

# COVID-19 Survey

**Supporting Self-Advocates, Families,  
Direct and Support Professionals  
Around Community Services  
During the Pandemic and Beyond**

October 16, 2020



Sponsored By:

**Vision for Equality**

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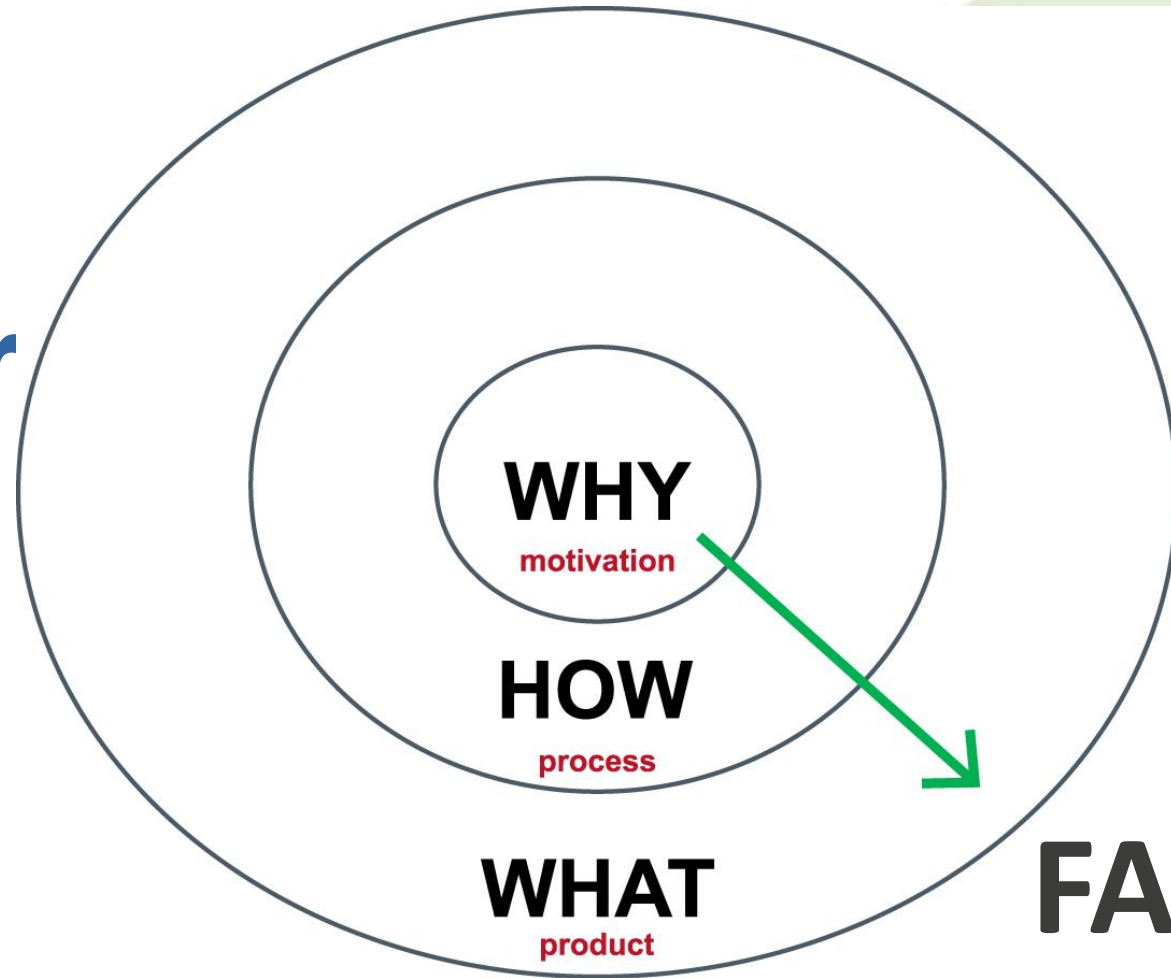


**Data reported June 2020**

Vision for Equality produced an independent statewide survey for self-advocates, families, caregivers and direct support professionals/service workers concerning the COVID-19 pandemic. The survey was not intended to be a scientific study.

