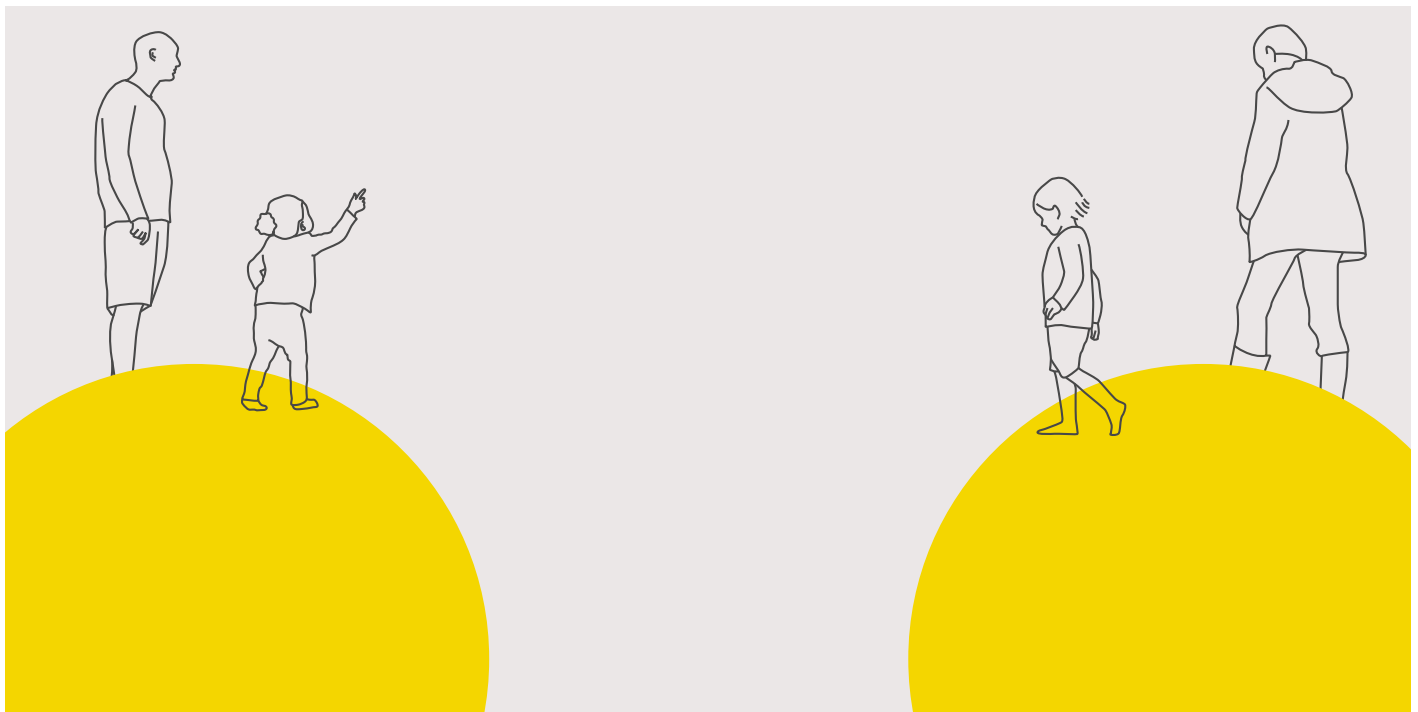


WIDENING DISPARITIES: THE UNIQUE CHALLENGES OF FAMILIES OF CHILDREN WITH SPECIAL NEEDS WITH SPECIAL NEEDS

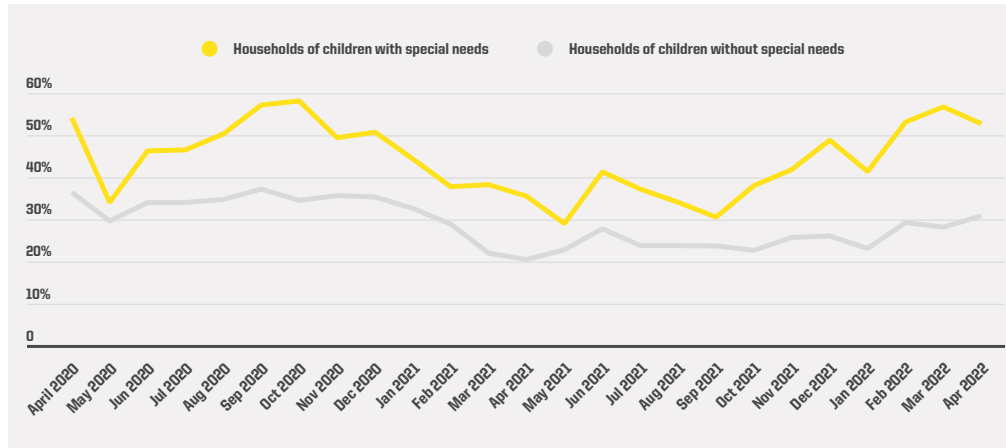
Families of children with special needs have continued to experience more material hardship, hunger, and emotional distress compared to those who do not have children with special needs.

In December 2020, we published [a blog post](#) that summarized the challenges that families of children with special needs have faced during the COVID-19 pandemic. This included disrupted preventive healthcare, lack of social support, and high levels of emotional distress.

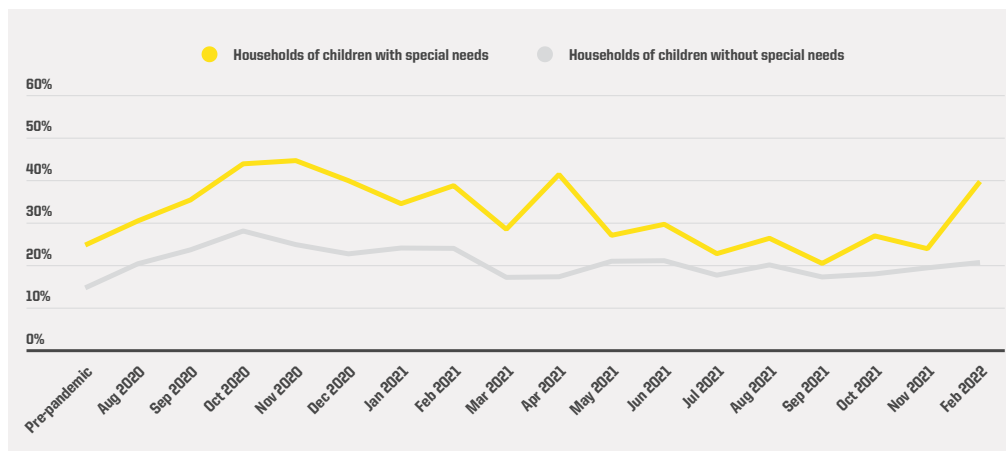


DISPARITIES IN MATERIAL HARDSHIP AND HUNGER

Trend of material hardship among families of children with vs. without special needs



Trend of hunger among families of children with vs. without special needs



Families of children with special needs have consistently experienced more material hardship than those of children without special needs. This difference has been widening since September 2021. **In April 2022, over half of households in our survey with children with special needs reported material hardship.**

Families of children with special needs also reported higher levels of hardship unpredictability,* than families of children without

special needs. This unpredictability is week-to-week and month-to-month changes in being able to pay for basic needs. We have found a significant association between unpredictability in paying for basic needs and increased parental and child emotional distress.

More households of children with special needs faced hunger compared to those of children without special needs. This hunger disparity has been widening since November 2021.

