

Federal Grants Support Medical Self-Determination and Alternatives to Guardianship for Autistic Adults

2022 Report to Congress

This 2022 [Report to Congress](#) describes supportive services and resources for individuals on the autism spectrum and their families. The report describes federal grants to projects that can help autistic adults retain their right to self-determination, including their medical decision-making rights, and avoid unnecessary guardianships.

Empowering Youth with Intellectual and Developmental Disabilities to Manage Their Healthcare Transitions

This five-year grant, started in FY 2021 established a national, person-centered resource center to empower youth with ID/DD in directing their own healthcare transitions from pediatric to adult models of care. The center is working to increase self-determination, independence, and quality of life for youth with ID/DD as they transition into adult models of care. Project activities include a national community of practice, co-led by members of the resource center's Youth Steering Committee, and a mobile app designed for youth with ID/DD to use during healthcare transitions. Anticipated outcomes of this initiative include that youth with ID/DD will lead their medical appointments and interactions with medical professionals; lead their at-home healthcare routines such as medication management; make decisions about their healthcare and wellness next steps, in consultation with providers, family members, and adult guardians; and learn how to proactively manage potential co-occurring health conditions.

Center for Youth voice, Youth Choice (CYvYC)

[CYVYC](#) is a five-year initiative, started in FY 2020, that created a resource center on alternatives to guardianship for youth with ID/DD. CYVYC developed a national coalition of stakeholders that endorse and share information about alternatives to guardianship and conduct research on the policies

and practices related to guardianship and its alternatives. An expected outcome of the initiative is that fewer youth are subject to guardianship.

National Resource Center for Persons with Intellectual and Developmental Disabilities and Co-Occurring Mental Health Conditions

The grant, awarded in FY 2022 will create a national, person-centered, culturally competent resource center to increase access to supports for individuals with ID/DD and mental and behavioral health conditions, enhance system capacity, and educate crucial system partners about the strengths and needs of individuals with ID/DD and mental health support needs. The objectives of this project are to create a Center that will provide an opportunity to elevate best practices in policy, clinical, and workforce capacity while improving the engagement of individuals with disabilities and their families in identifying effective treatment and support services. Expected outcomes include the development of effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural beliefs and practices, preferred languages, and communication strategies (including the use of AAC), health literacy, and other needs, designed to increase self-determination, empowerment, and quality of life for people with co-occurring ID/DD and mental health conditions.)



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