**GOAL:** To gather real time information about their personal experiences during the stay-at-home order.

**What's our  
Why?**

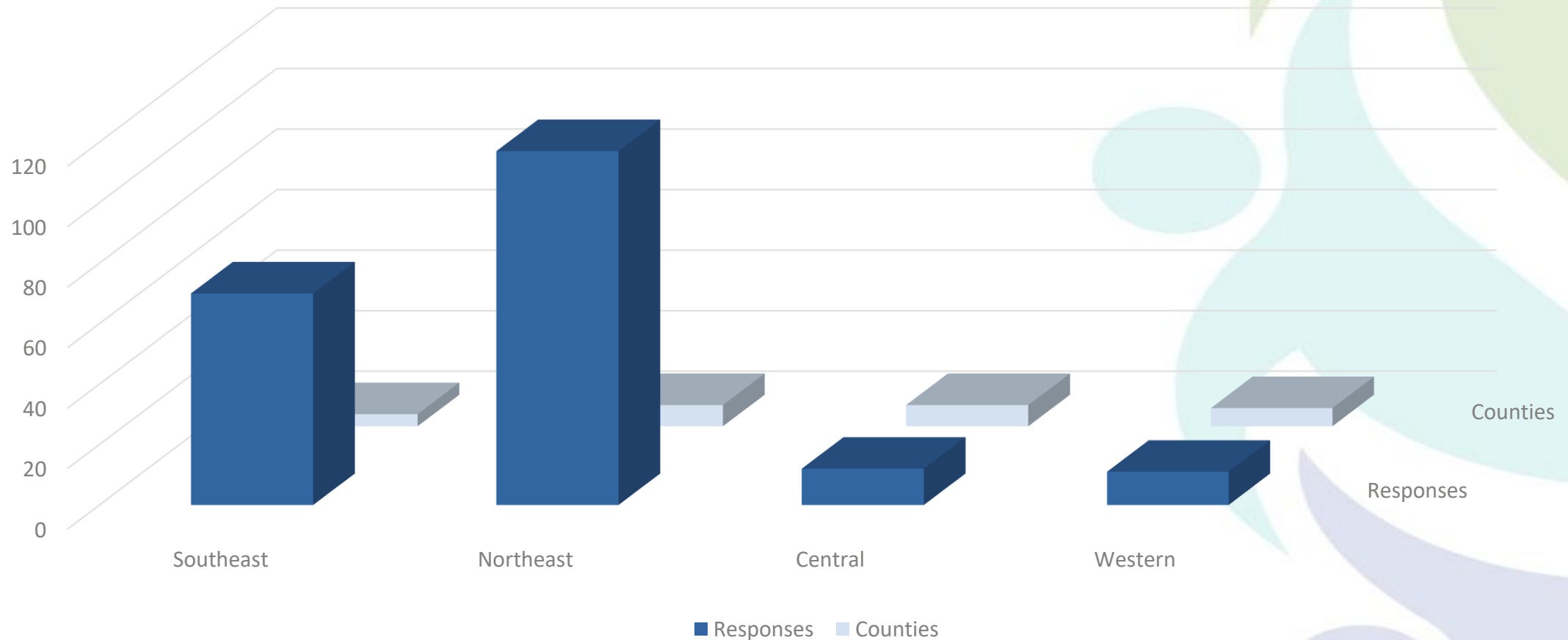


**FAMILY**

# Direct Support Professional/Service Worker Responses

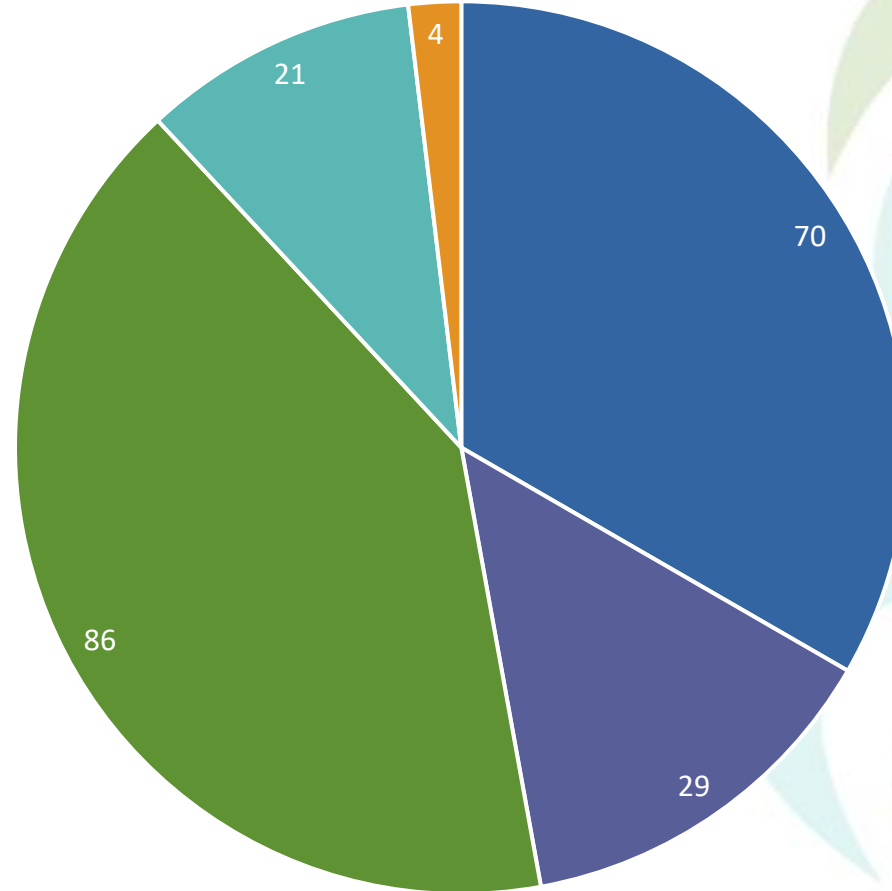
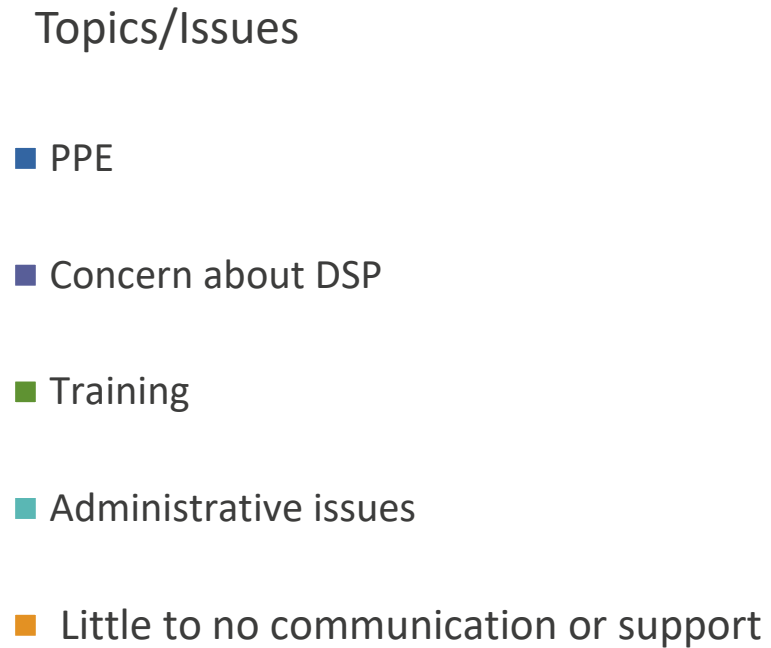
210 responses

