

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

Home and Community Based Waivers May Make Family Life Easier for Families of Children with Autism

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

Autism is a developmental disability that affects how people communicate and process information. Children with autism may need specialized services to help them learn to express themselves, regulate their emotions, and master independent living skills. Families of children with autism may find it challenging and stressful to coordinate services for their children, and some families may not be able to pay for services that their children need. Some parents of children with autism may also have difficulty holding a job outside the home while they are managing their children's unique care needs.

Home and Community Based Services waivers (HCBS Medicaid waivers) are state-funded programs that can help pay for services for people with disabilities, including autism. Currently, 11 states have waivers specifically to serve children with autism and their families. HCBS waivers can pay for disability-related services, and they may also provide health insurance through Medicaid to families who qualify. In a recent NIDILRR-funded study, researchers interviewed families of children with autism who were receiving HCBS waiver services related to their child's autism (autism waiver). The researchers wanted to find out what services the families received under the waiver, and what they liked or disliked about those services. They also wanted to learn about how the waiver program helped families' in the area of finances.

Researchers conducting a study of [Impacts and State Utilization of HCBS Waiver Services for Families and Children with Autism](#) interviewed 22 families of children with autism who were currently receiving services from the autism waiver program in Maryland. Interviews were conducted with one or both parents, and some interviews included other family members. The families had children ranging in age from 10-22 years, and they had been receiving waiver services for an average of 8 years. During the interviews, the researchers asked the participants to list the services their families received as part of the autism waiver, and to describe their experiences with those services, and how the waiver services impacted their family's financial life.

The participants reported using a variety of autism-related services through the waiver. The participants' perception of the different services they used are listed below:

- Intensive Individual Support Services (IISS): Under these services, children received one-on-one support after school or on weekends for help with academics, independent living skills, or socialization. Generally, the participants described this service positively, as they appreciated their children learning new skills while they could focus on other family obligations.

- Therapeutic integration: This service involved including children in recreational or artistic activities in the community. Overall, the participants described this service positively, although a few of them felt that their children did not enjoy it.
- Respite care: This service provided childcare for a limited number of hours each month, so that caregivers are able to take a break from providing childcare. The participants described this service positively in general, although some felt that they did not receive enough hours each month to meet their needs, or that the respite providers did not connect well with their children.
- Adult life planning: The participants with children aged 16-21 used this service to plan for transitioning to adult service systems. The participants who used this service described it positively overall, particularly for easing concerns about what lay ahead for their child as they approached adulthood.
- Family consultation: This service involved regular home visits from a caseworker who worked with the parents on behalf of the family rather than directly with the children. This service was the only mandatory service for the autism waiver and it had the most mixed responses. Some of the participants appreciated the involvement, while others felt that it was unnecessary or that the provider was incompetent.
- Some less-commonly used services reported by the participants included residential placement, such as group homes, and funding for home modifications, such as installing window locks or alarms. These services were described positively or very positively by the families who utilized them.

Across the different services, the participants had the most positive experiences with services that were flexible, when the service providers were competent and well-trained, and when the participants felt that they had choice in the types of services and the providers that they used. IISS workers were often identified as the service most valued for the personal relationships and flexible options available. The participants had more negative experiences with services if there was a lot of staff turnover or if staff were not properly trained, or if they had less control over the types of services received.

When asked about the effect of the waiver services on their family finances, the participants said that the waiver helped them pay for private therapies and other services that they might not otherwise have been able to afford for their children. The participants also reported finding the Medicaid coverage helpful for reducing their family's medical expenses. In addition, some of the participants said that having the waiver services for their children made it easier for the participants to gain or keep jobs outside the home. However, even when they could gain or keep jobs, there were still additional challenges such as attending many school meetings or picking up their children at school unexpectedly while working. These participants reported that having flexible work environments or a job located near their child's school helped mitigate these challenges.

The authors noted that HCBS waiver services can help improve quality of life for families of children with autism by removing financial barriers so children with autism can receive services in their homes and communities. The participants in this study especially appreciated services that were dependable, flexible, and delivered by competent providers. Future research may be useful to explore in-depth or identify other factors that are associated with family satisfaction with waiver services.

To Learn More

The [Rehabilitation Research and Training Center on Family Supports](#) conducts research and training on the programs that support families experiencing disability. Check out their research briefs on [Family Experiences with Long-Term Supports and Services for Family Members with Intellectual and Developmental Disabilities](#) and [Family Outcomes of Long-Term Supports and Services for Family Members with Intellectual and Developmental Disabilities](#).

The Centers for Medicare and Medicaid Services (CMS) released a report, [Autism Spectrum Disorders \(ASD\) State of the States of Services and Supports for People with ASD](#), which provides a nationwide summary of state services for people with ASD and related policies.

[The Arc of the United States](#) and its state chapters can assist families interested in learning more about HCBS waiver services in their state.

To Learn More About This Study

Eskow, K.G., and Summers, J.A. (2019) [Family perceptions of the impacts of a home and community-based services autism waiver: Making family life possible](#). *Journal of Applied Research in Intellectual Disabilities*, 32, 159-171. This article is available from the NARIC Collection.

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NARIC operates under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, Department of Health and Human Services, contract #GS-06F-0726Z.