



UCLA DEPARTMENT OF PREVENTIVE MEDICINE

# The Impact of COVID-19 on Families of Children with Developmental Disabilities



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*Candace Gragnani MD, MPH  
Denise M. Nunez MD, MPH  
Priyanka Fernandes MD, MPH*

# Presentation Overview

OUTLINE OF TOPICS



*Introduction/ Purpose*

*Materials & Methods*

*Results*

*Implications & Conclusions*

*Acknowledgments*

# Background

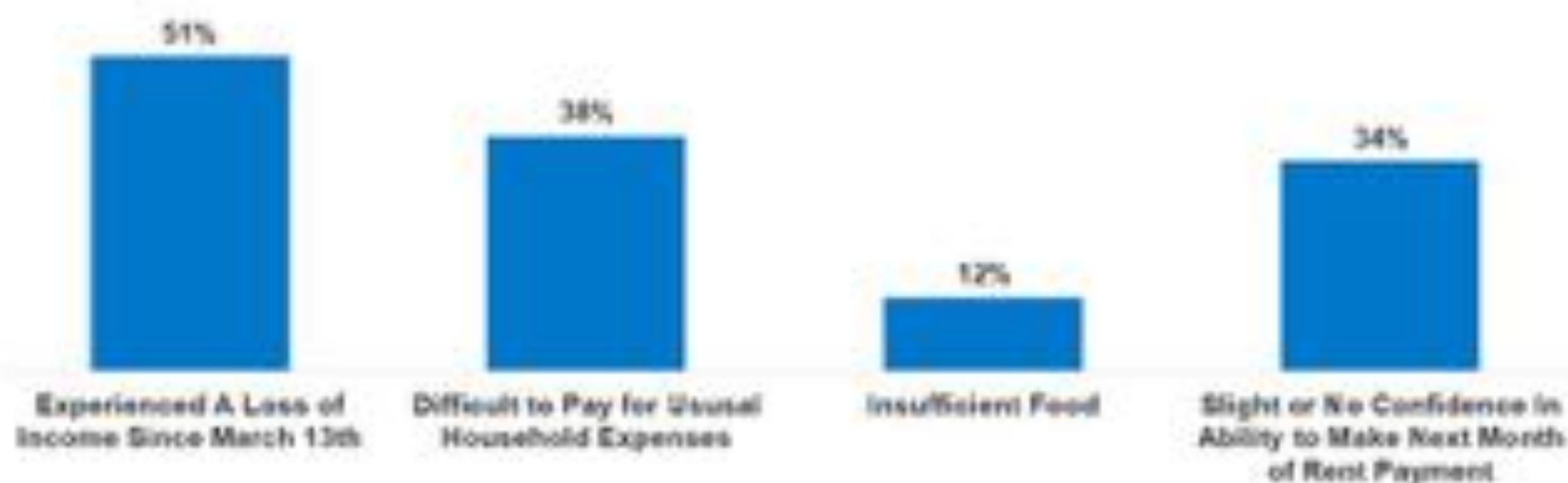




Figure 2

## Households with children report high rates of problems meeting basic needs during the pandemic.

Share of Adults in Households with Children Who Reported:



NOTES: Census Bureau Week 13 questionnaire defines "Usual Household Expenses" as food, rent or mortgage, car payments, medical expenses, student loans, and other expenses.

SOURCE: KFF Analysis of Week 13 of the Household Pulse Survey. Summary Tables (August 19<sup>th</sup>-August 31<sup>st</sup>).