24 Counties represented (35.8%)



# Communication from management

## 210 responses

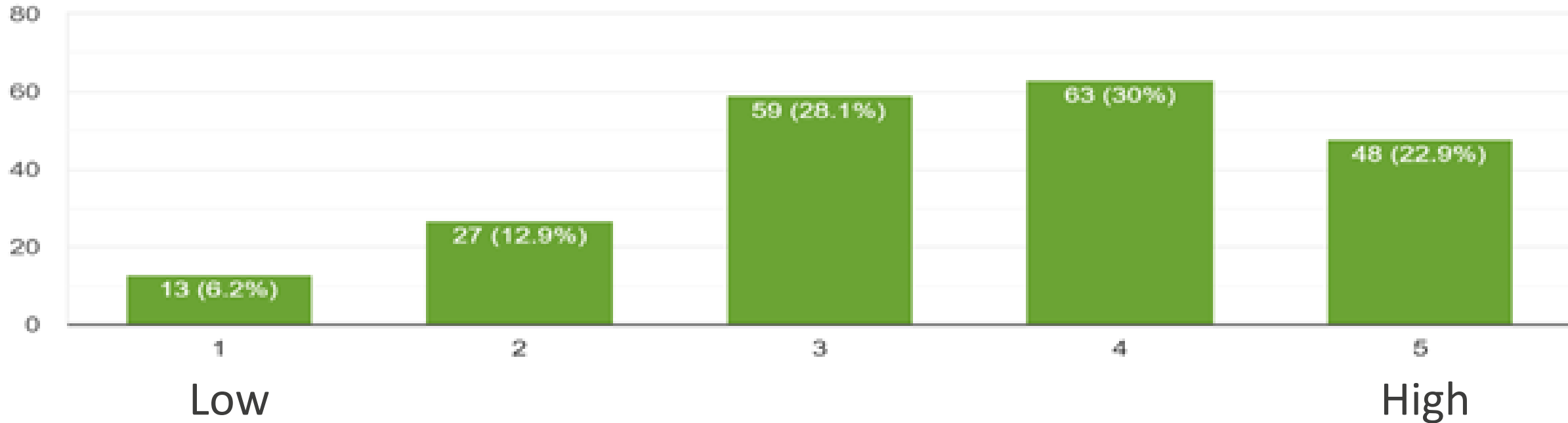


\*note: numeric value used

# DSP Coping

How would you rate your overall stress level since the stay at home order was issued? 1 being the least amount of stress and 5 being the most stress.

210 responses



# Describe Why You Rated the Above Question Related to Stress the Way You Did.

- “Because there was little to no support or empathy during the pandemic”
- “The complete disruption of daily life, work life, fear and all the extras steps and duties with little consideration of the workers.”
- “Risking our lives everyday but kept pushing through to help our clients”
- “Loss of income”
- “The conflicting information given to the public”

## Being an Essential Employee Also Meant

Serious concerns traveling during the stay at home orders and curfew enforcement...

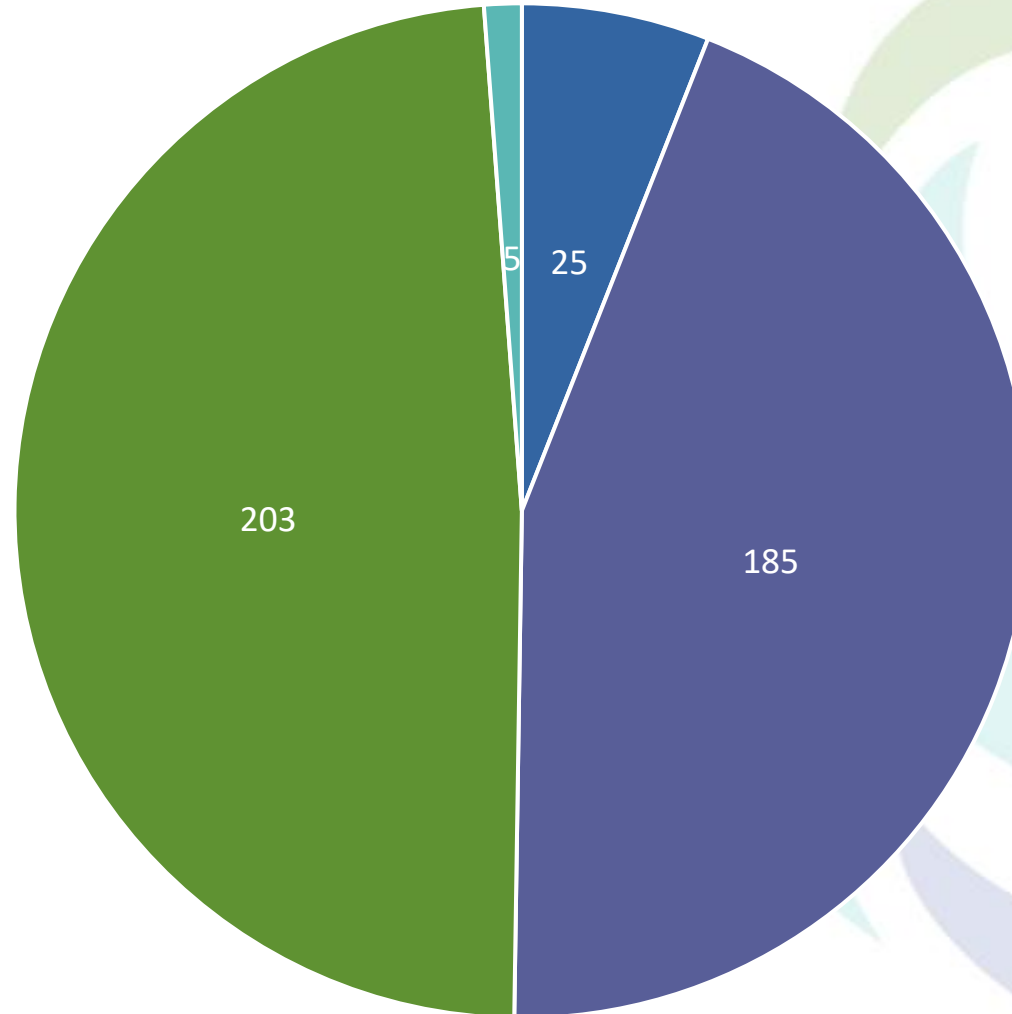
*“Fear of police harassment going to and from work during curfew hours.”*



