How Families of Children With Special Health Care Needs Are Coping in the “New Normal”
Webinar housekeeping

Minimize distractions
Lines have been muted

Engage and participate
Ask questions in the Q&A box

Report technical issues
For any technical issues, please send a message directly to the host through the chat box
Presenters

Alicia VanOrman
Senior Research Associate, PRB

Beth Jarosz
Program Director, PRB

Lilian Ansari
Family Advocate
Overview

• Overview of the data source

• Highlights from the latest survey
  • Vaccinations
  • Experiences of families with children with special health care needs (CSHCN)
  • Stress and mental health

• How to access the data

• How the pandemic has affected (and still affects) families
Project background

• **Purpose**: Track effect of pandemic on children and families

• **Approach**:
  - Internet panel (California and U.S. samples), web-based questionnaire
  - 60+ questions (varied across waves)
  - Approximately 1,500 respondents in each wave
  - Four waves, 1st Nov. 2020, 4th June 2022

*More information is at the end of this slide deck, which we will share*
## Collaborators

### NATIONAL (WAVES 1-3)

American Academy of Pediatrics (AAP), Centers for Disease Control and Prevention (CDC), Prevent Child Abuse America (PCAA), Tufts Medical Center’s Healthy Outcomes from Positive Experiences (HOPE)

### CALIFORNIA (WAVES 1-4)

Lucile Packard Foundation for Children’s Health (LPFCH), California Department of Social Services (CDSS) and California Department of Public Health’s (CDPH) Essentials for Childhood Initiative (EfC), CDPH’s Office of Suicide Prevention (OSP), KidsData at PRB
COVID-19 VACCINATIONS
Households with highest income are most likely to have oldest child fully vaccinated against COVID-19

VACCINATION COMPLETION, BY INCOME LEVEL, JUNE 2022

- **All Incomes**: 53% Full, 8% Partial, 8% Not
- **$100,000 or Higher**: 39% Full, 9% Partial, 8% Not
- **$60,000-99,999**: 32% Full, 8% Partial, 9% Not
- **$30,000-59,999**: 41% Full, 9% Partial, 6% Not
- **Less than $30,000**: 56% Full, 6% Partial, 38% Not

**Source:** KidsData from Family Experiences During the COVID-19 Pandemic.
Households with CSHCN are more likely to have oldest child fully or partially vaccinated against COVID-19

**VACCINATION COMPLETION, BY HOUSEHOLD CSHCN STATUS, JUNE 2022**

- **Households with CSHCN**
  - Not vaccinated: 29%
  - Partially vaccinated: 15%
  - Fully vaccinated: 56%

- **Households without CSHCN**
  - Not vaccinated: 44%
  - Partially vaccinated: 5%
  - Fully vaccinated: 52%

- **All Households**
  - Not vaccinated: 39%
  - Partially vaccinated: 8%
  - Fully vaccinated: 53%

**Source:** KidsData from Family Experiences During the COVID-19 Pandemic.
More than a third of caregivers with un(der) vaccinated child were worried about side effects

CAREGIVER REASON FOR NOT VACCINATING CHILD AGAINST COVID-19, JUNE 2022

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worried about side effects</td>
<td>35%</td>
</tr>
<tr>
<td>Worried developed too quickly</td>
<td>20%</td>
</tr>
<tr>
<td>Don't have enough information</td>
<td>18%</td>
</tr>
<tr>
<td>Don't think it's necessary</td>
<td>22%</td>
</tr>
<tr>
<td>Don't believe in vaccines</td>
<td>10%</td>
</tr>
<tr>
<td>Plan to or child too young</td>
<td>42%</td>
</tr>
</tbody>
</table>

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
EXPERIENCES FOR HOUSEHOLDS WITH CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)
By summer 2022, in-person school had resumed for almost all households

HOUSEHOLDS WHERE SCHOOL WAS STILL CLOSED FOR THEIR CHILD, BY WAVE

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
Share with after school activities still cancelled also fell, but remained higher for households with CSHCN

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
Households with CSHCN continued to have higher concern about youngest child being behind at school

**LEVEL OF CONCERN FOR HOUSEHOLDS WITH CSHCN, BY WAVE**

<table>
<thead>
<tr>
<th>Wave</th>
<th>Slightly/Not at all</th>
<th>Moderately</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2021</td>
<td>44%</td>
<td>34%</td>
<td>22%</td>
</tr>
<tr>
<td>June 2022</td>
<td>48%</td>
<td>39%</td>
<td>14%</td>
</tr>
</tbody>
</table>

**LEVEL OF CONCERN FOR HOUSEHOLDS WITHOUT CSHCN, BY WAVE**

<table>
<thead>
<tr>
<th>Wave</th>
<th>Slightly/Not at all</th>
<th>Moderately</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2021</td>
<td>60%</td>
<td>26%</td>
<td>15%</td>
</tr>
<tr>
<td>June 2022</td>
<td>73%</td>
<td>18%</td>
<td>8%</td>
</tr>
</tbody>
</table>

*Source: KidsData from Family Experiences During the COVID-19 Pandemic.*
In more than one-third of households with CSHCN, children were still behind at school.

