

The Effect of the COVID-19 Crisis on Access to Services for Individuals with Down Syndrome

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INTRODUCTION

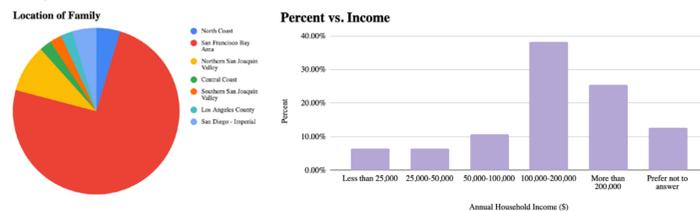
The recent COVID-19 pandemic has had devastating impact on many aspects of life, including access to services.¹ There has been some research on the decrease in access to effective services for individuals with intellectual or developmental disabilities in general², but nothing to date has examined the impact on children with Down Syndrome (DS) specifically. This population is disproportionately impacted due to higher risk of complications and necessity of services for co-occurring medical conditions and behavioral development.³ It is, therefore important to study how and why access to services has changed, especially considering differences by race since healthcare disparities often present barriers for minority populations.⁴

OBJECTIVE

The aim of this study is to explore what services were accessed before the COVID-19 crisis, if/how they changed, and what factors contributed. Further analysis is conducted to determine whether there are differences in services accessed by race/ethnicity.

METHODS

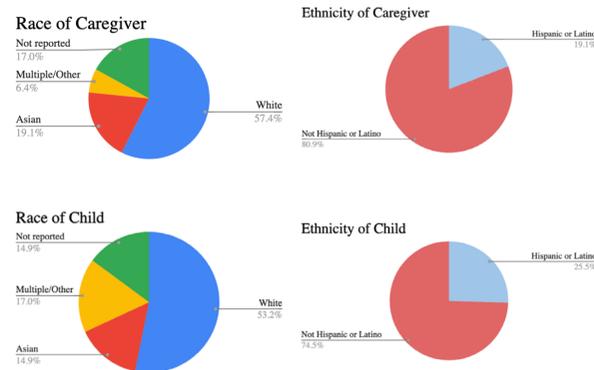
- Data was collected across California from surveys filled out by caregivers (mean age= 43.13, SD= 6.87) of children with DS aged 12-17 (mean age= 9.34, SD= 4.66). 47 participants were included in



- Caregivers were surveyed regarding:
 - Access to services– Did [child] receive services before the beginning of the COVID-19 crisis (e.g., Physical therapy, behavioral therapy)?; Which of the following services did [child] receive before the beginning of the COVID-19 crisis? (Check all that apply)
 - Change in access– Has [child]'s access to services changed during the COVID-19 crisis?; How has [child]'s access to services changed during the COVID-19 crisis?
 - Factors contributing to changes in access– Which of the following has contributed to the change in services received by [child] during the COVID-19 crisis?
- Analyses
 - Descriptive analyses– characterize participant demographics and describe access to services in the sample
 - Crosstabulations– examine the change in access to services and factors contributing to the change across race/ethnicity.

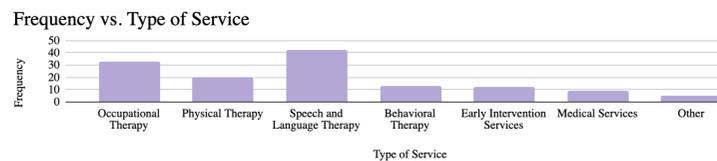
RESULTS

DEMOGRAPHICS



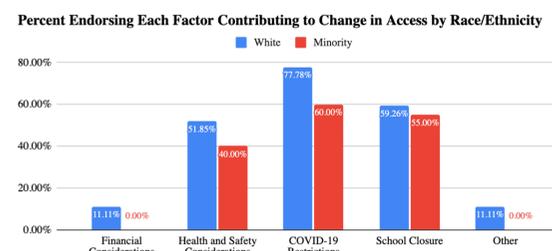
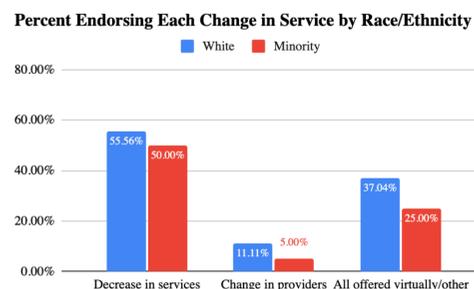
ACCESS TO SERVICES