*

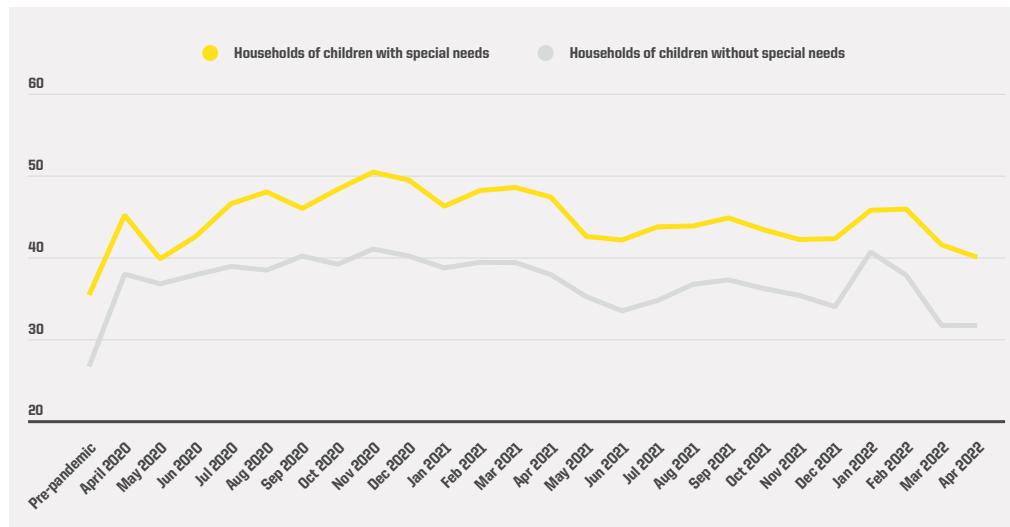
As indicated by the coefficient of variance metric. We obtain the hardship unpredictability coefficient of variance metric by calculating the standard deviation divided by the mean of hardship numbers assessed at multiple time-points during the pandemic.

“Balancing finances and work schedules so that we have the income to cover housing and utility costs, while at the same time making sure our special needs (autistic) child receives the therapies and treatments he needs to thrive.”

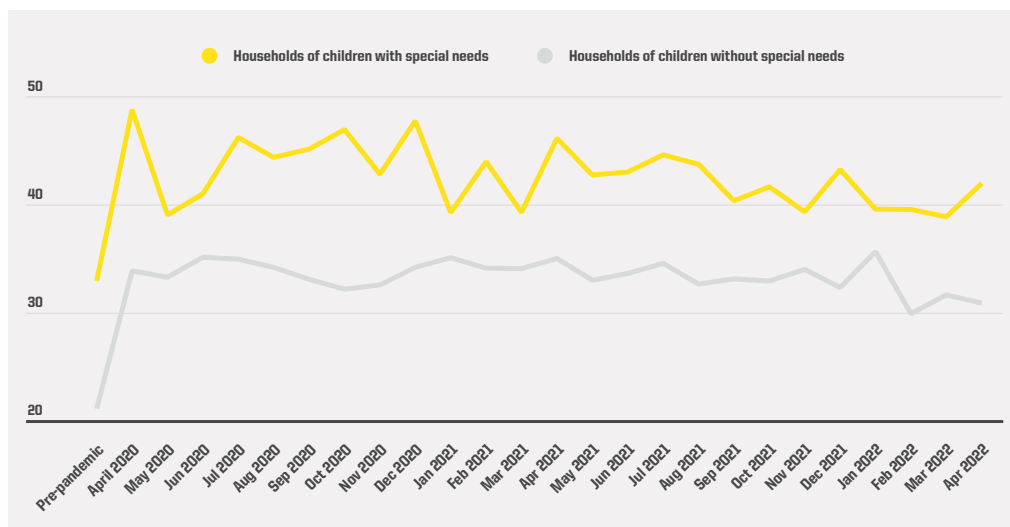
Parent in Georgia

EMOTIONAL DISTRESS HAS BEEN ELEVATED IN BOTH PARENTS AND CHILDREN

Trend of parents' emotional distress among families of children with vs. without special needs



Trend of children's emotional distress among families of children with vs. without special needs



Throughout the pandemic, parents of children with special needs have consistently reported higher levels of emotional distress* than parents of children without special needs.

Similarly, these parents have consistently indicated that their children have been exhibiting signs

of greater emotional distress** than children in households without a child with special needs. We analyzed the average child emotional distress among these two groups; these data show that all children in households with a child with special needs exhibited a higher level of emotional distress.