# COVID-19 Experience

210 respondents gave multiple answers

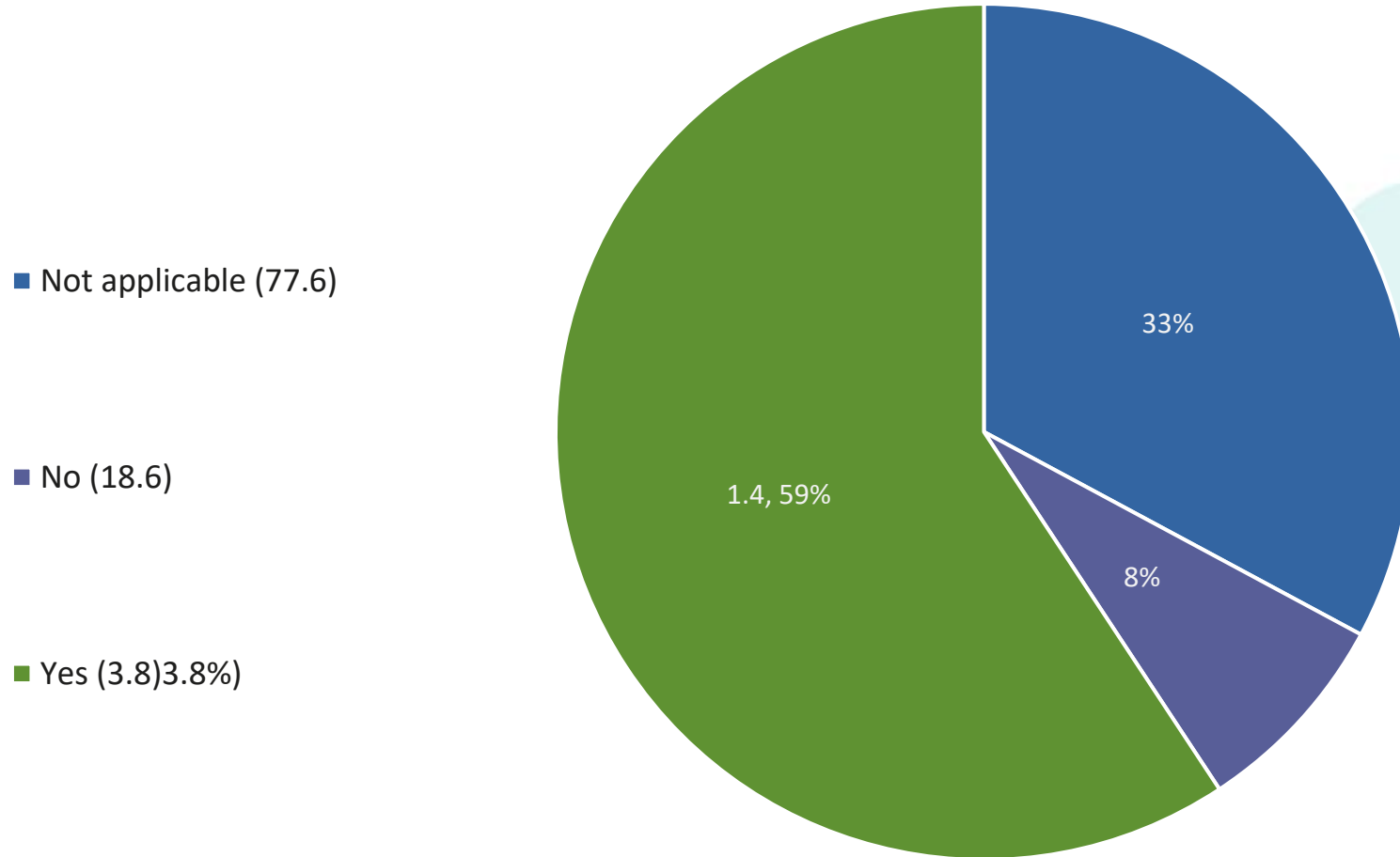
- Lost someone they knew (25)
- Did not lose anyone (185)
- Unknown/No dx (203)
- Not notified about exposure (5)



\*note: numeric value used

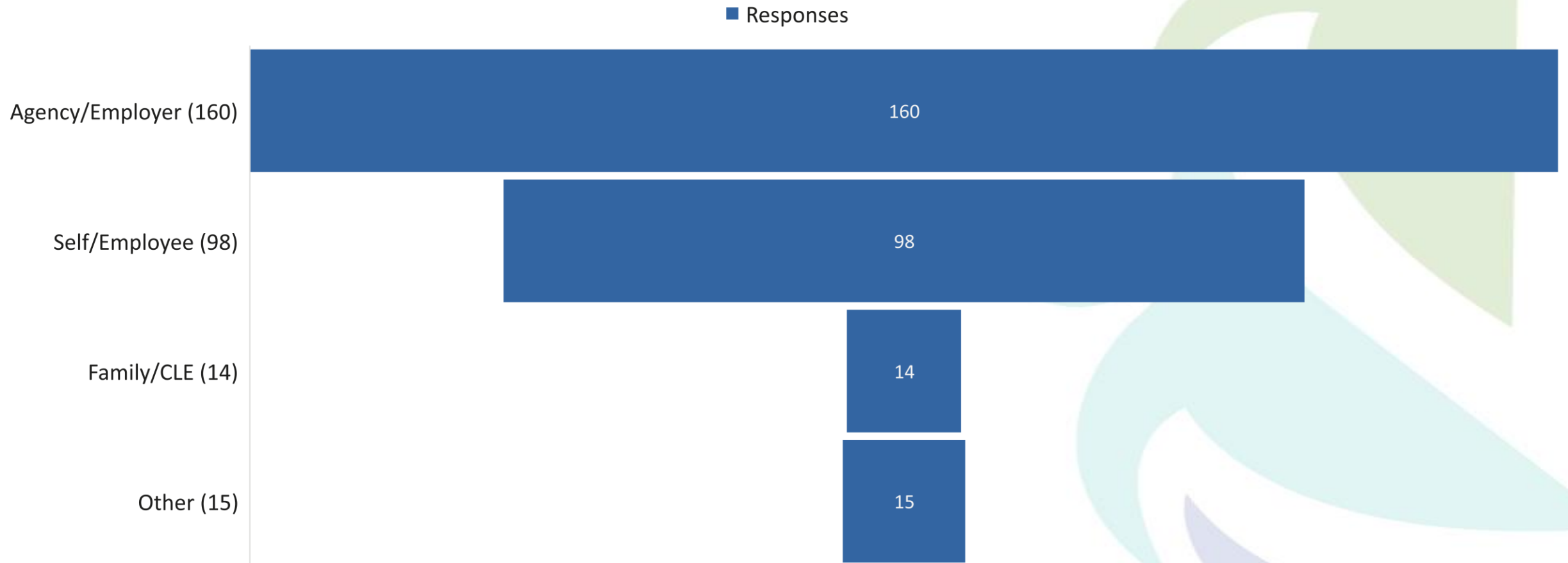
# Were you allowed to visit the person you supported during a COVID-19 in patient hospitalization? 210 responses