**KFF**

Image source: Garfield R and Chidambaram P. Children's Health and Well-Being During the Coronavirus Pandemic. Kaiser Family Foundation, September 2020. Available at: <https://www.kff.org/coronavirus-covid-19/issue-brief/childrens-health-and-well-being-during-the-coronavirus-pandemic/>

## Services Accessed to Support Children with Special Health Care Needs (CSHCN) Before Pandemic: Wave 1: Nov 2020

| Category                   | Percent |
|----------------------------|---------|
| Care Coordinator           | 14.2%   |
| Care Management            | 10.7%   |
| Special Medical Equipment  | 2.7%    |
| Home Health Nurse or Aide  | 1.2%    |
| Legal Counseling           | 4.2%    |
| Mental Health Services     | 10.8%]  |
| Respite Care               | 0.0%    |
| Social Work Services       | 11.4%   |
| Special Education Services | 18.8%   |
| Therapeutic Services       | 21.4%   |
| Any Service                | 81.7%]  |

**Definition:** Estimated percentage of adults with caregiving responsibilities for children with special health care needs (CSHCN) ages 0-17 who accessed services to help support their CSHCN in the period before the COVID-19 outbreak in March 2020, by type of service (e.g., in Wave 1 (Nov. 9–Dec. 11, 2020), 14.2% of California caregivers of CSHCN had accessed care coordinator services before the pandemic).

**Data Source:** <https://www.aap.org/child/airp> Family Experiences During the COVID-19 Pandemic (Dec. 2020) Questionnaire. American Academy of Pediatrics, Centers for Disease Control and Prevention, Prevent Child Abuse America & Tufts Medical Center, California (examples: Lucile Packard Foundation for Children's Health & California Essentials for Childhood Initiative) (California Dept. of Public Health, Injury and Violence Prevention Branch & California Dept. of Social Services, Office of Child Abuse Prevention).

**Footnote:** Children with special health care needs (CSHCN) have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally. Mental health services include mental and behavioral health supports from a counselor, psychiatrist, psychologist, or therapist. Therapeutic services include occupational therapy, physical therapy, speech therapy, and applied behavioral analysis. Special education services include supports from special education lessons, materials or aides. The questionnaire was administered during the following periods: Nov. 9–Dec. 11, 2020 (Wave 1); Mar. 22–Apr. 12, 2021 (Wave 2). These data are subject to both sampling and nonsampling error. The notation [ ] refers to estimates that have been suppressed because (a) fewer than 20 caregivers of CSHCN reported use of services, or (b) the margin of error for the estimate is greater than 10 percentage points. The annotation [ ] indicates that the margin of error is between 5 and 10 percentage points.

## Services Accessed to Support Children with Special Health Care Needs (CSHCN) During Pandemic: Wave 2: March 2021

| Category                   | Percent |
|----------------------------|---------|
| Care Coordination          | 18.4%   |
| Care Management            | 21.2%   |
| Durable Medical Equipment  | 6.7%    |
| Home Health Nurse or Aide  | 12.8%   |
| Legal Counseling           | 6.6%    |
| Mental Health Services     | 28.2%   |
| Respite Care               | 8.2%    |
| Social Work Services       | 18.7%   |
| Special Education Services | 24.2%   |
| Therapeutic Services       | 17.2%   |
| Any Services               | 79.2%   |

**Definition:** Estimated percentage of adults with caregiving responsibilities for children with special health care needs (CSHCN) ages 0-17 who accessed services to help support their CSHCN in the period after the COVID-19 outbreak in March 2020, by type of service (e.g., in Wave 2, 18.4% of California caregivers of CSHCN had accessed care coordination services during the pandemic).

**Data Source:** Family Experiences During the COVID-19 Pandemic (Apr. 2021). Questionnaires: American Academy of Pediatrics, Centers for Disease Control and Prevention, Prevent Child Abuse America & Tufts Medical Center; California overnights: Lucile Packard Foundation for Children's Health & California Essentials for Childhood Initiative (California Dept. of Public Health, Injury and Violence Prevention Branch & California Dept. of Social Services, Office of Child Abuse Prevention).

**Footnote:** Children with special health care needs (CSHCN) have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health-related services of a type or amount beyond that regularly provided to children generally. Mental health services include mental and behavioral health supports from a counselor, psychiatrist, psychologist, or therapist. Therapeutic services include occupational therapy, physical therapy, speech therapy, and applied behavioral analysis. Special education services include supports from special education resource specialists or aides. The questionnaire was administered during the following periods: Nov. 9–Dec. 11, 2020 (Wave 1); Mar. 22–Apr. 12, 2021 (Wave 2). These data are subject to both sampling and non-sampling error. The notation § refers to estimates that have been suppressed because (a) fewer than 20 caregivers of CSHCN reported use of services, or (b) the margin of error for the estimate is greater than 10 percentage points. The annotation (†) indicates that the margin of error is between 5 and 10 percentage points.