“Our daughter has cerebral palsy and epilepsy. Prior to the pandemic it was very difficult to find someone qualified to care for her. During the pandemic it has been practically impossible to find someone who is qualified and vaccinated and available for the hours that we need.”

Parent in Virginia

* a composite of depression, anxiety, stress, and loneliness symptoms

** a composite of fear/anxiety and fussiness/defiance

THE MAJORITY OF FAMILIES WHO NEEDED SERVICES AND SUPPORTS REPORTED RECEIVING THEM

Additionally, we asked caregivers about their access to and utilization of services and assistive supports their children needed. The majority of families in our survey who needed these services/supports reported they received them during the pandemic. Two in three parents of children with special needs also indicated that they were satisfied with these services and that the services met their children’s needs. Considering that access to

many in-person supports and services have been limited and unpredictable during the pandemic, these parents’ experiences are encouraging.

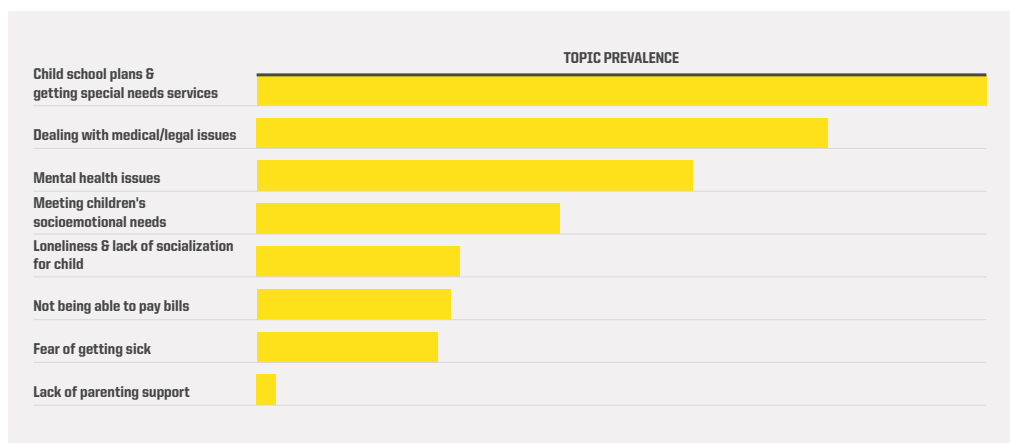
Other challenges, such as concerns about children’s education and socioemotional development, material hardship, and hunger, may be the contributing factors to the declines in well-being we have observed among these households.

“[Our biggest challenge is] paying for medical treatments. The therapies and treatments my child needs are expensive even with “good” insurance.”

Parent in Washington

CHALLENGES AMONG FAMILIES OF CHILDREN WITH SPECIAL NEEDS

Challenges reported with significantly higher prevalences among households of children with special needs



To explore the challenges families of children with special needs have experienced, we used structural topic modeling to analyze parents’ responses to the open-ended question “What are the biggest challenges and concerns for you and your family right now?”

The bar chart above shows topics with significantly higher prevalence among families with a child with special needs, in comparison to families of children without special needs. Parents of children with special needs reported more challenges

“My son receives multiple therapies each week, in ABA, OT and speech. Thankfully our private insurance pays for these services, but we still have over \$1000 in copays every month.”

