SELF-DIRECTED SERVICES
Challenges and Training Needs

Self-direction is a Medicaid service option where people with disabilities and their families select, purchase, and manage their own supports using individually-set budgets. They also typically recruit, hire, train, and supervise their own staff. While self-directed services enhance the quality of life of people with disabilities and their families, it is important to learn about the challenges they face using self-directed services and the training they need.

The goal of this study was to better understand the challenges faced by people who self-direct and their natural supports when using self-directed services and what training topics would help support self-direction. In 2020, 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. There were 413 respondents who answered quantitative questions about the sustainability of self-direction. There were 238 respondents who wrote comments about using self-directed services compared to traditional services, which were used to determine specific challenges in self-directed services. There were 97 who shared one or two training topics they would like to have presented by their fiscal intermediary.

Challenges of Using Self-Directed Services

The challenges of using self-directed services include time-consuming and confusing processes, budget and reimbursements difficulties, lack of funding for specific services, and managing staff. People experienced the following challenges: paperwork (84%), staffing (83%), rule changes in self-directed services (80%), individual goods/services considered disallowable (71%), budget issues (68%), complicated reimbursement process (53%), need more case manager support (47%), and not enough money in the budget to hire or reach goals (46%, see Figure 1).

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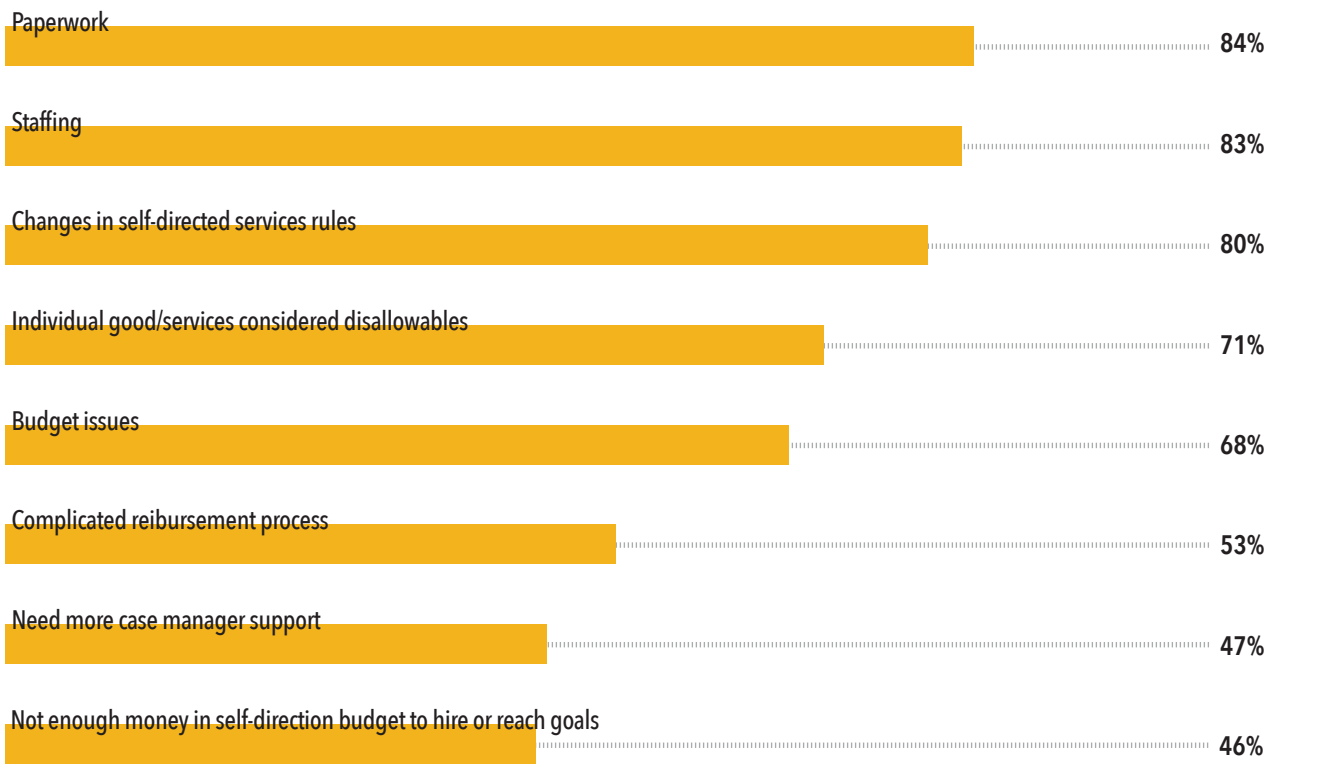
Figure 1. Challenges of self-direction