CHILDREN'S PROGRESS TOWARDS CATCHING UP AT SCHOOL, BY HOUSEHOLD CSHCN STATUS, JUNE 2022

- Fell further behind: 5% Households with CSHCN, 4% Households without CSHCN, 5% All Households
- Still behind but catching up: 33% Households with CSHCN, 18% Households without CSHCN, 22% All Households
- Caught up or now ahead: 22% Households with CSHCN, 25% Households without CSHCN, 24% All Households
- Did not fall behind: 23% Households with CSHCN, 40% Households without CSHCN, 35% All Households
- No change: 17% Households with CSHCN, 14% Households without CSHCN, 15% All Households

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
Two-thirds of caregivers with CSHCN were concerned about children’s safety since public health orders were rolled back.

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**Source:** KidsData from Family Experiences During the COVID-19 Pandemic.
Caregivers in CSHCN households were more likely to be concerned about oldest child's mental health

LEVEL OF CONCERN FOR HOUSEHOLDS WITH CSHCN, BY WAVE

<table>
<thead>
<tr>
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<th>Slightly/Not at all</th>
<th>Moderately</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2021</td>
<td>18%</td>
<td>45%</td>
<td>38%</td>
</tr>
<tr>
<td>June 2022</td>
<td>14%</td>
<td>40%</td>
<td>46%</td>
</tr>
</tbody>
</table>

LEVEL OF CONCERN FOR HOUSEHOLDS WITHOUT CSHCN, BY WAVE

<table>
<thead>
<tr>
<th>Wave</th>
<th>Slightly/Not at all</th>
<th>Moderately</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2021</td>
<td>68%</td>
<td>24%</td>
<td>8%</td>
</tr>
<tr>
<td>June 2022</td>
<td>73%</td>
<td>22%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
In CSHCN households, children who need mental health services were more likely to receive treatment/counseling.

CHILDREN WHO RECEIVED NEEDED MENTAL HEALTH COUNSELING IN PAST YEAR, BY HOUSEHOLD CSHCN STATUS, JUNE 2022

- With CSHCN: 62%
- Without CSHCN: 52%
- All Households: 59%

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
Caregiver stress hasn’t gone down!

CAREGIVER NERVOUS/STRESSED MOST OF THE TIME IN THE PREVIOUS MONTH, BY HOUSEHOLD CSHCN STATUS, BY WAVE

<table>
<thead>
<tr>
<th></th>
<th>July 2021</th>
<th>June 2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Households with CSHCN</td>
<td>34%</td>
<td>39%</td>
</tr>
<tr>
<td>Households without CSHCN</td>
<td>27%</td>
<td>31%</td>
</tr>
<tr>
<td>All Households</td>
<td>29%</td>
<td>33%</td>
</tr>
</tbody>
</table>

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
Caregivers were under emotional strain, with troubling consequences

CAREGIVER SHOUTED, YELLED, SCREAMED AT CHILDREN IN THE PAST WEEK, BY HOUSEHOLD CSHCN STATUS, BY WAVE

<table>
<thead>
<tr>
<th>Wave</th>
<th>Households with CSHCN</th>
<th>Households without CSHCN</th>
<th>All Households</th>
</tr>
</thead>
<tbody>
<tr>
<td>November 2020</td>
<td>54%</td>
<td>47%</td>
<td>44%</td>
</tr>
<tr>
<td>March 2021</td>
<td>60%</td>
<td>45%</td>
<td>37%</td>
</tr>
<tr>
<td>July 2021</td>
<td>56%</td>
<td>44%</td>
<td>37%</td>
</tr>
<tr>
<td>June 2022</td>
<td>53%</td>
<td>40%</td>
<td>34%</td>
</tr>
</tbody>
</table>

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
Households with higher income were more likely to have access to telehealth for mental health