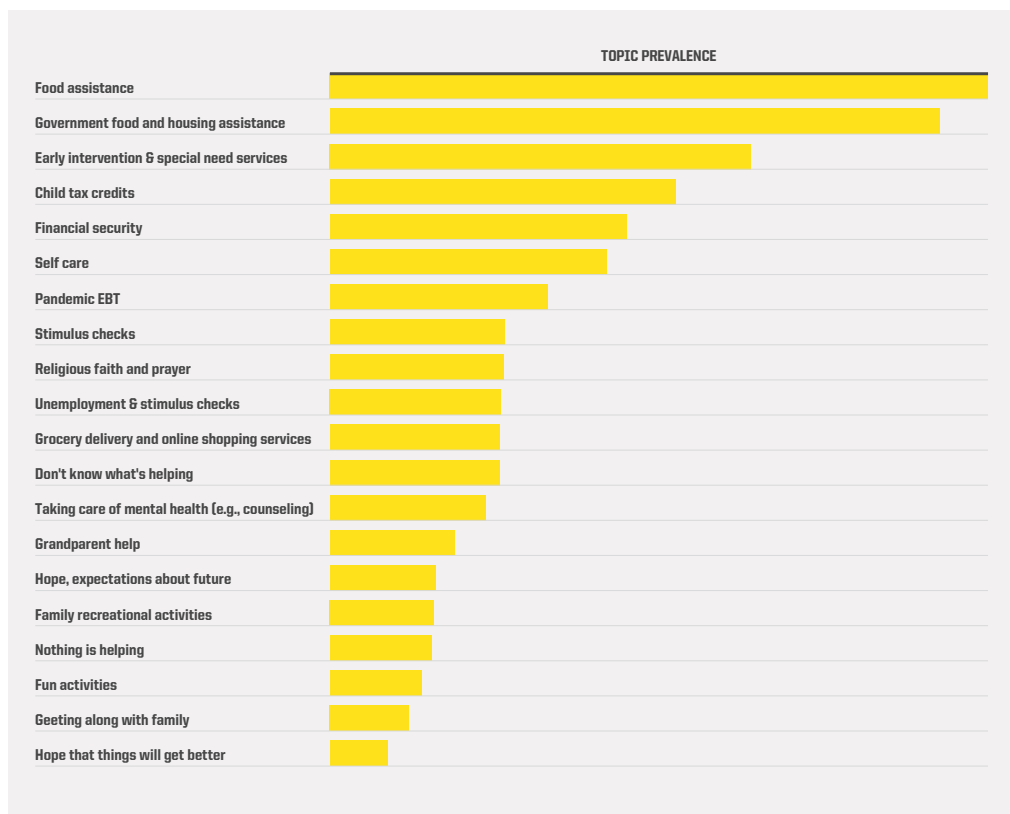
Parent in Texas

in children’s school plans and socioemotional development, getting

support services, mental health, financial strain, and fear of getting sick.

FACTORS THAT HELP FAMILIES OF CHILDREN WITH SPECIAL NEEDS

Supports reported with significantly higher prevalences among households of children with special needs



Using the structural topic modeling technique, we also assessed parents’ responses to the open-ended question “What is helping you and your family the most right now?”

According to the bar chart above, factors that have been helping households of children with special

needs mainly focus on financial assistance, early intervention and special needs services, support from family/friends, as well as hope/faith.

We will continue to gather information to understand the unique circumstances and experience of families with children with special needs.

“We are scared of the healthcare bills coming in around my new baby’s birth, she is disabled. They may hit \$100,000. We are concerned about our ongoing ability to pay for her needs.”

Parent in Connecticut

“[Our biggest challenge is] having no support with our special needs child. We are burnt out.”

Parent in Maryland

ABOUT THE RAPID PROJECT

Data presented in this fact sheet are based on RAPID household surveys. Analyses are based on responses collected from 14,032 caregivers between August 2020 and April 2022. These caregivers represent a range of voices: 8.82% are Black/African American, 13.71% are Latinx, and 34.34% live at or below 200% of the federal poverty level. In addition, 12.58% of parents reported having child(ren) with disabilities in their households. Proportions/percentages are calculated based on the item-level response rates, not on the total sample. The data for these analyses are not weighted.

The RAPID project includes a survey of caregivers with children under age 6 and a survey of child care providers and other adults who care for children under age 6.

These surveys are designed to gather essential information continuously regarding the needs, health-promoting behaviors, and well-being of children and their families and important adults in their lives.

RAPID collects data monthly from 1,000 caregivers and child care providers in all 50 states. The surveys are national in scope, though not technically nationally representative. RAPID collects snapshots of data across time and can also assess trends longitudinally.

For more information about RAPID study design and methods, see [here](#).

RAPID is under the direction of Philip Fisher, PhD, Director of the newly formed Center on Early Childhood at Stanford University

1,000+

surveyed
bi-weekly

98

surveys

17,000+

unique
households

50

US states

