

# Experiences with Self-Directing Supports During the COVID-19 Pandemic

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## BACKGROUND

People in New York State who used self-directed supports and their natural supports (e.g., parent, guardian, sibling, other relative, ally) completed a survey about their experiences with self-direction. Most participants were a natural support, defined as the lead, unpaid person who provided support to someone using self-direction. Questions about emergency preparedness and experiences with self-direction during the COVID-19 pandemic were included. There were 282 participants who answered at least one question related to emergency preparedness or COVID-19 experiences.

## METHODS

The survey collected both broad quantitative trends in self-directed supports and qualitative responses of individual experiences. Information was gathered to better understand the impact of the COVID-19 pandemic on self-direction in New York State and lessons learned about emergency preparedness. Descriptive analysis was used to summarize the quantitative data. The researchers used a multi-stage process of open and axial coding to analyze the open-ended survey questions and identify themes.

## RESULTS

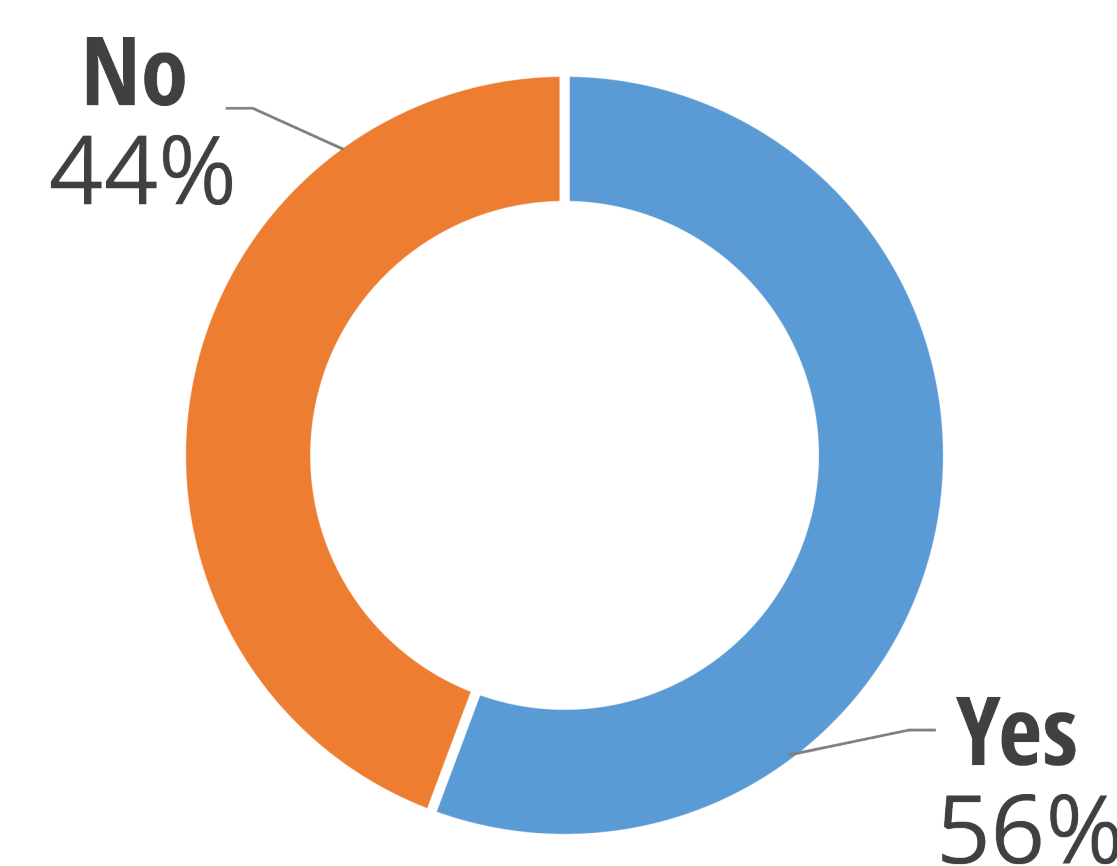
People with disabilities and their families enjoyed the choice and control self-direction gave them in decision-making for precautions for COVID-19. However, self-direction often relies on a family member or other caregiver to help manage the self-direction plan. This presented challenges due to the nature of COVID-19. Several themes emerged around the role of natural supports in emergency planning as well as considerations for staffing, accessing the community, and considerations for accessing services in an emergency. The survey was fielded in Fall 2020. Therefore, results reflect experiences up to that point in the pandemic.