- 95.7% accessed services before COVID-19 crisis
 - On average, participants accessed 2.85 services (SD=1.37)



- 78.7% reported change in services accessed
 - Increased (0%)
 - Decreased (56.8%)
 - Change in providers (9.1%)
 - Virtual/Other (34.1%)
- Caregivers reported that the following factors contributed:
 - Financial considerations (6.2%)
 - Health and safety considerations (24.7%)
 - COVID-19 restrictions (38.1%)
 - School closure (28.9%)
 - Other (2.1%)

ACCESS BY RACE/ETHNICITY



SUMMARY

A majority of participants accessed services and experienced a change (decrease) in services accessed due to a variety of factors associated with the pandemic. Access to services differed by race in this sample.

CONCLUSIONS

- The current study shows how the COVID-19 crisis affected families of children with DS and how race contributed.
- Future directions include: Looking at differences by socioeconomic status/education level, expanding to more states with different levels of restrictions, and exploring long-term implications of changes in access to services

STRENGTHS &

- Strengths:
- Only study on individuals with DS
 - Some racial diversity
- Limitations
- Relatively small sample
 - Mostly within one region

ACKNOWLEDGEMENTS

A special thank you to the organizations that distributed the survey and the families that took the time to fill them out. I would also like to thank my mentors, Dr. Angela Thurman, Dr. Leonard Abbeduto, and Dr. Dimachkie, for guiding me through the project with support from the MIND institute and the Kennedy Krieger Institute.

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INTRODUCTION

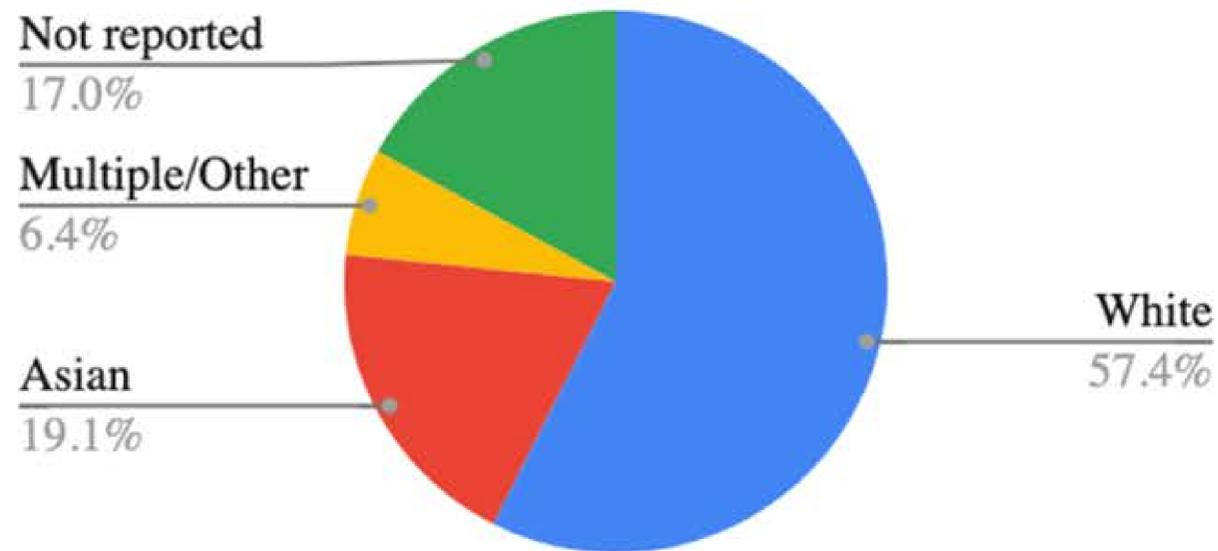
- COVID-19 pandemic has had devastating impact on many aspects of life, including access to services.¹
- Limited research on impact on access to effective services for individuals with ID/DD², but nothing DS specific
 - This population is disproportionately impacted due to higher risk of complications and necessity of services for co-occurring medical conditions and behavioral development.³
- Important to study how and why access to services has changed
 - Also important to consider differences by race since healthcare disparities often present barriers for minority populations.⁴