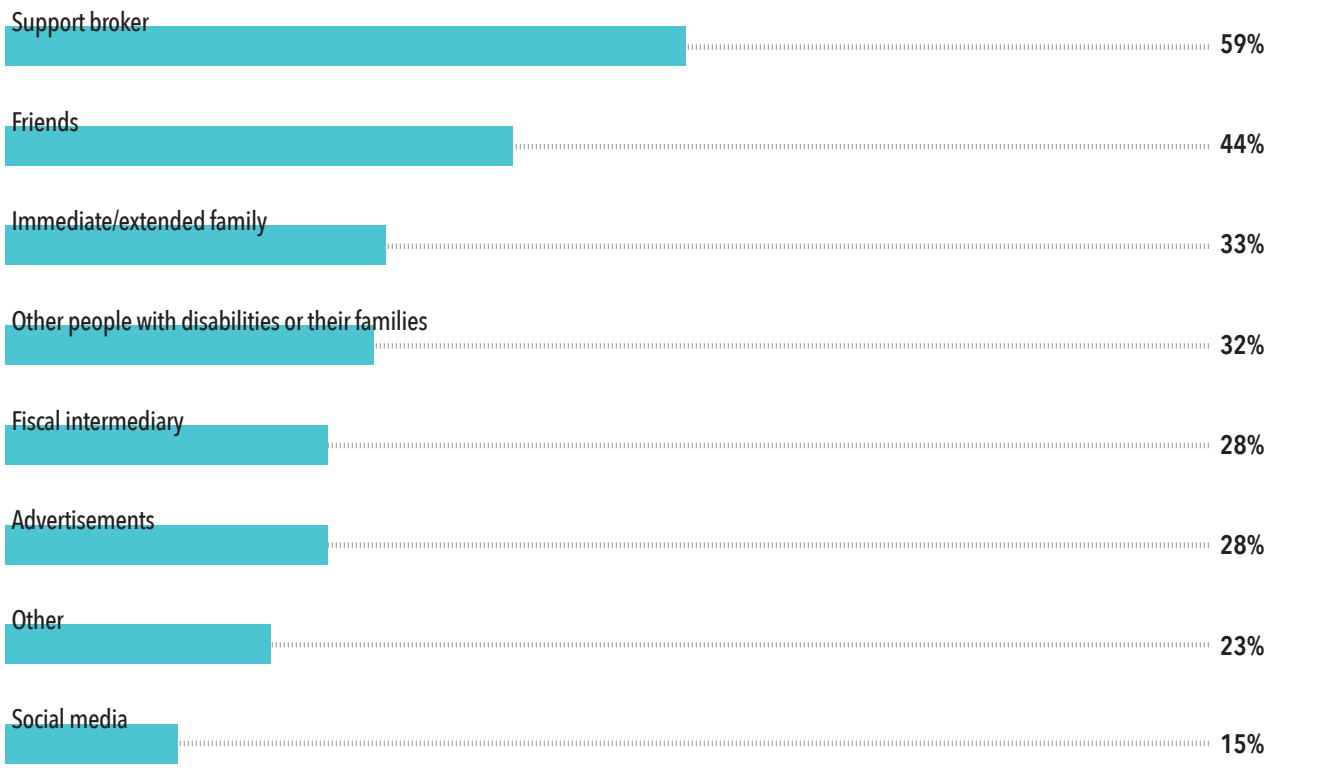


Time-Consuming and Confusing Processes. Creating schedules for staff, learning about the budget, and completing the paperwork were all time-consuming for respondents. Many families acknowledged there was a steep learning curve when beginning self-directed services. Respondents found the paperwork overwhelming; there was too much, the budget was cumbersome, and not all forms were online. The process was confusing to many people because of their lack of experience or understanding of the rules, unclear reimbursement guidelines, frequent changes, and the overwhelming amount of information. Because of this, most people needed a natural support for self-directed services to work.

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 some line items in the budget could not be adjusted. Respondents were also concerned about having the funds to sustain housing in the future. The lack of funding for specific activities means that families need to pay with their personal funds or the person would not be able to participate. The budget and funding guidelines did not allow for activities designed specifically for people with disabilities, which were a preference for a few people. Crisis intervention and guidance was not available in times of need, such as during the pandemic. Reimbursements included completing extra paperwork and took a long time.

Managing Staff. Specific challenges in managing staff included 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 staff turnover was a significant problem. In self-directed services, there were no back-up staff if people were sick or if staff left. Training staff was challenging because it was not available through an agency. Not all families have the time, resources, knowledge, or skills to conduct training.

Figure 2. Where people self-directing find new staff



Respondents identified where the person who self-directs typically finds new staff. They found staff through support brokers, friends, family members, other people with disabilities or their families, advertisements, fiscal intermediary, social media, and other ways. Respondents were also asked how they delivered training to staff. Overall, respondents provided the majority of training, followed by training from a support broker, conferences or workshops, a consultant/outside agency, family or friends, online, or other sources.

Training Topics for Self-Directed Services

Respondents shared training topics, not already required, that they would like their fiscal intermediary to present. The topics fall into five areas: person-centered thinking, support skills, community living, health and wellness, and self-direction procedures. While some training topics may be specific to staff e.g., staff professionalism) or natural supports (e.g., self-direction procedures), other trainings may be opened to whomever would benefit from the information.