## THEMES

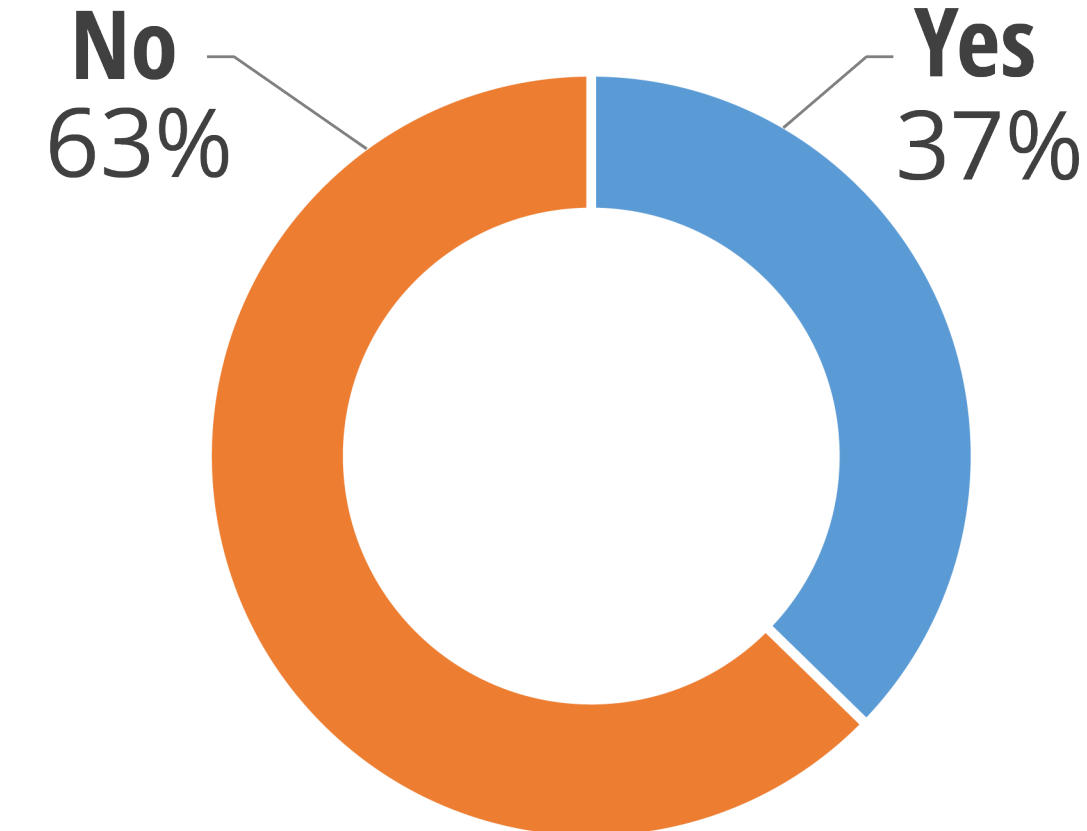
### Planning Process

Experiences ranged from feeling “well-prepared” to feeling that the pandemic was so unexpected that there was little planning that could be beneficial. For some, experiencing the pandemic demonstrated the importance of planning, motivating them to develop a disaster preparedness plan. Planning must include everyone who will provide support. While having a plan provides support and reassurance to families, managing stress and anxiety was unable to be addressed in a plan.