# Our Purpose

## *Introduction*

### **Investigate**

Understand the impacts of a global pandemic on children with special needs

### **PROTECT**

Children with special needs are in a vulnerable group, further challenged by COVID related changes





# Study Activities

## FAMILIES

Longitudinal survey for families

Nov 2020- Feb 2021 & October 2021

## EXPERTS/SERVICE PROVIDERS

Modified Delphi method

Survey & Discussion

## INTERVENTION

Interactive Forum (remote & in-person)

Resources, services, emergency preparedness



# Main Aims

- Understand main challenges faced by families of children with developmental disabilities
  1. Economic
  2. Educational
  3. Health
- Use family unit characteristics as predictors of challenges
- Identify areas for potential interventions



# Methods

## Recruitment Strategies

Outreach to:

1. Virtual Clinics: UCLA LEND Clinic, UC-Riverside Clinic
2. UCLA Medicine-Pediatric clinics
3. Online Blogs "Mommy Blogs" for children with special needs

## Timeframe

November 2020- February 2021

Follow up survey October-November 2021

## Incentives

25 dollar gift cards per survey



# Survey Structure



## DEMOGRAPHICS

*Family & Child Level data*

Questions about household economic factors, education and employment derived from US-Census



## SERVICE ACCESS

*Family & Child Level data*

Questions about services accessed, frequency & intensity assessed.  
Changes as a result of COVID-19 related policies investigated



## FAMILY SCALES

*Family Environment Scale (FES)*  
*Parental Sense of Competence (PSC)*  
*Perceived Social Support*



## COVID-19 BEHAVIORS & IMPACTS

*COVID-19 Behaviors*  
*COVID-19 Perceptions*  
*Physical Health*  
*Mental Health*

# Questionnaire Details

## Questionnaire Development

Surveys questions were obtained from:

US-Census

NSCHCN (National Survey for Children with Special  
Healthcare Needs)

Autism Services Survey

LAUSD

## Timeframe

November 2020- February 2021

Follow up survey October-November 2021

## Incentives

25 dollar gift cards per survey



Vohra R, Madhavan S, Sambamoorthi U, St Peter C. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*. 2014;18(7):815-826.  
doi:10.1177/1362361313512902

# Questionnaire Details



## Sample Questions: Service Access

*(Do)es your child(ren) with special healthcare needs currently need any of the following therapy services? Select all that apply*

*Have you had any difficulty accessing the therapies listed?*

*Is [name\_child1] receiving speech and language services?*

- *How long has your child received this service in months?*
- *How many times per week?*
- *How many days per month?*
- *How long are sessions in minutes?*

## Sample Questions: COVID-19 Questionnaire

*I have greater difficulty in managing my child's behaviors since COVID-19 related changes.*

*During the pandemic, how has the physical health of your child(ren) with special needs been affected (e.g., diet, physical activity, sleep pattern/quality, stress levels, substance use, emotional well-being)?*

# Questionnaire Details

## Example Questions: Family Environment Survey

*Family members really help and support one another.*

*We fight a lot in our family.*

## Example Questions: Perceived Social Support

*You can't get away with much in our family.*

*We are not really encouraged to speak up for ourselves in our family.*



## Example Questions: Parental Sense of Competence

*Sometimes I feel like I'm not getting anything done.*

*A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one*



# Results

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# Sample Characteristics

- 38.9% (21/54) were from UCLA Primary care clinics (Pediatrics and Medicine-Pediatrics)
- 25.9% (14/54) were from UCLA LEND clinic/Neurology clinic
- 35.2% (19/54) were recruited from outside the UCLA Health System
  - 1 from the UC Riverside LEND clinic
  - Clinics in the Southern California AAP Chapter 2 listserv
  - Facebook groups