Person-Centered Thinking

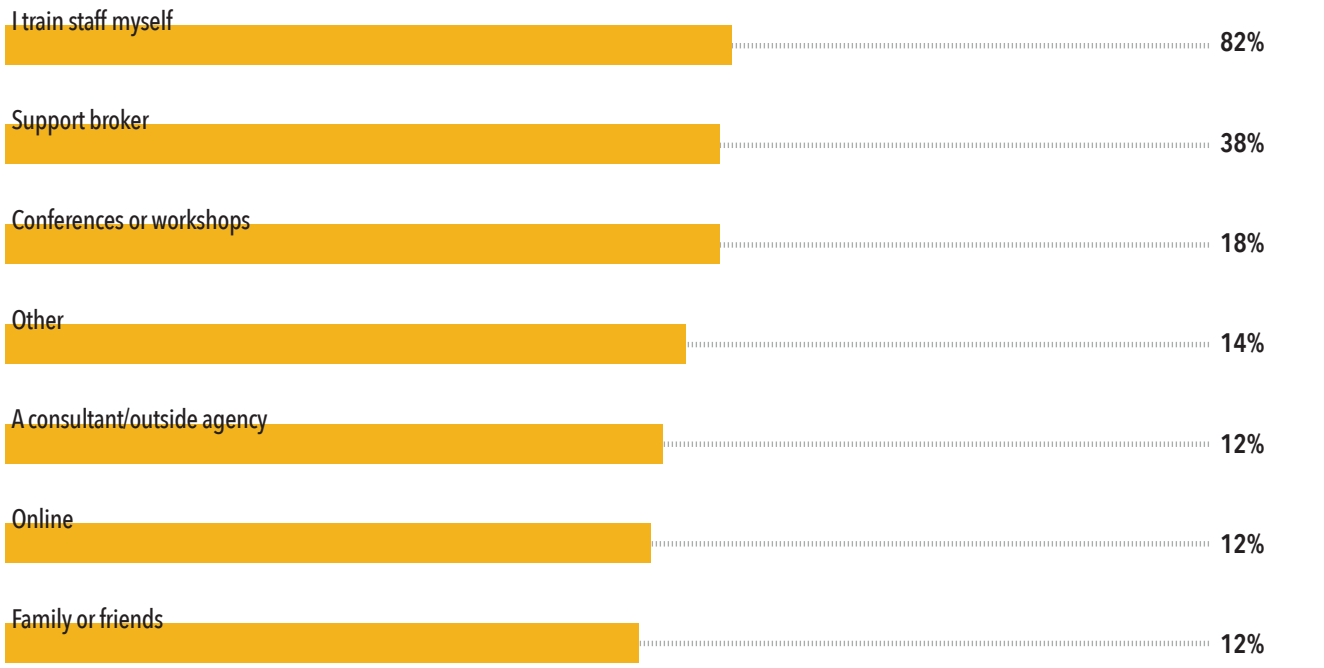
Respondents wanted to learn about specific disabilities, common supports, and how to focus on the individual's personal interests and goals.

- Understand the characteristics and needs of specific disabilities, how people may be affected, and common supports people may receive.
- Use person-centered thinking and planning to learn about the individual's strengths, interests, and personal goals to better support the individual.

Direct 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

Figure 3. Who trains staff?



access to training in ethics and competencies for direct support professionals.

- Develop knowledge and skills in order to directly support people with a particular disability or support need.
- Use positive behavior supports to decrease negative behavior, increase positive behavior, and increase communication.
- Learn about competencies and ethics of direct support professionals so staff can better support the people they serve. Natural supports would also like training for themselves on using best practices for managing staff.

Community Living

Respondents wanted to learn more about finding 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.

- Know "how to find and keep a job" that is a good fit for the person.
- 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.
- Develop skills to teach and support activities of daily living.
- Develop knowledge and skills to facilitate relationships and access community resources and activities.

Health and Wellness

Respondents wanted to learn about supporting 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.

- Know how to find or provide emotional support for people with disabilities.
- Develop the knowledge and skills to support a healthy diet and exercise habits for people with disabilities.
- 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.

- Understand safety concerns and measures in the home and community, as well as "what happens in an emergency."

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 any changes and updates to the rules and procedures.

- Learn the rules and procedures of self-direction, related information, and ideas for successful self-direction during onboarding.
- Understand the budget, allowable expenses, "how the pay system works," and how to request reimbursements.
- Understand how to complete timesheets accurately.
- Learn how to prepare for the future, including options available, steps to take, and considerations for planning.
- Keep updated on any changes to self-directed services.

Conclusion

Self-directed services allow greater choice and control for people with disabilities. People who self-direct and their natural supports would benefit from additional information and training to learn more about how to manage self-direction and work through challenges.

The challenges of using self-directed services include time-consuming and confusing processes, limitations of the funding structure, and managing staff. People who self-direct and their natural supports believe the benefits of using self-directed services outweigh the challenges. Though it may take more time and effort, self-direction provides opportunities for increased choice, control, and self-determination of people with disabilities and their families.