CENTER ON YOUTH VOICE YOUTH CHOICE | PROJECT SUMMARY

Guardianship entails the loss of key civil rights and can impede self-determination (Millar, 2014; NCD, 2019; Rood et al., 2014). Thus, it can be construed as in conflict with the goals of several federal laws and policies, including education and transition processes mandated by the Individuals with Disabilities Education Act, self-determination goals of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, and the integration mandate of the Americans with Disabilities Act. Despite a growing array of less restrictive alternatives, guardianship remains deeply embedded in our cultural response to people with intellectual and/or developmental disabilities (IDD) (Crane, 2015). The National Core Indicator Survey, which includes data from people with IDD who receive services from state IDD agencies, found that in 2015-2016, 58% of respondents ages 18-22 had a guardian (NCD, 2019). Research indicates that as youth with IDD reach the age of majority, they, their parents, and the professionals that advise them are often not well-informed about guardianship or knowledgeable of less restrictive alternatives (Jameson et al, 2015). Public policies are shifting the provision of services of people with IDD to least restrictive, integrated settings and outcomes. This shift must encompass guardianship and entail the use of least restrictive decision-making supports and services for individuals with IDD.

This Center will host a variety of multi-stakeholder activities with the goal of diverting youth with IDD away from guardianship to less restrictive options.

The goals of this Center are to ensure that:

1) stakeholders have more information about alternatives to guardianship
2) an increased number of students have more decision-making options
3) fewer students are subject to guardianship

Major activities of the Center

1) Research that provides a national overview of the policies and practices related to guardianship and its alternatives
2) Development of a national coalition of key stakeholders that endorses and shares information about alternatives to guardianship with their members and constituents
3) Establishment and facilitation of multi-stakeholder teams in 10-15 states, that will develop and implement action plans to increase use of guardianship alternatives
4) Development and implementation of a Youth Ambassador program that provides support, mentorship, and leadership development to up to 50 youth with IDD who will co-lead state teams, serve on the advisory board, and serve as resource contacts in their states
5) Resource development and dissemination for a broad and culturally and linguistically diverse stakeholder group
6) Robust evaluation that facilitates organizational and community sustainability to continue and refine the work

Target audiences

- youth with IDD
- parents and caregivers
- school staff and administrators
- advocates
- vocational rehabilitation counselors
- healthcare providers
- lawyers
- financial professionals
- state IDD agencies
- service providers

The Center will be integrated within a rich network of research, training, and systems change initiatives, and maintain an emphasis on cultural and linguistic competence and engagement with various communities. A strong partnership of youth with IDD, family members, practitioners, and researchers will contribute to expertise and effectiveness of the Center. An Advisory Committee comprised of at least 75% youth and young adults with IDD will guide all of its major activities.

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CENTER ON
YOUTH VOICE
YOUTH CHOICE
INSTITUTE FOR COMMUNITY INCLUSION, UMASS BOSTON

About

The Center is a project of the
Institute for Community Inclusion at UMass Boston (ICI)

in partnership with:
Center for Public Representation (CPR)
Self Advocates Becoming Empowered (SABE)
Human Services Research Institute (HSRI)

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For more information

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