# Demographics

| Variable   | N (%)<br>(n=54) |
|--|-----------------|
| Relationship to child/ren with developmental disability      |                 |
| Parent   | 52 (96.3%)      |
| Children with special needs in household [median (min, max)] | 1 (1,7)         |
| Household size [median (min, max)]                           | 4 (1,10)        |
| Hispanic   | 18 (34%)        |
| Race   |                 |
| White  | 32 (60.4%)      |
| Asian American, Native Hawaiian or Pacific Islander          | 8 (15.1%)       |
| Black or African American                                    | 4 (7.5%)        |
| Native American or Alaska native                             | 1 (1.9%)        |
| Highest degree   |                 |
| High school diploma or GED                                   | 2 (3.8%)        |
| Associates/Bachelor's degree                                 | 28 (52.8%)      |
| Master's degree or higher                                    | 22 (41.5%)      |
| Marital status   |                 |
| Married  | 41 (77.4%)      |
| Single   | 6 (11.3%)       |
| Divorced   | 5 (9.4%)        |
| Separated  | 1 (1.9%)        |

# Demographics (Economic)

| Variable                  | N (%)<br>(n=54)     |                     |
|---------------------------|---------------------|---------------------|
| Health Insurance (Family) |                     |                     |
| Private                   | 41 (75.9)           |                     |
| Medicaid (MediCal)        | 19 (35.2)           |                     |
| Medicare                  | 3 (5.6)             |                     |
| Employment status         | Current (n=52)      | Pre-pandemic (n=51) |
| Full-time                 | 21 (40.4)           | 21 (41.2)           |
| Part-time/Self-employed   | 11 (21.2)           | 16 (31.4)           |
| Unemployed                | 16 (30.8)           | 7 (13.8)            |
| Remote work option (n=45) | 25 (55.6)           |                     |
| Unemployment Insurance    |                     |                     |
| Applied/Received          | 12 (23.5)/11 (21.6) |                     |
| Social Security Benefits  |                     |                     |
| Not receiving             | 44 (86.3%)          |                     |
| Household income          |                     |                     |
| <\$35,000                 | 8 (15.7)            |                     |
| \$35,000-\$99,999         | 14 (27.5)           |                     |
| \$100,00-\$149,999        | 11 (21.6)           |                     |
| \$150,000 and higher      | 18 (35.3)           |                     |

# Educational Need (Child-level information)

| Variable                         | N (%)<br>(n=54) |
|----------------------------------|-----------------|
| Age of child [median (min, max)] | 9 (6, 13)       |
| Male sex                         | 38 (70.4)       |
| Diagnosis                        |                 |
| ASD                              | 23 (42.6)       |
| ADD/ADHD                         | 20 (37.0)       |
| Learning disability              | 9 (16.7)        |
| Intellectual disability          | 11 (20.4)       |
| Behavioral problems              | 14 (25.9)       |
| Individualized Education Plan    | 37 (68.5)       |
| Class delivery                   |                 |
| Remote                           | 38 (76.0)       |
| In-person                        | 3 (6.0)         |
| Hybrid                           | 5 (10.0)        |
| School-based services            |                 |
| Speech and language              | 39 (81.3)       |
| Counseling services              | 15 (41.7)       |
| Special classes                  | 12 (36.4)       |
| Behavioral interventions         | 12 (31.6)       |

## Educational Need (Child-level information)

| Variable  | N (%)<br>(n=54) |
|---|-----------------|
| Satisfaction with current educational environment |                 |
| Satisfied   | 20 (37.7)       |
| Neutral   | 9 (17.0)        |
| Unsatisfied                                       | 20 (37.7)       |
|   |                 |
|   |                 |
| Change in satisfaction related to COVID-19        |                 |
| Increased   | 3 (5.7)         |
| Unchanged   | 10 (18.9)       |
| Decreased   | 36 (67.9)       |

