

Families: What They are Saying, and how UCEDDs and LENDs can help

AUCD Early Childhood SIG

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UCONN

UNIVERSITY CENTER FOR
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DEVELOPMENTAL
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The Knowledge, Attitudes and Behaviors of Parents of Children with Disabilities COVID-19

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Responses by state

State	Frequency	Percent	State	Frequency	Percent
Alaska	1	0.2	Nebraska	9	1.8
Arizona	14	2.8	Nevada	2	0.4
Arkansas	1	0.2	New Hampshire	3	0.6
California	10	2.0	New Jersey	2	0.4
Colorado	44	8.9	New Mexico	1	0.2
Connecticut	107	21.6	New York	20	4.0
Florida	10	2.0	North Carolina	10	2.0
Georgia	40	8.1	North Dakota	5	1.0
Hawaii	35	7.1	Ohio	2	0.4
Illinois	1	0.2	Oklahoma	1	0.2
Indiana	6	1.2	Oregon	2	0.4
Iowa	20	4.0	Pennsylvania	7	1.4
Kansas	3	0.6	South Carolina	4	0.8
Kentucky	7	1.4	South Dakota	1	0.2
Louisiana	12	2.4	Tennessee	3	0.6
Maine	9	1.8	Texas	6	1.2
Maryland	4	0.8	Utah	1	0.2
Massachusetts	11	2.2	Vermont	5	1.0
Michigan	3	0.6	Virginia	5	1.0
Minnesota	22	4.4	Washington	17	3.4
Mississippi	1	0.2	West Virginia	1	0.2
Missouri	7	1.4	Washington, DC	7	1.4
Montana	5	1.0	American Samoa	3	0.6
			Wisconsin	3	0.6
			Wyoming	1	0.2
			U.S. Virgin Islands	1	0.2