OBJECTIVE:

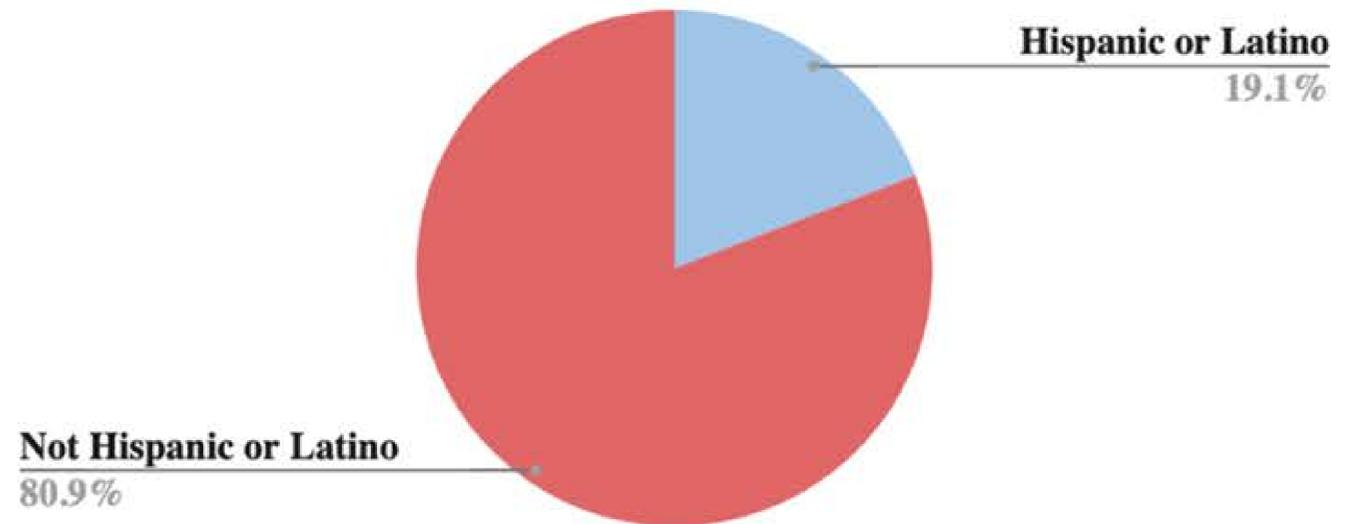
- Explore what services were accessed before the COVID-19 crisis
- Explore if/how they changed
 - Determine factors contributing to change
- Explore changes in services accessed by race/ethnicity