# Service Need

| Variable                           | Enrolled<br>(n=54) | Experienced Difficulties<br>(n=27) |
|------------------------------------|--------------------|------------------------------------|
| Social Services <sup>1</sup>       | 18 (33.3)          | 16 (59.3)                          |
| <i>Respite Care</i>                | 18 (33.3)          | 10 (37.0)                          |
| <i>Day Programs</i>                | 8 (14.8)           | 5 (18.5)                           |
| Medical Services <sup>2</sup>      | 34 (63.0)          | 12 (44.4)                          |
| <i>Psychiatry</i>                  | 10 (18.5)          | 5 (18.5)                           |
| <i>Psychotherapy</i>               | 16 (29.6)          | 5 (18.5)                           |
| Therapy Services <sup>3</sup>      | 40 (74.1)          | 24 (88.9)                          |
| <i>Speech/Language</i>             | 32 (59.3)          | 10 (37.0)                          |
| <i>Occupational</i>                | 23 (42.6)          | 12 (44.4)                          |
| <i>Applied Behavioral Analysis</i> | 16 (29.6)          | 8 (29.6)                           |
| <i>Social Skills</i>               | 16 (29.6)          | 10 (37.0)                          |

# Impacts of COVID -19

| Variable                                    | N (%)<br>(n=35) |
|---|-----------------|
| Person in household diagnosed with COVID-19 | 8 (22.8%)       |
| Knowledge of death from COVID-19            | 12 (35.2%)      |
| Impact due to COVID-19                      |                 |
| Mental issues                               | 22 (64.7%)      |
| Physical issues                             | 20 (58.8%)      |
| Finances issues                             | 14 (41.2%)      |
| Childcare issues                            | 18 (52.9%)      |
| Child Behavior difficulties                 | 24 (70.6%)      |
| Relationship difficulties                   | 12 (38.7%)      |
| Actions                                     |                 |
| Advocacy/Involvement                        | 13 (37.1%)      |
| Would you consider vaccinating your child   |                 |
| Yes   | 27 (77.1%)      |
| No  | 2 (5.7%)        |
| Unsure                                      | 6 (17.1%)       |
| Emergency Preparedness Plan                 | 19 (54.3%)      |
| Accounts for child with special needs       | 17 (48.6%)      |
| Updated due to pandemic                     | 14 (40.1%)      |

# Qualitative Data- Impacts of COVID-19

| Variable                                | Quotes  |
|---|---|
| Recommendations for service improvement | <i>"train the teachers"</i>   |
|   | <i>"resume evaluations"</i>   |
|   | <b><i>"My kids are having a very difficult time with the online learning and several of them have adhd. They can't sit still, can't juggle the assignments and the access to the platforms. I'm not tech savvy either and have 8 kids. I can't help them. The schools haven't put forth effort for the most part to help their special needs and it is excuse after excuse."</i></b>  |
| Success with obtaining services         | <i>"private services"</i>   |
|   | <i>"advocacy"</i>   |
|   | <i>"virtual methods"</i>  |
|   | <i>"great teachers"</i>   |
|   | <b><i>"I have become a bulldog to advocate for my kids. I'm infuriated. I am demoralized by how the districts don't care and do what's necessary to get the child under enough control or managed enough so the parents go away. That's been my experience. They don't care. They can't even figure out what they're doing next week so we are low on the priority. Lend at UCLA has helped us with some advocating. Overall, it's been the worst academic experience of my 22 years of parenting."</i></b> |
| Physical health solutions               | <i>Exercise "yoga", "trampoline", "zoom play with friend"</i>   |
| Coping tools                            | <i>"zooming with family"</i>  |
|   | <i>"meditation"</i>   |
|   | <i>"talking about things together"</i>  |
|   | <i>"antidepressants"</i>  |
|   | <b><i>"Laughter, Gratitude , Mindfulness, Perspective. Going to the beach And we all love to read and have a great home library and use that to help our minds travel when we are stuck in place."</i></b>  |