Percentages



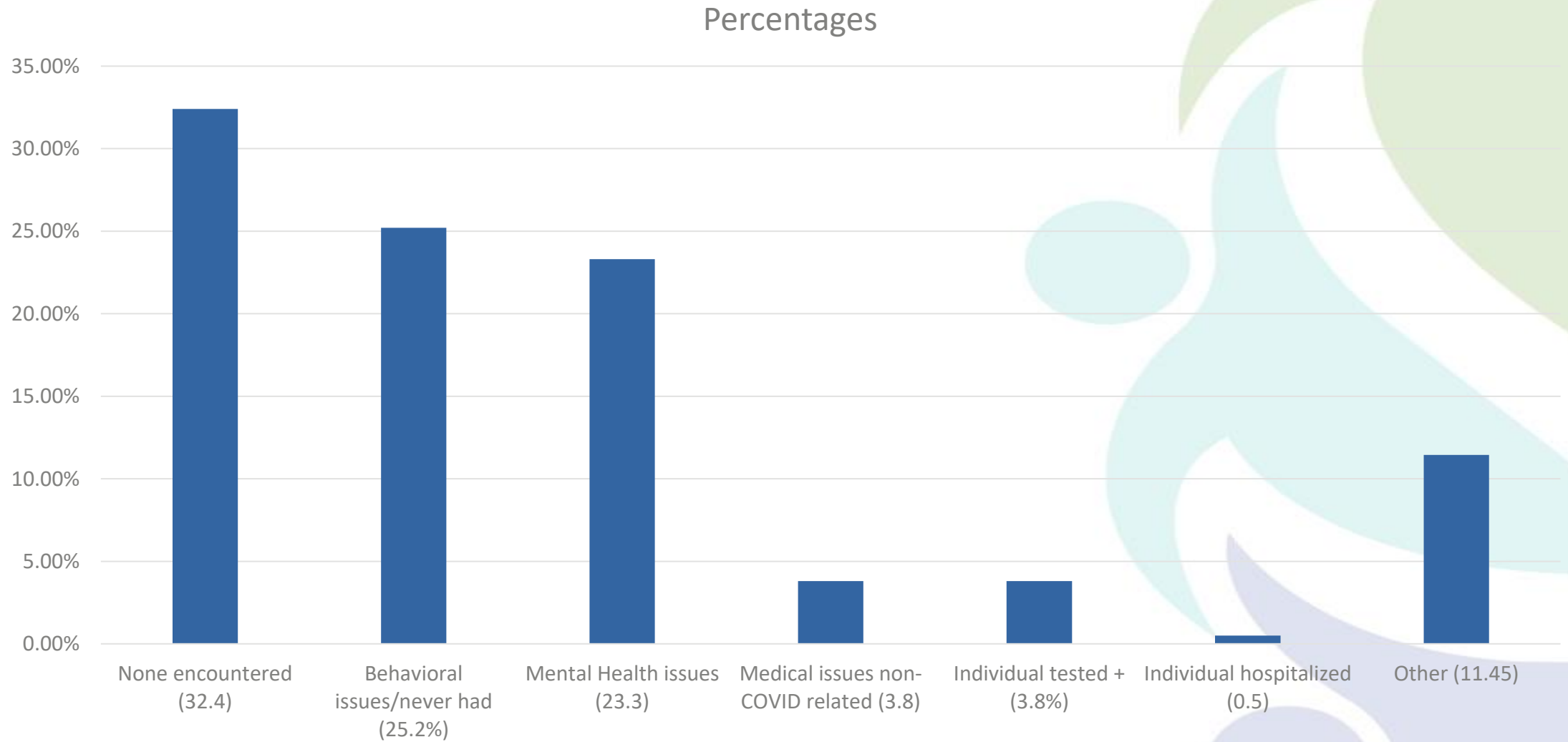
# Where did you get PPE/masks?

210 respondents/287 responses



Other:  
5  
Volunteers, non needed /virtual, union got involved,  
none were provided, got one in the beginning