Household Mental Health Telehealth Availability, by Income Level, June 2022

- **All Incomes**: 8% Available, 28% Not available in area, 53% Don't know/Unsure how to access
- **$100,000 or Higher**: 5% Available, 17% Not available in area, 66% Don't know/Unsure how to access
- **$60,000-99,999**: 8% Available, 23% Not available in area, 62% Don't know/Unsure how to access
- **$30,000-59,999**: 8% Available, 35% Not available under health coverage, 45% Don't know/Unsure how to access
- **Less than $30,000**: 13% Available, 34% Not available under health coverage, 41% Don't know/Unsure how to access

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
CSHCN households more likely to be using telehealth mental health services

MOST RECENT MENTAL HEALTH TELEHEALTH SERVICES RECEIVED IN HOUSEHOLD, BY HOUSEHOLD CSHCN STATUS, JUNE 2022

<table>
<thead>
<tr>
<th>Service</th>
<th>Households with CSHCN</th>
<th>Households without CSHCN</th>
<th>All Households</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used in past week</td>
<td>11%</td>
<td>4%</td>
<td>7%</td>
</tr>
<tr>
<td>Used in past year</td>
<td>28%</td>
<td>13%</td>
<td>18%</td>
</tr>
<tr>
<td>Used when most offices were closed</td>
<td>25%</td>
<td>12%</td>
<td>16%</td>
</tr>
</tbody>
</table>

Source: KidsData from Family Experiences During the COVID-19 Pandemic.
Summary of survey findings

CHALLENGES FOR CSHCN

• More disruptions to school and activities
• Farther behind at school
• More concern about mental health

BRIGHT SPOTS

• Many trends moving in positive direction
• More likely to get needed mental health care

Other studies of child well-being during the pandemic have similar findings (e.g., First 5 LA’s Family Survey Results: Parenting Young Children Through The COVID-19 Pandemic)
Where can you get the data?

KidsData.org
Find data about the health and well being of children in communities across California:

Enter a location and/or a topic, e.g. "Los Angeles foster care"

Well-Being During the Pandemic

Investigate the COVID-19 pandemic's impacts on children and families.
FAMILY EXPERIENCES
Lilian Ansari
Family Advocate
DISCUSSION
Stay connected with KidsData on social media

@KidsData  linkedin.com/showcase/kidsdata-org/  @KidsData@sfba.social
ADDITIONAL INFORMATION ABOUT THE SURVEY...
## Questionnaire samples

<table>
<thead>
<tr>
<th></th>
<th>California Wave 1</th>
<th>California Wave 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size</td>
<td>1,526</td>
<td>1,575</td>
</tr>
<tr>
<td>Female</td>
<td>54%</td>
<td>53%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS diploma or less</td>
<td>42%</td>
<td>42%</td>
</tr>
<tr>
<td>4-year degree or more</td>
<td>30%</td>
<td>28%</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under $30,000</td>
<td>28%</td>
<td>21%</td>
</tr>
<tr>
<td>$100,000 or above</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>CSHCN</td>
<td>29%</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>California Wave 1</td>
<td>California Wave 4</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Black</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>White</td>
<td>28%</td>
<td>27%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>49%</td>
<td>49%</td>
</tr>
<tr>
<td>Asian</td>
<td>9%</td>
<td>11%</td>
</tr>
<tr>
<td>Native American</td>
<td>2%</td>
<td>2%</td>
</tr>
</tbody>
</table>
Questionnaire topics

All Waves

- Disruptions in education, health care, and social activities
- Emotional and behavioral health
- Economic security
- Child and caregiver safety
- Adverse childhood experiences
- Positive childhood experiences
- Caring for CSHCN

New in Wave 2

- Falling behind at school

New in Wave 3

- Child mental health

New in Wave 4

- Family mental health care access and utilization
- COVID-19 vaccination status and barriers to vaccination
HOW TO STAY INFORMED THROUGH KIDSDATA
See Data by Topic

Make a selection:
(Expand all | Collapse all)

- Child and Youth Safety
  - Bullying and Harassment at School (summary)
  - Child Abuse and Neglect (summary)
  - Childhood Adversity and Resilience (summary)
  - Foster Care (summary)
  - Gang Involvement (summary)
  - Intimate Partner Violence (summary)
  - School Safety (summary)
- Children with Special Health Care Needs
See Data by Region

Select a region:
(Expand all | Collapse all)

California (State-level Data)
- Legislative Districts (What's My District?)
- State Assembly Districts
- State Senate Districts
- U.S. Congressional Districts
- Counties, Cities and School Districts
  - Alameda County
  - Alpine County
  - Amador County
  - Butte County
Thank you