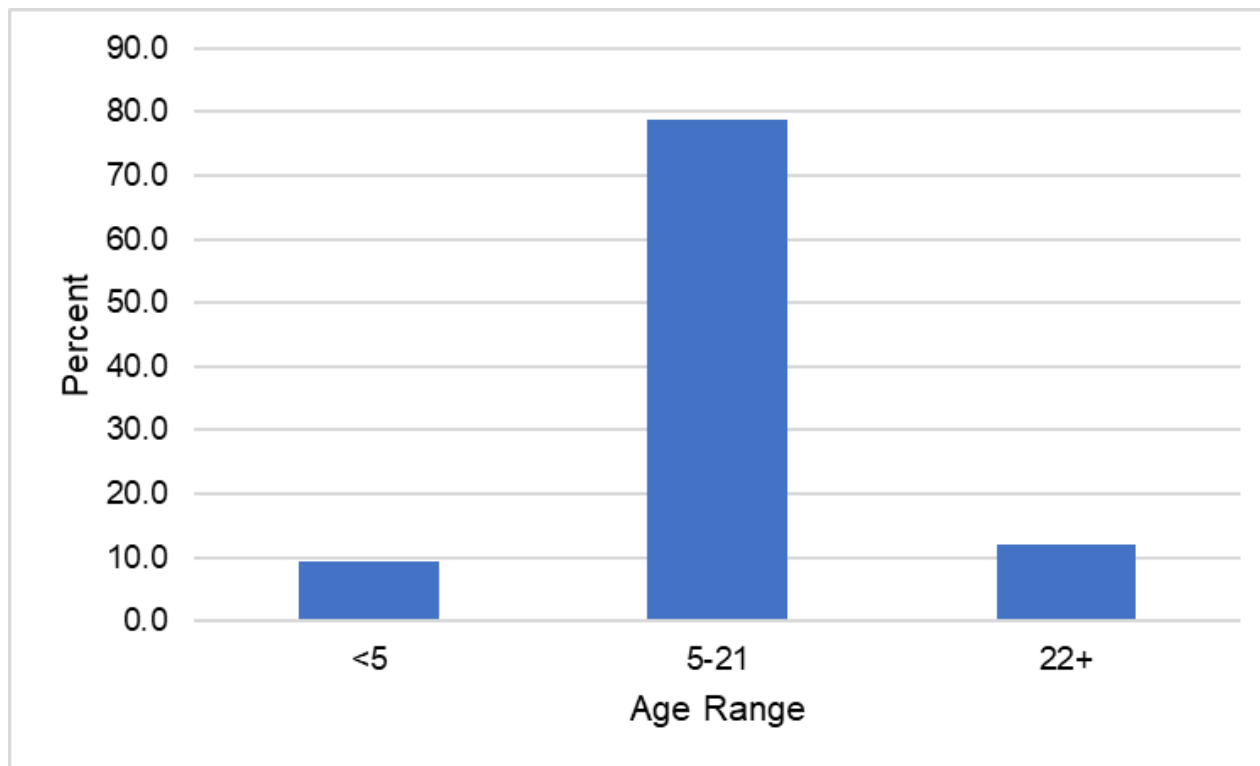
Population: Respondents

- **Age:** 44.23 (23-83)
- **Gender:** 79.8% female
- **Race/ethnicity:** Mostly white,
• (followed by LatinX/Hispanic, African American, Asian/Pacific Islander, Black, Native American/Indigenous)
- **Education level:** 71.1% completed at least 4-year college degree
- **Marital status:** 81.1% married or living with partner

Population: Child with special health care need and/or diagnosed disability

n=673

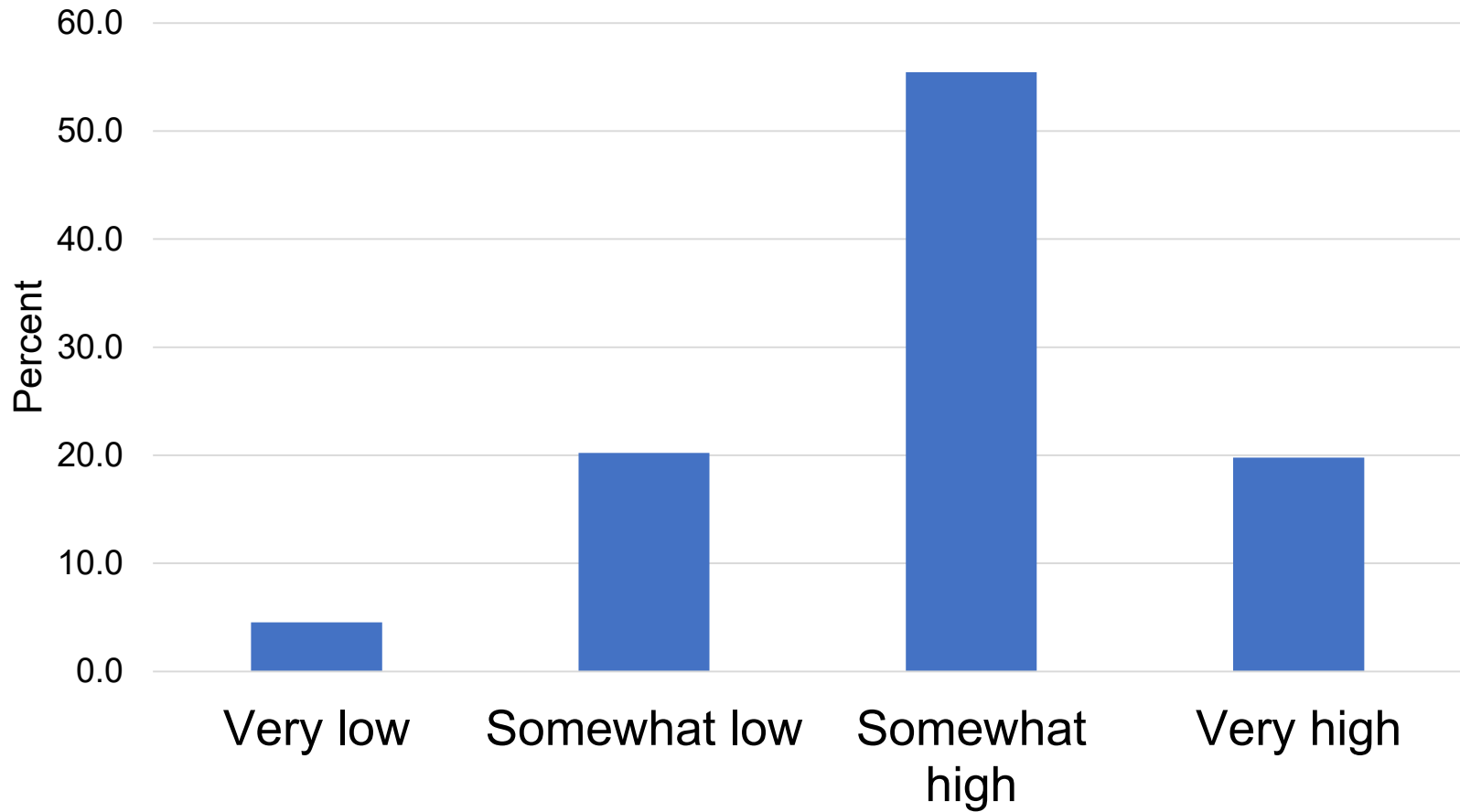
Mean=13.7 \pm 7.8years (6 months-62 years)



