

SEED Study to Explore Early Development

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What have we learned from SEED so far?

This edition of the Study to Explore Early Development (SEED) Newsletter highlights some research findings that may be of interest to you. SEED has helped us learn about children with autism and other developmental disabilities. You may have participated in SEED 1 (2007–2011), SEED 2 (2012–2016), SEED 3 (2017–2020), SEED Teen (2018–2021), the COVID-19 Impact Assessment (2021), or most recently, SEED Follow-Up (2022–2026). Each phase of SEED has given us a lot of information that will help us understand the needs of communities and families.

In this issue, we will share what we learned about the COVID-19 pandemic's impact on the health, behavior, and well-being of young children and their families.

The COVID-19 pandemic started in the middle of SEED 3 activity. This presented SEED with a unique opportunity to directly compare information we collected just before and after the start of the pandemic to learn about its impact.

We learned that:

- During the stay-at-home phase of the pandemic, behavioral and emotional problems increased in children without disabilities but decreased among children with autism.
- The communication skills of children with autism worsened during the stay-at-home phase of the pandemic.

This suggests that while stay-at-home policies of the COVID-19 pandemic may have had positive impacts on the daily living skills, socialization, and behavioral and emotional well-being of children with autism, these benefits may have occurred at the cost of communication skills. These findings indicate the need for strategies to maintain appropriate services for all families in future public health emergencies.

We learned how the COVID-19 pandemic affected the financial lives of families of children with and without developmental disabilities.

To control the spread of COVID-19, communities enacted public health measures that impacted many families. We compared the financial impacts of the COVID-19 pandemic on families of children without developmental disabilities to those with autism or another disability.

We found that:

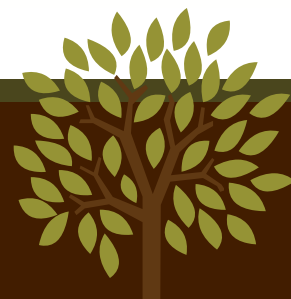
- Parents of children with autism were less likely to work from home and more likely to report problems paying bills during the pandemic compared with other parents.
- Families with lower incomes before the pandemic experienced job loss, reduced work hours, problems paying bills, and fear of losing their homes compared with families with higher incomes, regardless of whether their children had a developmental disability.
- Parents from racial and ethnic minority groups were more likely than others to report experiencing problems paying bills and the fear of losing their homes.

We learned about how remote delivery of behavioral and other services during the COVID-19 pandemic affected children with developmental disabilities.

Many children transitioned to telehealth services during the COVID-19 pandemic. In our survey of children enrolled in SEED 3, caregivers reported that most children with autism and other developmental disabilities received fewer hours of therapy during the COVID-19 pandemic than they had before the pandemic.

- Up to 11% of caregivers were unable to use telehealth for their child.
- As few as 38% of caregivers received parent training to deliver social skills training services at home. It was more common for caregivers to receive training on how to deliver behavior therapy at home, with up to 58% of caregivers receiving this type of training.
- Children with autism received less speech/language therapy than children with other developmental disabilities.
- For children with autism who had more problems with social skills, behavioral telehealth during the pandemic was less effective than in-person services before the pandemic.

Training programs for caregiver support and more effective telehealth delivery of services for children with developmental disabilities may help prevent these problems in future public health emergencies.



We learned how health and education services for young children changed during the COVID-19 pandemic.

- During the pandemic, more than half of all children missed or delayed regular health or dental appointments.
- More children with autism missed or delayed their specialty services compared with children with other developmental disabilities. Caregivers of children with autism also reported more problems getting health care of any kind because of issues with telehealth services, or problems with wearing a mask.
- During school closures, fewer children with autism were offered live classes online compared with children with another developmental disability. Additionally, individual special education plans were greatly disrupted for half of the children with autism.

Minimizing service disruptions for all children, and ensuring that specialty care continues, will be critical for serving families in future public health emergencies. Additional services may be needed to offset these disruptions.



ADAPTIVE FUNCTIONING



What is adaptive functioning? This term refers to the everyday skills and abilities that children learn in order to care for themselves. These skills include feeding and dressing, keeping clean,

and communicating and interacting with others. Children with autism who enrolled in SEED showed a wide range of strengths and limitations in their adaptive skills and functioning. We found that adaptive functioning is just as important, if not more important, than measures of their cognitive abilities (such as IQ) or the severity of their other symptoms in predicting their support needs.

Many previous studies defined intellectual disability in children with autism using only IQ scores. However, healthcare providers also consider adaptive skills when making this diagnosis. Our research found that children at every IQ level had adaptive support needs. We also found that many children had strengths in their

adaptive skills that may not be reflected by their IQ. When IQ and adaptive functioning are used together to define intellectual disability, the percentage of children with autism and intellectual disability drops from 63% to 38%. Additionally, we saw fewer differences in intellectual disability rates among racial and ethnic groups. This highlights the importance of considering adaptive functioning when describing intellectual disability in children with autism—and to recognize both their challenges and strengths.

We will let you know about other SEED research findings in future issues of the SEED Newsletter.



Please visit the [SEED Follow-up Study](#) website to see a video that we created to encourage young adults to participate in the study.



The CDC SEED program delivers a regular newsletter exclusively for SEED participants. The content includes up-to-date research findings and resources and programs for building strong families. Opt in today to receive these valuable updates.