# What out of the ordinary challenges did the person you support encounter? 210 responses



## How do we move the needle?



Double pay

Support

PPE supplied

Open door policy

Brainstorming

No support

No hazard pay

Hard work/

Supervisors at home

Little to no empathy

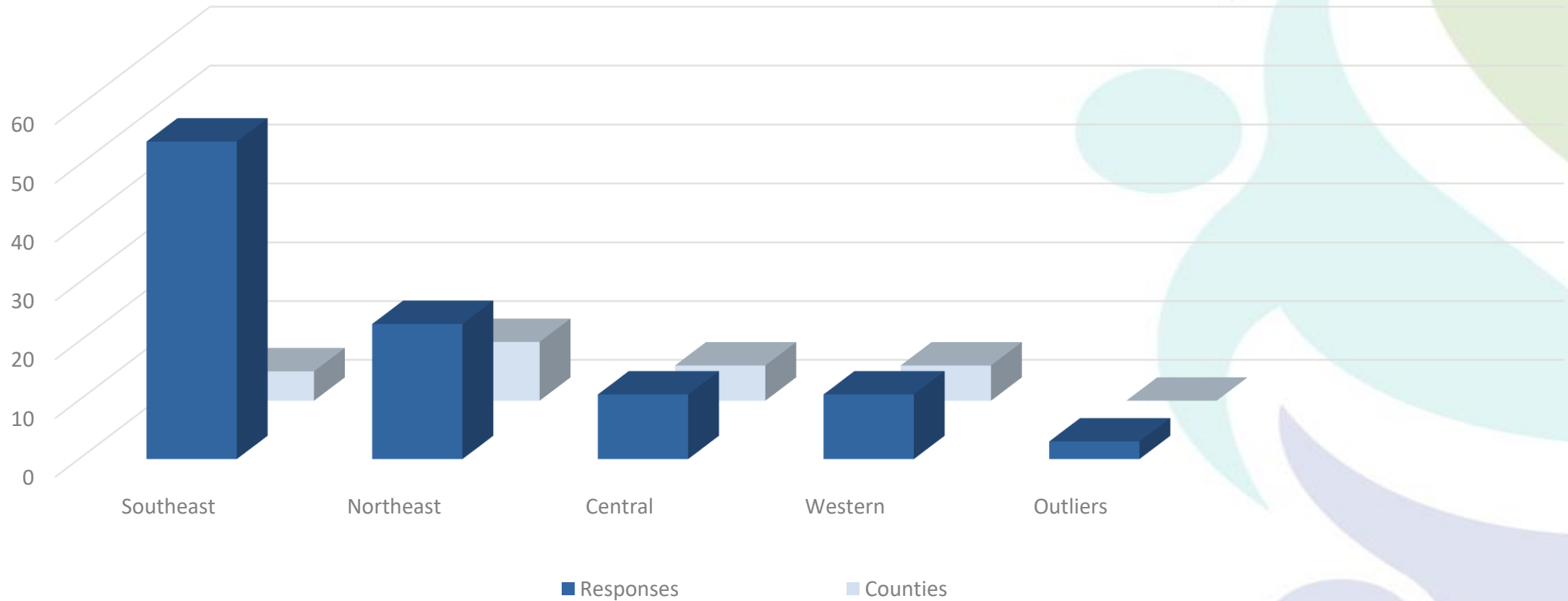


**Families are lifting the system, especially during the COVID-19 crisis**

# Family, Caregiver, Self-Advocate Responses

111 responses

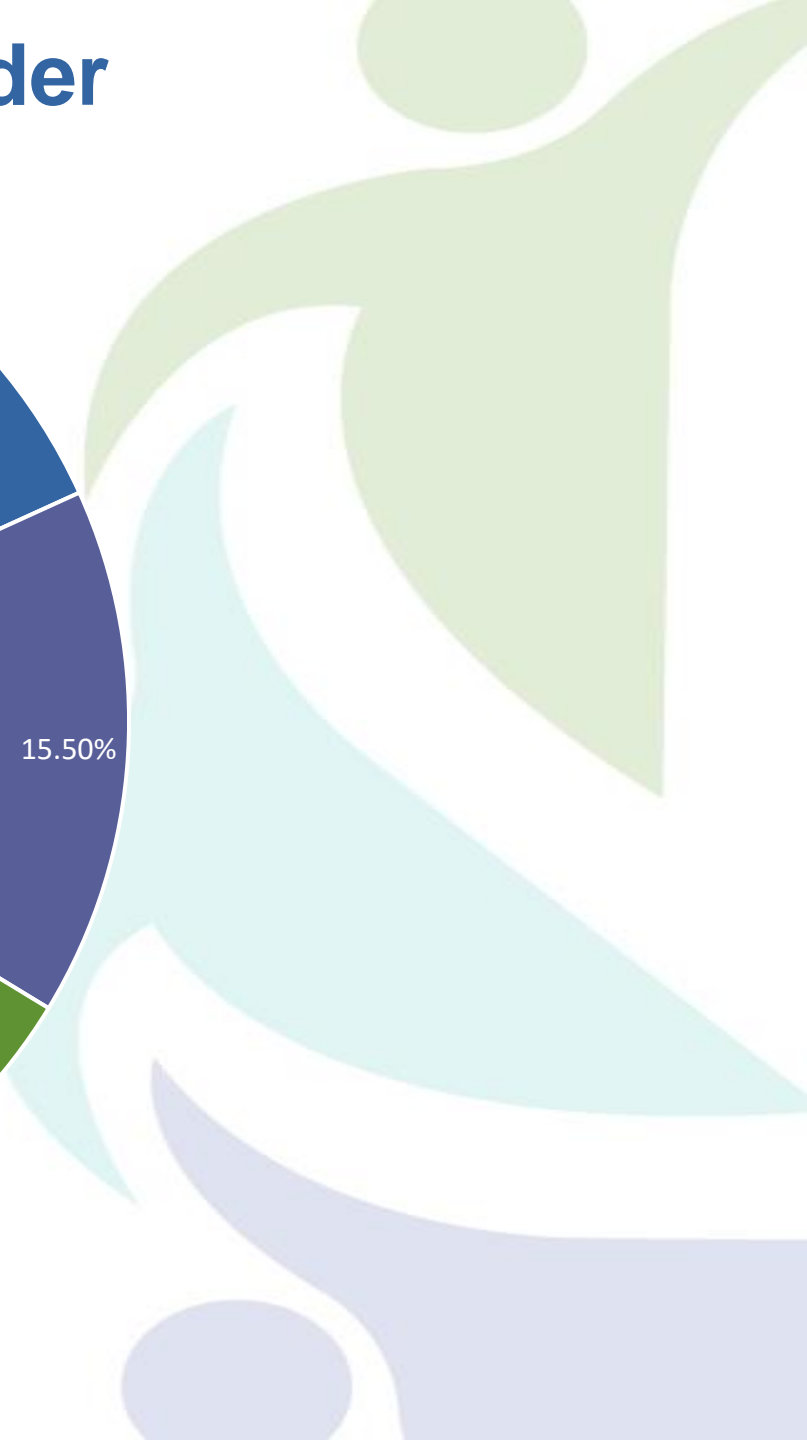
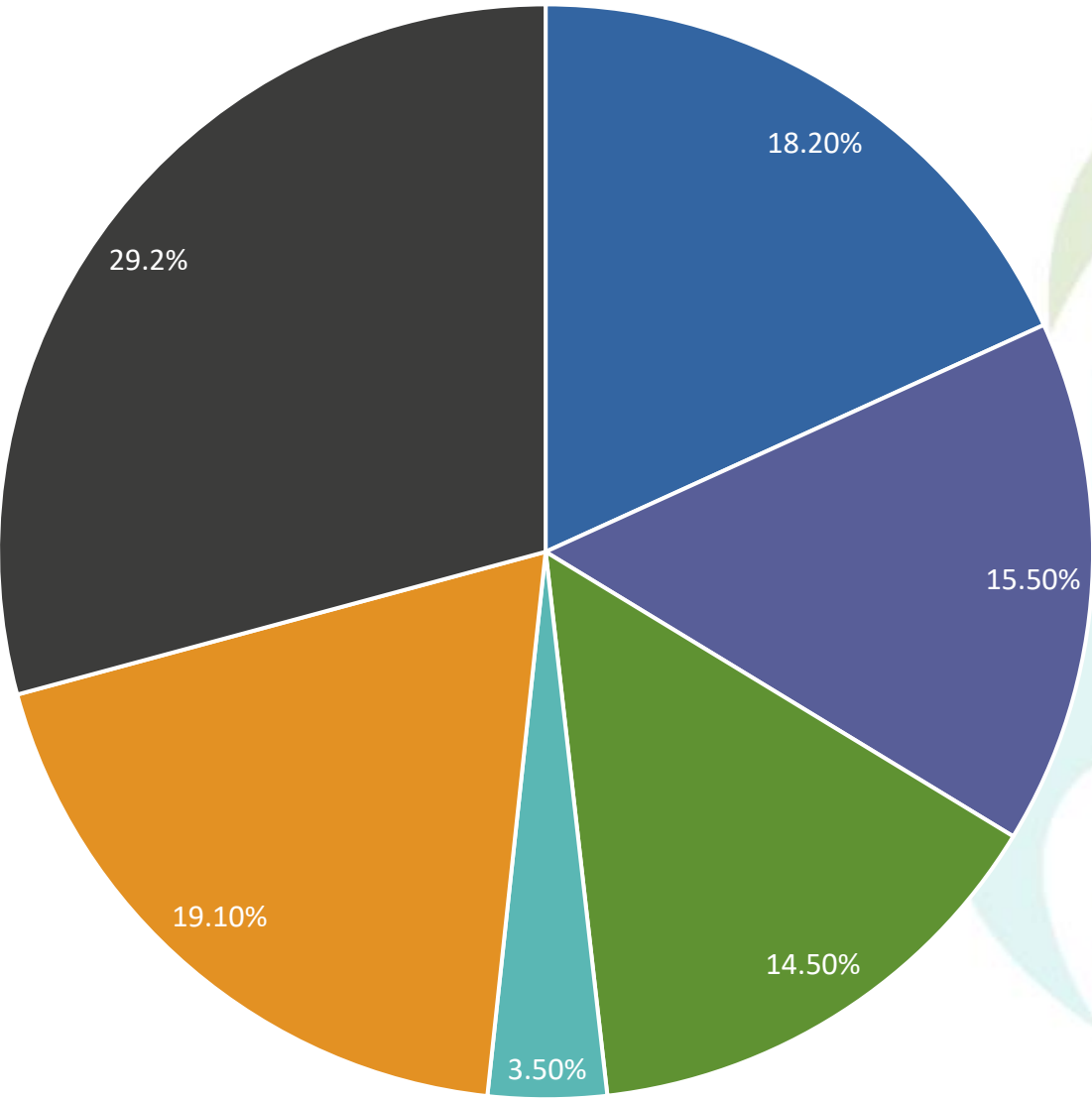
30 counties represented (44.8%)



