

Mental Health Effects

of the COVID-19 Pandemic on People with Down Syndrome and their Families

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Background: The COVID-19 pandemic has resulted in unprecedented impacts on the lives of people globally. One study of 46 adults with DS in Italy found worsening of depression, social functioning, and adaptive living skills (but improvement in aggression) compared to pre-pandemic levels (Villani, et al., 2020). More research is needed on the impact of the pandemic on the mental health of people with DS and their caregivers.

Methods: 261 parents/caregivers recruited through email and social media through DS support organizations completed online survey. Measures include the:

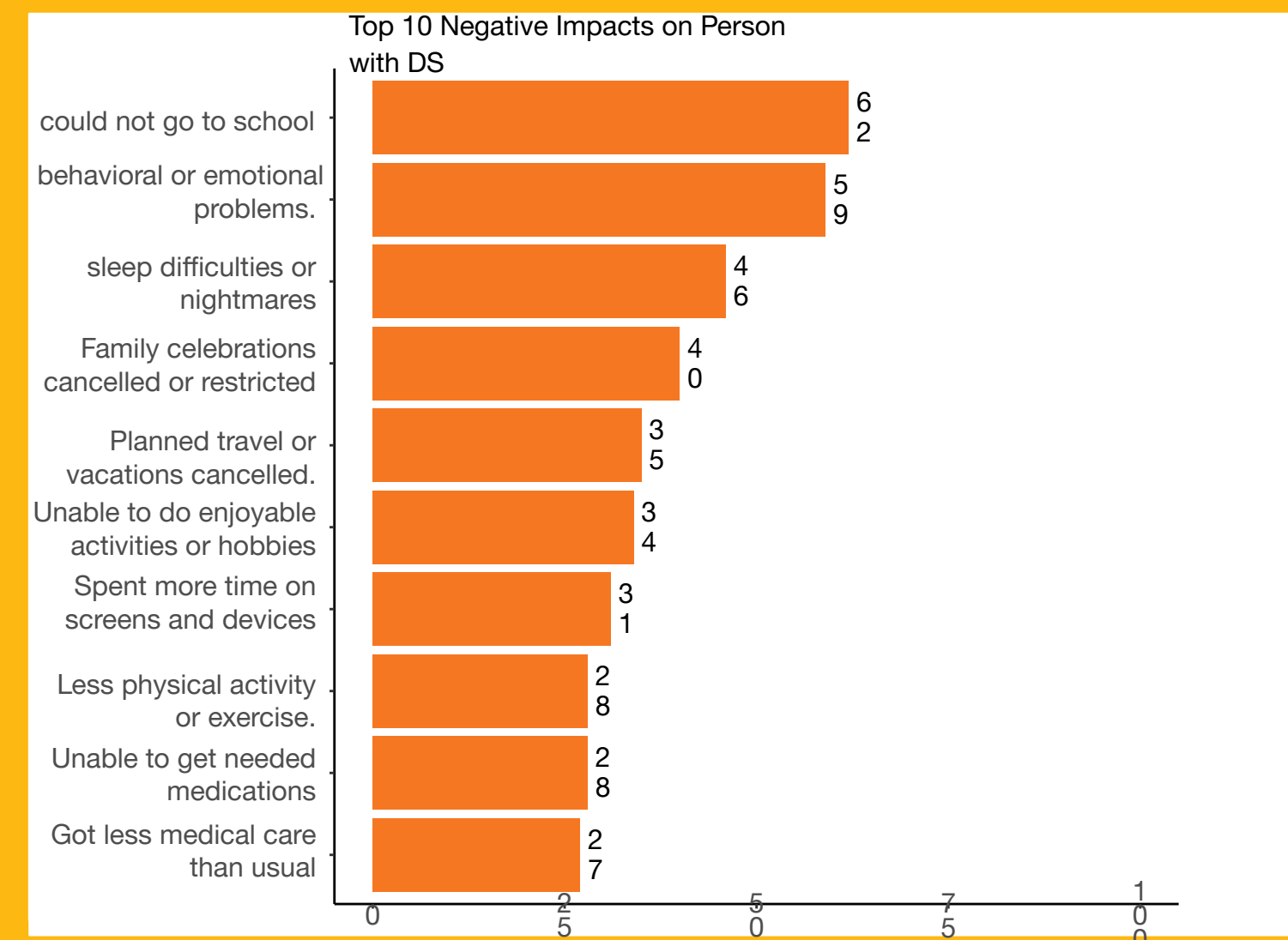
(1) 92 Item Epidemic Pandemic Impacts Inventory (EPII; Grasso, 2020) which assesses pandemic-related impacts on the person with DS and/or others in the household (2) Patient Health Questionnaire 8 (PHQ8; Kroenke, 2009), which assesses parent depression.

