

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

The COVID-19 Pandemic Has Taken a Toll on Latinx Families with Children with IDD, but There Are Some Positives as Well

A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

The COVID-19 pandemic has had a significant impact on society at large. This is especially true for communities that have a longstanding history of marginalization, such as the Latinx community. During the pandemic, the Latinx community has experienced higher rates of COVID-19 infections and COVID-19-related deaths than non-Latinx white communities. Additionally, research has shown that members of the Latinx community are more likely to be uninsured relative to other racial and ethnic groups so they may be less likely to seek medical care, even if they are exposed to COVID-19.

The effects of the pandemic also extend beyond physical health to economic and mental health. Many Latinx workers, especially women, experienced job losses and increased feelings of isolation, anxiety, and depression due to pandemic-induced restrictions. These issues are particularly magnified for Latinx caregivers of children with intellectual and developmental disabilities (IDD). While some research has examined the impact of the pandemic on caregivers in general, there has been little investigation into its impact on Latinx caregivers of children with IDD specifically.

In a recent NIDILRR-funded study, researchers sought to explore the effects of the pandemic on Latinx caregivers' perceived general health, mental health, and well-being and what factors such as social and financial supports were related to their well-being. The researchers also set out to determine the impacts of the pandemic on these families' daily eating and physical activity habits and to understand any common themes from the caregivers' experiences during the pandemic.

For this study, researchers from the project [Promoting Obesity Prevention Among Latinx Children with Developmental Disabilities and Families Through Engaged Research](#) interviewed 37 female caregivers of children with IDD from 2 urban US cities. The caregivers were all of Latinx descent and were either the mother or caregiver with custody of a child between the age of 6 and 17 diagnosed with autism spectrum disorder, Down's syndrome, and/or intellectual disability. The study consisted of 3 separate 60--75-minute phone or web video interviews over the course of 4-6 weeks between July 2020 and March 2021. The participants had the option to be interviewed in English or Spanish.

At the first interview, the participants answered questions regarding demographics, such as employment and insurance status, family income, and marital status. They also answered questions about their child's health, health behaviors such as eating behaviors and exercising, quality of life, and home environment. At the second interview, participants answered questions about their own physical and mental health,

health behaviors, available social supports, and well-being. At the third interview, the participants answered questions regarding physical activity and behavior for both the child and caregiver and collected information about the pandemic's effects on the family and the family's health behaviors, such as job losses, financial stresses, and food security. The researchers also asked participants if any family members had negative economic changes (i.e., job loss); if the family received any direct financial support; or if the child had access to online special education, routine therapies, and IDD-related services during the pandemic.

Regarding the caregivers' physical and mental health, the researchers found the following:

- More than half of the caregivers had some type of health insurance.
- Caregivers reported that they engaged in an average of about five hours per week of leisure and moderate-to-vigorous physical activity.
- Caregivers reported moderately high perceived social support (most of which came from a significant other).
- Caregivers reported fair to good perceived physical health and moderate levels of energy.
- Caregivers reported moderately high overall symptoms of depression. However, those with higher income, more social support, better health, and more energy reported fewer symptoms of depression.

The participants reported that the pandemic had an impact on areas such as economic impact, mental health and well-being, their child's development and behavior, physical activity, and eating habits and routines. Specifically:

- 38% of families reported low or very low food security during the pandemic.
- 70% of families had at least one negative economic change because of the pandemic.
- 62% of the families did not receive financial benefits from the government during the pandemic.
- Common mental health and well-being stressors were concerns about finances, employment, lack of childcare, and fears of infection.
- While 54% of the children maintained access to two of the three services categories (i.e., online special education, routine therapies, and IDD-related services), regular face-to-face school, therapy, and extracurricular activities were disrupted, leading to worries about social isolation and loss of academic and developmental skills.
- 62% of caregivers reported an increase in sedentary time and a decrease in physical activity.

- 76% of caregivers reported changes in eating habits and disruptions to routines. These included not being able to afford fresh foods or diet-specific foods.

Despite the challenges, the caregivers also reported positive experiences and changes during the pandemic. These included getting support from their community such as food pantries and free COVID testing; using lockdown periods as a time for family bonding; learning new skills through technology; using free time to engage in physical activity or work on developmental skills with their child; and, for those able to afford quality food, being able to exercise more control over what their family ate.

The authors noted that the results of this study were consistent with prior research regarding the negative effects of financial worries on stress levels and findings that increased social support appears to have a positive effect on well-being and mental health.

As a next step after the three interviews were completed, the researchers created personalized reports to share with each participant, including a summary of their responses and a list of resources and recommendations to support access to healthy foods and physical activity. They also created general information products based on the study findings to distribute to the community. In addition, the researchers collaborated with community partners to create webinars designed to meet the information needs of Latinx families with children with IDD. The authors noted that the findings of the study and the welcome reception of the information products that followed may suggest a need to improve culturally relevant and linguistically competent support and mental health services through more funding. Results from this study also suggest the need for improved community partnerships to create robust support systems to improve the overall health and well-being of children with IDD and their caregivers, particularly those from diverse racial and ethnic backgrounds.

[To Learn More](#)

The information products developed by this project are available in English and Spanish at <https://sites.utexas.edu/poder/>

[To Learn More About this Study](#)

Suarez-Balcazar, Y.; Mirza, M.; Errisuriz, V.L.; Zeng, W.; Brown, J.P.; Vanegas, S.; Heydarian, N.; Parra-Medina, D.; Morales, P.; Torres, H.; Magana, S. [Impact of covid-19 on the mental health and well-being of Latinx caregivers of children with intellectual and developmental disabilities](#). International Journal of Environmental Research and Public Health 2021, 18, 7971. This article is available from the NARIC collection.

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