METHODS

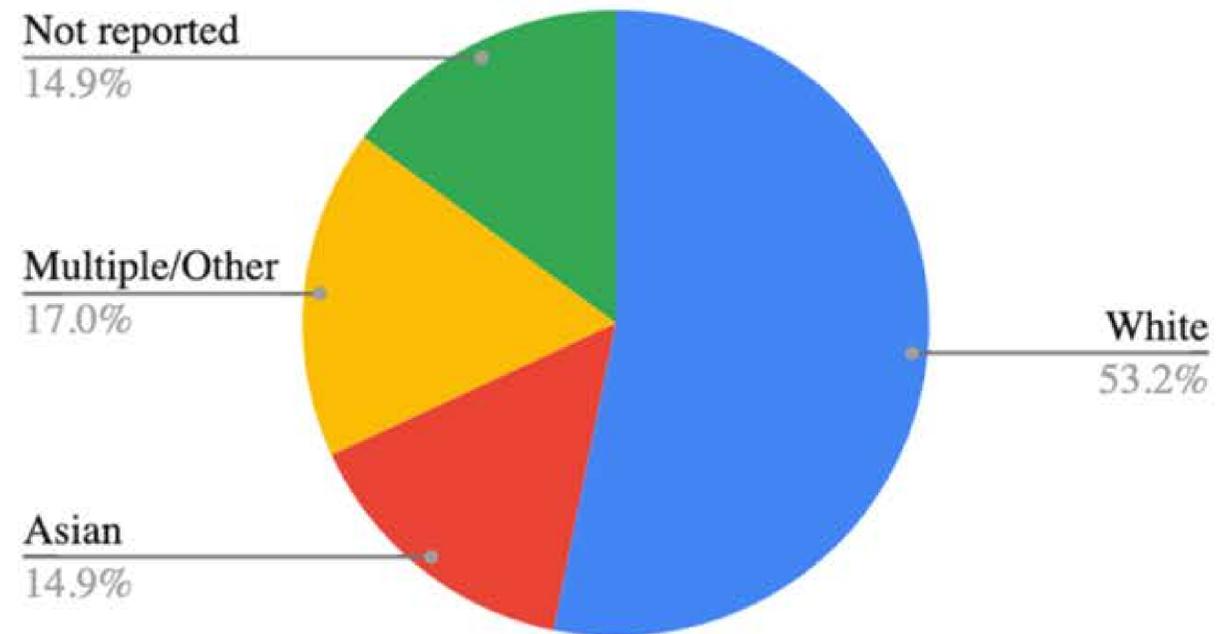
Race of Caregiver



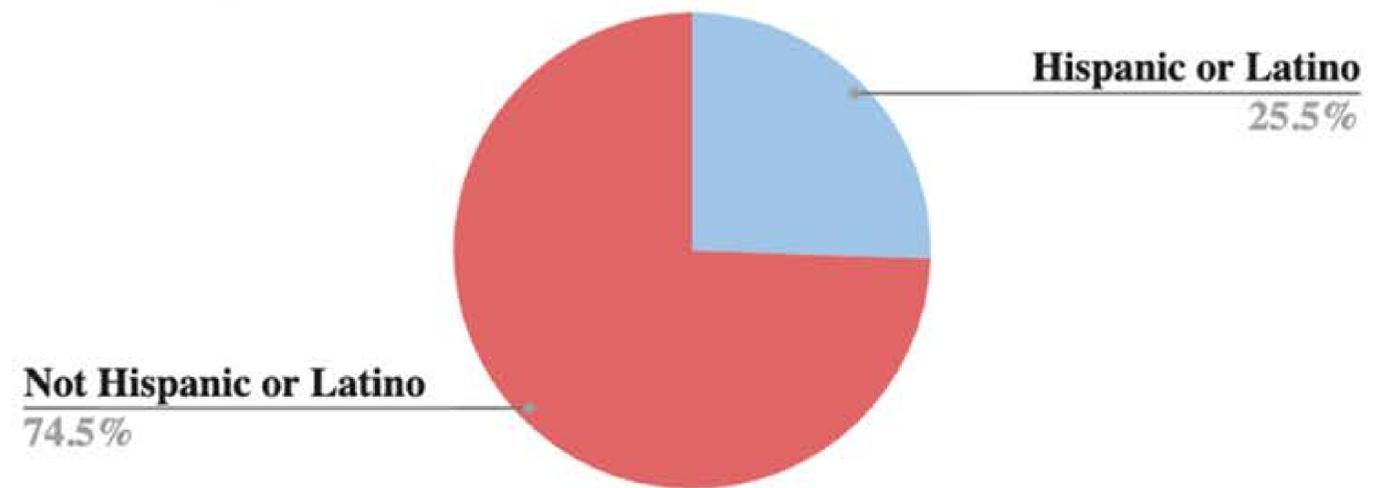
Ethnicity of Caregiver



Race of Child



Ethnicity of Child



METHODS

- **Caregivers were surveyed regarding:**

- Access to services

Did [child] receive services before the beginning of the COVID-19 crisis (e.g., Physical therapy, behavioral therapy)?

Which of the following services did [child] receive before the beginning of the COVID-19 crisis? (Check all that apply)

- Change in access

Has [child]'s access to services changed during the COVID-19 crisis?

How has [child]'s access to services changed during the COVID-19 crisis?