# Potential Family Unit Predictors

| Variable   | Experience difficulties (n=27) | Did not experience difficulties (n=18) | P Value     |
|--|--------------------------------|--|-------------|
| No. of children with developmental disabilities in household [mean (SD)] | 1.4 (1.28)                     | 1.1 (0.24)                             | 0.51        |
| Household size [mean (SD)]   | 4.5 (2.17)                     | 3.7 (1.33)                             | 0.28        |
| <b>Marital status</b>  |                                |  |             |
| Married  | 22 (81.5%)                     | 14 (77.8%)                             | <b>0.12</b> |
| Single   | 1 (3.7%)                       | 4 (22.2%)                              |             |
| Divorced   | 3 (11.1%)                      | 0 (0.0%)                               |             |
| Separated  | 1 (3.7%)                       | 0 (0.0%)                               |             |
| Work from home option  |                                |  |             |
| Yes  | 11 (45.8%)                     | 6 (40.0%)                              | 0.66        |
| Yes, but choose not to   | 2 (8.3%)                       | 1 (6.7%)                               |             |
| No   | 6 (25.0%)                      | 2 (13.3%)                              |             |
| Health insurance type  |                                |  |             |
| Private  | 23 (85.2%)                     | 14 (77.8%)                             | 0.69        |
| Medicare   | 2 (7.4%)                       | 2 (11.1%)                              | 1.00        |
| MediCal/Medicaid   | 12 (44.4%)                     | 6 (33.3%)                              | 0.46        |
| Self-pay   | 1 (3.7%)                       | 2 (11.1%)                              | 0.55        |

# Potential Family Unit Predictors

| Variable                                      | Experience difficulties (n=27) | Did not experience difficulties (n=18) | P Value         |
|---|--------------------------------|--|-----------------|
| <b>Household income</b>                       |                                |  |                 |
| Less than \$25,000                            | 4 (14.8%)                      | 0 (0.0%)                               | <b>0.06</b>     |
| \$25,000-\$34,999                             | 0 (0.0%)                       | 2 (11.8%)                              |                 |
| \$35,000-\$49,999                             | 0 (0.0%)                       | 1 (5.9%)                               |                 |
| \$50,000-\$74,999                             | 3 (11.1%)                      | 4 (23.5%)                              |                 |
| \$75,000-\$99,999                             | 4 (14.8%)                      | 0 (0.0%)                               |                 |
| \$100,000-\$149,999                           | 7 (25.9%)                      | 3 (17.6%)                              |                 |
| \$150,000-\$199,999                           | 2 (7.4%)                       | 0 (0.0%)                               |                 |
| \$200,000 and above                           | 7 (25.9%)                      | 7 (41.2%)                              |                 |
| Parental Perceived Social Support [mean (SD)] | 5.157 (1.7308)                 | 5.099 (1.5942)                         | 0.92            |
| Parental Sense of Competence [mean (SD)]      | 66.6 (12.48)                   | 73.0 (14.81)                           | 0.17            |
| <b>Family Environment Scale [mean (SD)]</b>   |                                |  |                 |
| Cohesion                                      | 40.3 (12.63)                   | 45.9 (6.41)                            | <b>0.12</b>     |
| Expressiveness                                | 47.2 (8.69)                    | 50.9 (5.98)                            | <b>0.15</b>     |
| Moral-Religious Emphasis                      | 44.5 (6.51)                    | 51.7 (8.21)                            | <b>&lt;0.01</b> |
| Organization                                  | 45.5 (6.84)                    | 50.9 (5.50)                            | <b>0.01</b>     |

# Limitations

- Recruitment method
  - Online only survey
- Recruitment timeframe
  - Longer than expected
- Length of the survey



# Implications & Conclusions



- Household income may play a larger role than we acknowledge
- Educational services may need to develop best practices for remote learning
- Medical services delivery were less affected compared social/therapy services
- Investment in family mental and physical health during extreme constraints must be prioritized
- Family unit characteristics may predict which families may perform better in crises
- Community-based lifestyle interventions pose an opportunity to improve physical health

# Next Steps



- Multi-variate analysis for current study
- Putting results into context with provider survey results
- Follow-up survey later this year
- Identifying feasible interventions to improve educational, physical and mental health experiences through the Community-based Lifestyle Intervention Node of AIR-P



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