# Services received during stay-at-home order

## 108 responses

- Self-direction/little disruption 18.2%
- Residential continued 15.5%
- In home habilitation 14.5%
- Companion 3.5%
- Nothing was offered 19.1%
- **Other 29.2%**



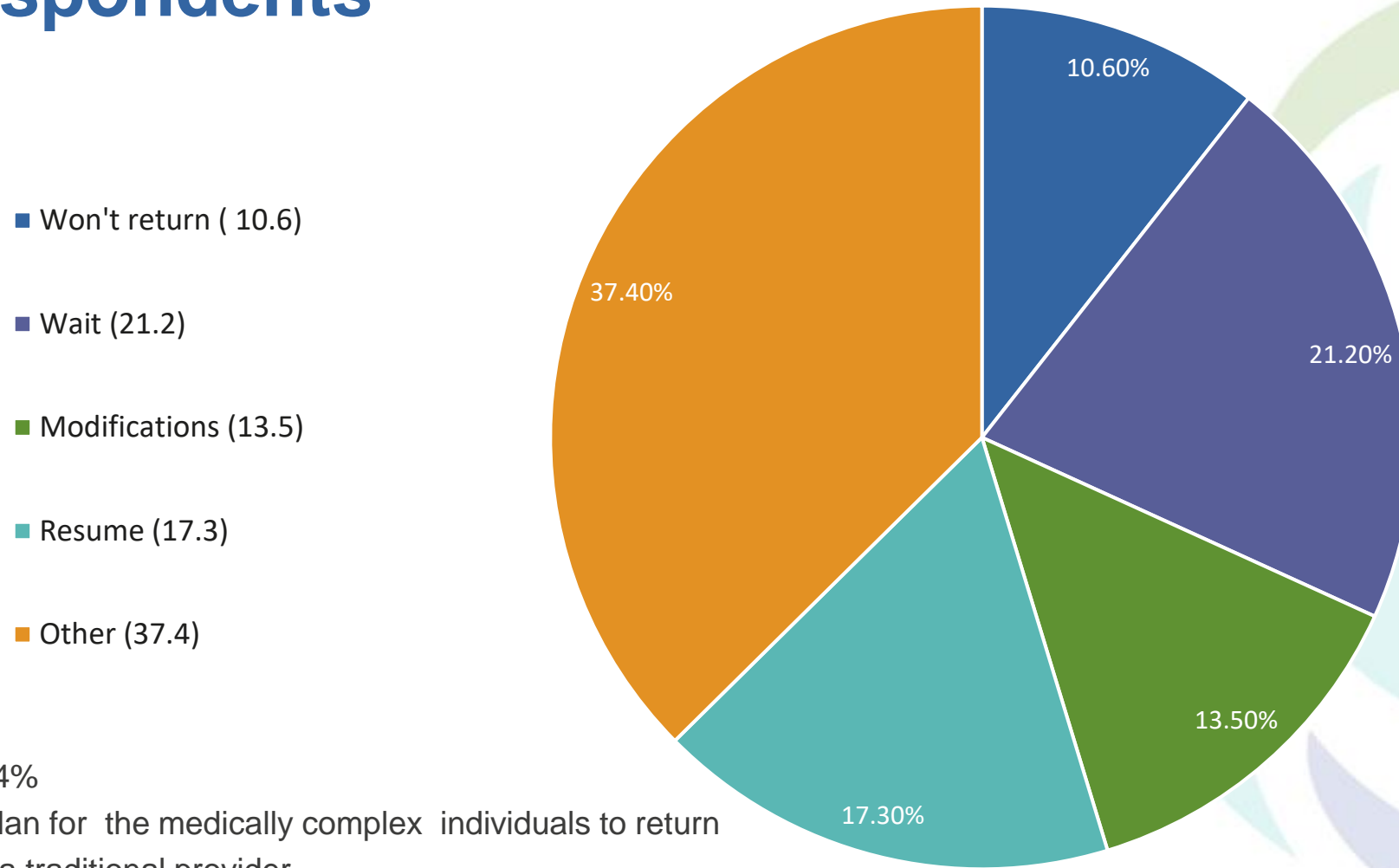


## Other: 29.2%

- A combination of remote services including behavioral health
- Outside respite
- **Services approved/NO staff**
- **Parents became staff**
- Online observation and advice
- Daily chats with CPS
- Personal care
- 1 hour per week check in



# When programs/services reopen 104 respondents



Other included: 37.4%

- Waiting for a plan for the medically complex individuals to return
- Will stop using a traditional provider
- Move to Self-direction and In-home supports