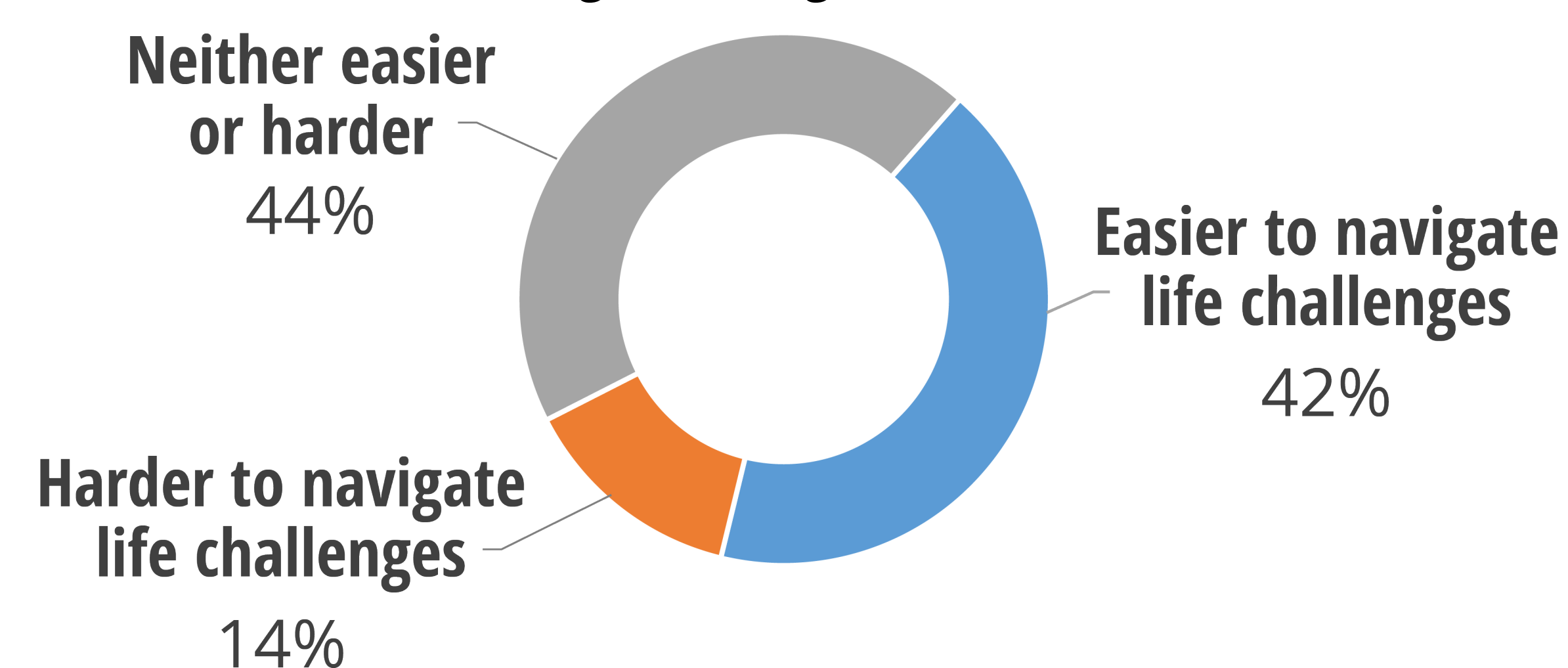
**Figure 1. Percent with an Emergency Preparedness Plan**



**Figure 2. Percent who used Disaster Preparedness Plan During Pandemic**



**Figure 3. Impact of Self-Direction on Navigating Life Challenges During the Pandemic**



### Daily Life

Several aspects of daily life were impacted by the pandemic. Living arrangements for the person who self-directs were impacted. In some cases, the person self-directing moved from independent living into their family home to ensure adequate support. In other cases, people self-directing remained in independent living, unable to visit with family members during the early days of the pandemic.

Activities in the community, a key feature of self-direction, were not available during the pandemic. While disruption to routines and social experiences was significant, families and staff took creative approaches to coming up with safe, engaging activities.

Skill development for the person who self-directs was identified as a potential way to mitigate loss of staff or increased dependence on natural supports during an emergency such as the pandemic.

The health and wellbeing of people who self-direct and their families was impacted. Anxiety, fear, and stress increased as uncertainty about staying safe, upended routines, loneliness, and boredom set in.

**“I have made all of the adaptations in my life that were necessary for safety.”**

○○○

**“We were all home together for extended periods while navigating the uncertainty.”**

○○○

**“No work, no staff, no activities.”**

○○○

**“[He] lost all the community activities that he valued. His whole life changed and he did not leave our property for four months.”**

**“Nothing about Covid could be addressed in a plan.”**

○○○

**“It has driven us to come up with a plan for her future in case anything happens to my husband and/or me.”**

○○○

**“The parent worked endless amounts of hours for free.”**

○○○

**“If not for parents [our daughter] likely would have had to quit her part-time job. She is very proud as an essential worker.”**

### People

People played a crucial role in the continuity of self-direction during the pandemic.

Staffing during the pandemic was a critical issue for many people who self-direct. For some, staff were unable or unwilling to work. In many of these cases, natural supports became unpaid staff. Others were grateful for the flexibility of staff and willingness to continue working in the early months of the pandemic. Some families hoped that for future emergencies, they would have additional trained staff to serve as back-ups to ensure continuity of staffing and reduce reliance on natural supports.

Natural supports were critical during the uncertain first several months of the pandemic, filling in for staff though they could not be paid for the work that staff typically did. Natural supports taking on the role of staff allowed some semblance of self-direction to continue during the pandemic.

### Flexibility

Ultimately, the pandemic required a lot of flexibility from everyone in self-direction. Individuals, families, staff, and service providers continually adapted to changing daily activities, how supports and services were delivered, and their living arrangements.