What are your 2 Needs for Your Family Right Now?

Rank	Concrete need
1	Special Education (EI, Supports)
2	Money/finances (financial, money, bills, income)
3	Child care/respite
4	Daily routine structure (structure, routines, ways to fight boredom)
5	Mental health/stress relief/emotional support
6	Physical health (physical health, health, physical well-being)

What is your current anxiety level?



What Families Told Us

Both parents are laid off

Ensuring that our son gets the supports he needs during this time - I am worried that he will regress in learning and behaviors because of the decrease in supports. He has been doing REALLY well and I don't want him to regress

Continued support from other parents with children who required special education services at the EI and ECE level

Understanding what IEP services my son should be receiving and how he should be receiving those services

Trying to juggle digital learning with disabilities and working full time

ECPC/DEC Family Cohort Early Childhood Personnel Center/ Division for Early Childhood

- Family Cohort 1 & 2 families = 25 states
- (Arizona, Colorado, Connecticut, District of Columbia, Florida, Georgia, Hawaii, Illinois, Indiana, Massachusetts, Michigan, Minnesota, Mississippi, Montana, Nebraska, North Dakota, Nevada, New York, Rhode Island, South Carolina, South Dakota, Texas, Virgin Islands, Washington, Wyoming)

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- Family Cohort Member Affiliations: Parent Centers (PTI), State Family Organizations, Interagency Coordinating Council (ICC) members, Partners in Policy Making Graduate, Trained Parent Advocate, LEND graduate.
- **All families have children currently receiving or have received EI/ECSE services.** They are all focused on leadership at the early childhood level.

Top 5 Concerns from Family Cohort

1. Overwhelmed, stressed and exhausted! *with everything: school, working from home and not knowing what is coming next.*
2. Protecting health and safety of family – big concern is the disparity.
3. Need accurate and real time information and guidance – *expected to be an educator and modify work sent home without support and guidance.*
4. Been able to step back and see child and family's strengths but also the challenges.
5. Allowing the family to be a family! Sometimes we need to just take a break from it all.

Top 10 things UCEDDs or LENDs can do: It is not business as usual

1. Position the UCEDD to be a resource for families to support each other (*parent to parent mentoring*).
2. Act as clearinghouse for resources and referrals to help families access food, shelter and safety (*service coordination and community building*).
3. Identify your state resources in technology, and link families and practitioners to resources, including training (*not all families have the capacity, or want to be on the receiving end of a zoom/google classroom etc.*).
4. Develop “easy to use” tool kits for families and practitioners about service delivery options and models(*tip sheets for families - tip sheets for practitioners*).
5. Provide TA to EI/ECSE/Special Education programs and staff on how to meet family needs (*listen to the families*).

Top 10 things UCEDDs or LENDs can do:

Continued

6. Provide training to families and practitioners on coordinating and collaborating on service delivery options and technology applications to facilitate remote learning (*teaming*).
7. Develop strategies to help service delivery teams measure educational progress (*asking families to collect data is not the answer*).
8. Provide opportunities for groups of stakeholders to come together to use their experiences to plan proactive strategies (*family driven*).
9. Provide ongoing self-care routines for those we serve (families, PWD).
10. Embed disaster planning objectives into 5 year UCEDD plan. and include families and PWD (*be proactive, not reactive*).

Nothing should go back to normal.

Normal was not working.

If we go back to the way things were, we will have lost the lesson.

May we rise up and do better.