

National Core Indicators® Data Highlight

What Do NCI Data Tell Us About Parents with Intellectual and Developmental Disabilities?

In the 2018-2019 NCI In-Person Survey of people with intellectual and developmental disabilities (IDD), 3.4% were parents. Across the participating states, the percentage ranged from a high of 10.4% to a low of 0.8%

Why does it matter? People with IDD increasingly grow up in their communities, attend school, and engage in a range of civic, cultural, and spiritual activities. Many are also developing loving relationships and finding life partners. As with other hard-fought rights, a growing number of people with IDD are exerting their rights to become parents. The developmental disabilities and child welfare systems are challenged to respond to parents with IDD by finding ways to support successful parenting. In the past, child welfare agencies have, in some instances, treated these families with suspicion and in many instances have terminated parental rights (only 43% of parents in the 2018-2019 NCI In-Person Survey with children under 18 were living with that child). IDD agencies are exploring waiver supports for parents with IDD. Such supports include transportation, childcare, parent training, peer supports, money management, adaptive equipment, and coordination with early intervention.



Photo courtesy of the Association for Successful Parenting

Questions to ask: What supports for parents with IDD are included in your Home and Community-Based Services (HCBS) Waiver menu. In what ways can DSPs provide support to the parent with IDD as well as the child? How do services and supports take into consideration the changing needs of the children? Has there been coordination between child welfare and developmental disabilities staff to ensure that termination of parental rights is not the default but a last resort? Is parental training available regarding nutrition, cleanliness, safety, and other issues? Have other innovative approaches been initiated including parenting groups that can provide peer support, home visitation, and joint parenting? Do school curricula for students with IDD include sex education as well as orientation to parenting?

Want to know more?

- National Research Center for Parents with Disabilities: Parents Empowering Parents. The Heller School for Social Policy and Management, Brandeis University. <https://heller.brandeis.edu/parents-with-disabilities/info-resources-research-briefs/parenting-tips-strategies/advice-intellectual-disabilities.html>
- The Arc. Parents with Intellectual Disabilities. <https://thearc.org/wp-content/uploads/forchapters/Parents%20with%20IDD.pdf>
- The Association for Successful Parenting: A Chance to Parent. <https://achancetoparent.net/>
- Child Welfare Information Gateway. *Services for Parents with Disabilities*. U.S. Department of Health and Human Services. <https://www.childwelfare.gov/topics/systemwide/service-array/services-disabilities/youth/disabilities/>
- National Council on Disability. *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children. Toolkit*. <https://ncd.gov/publications/2012/sep272012>