	N = 261
	Mean (SD)
Caregiver age:	38.4 (8.87)
Child Age	7.04 (7.09)
Ethnicity	
Hispanic	26 (10.0%)
Non-Hispanic	234 (89.7%)
Missing	1 (0.4%)
Race	
American Indian/Alaskan Native	9 (3.4%)
Asian	9 (3.4%)
Black/African American	15 (5.7%)
Native Hawaiian/Other Pacific Islander	3 (1.1%)
White	220 (84.3%)
Other	3 (1.1%)
Free/Reduced Lunch	
Yes	150 (57.5%)
No	69 (26.4%)
Unsure/Dont know	4 (1.5%)
Does not apply	36 (13.8%)
Missing	2 (0.8%)
Difficulty Paying for Health Insurance	
Yes	110 (42.1%)
No	147 (56.3%)
Not Applicable	3 (1.1%)
Choose not to answer	1 (0.4%)

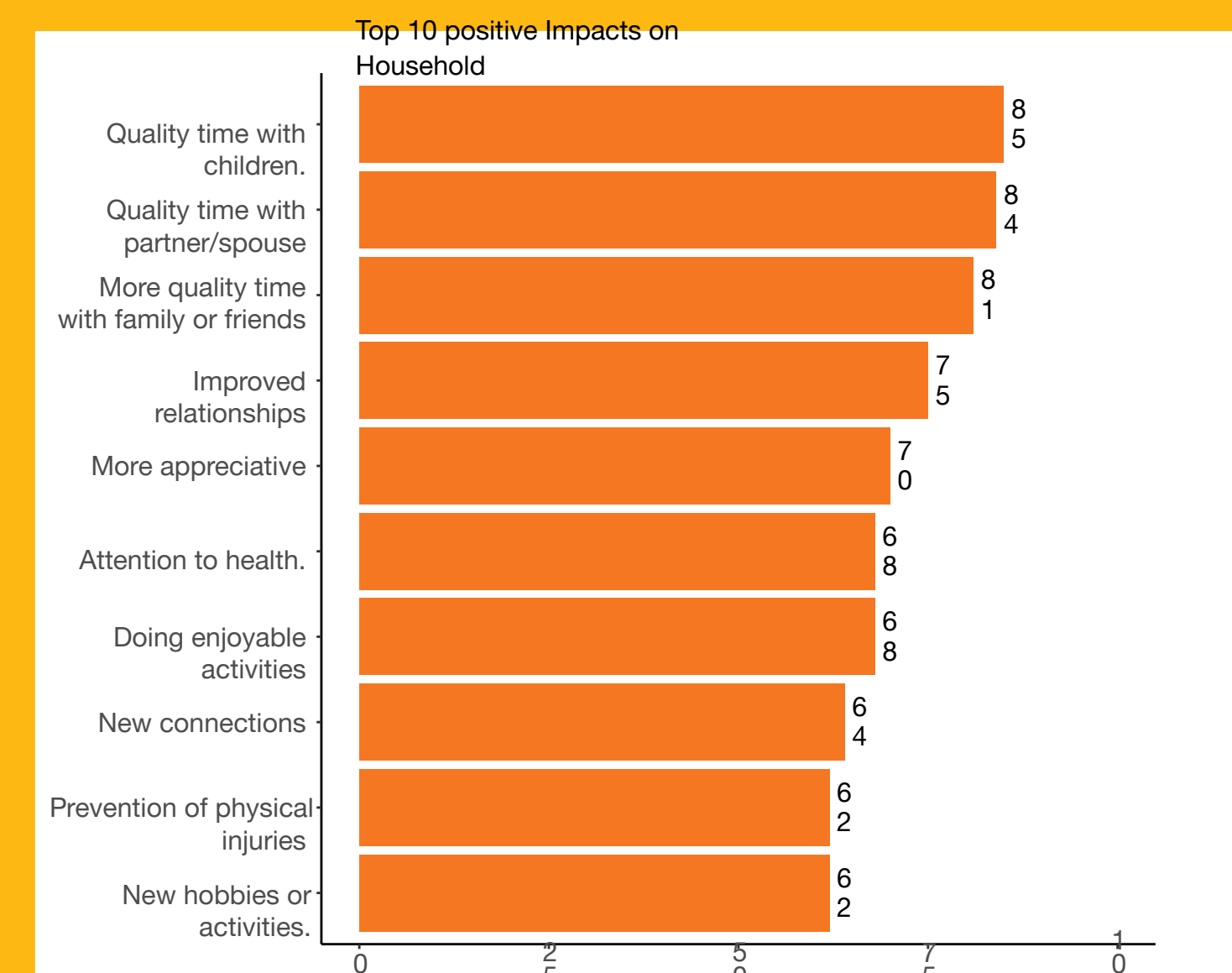
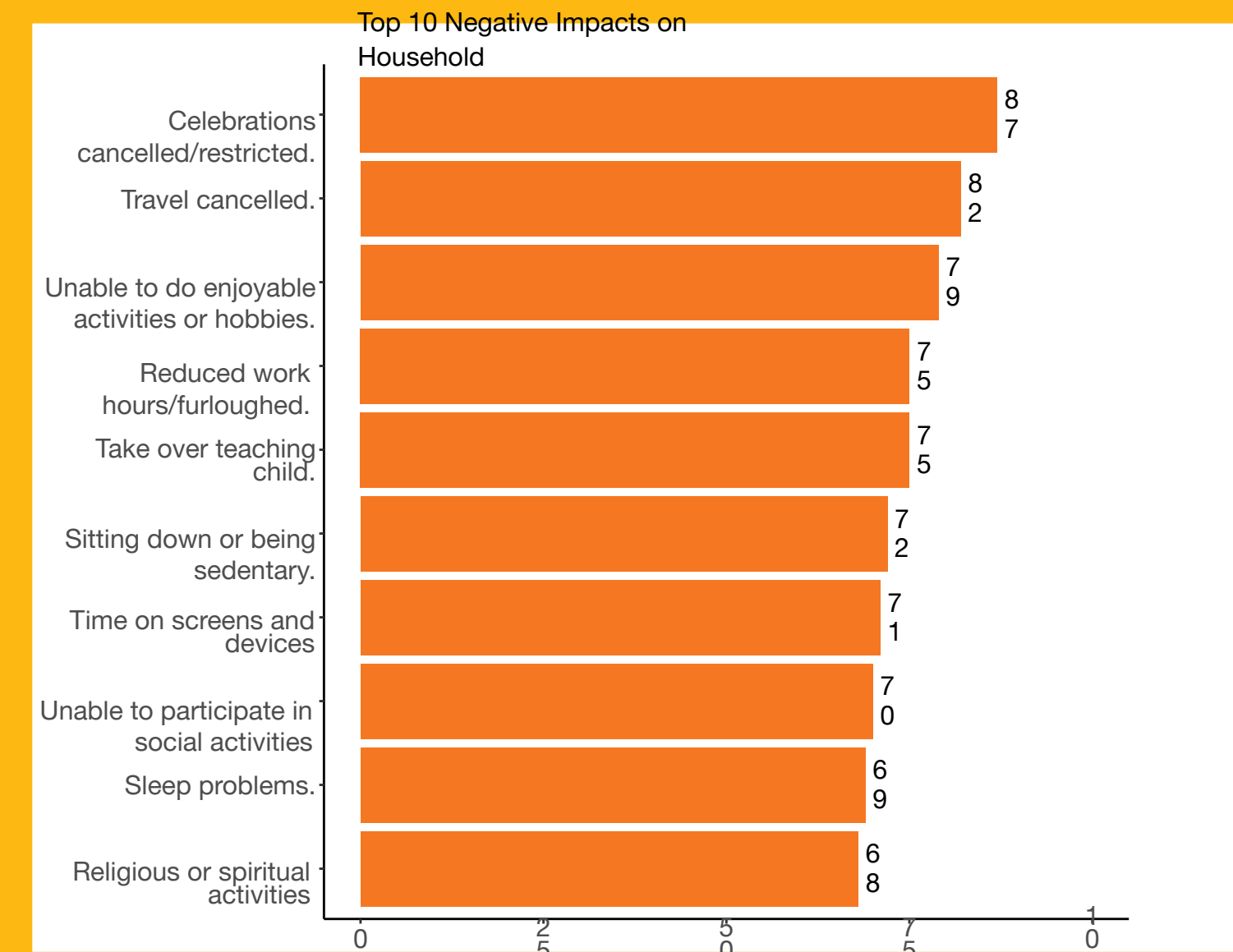
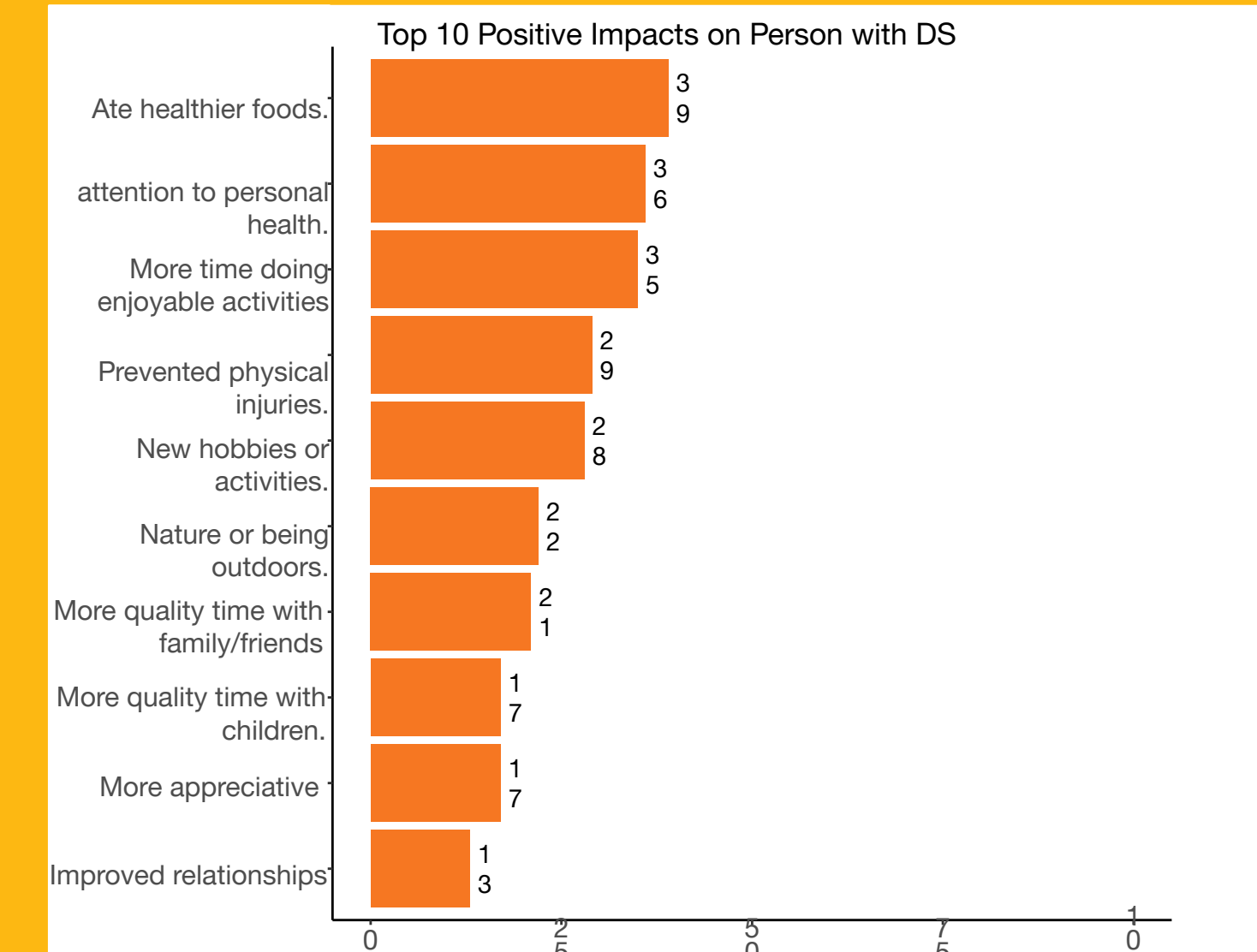
Child/Adult with DS

