

Increasing Access to Quality Healthcare for People with Disabilities: A Co-Designed Educational Curriculum for Family Medicine Residents

Resource Index

Thank you for engaging with the content of this project. Here are additional resources which can be used in your personal learning or applied to practice, with information for you as a provider and also for individuals and families who you work with.

The categories are organized alphabetically by topic.

Ableism

[Barriers to Health Care for People with Disabilities](#)- A chart that goes over the barriers to health care.

[Dear Everybody Campaign](#) – This is a movement to end stigma and eliminate bias against people with disabilities. It contains videos and printable resources.

[Disability Etiquette](#) – A document from the United Spinal Association that contains tips on interacting with people with varied disabilities.

[Disability Map Training](#) - Training by the City of Philadelphia to highlight disability in the city and demographic data with disability.

[Disability Voices United](#) – This statewide organization is led by and for individuals with disabilities and supports advocacy efforts for disability.

[Do2Learn](#) – A visual schedule creator. This can be used to make visuals for a provider visit or office.

[NCMRR Virtual Workshop: Ableism in Medicine and Clinical Research \(Day 1\)](#)- A virtual workshop to discuss ableism in medicine and clinical research.

[NCMRR Virtual Workshop: Ableism in Medicine and Clinical Research \(Day 2\)](#)- A virtual workshop to discuss ableism in medicine and clinical research.

[NPR People with Disabilities Fear Pandemic Will Worsen Medical Biases](#) – Article discussing disabled people’s concerns about healthcare during COVID-19.

Accessibility

[Hyperlegible font](#) – This font can be copied and used for individual use and is optimally legible for individuals who are partially visually impaired.

[PlainLanguage.gov](#) - This website provides information about plain language, including guidelines, training, and examples.

[Inclusive Health Principles and Strategies – Special Olympics](#) - An overview of strategies to increase inclusive practices in healthcare settings.

[Accessible Virtual Meetings](#) - Tips to consider when hosting a virtual meeting space.

[Readability Calculator](#) – This tool allows you to enter text and determine how easily your intended audience will be able to read and understand the content.

Advocacy Organizations

[The Arc of Pennsylvania](#) - A community-based organization representing and supporting people with disabilities in education, health, advocacy, and through training. Individuals are represented by their local Arc subsidiary, and larger advocacy is supported statewide.

[Brain Steps](#) - Supports individuals with acquired brain injuries in the school system. They provide education and support to teachers, families, and support in navigating appropriate accommodations and IEP needs for individuals with brain injury.

[Centers for Independent Living](#) - Each state has a Center for Independent Living. They are a community-based, cross-disability, non-profit designed and operated by people with disabilities. They offer support, advocacy, and information about independent living opportunities and options for people with disabilities.

[Disabled in Action of Pennsylvania](#) - An organization of individuals with disabilities who are working to support civil rights for local resources and federal rights.

[Disability Rights PA](#) – Helps people with disabilities across advocacy needs in PA. Disability Rights assists with legal issues, providing support from attorneys and experts. They provide information, referrals to other organizations, and general advocacy. Specialty topics include discrimination, education, assistive technology, voting access, Medical Assistance, and more.

[Education Law Center](#) - Working to ensure all students in school have access to a quality public education. Collaborate with lawmakers and grassroots organizations to advocate for education rights and resources.

[How a Case Manager Can Help \(video\)](#) - Overview of case managers and support workers for families with IDD.

[Inglis](#) – This organization offers innovation centers in Philadelphia and Pittsburgh to support individuals in accessing assistive technology and home modifications. They also offer

community services, a long-term care community for individuals with physical disabilities, and support in finding wheelchair accessible apartments.

[Intermediate Units](#) - A statewide organization representing the 29 regional educational service agencies in Pennsylvania. They provide special education services, preschool programs, therapy, education for educators, and work closely with public school districts to serve students receiving special education.

[Liberty Home Solutions](#) – Liberty Home Solutions works with the Centers for Independent Living to provide home modifications for individuals with disabilities to stay safely in their homes and communities. They support finding and supplying modifications based on an individual's needs and can support financially.

[PA Assistive Technology Foundation](#) - Helps people with disabilities get assistive technology from both low interest and 0% financial interest. They offer mini grants for people who are getting loans. They also provide information on other possible sources of funding.

[PA Family Network](#) – This organization exists within Vision for Equality PA. They are supported by ODP and work to support individuals and families to maximize collaboration and community engagement.

[PA Health Access Network](#) - A statewide, consumer driven organization working to protect and expand quality, affordable health care access for people across Pennsylvania.

[PA Health Law Project](#) - Working to increase access to healthcare for individuals from historically underserved populations. They provide free legal services and help individuals navigate the complex healthcare system to get the quality care they need.

[PA Secondary Transition](#) - A statewide resource providing information about the transition from the school system for individuals with disabilities. Focus on post-secondary education, employment, and independent living.

