural supports (e.g., parent, sibling, other relative, friend) were asked to complete the survey from the perspective of the natural support. The survey asked respondents to describe their plans for sustaining self-direction after the primary natural support can no longer provide assistance. It also asked respondents who had transitioned from one primary natural support to another to share what did and did not work during the transition. There were 413 respondents who answered quantitative questions about the sustainability of self-

direction. There were 290 respondents who had not made the transition from one primary natural support to another; they shared their plans for sustaining self-direction in the future. Among the respondents who have transitioned from one primary natural support to another, 41 shared what worked during the transition and 37 shared what did not work.

Sustainability Plans

Respondents shared their plans for sustaining self-direction. They described the documentation and contents of their plans, the importance and challenges of identifying a replacement natural support, and acknowledged that many of their plans were still a work in progress. Ultimately, the purpose of planning was to ensure the highest quality of life across the lifespan of the person who is self-directing. The planners wanted the person who is self-directing to "have a fulfilled life and be treated with respect and care to the highest level."

The Plan

Respondents described the documentation they had in place and the important aspects of their plans, including the people who would be involved, staffing, housing, day-to-day responsibilities, and preparations for the person self-directing.

Documentation was a large part of creating a plan for the sustainability of self-direction. The amount of documentation was substantial, with one participant noting, "I have a file cabinet of plans." Sometimes the documentation was

informal, including contact information and the person’s daily routine, therapies, medical information, and food restrictions. Formal documentation included a special needs trust, a pooled income trust, guardianship, power of attorney, a will, living wills, and Achieving a Better Life Experience (ABLE) accounts.

Family members were often reported as the people who would eventually take on the role of natural support. They would also fill roles such as formal guardians and serve as trustees. Other important relationships included friends, brokers, care coordinators, and staff.

Finding and maintaining reliable staff was important for sustainability. The natural support was key to manage and fill in for staff: “When staff cancels, there is no back up plan other than natural supports.”

Housing was included in plans to ensure the person self-directing continued to have “a safe place to live.” Families purchased a home, willed the family home to the person, or altered their existing home to “make a separate part of the house for him.” One participant shared plans to “build an uncertified residence with 12 apartments” specifically for people who were

self-directing. In some cases, the person would need to be placed in a residential home.

Support for the coordination of services and daily oversight were planned. This involved paying bills, finding daily activities, and managing logistics such as determining if activity fees were reimbursable and finding staff.

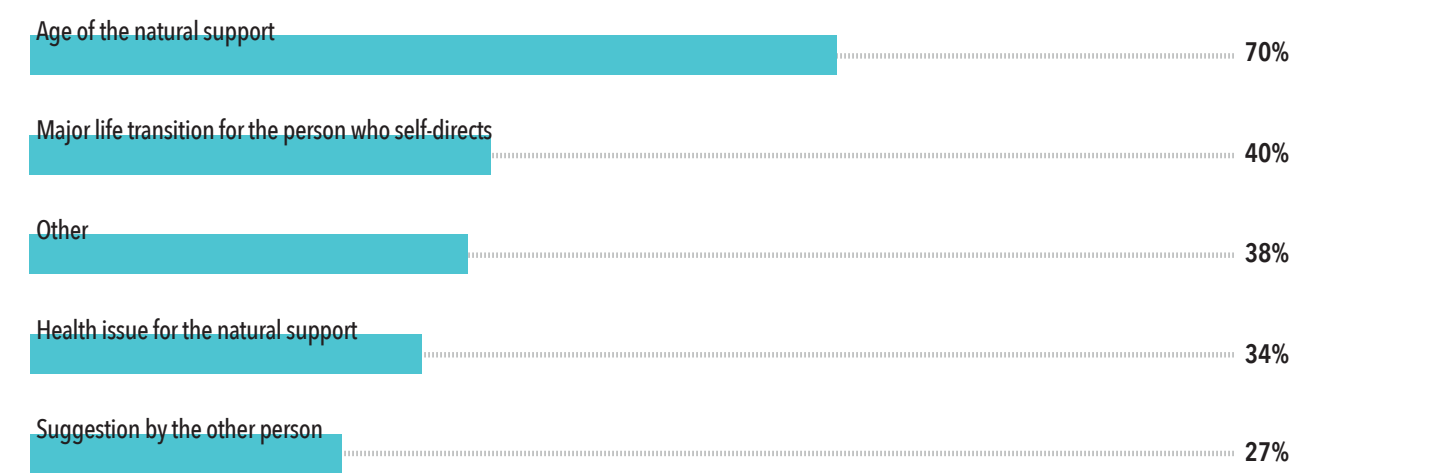
Natural Support Replacements

Respondents selected the reasons they began planning for the next natural support (see Figure 1). Overall, the age of the natural support was the primary reason they began planning.