- Factors contributing to changes in access

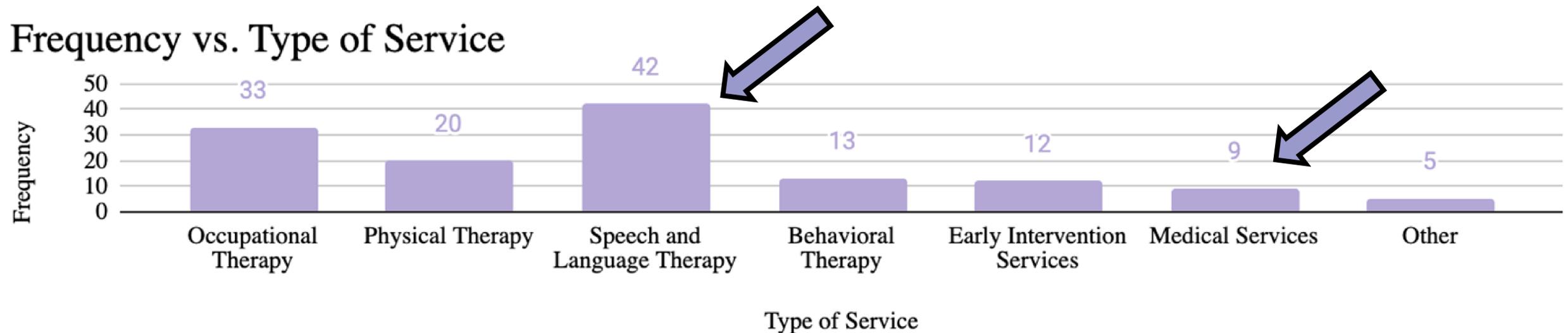
Which of the following has contributed to the change in services received by [child] during the COVID-19 crisis?

- **Analyses**

- Descriptive analyses— characterize participant demographics and describe access to services in the sample
 - Cross-tabulations— examine the change in access to services and factors contributing to the change across race/ethnicity.

