

RESOURCES FOR DISABLED PEOPLE & CAREGIVERS

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Advocacy Groups & Practical Resources

The following is a non-exhaustive list of national caregiving advocacy groups. Each website has resource libraries, links and other materials that may prove helpful.

- [Special Needs Alliance](https://www.specialneedsalliance.org): A national alliance of attorneys for special needs planning. Information on ABLE accounts, special needs trusts, special education and government benefits. Also has a [Caregiving Resources](#) page with multiple links to organizations with additional resources for caregivers of disabled persons, seniors, persons with dementia, and veterans. (<https://www.specialneedsalliance.org>)
- [Family Caregiver Alliance](https://www.caregiver.org): “For more than 40 years, FCA has provided services to family caregivers of adults with physical and cognitive impairments, such as Parkinson’s, stroke, Alzheimer’s and other types of dementia. Our services include assessment, care planning, direct care skills, wellness programs, respite services, and legal/financial consultation vouchers.” [Resource page](#) includes lists of “caregiving tips, information and encouragement about taking care of yourself as a caregiver, connections to community organizations and agencies, and overviews of health conditions.” (<https://www.caregiver.org>)
- [National Alliance for Caregiving](https://www.caregiving.org): An advocacy organization for positive change in caregiving sustainability, finances, systems change, etc. The site includes advocacy toolkits and other resources. (<https://www.caregiving.org>)
- [Caring Across Generations](https://caringacross.org): “Working to build real, helpful, thoughtful care systems. We transform cultural norms and narratives about aging, disability and care; win policy change at every level; and unite a powerful coalition across the millions of us who are touched by care.” [Extensive resources](#) on many topics, issues, needs. (<https://caringacross.org>)
- [National Organization for Rare Disorders](https://rarediseases.org): “NORD has been a national steward and a steadfast partner helping those who battle and care for rare disease feel seen, heard, supported, and connected. We’re a full-service, mission-driven, and independent nonprofit reimagining a future where every person with a rare disease and their families live their best lives. NORD was the first national nonprofit to represent all individuals and families affected by rare disease. Today we’re the only organization working at the intersection of care, research, policy, and community for all rare diseases.” NORD resources are designed for those with rare disease (and are extensive); however, NORD’s [State Resource Center](#) covers many services that apply to persons with disabilities generally. It’s searchable by state: topics include assistance programs, education resources, legal & advocacy services, caregiver support, and disability services. (<https://rarediseases.org>)
- [Family Voices](#): “A national nonprofit led by families and friends of children and youth with special health care needs (CYSHCN) and disabilities. We connect a network of family-led

organizations across the United States that provide support to families of CYSHCN. We promote partnership with youth and families at all levels of health care, from individual care to policy and decision-making, to improve policies and systems of care for children.” Offers courses in advocacy and leadership, and information on transitioning youth and genetics. Julie Beckett, the mother of [Katie Beckett](#), was a co-founder. (<https://familyvoices.org>)

- [Little Lobbyists](#): A family-led group advocating for kids with complex medical needs and disabilities. “We advocate for all kids with disabilities: mobility, sensory, mental health, intellectual and developmental disabilities, and chronic health conditions.” The focus of LL is on children under the age of 21; however, the group aligns itself with the priorities of the disability community in general. (<https://littlelobbyists.org>)
 - [Organizers \(digital & analog\)](#): Our phones have become extensions of our brains, and there’s an app for everything, it seems, including caregiving. Some people, though, still do better with pen and paper. Here are some options for getting organized:
 - [Best Caregiving Apps of 2024](#) (Caring.com)
 - [21 Highly Rated Apps for Family Caregivers](#) (Seniorly.com)
 - [25 Life-Changing Apps for People with Disabilities](#) (TheMighty.com)
 - [Etsy](#): Most people think of Etsy as a craft web-seller; however, there are tons of stores that offer unique products, including downloadable/printable planner pages, for those with disabilities, special needs, and/or seniors. Try a few search terms, including “caregiver,” “disability,” “special needs” and so on.
 - [Bullet Journal](#): Forget the Pinterest boards or Instagram accounts that show the BuJo as a work of personal art. Bullet journaling is for folks who thrive on lists—and it’s an entire philosophy of organization/planning, completely customizable to your personal experience. There’s even a book—[The Bullet Journal Method](#). (<https://bulletjournal.com>)
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Information on Medicaid & Medicare