# Back to Normal?



# Communication

Not everyone has access to technology



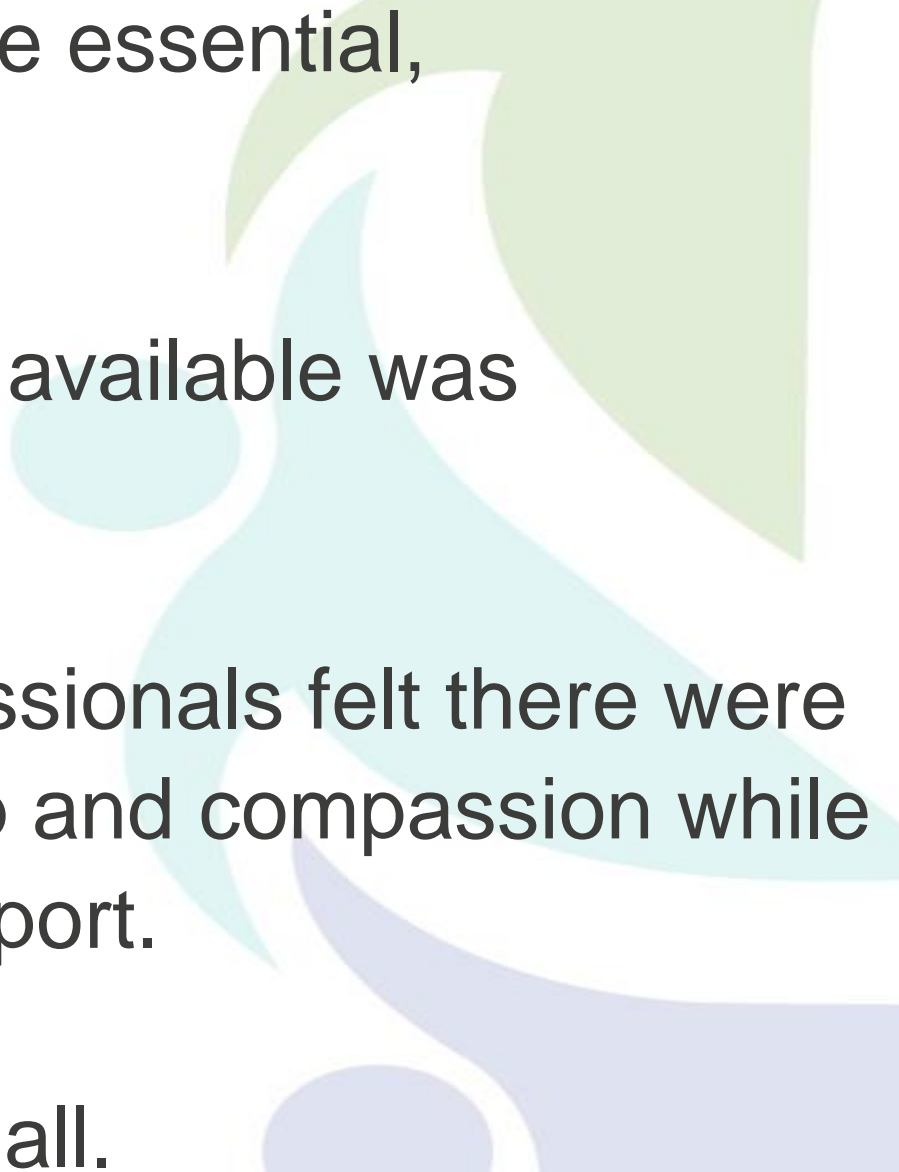
Most information was only in English



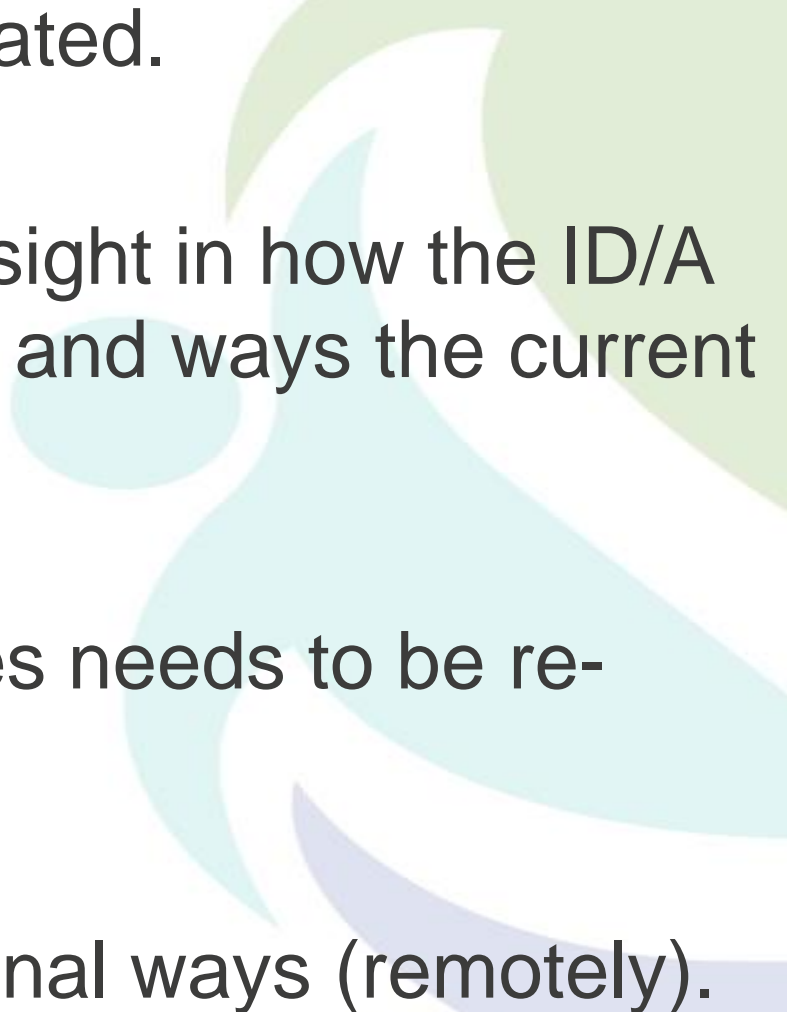
**Communication is a Problem**



## What we learned

- Direct Support Professionals (DSPs) are essential, undervalued and underpaid.
  - The support they offered families when available was appreciated and valued by them.
  - Some families and direct support professionals felt there were providers who demonstrated leadership and compassion while others left their staff with little to no support.
  - Communication must be accessible for all.
- 

## What we learned

- Family supports cannot be under-estimated.
  - Family experiences provide valuable insight in how the ID/A services can be modified going forward and ways the current system can be improved.
  - The traditional way of delivering services needs to be re-evaluated.
  - People can be supported in non-traditional ways (remotely).
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Despite challenges, little to no services, increased stress and sometimes experiencing their own medical problems...

**Family Caregivers did not consider institutionalization as an alternative service.**

## COVID-19 has Added Insult to Injury...

- **DSP Vacancy Rate**

**18 – 20%**

- **Turnover Rate**  
(annualized)

**55%**

**Direct Support Professionals (DSP) need a living wage to support our loved one's who experience a disability**





**Vision for Equality**  
Serving People with Disabilities and Their Families

We hope to utilize the results of the survey to create solution-based discussions and action with policy makers for Self-Advocates, Family Caregivers and Direct Support Professionals.

For follow up questions related to this presentation please contact:

Vision for Equality at

[Visionforequality@Visionforequality.org](mailto:Visionforequality@Visionforequality.org)