RESULTS

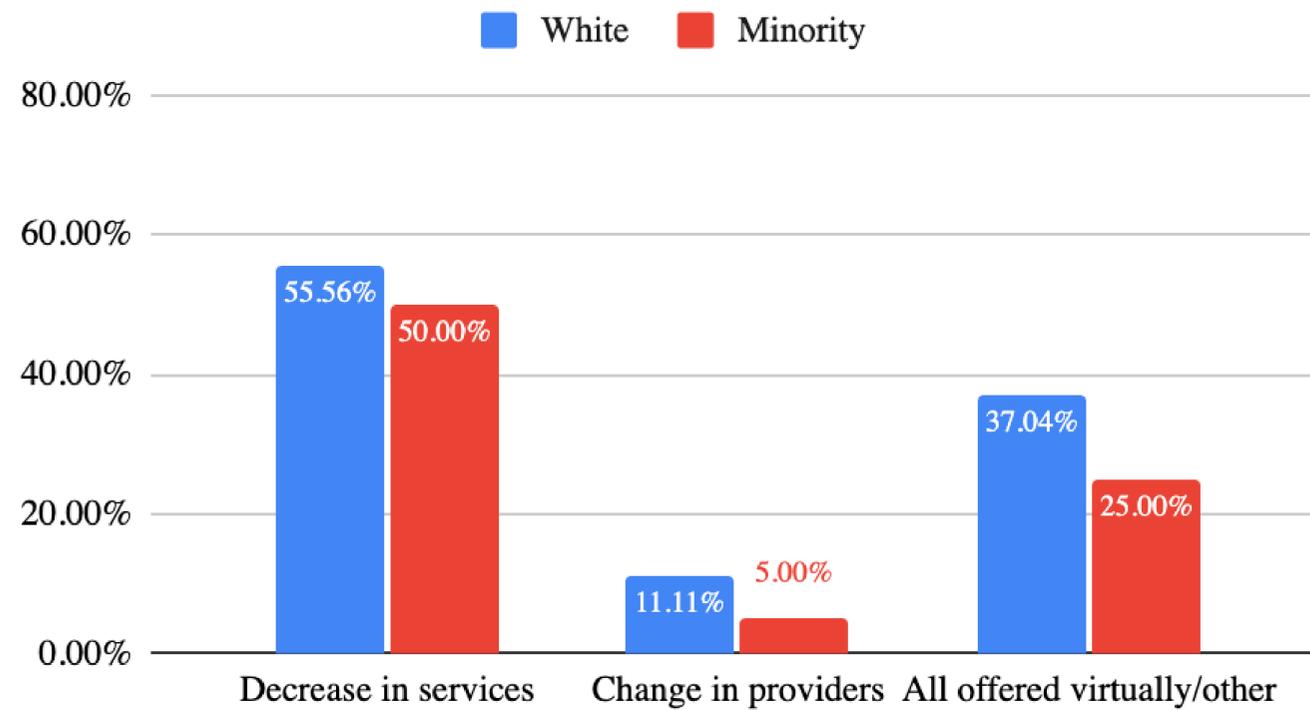
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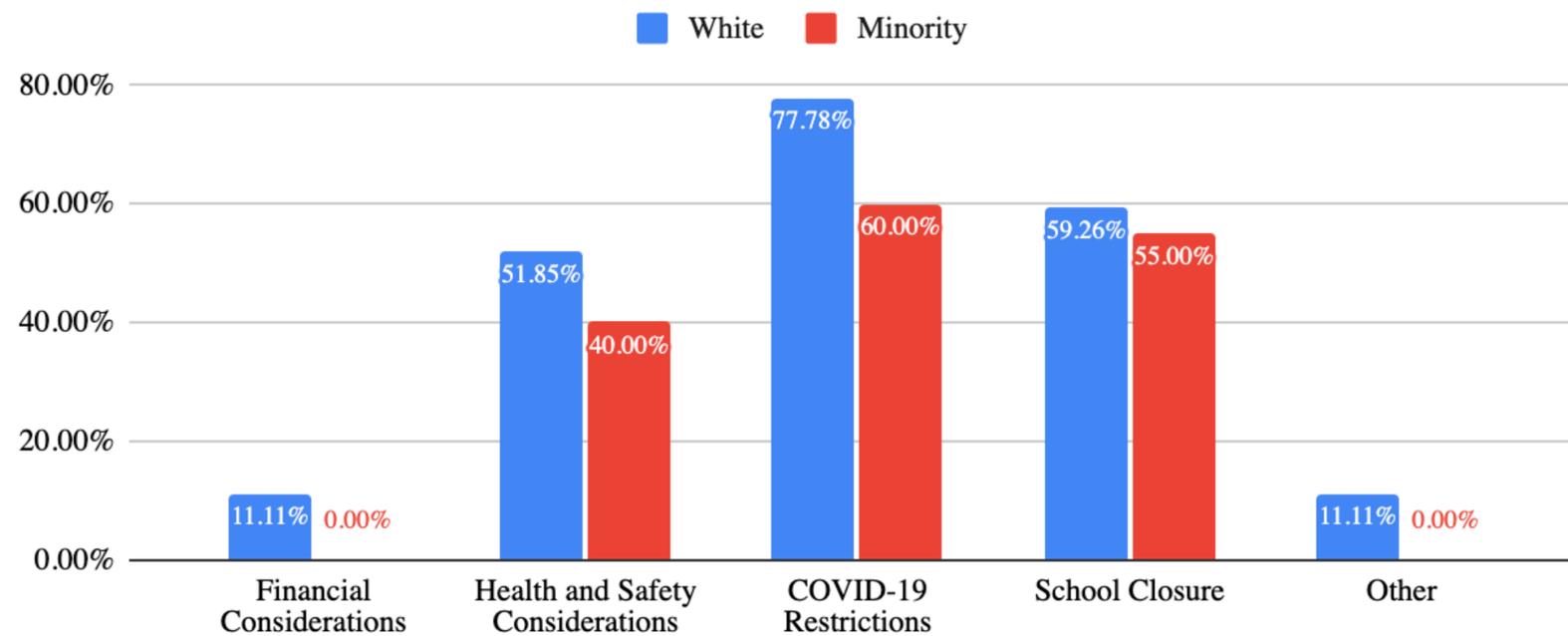
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RESULTS

Percent Endorsing Each Change in Service by Race/Ethnicity



Percent Endorsing Each Factor Contributing to Change in Access by Race/Ethnicity



CONCLUSIONS

- Majority of participants accessed services
- Majority experienced a change (decrease) in services accessed due to a variety of factors associated with the pandemic
- Differences when comparing White vs Minorities, but not in the direction that was expected.
- Strengths:
 - Only study on individuals with DS
 - Some racial diversity
- Limitations
 - Relatively small sample
 - Mostly within one region
- Future directions include: Looking at differences by socioeconomic status/education level, expanding to more states with different levels of restrictions, and exploring long-term implications of changes in access to services