States and the federal government have websites devoted to Medicaid and Medicare application and coverage rules; however, given the current upheaval at the federal level, the following sites may provide the best information:

- Kaiser Family Foundation: [Medicaid 101](#)
- [Kids’ Waivers](#) (<https://www.kidswaivers.org>)
- Center on Budget and Policy Priorities: [Introduction to Medicaid](#)
- Congressional Research Service: [Medicaid Section 1915\(c\) Home and Community-Based](#)

Services Waivers

- National Council on Aging: “[What Is Medicare and How Do I Get Started?](#)”
 - AARP: “[What Is Medicare and How Does It Work?](#)”
 - Healthline: “[What to Know about Medicare Disability Coverage](#)”
 - [Centers for Medicare & Medicaid Services](#) (CMS)
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Understanding the Civil Rights of People with Disabilities

A non-exhaustive list for understanding the unique context of civil rights for people with disabilities:

- [Judy Heumann](#) (official website: <https://judithheumann.com>)
 - [National Disability Rights Network](#) (<https://www.ndrn.org>)
 - ACLU: [Disability Rights](#) (<https://www.aclu.org/know-your-rights/disability-rights>)
 - [ADA National Network](#) (<https://adata.org>)
 - The Arc: [Civil Rights](#) (<https://thearc.org/policy-advocacy/civil-rights/>)
 - [Olmstead Rights](#): I am Olmstead (<https://www.olmsteadrights.org>)
 - Little Lobbyists (<https://littlelobbyists.org/blog/>):
 - “[Know Your Rights: The Community Integration Mandate](#)”
 - “[Know Your Rights: The Olmstead Decision](#)”
 - “[What Is Section 504? Disability Rights 101](#)”
 - “[Using Our Words: Being a Better Disability Ally](#)”
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Some Books on Disability (a non-exhaustive list)

Nonfiction

- [Demystifying Disability](#), by Emily Ladau
- [Disability Visibility](#), ed. Alice Wong
- [Brilliant Imperfection](#), by Eli Clare
- [Life As We Know It](#), by Michael Berube
- [Enabling Acts \(the Hidden Story of the ADA\)](#), by Lennard Davis

- [A Disability History of the United States](#), by Kim E. Nielsen
- [Being Heumann](#), by Judy Heumann
- [Against Technoableism: Rethinking Who Needs Improvement](#), by Ashely Shew
- [What Can a Body Do? How We Meet the Built World](#), by Sarah Hendren
- [Everything No One Tells You About Parenting a Disabled Child](#), by Kelley Coleman

Novels That Find Comic Truth in Disability (from [Electric Lit](#))

- *Range of Motion*, by Brian Trapp
- *The Magic Kingdom*, by Stanley Elkin
- *Hunchback* by Saou Ichikawa
- *The Colony* by Jillian Weise
- *The Revised Fundamentals of Caregiving* by Jonathan Evison
- *A Room Called Earth* by Madeleine Ryan
- *Family Life* by Akhil Sharma
- *Old School Indian* by Aaron John Curtis
- *Be Brief and Tell Them Everything* by Brad Listi
- *Will There Never Be Another You* by Patricia Lockwood

Poetry by Caregivers

- Bass, Ellen. *The Human Line*. Copper Canyon Press, 2007.
 - ---*Indigo*. Copper Canyon Press, 2020.
 - ---*Like a Beggar*. Copper Canyon Press, 2014.
 - ---*Mules of Love*. BOA Editions, Ltd., 2002.
- de la Paz, Oliver. *The Boy in the Labyrinth*. University of Akron Press, 2019.
- McPherson, Sandra. *The Space Between Birds*. Wesleyan University Press, 1996.
- Shaughnessy, Brenda. *Our Andromeda*. Copper Canyon Press, 2012.
- Teicher, Craig Morgan. *The Trembling Answers*. BOA Editions, Ltd., 2017.