Caregiver/Household

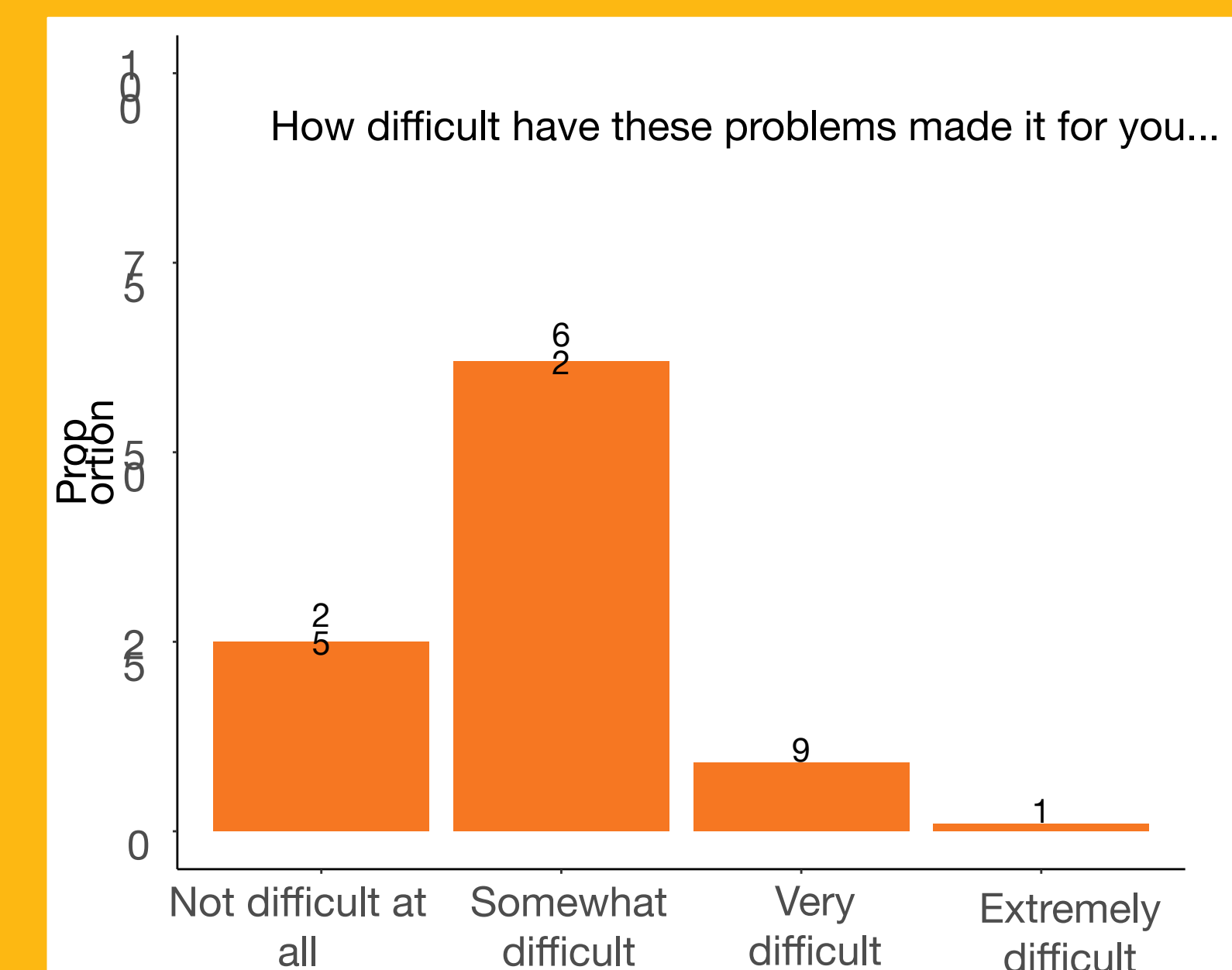
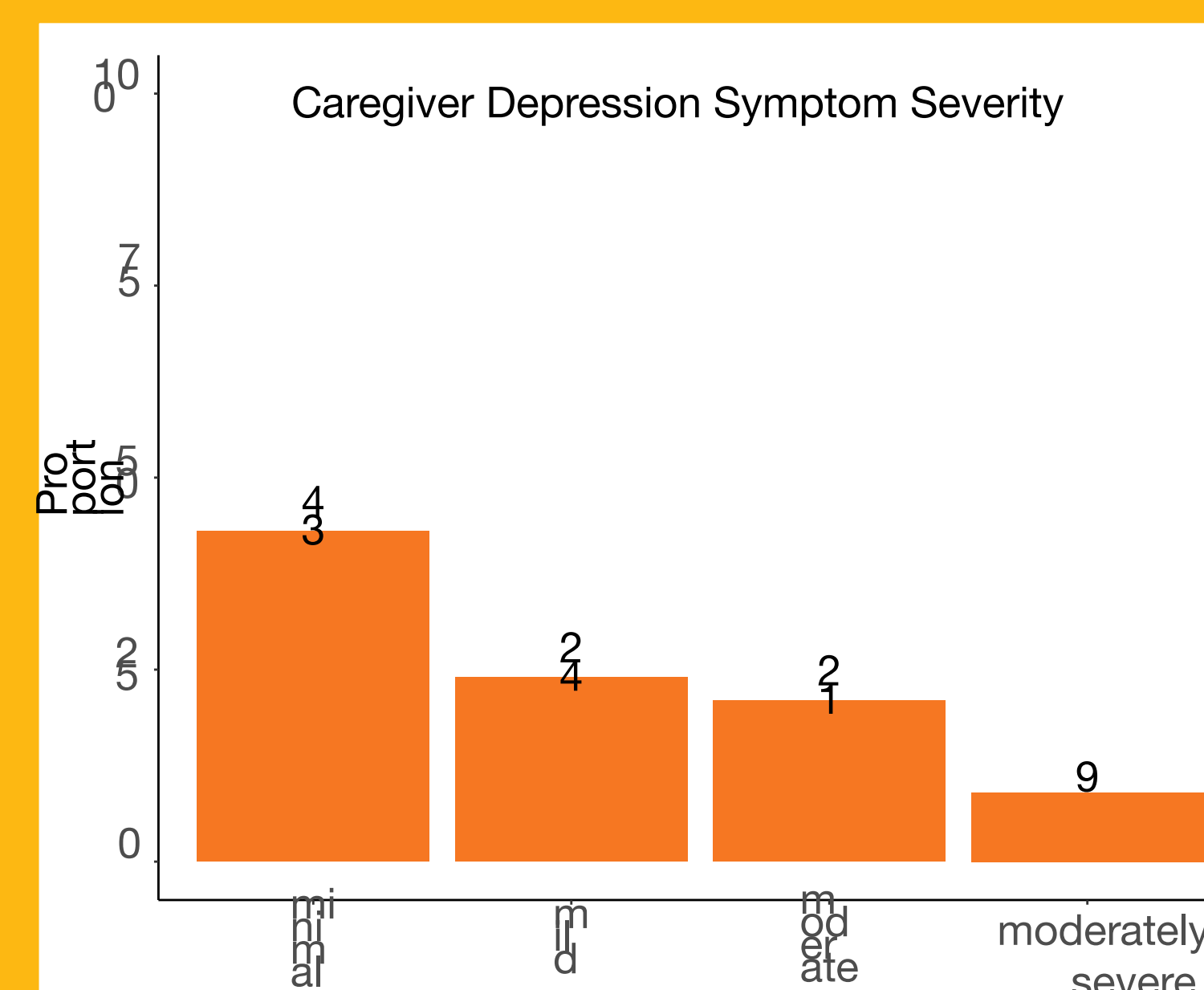
Negative Impacts



Positive Impacts



Caregivers report significant depressive symptoms.



Results

- Caregivers reported significant increases in behavioral/emotional (59%) and sleep problems/nightmares (46%).
 - Recent study reported child's increase in emotional/behavioral problems (16%) or sleep problems (13%), but not restricted to parents.
- Difficulties obtaining medications (28%) and/or medical care (27%) for person with DS were also common.
- 30% of caregivers reported depression symptoms above recommended clinical cutoff (>=10) on PHQ-8.
 - Pre-pandemic epidemiological surveys estimated prevalence of 8.6% (Kroenke et al., 2008).

Next Steps

- Examine predictors of mental health symptoms, including social determinants of health.
- Examine changes over time and recovery trajectories.

Limitations

- Online survey. Not epidemiological. Cross-sectional so far.

Implications

- Recent study found that parental emotion coaching and maintenance of routines buffered effect of COVID-related stress on children's mental and behavioral health (Cohodes, et al., 2021).
- Need for monitoring of behavioral, emotional, sleep changes in person with DS and caregivers.
- Referrals to mental health supports.
- Advocacy for access to healthcare, telehealth, etc.

References

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Questions?

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