

Cutting-Edge Articles, Research and Websites On Supporting People with IDD and their Families

Seven Trends Shaping IDD Support (2025-2026)

A widely shared piece by Dr. Craig Escudé (IntellectAbility) identifies person-centered approaches as the foremost trend, with even greater emphasis on tailoring services to individual needs, preferences, and goals – ensuring people with IDD are active participants in their own support and decision-making. Advances in assistive technology, from smart home devices to communication tools and health monitoring apps, are also flagged as key drivers of autonomy and quality of life.

What's New in IDD Care for 2026

Published in early 2026, this piece highlights that person-centered care is now an expectation – not a buzzword – with families demanding services that reflect real people, routines, and goals. A key trend is integrated support: addressing emotional, behavioral, medical, and social needs together. Technology is also featured prominently, with the emphasis on tools that improve communication and transparency without replacing human connection.

KU Study: 43 Years of IDD Funding Trends (March 2026)

Researchers at the KU Life Span Institute published findings showing that federal and state expenditures supported almost 1 million people with IDD in FY2023 across healthcare, home and community-based services (HCBS), and other areas. Family supports – which provide financial and other assistance to families with a child or adult with IDD – served 602,856 individuals, growing from \$9.2 billion in FY2017 to \$11.1 billion in FY2023. The piece also raises alarm about proposed federal cuts to IDD research infrastructure.

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Key Websites: Supporting People with IDD and Their Families

A curated resource guide of leading organizations, research centers, and information hubs for professionals, families, and advocates in the IDD field. Compiled June 2026.

Website / Organization	URL	Description
The Arc of the United States	https://thearc.org	The nation's leading nonprofit advocating for and supporting people with IDD and their families since 1950. Covers rights, inclusion, community resources, local chapter finder, and policy advocacy.
American Association on Intellectual and Developmental Disabilities (AAIDD)	https://aaid.org	Promotes progressive policies, sound research, effective practices, and universal human rights for people with IDD. Offers journals, position statements, professional development, and standards.
National Association of State Directors of Developmental Disabilities Services (NASDDDS)	https://nasdds.org	Represents state agencies providing services to children and adults with IDD. Promotes systems innovation and home and community-based services (HCBS) policy at the national level.
IDD Toolkit (Vanderbilt Kennedy Center)	https://iddtoolkit.vkcites.org/resources/	A comprehensive healthcare resource maintained by Vanderbilt Kennedy Center. Offers tip sheets on specific disabilities, their effects on individuals and families, and treatment and service options. Includes resources for primary care of adults with IDD.
IDD Health Equity	https://iddtheequity.org/resources/	Focuses on healthcare equity for people with disabilities. Features resources from the Nisonger Center at Ohio State, Special Olympics health programming, and innovation-oriented tools to help healthcare systems better serve people with IDD.
IntellectAbility (ReplacingRisk.com)	https://replacingrisk.com	Clinically-oriented insights and practice tools from Dr. Craig Escudé, MD. Includes the IDD Health Matters podcast, articles on emerging trends, and the Curriculum in IDD Healthcare e-learning course for clinicians.
WashU Intellectual and Developmental Disabilities Research Center (IDDRC)	https://iddrc.wustl.edu	One of 15 federally funded IDDRCs nationwide, part of a network committed to advancing knowledge, prevention,

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<p>Patient-Centered Outcomes Research Institute (PCORI) — IDD Focus</p>	<p>https://www.pcori.org</p>	<p>and treatment of IDD. Affiliated with the Association of University Centers on Disabilities (AUCD).</p> <p>Funds high-quality, patient-centered comparative effectiveness research on IDD. Current priorities include oral health, gastrointestinal health, and improving care delivery for people with IDD, with attention to racial and ethnic health disparities.</p>
<p>KU Life Span Institute / State of the States in Developmental Disabilities</p>	<p>https://sl.ku.edu</p>	<p>University of Kansas research center tracking 40+ years of IDD funding and service trends. Produces the State of the States report, a key national resource for policymakers, researchers, and advocates.</p>
<p>Association of University Centers on Disabilities (AUCD)</p>	<p>https://www.aucd.org</p>	<p>A national network of University Centers for Excellence in Developmental Disabilities (UCEDDs), Leadership Education in Neurodevelopmental Disabilities (LEND) programs, and IDDRCs. Connects research, training, and community.</p>

Note: This list reflects current leading resources as of June 2026. Federal funding for several IDD research infrastructure programs is under review; check individual sites for current status.