[PEAL Center Pennsylvania](#) - Focus on families with a child with a disability from birth to age 26 and support access to appropriate education and health care. PEAL provides resources for individuals, families, and professionals to support individuals with disabilities in accessing a full community-based lifestyle.

[Tech OWL](#) - Supports people with disabilities to explore technology and tools that can be used for independence. They have a lending library where you can try different types of technology. They also answer questions, have demonstrations, and training opportunities. TechOWL also offers free specialty phones and lightly used equipment.

[Vision for Equality PA](#) – Support people with disabilities in equal access to support and services. They engage in advocacy efforts to ensure people with disabilities receive appropriate services and are able to access their communities. Programs include services across the lifespan.

Augmentative and Alternative Communication

[Cristian Rosas: Taking My AAC Into Adulthood](#) – Cristian is an adult with a disability who uses AAC to communicate. In this 36-minute video presentation, he shares his experience transitioning from pediatric care, starting an adult day program, and the tools which helped him to be successful.

[How to be a Respectful Communication Partner](#) – 10 strategies to put an AAC user first in your conversations, from interviews with AAC users led by AssistiveWare.

[AAC and Stimming](#) – Understanding the role of stimming in communication.

[Intermittent, Unreliable, Insufficient, and Expensive Speech](#) – This blog post helps define the range of nonspeaking to fully speaking, and how AAC and communication aids can help bridge the gap.

[AbleNet](#) – A provider of AAC devices which are medical grade and can be covered by insurance. They offer trial periods, online resources, and training opportunities for providers.

[AAC in Adults with Developmental Disabilities](#) – A collection of information and resources to support AAC with adults with IDD.

[Penn State University AAC Learning Moodle](#) – Online resource site including learning modules about AAC, how to use AAC as a provider, and supporting individuals in practice.

[Four Key Goals of Adult Life: The Role of AAC in Supporting Self-Determination](#) – A 27-minute video from Anthony Arnold, an AAC user, about his life and transitions through adulthood.

Autism

[Autism Resource Guide](#) - Provides an overview of autism spectrum disorder, support, and resources for families including education support.

[LISTEN Movie](#) – A short film highlighting nonspeaking individuals with autism and the ways they are represented in books, theater, and film, as well as ways the narrative is changing.

[Living Our Lives Through Letters](#)- YouTube video from a person who identifies as a non-speaking person with autism and uses Spelling to Communicate.

[Screening for Autism Spectrum Disorder in the Primary Care office](#)- Article that goes over what ASD is and signs for primary care to observe.

[Resource Guide for Autism](#)- PowerPoint that provides an overview of autism spectrum disorder, services and various resources.

Behavioral Health

[Behavioral HealthChoice List](#)- List showing organizations and counties served.

PDF lists of Crisis Services based off County

[Bucks County Crisis](#)

[Chester County Crisis](#)

[Delaware County Crisis](#)

[Montgomery County Crisis](#)

[Philadelphia County Crisis](#)

Caregiver Support Networks

[All on Our Own \(video\)](#) - Highlights the difficulties in finding consistent care for adults with IDD in the community.

[ASERT Support Groups](#) - Support groups and social groups across the state of Pennsylvania by county.

[Association for Autism and Neurodiversity](#) - Offers a wide variety of virtual support groups for individuals with ASD, their family, and supporters.

[The Global Tracheostomy Collective](#) - Offers online forums for family caregivers and individuals who use tracheostomy.

[National Task Group \(NTG\) on Intellectual Disabilities and Dementia Practices](#) - A central resource for caregivers and healthcare professionals offering family support committees, online events and webinars, diagnostic resources, publications, research, and trainings.

[Parent to Parent of PA](#) - Empowers and supports parents across Pennsylvania through connection with one another. Matches parents with others who are experiencing similar circumstances.

[Parents Helping Parents](#) - Provides support, information, and training for parents and caregivers of individuals with disabilities throughout the lifespan, including support with transitions to adulthood.

Vision for Equality

[Philadelphia Support Groups](#) - Support group for families, parents, caregivers, and friends of people with disabilities. Provides support for individuals in childhood through their transition into adulthood.

[Family Support Projects](#) - Offers workshops for individuals with disabilities and their families about topics including future planning, health equity, technology, participant directed

services, and wellness to expand community engagement and engaging with supports through adulthood.

Community Resource Collections

[PA Rehabilitation Council](#) – Provides a menu of resources for individuals with disabilities across Pennsylvania related to advocacy, employment, technical assistance, and training.

[A Bridge to Independence](#) – Offers service coordination and access to community resources in Northwest, Northeast, Southwest, and Southeast PA Counties.

[Disability Resources Pennsylvania Directory](#) – Provides information about specific topics and contacts for Social Security, Centers for Independent Living, advocacy and legal aid, and other supports in PA.

[Olmstead Rights, Pennsylvania Disability Resources](#) – Government agencies and disability rights agencies in PA who can assist with advocacy, home health, home care, Medicaid, and accessing community resources.

[UMPC Disability Resources](#) – Highlights a selection of resources for individuals with disabilities in and around Pittsburgh, PA.