Sixty percent of respondents said that siblings would take on the role of the natural support in the future and 40% said siblings would not be a natural support. Trusted non-siblings who could be a future natural support for people self-directing included their other relatives (61%), friends (22%), neighbors (2%), and other people (16%).

Plans for identifying a replacement natural support ranged in levels of preparation, with a need for flexibility. In some cases, the person who was self-directing was still a minor, and plans would change as the person ages.

Figure 1. Reasons for Planning Natural Support Replacement



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

Other respondents noted that the selected person might not be able to take on that role permanently. Barriers to selecting a natural support included the time commitment and complexity of implementing the plan.

Several respondents planned to have a team of people take on the natural support role. They divided aspects of running a self-direction plan across several people, appointing specific people to carry out specific functions. This meant hiring more professionals, sharing roles across various family members, or “re-building their Circle of Support.”

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 or hoped that it would all work out, even with no plan in place.

Many respondents had “loose plans but nothing solid.” One parent noted that “if one of us dies, the other will have to set more concrete plans.” Some respondents had part of a plan in place, but nobody to run the self-direction plan. Other respondents had people identified, often suggesting a guardian or other family members who they hoped would take the lead, but had no concrete plans written. They worried about the “burden” the role of a replacement natural support would place on others, especially siblings of people self-directing. Some respondents felt that they had no options for putting a plan into place. They described how difficult it would be for another person to take on their role.

Respondents were unsure of how pieces of the plan would be carried out once they no longer managed it. Many respondents spent a lot of time finding and coordinating daily activities. Most respondents were hopeful that self-direction would continue, whether or not a concrete plan was in place. Some had a developed plan and hoped that it would be carried out the way they

intended. Others hoped that another person would step up to take on the responsibility.


Text box: “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?”

What Worked and What Didn’t Work

Respondents who had transitioned from one natural support to another were asked what worked—and didn’t work—during the transition. Preparation was essential for the transition. Meetings with the Circle of Support helped to educate everyone on various aspects of the plan and how to keep it running. A Circle of Support is a group of people that the person chooses to help them make life decisions. Documentation also helped. When the replacement natural support was not included in the day-to-day aspects of the plan, the transition didn’t go smoothly.

Many respondents described how formal and informal teams came together to support the transition of natural supports. Others had experiences where people did not step in and supports did not go as planned. Sometimes a family member did not want to take on the role or there was “no one to help when staff was ill.” Even well-thought-out plans did not always work out as some pieces “fell apart almost immediately.” Some respondents were not able to access services during the transition of natural supports because they were not able to get forms or did not understand the self-direction process.

It was important to remember the emotional aspects around the loss of a natural support. Simply being “able to have a proper funeral



[and] mourning period” helped one person with the grieving process. In another case, the fiscal intermediary helped a man “better understand the death of his brother.”

The transition of natural supports was affected by the independence of the person self-directing. Some felt that self-direction could not function without a natural support because the person who was self-directing “can’t do it on his own.” Other natural supports were working with the person who is self-directing to take on more responsibility. One participant pursued their own independence, saying, “I took a chance and walked to the stores by myself.”

Conclusion

People with disabilities and their natural supports in New York State shared their plans for sustaining self-direction after the primary natural support is no longer able to serve in that role. The purpose of a sustainability plan is to ensure the highest quality of life for the person who is self-directing. Practical implications for families planning for the sustainability of self-directed supports through the transition of natural supports include:

- Incorporating intentional planning into self-direction plans
- Providing information for families to plan sustainability and transitions
- Strengthening the Circle of Support through regular meetings
- Documenting contact information for staff, healthcare providers, and everyone involved in the self-direction plan
- Training natural supports and other family members about preparing for the future, including financial planning, wills, housing options, special needs trusts, and ABLE accounts
- Planning to support the person who is self-directing during the grieving process