Crisis Centers & Crisis Lines

[Crisis Intervention by County](#) - Provides information for every county in Pennsylvania to contact via website, phone, and their crisis services number.

Suicide and Crisis Lifeline: Call or text 988. Available 24/7.

National Domestic Violence Hotline: 1-800-799-7233 (SAFE) or text START to 88788. Available 24/7.

[National Alliance on Mental Illness – Navigating a mental health crisis resource guide](#). Provides information to be proactive before an event takes place, what to do during a crisis, information about potential admissions and treatment, and resources for caregivers.

Down Syndrome

[Adult Down Syndrome Center](#) – Resources for providing care for adults with Down syndrome, as well as connections to community events and programs.

[Down Syndrome Medical Interest Group Speaker Series](#)- A regular speaker series that shares knowledge and experiences related to people with Down Syndrome and clinical research.

[Their Project ECHO care for Down Syndrome patients and resources.](#)

[Challenging Behaviors in Adults with Down Syndrome Guide](#)

[National Down Syndrome Society 321go!](#)- The program to promote a healthy lifestyle has a program guide, fitness kit and other resources.

[National Down Syndrome Society Women's Health-](#) A guide that addresses Women's Health and Down Syndrome, including cases, resources, and visual support.

Example Forms of Medical Necessity

[This link contains examples of completed forms for durable medical equipment \(DME\), physical clearance forms, nursing and home health coverage, and medical assistance.](#)

Future Planning for Family Caregivers

[Future Planning Guidebook, NY Office for the Aging](#) – Provides a resource for older caregivers of adults with IDD including steps to consider for healthcare, finances, decision making, and housing.

[The Arc Center for Future Planning](#) – National resource providing information about future planning, tools for families and individuals with IDD to build a future plan and see how other individuals have planned for the future.

[State Policies and Practices to Support Person-Centered Planning Across the Lifespan for Individuals with Intellectual and Developmental Disabilities and Their Aging Caregivers](#) – A guide from Centers for Medicare and Medicaid on person-centered planning including spotlights on successes in different states.

Got Transition

[Parents and Caregivers](#) - Support for parents and caregivers of individuals with disabilities to manage healthcare transition to adulthood and prepare for future decision making.

[Youth & Young Adults](#) - Information for individuals with disabilities to learn about medical transition to adulthood.

Home Modifications

[Epilepsy Foundation, Staying Safe at Home](#) – Tips and areas to consider for home safety and modifications for individuals who experience seizures.

[Creating a Wheelchair-Accessible Home: Tips & Ideas](#) – Considerations for each room of the home for wheelchair users when creating accessible home spaces.

[Finding Funding for Home Modifications and Handicap Accessible Vehicles](#) – Outlines a variety of possible funding methods for obtaining home modifications and vehicles.

[The Universal Design Program](#) – Learn about universal design or sign up for a free continuing education course about universal design and home accessibility.

[USC Leonard Davis School of Gerontology Home Modifications Resources](#) – A collection of research, websites, videos, and consumer resources about home modifications.

Interdisciplinary membership organizations for healthcare professionals

[American Academy for Cerebral Palsy and Developmental Medicine \(AACPDM\)](#)

[American Academy of Developmental Medicine and Dentistry \(AADMD\)](#)

[American Association on Intellectual and Developmental Disabilities \(AAIDD\)](#)

[Developmental Disabilities Nurses Association \(DDNA\)](#)

[Down Syndrome Medical Interest Group \(DSMIG\)](#)

[Intellectual Disability Mental Health Connect](#)

[International Association for the Scientific Study of Intellectual and Developmental Disabilities \(IASSIADD\)](#)

[International Association for the Study of Pain, Pain in Intellectual and Developmental Disabilities Special Interest Group \(PIDDSIG\)](#)

[National Leadership Consortium on Developmental Disabilities](#)

[Special Olympics Healthy Communities](#)

Mental Health Resources

[Behavioral Health Managed Care Organizations \(BH-MCOs\)](#) - People with disabilities who have HealthChoices, a managed care program for Medicaid and Medical Assistance recipients, have an assigned behavioral health organization to help them find qualifying providers.

[Finding a Therapist that Fits You Well](#) – This is a resource for individuals with IDD about finding a mental health professional.

[Human Services Inc-](#) Provides a variety of services including outpatient clinical services and community support programs.

[Mental Health First Aid](#) - Healthy minds Philly has a mental health first aid that teaches people to identify, understand, and respond to mental health needs. It also has other resources, including a live chat.

Vanderbilt Toolkit for Primary Care Providers Resources

[Initial Management of a Behavioral Crisis in Intellectual and Developmental Disabilities](#)

[Identifying Symptoms and Signs of Mental Distress in Adults with Intellectual and Developmental Disabilities](#)

[Risk Assessment for Adults with Intellectual and Developmental Disabilities in Crisis](#)

[My Coping Tool: How I Deal with Stress](#) - For patients to complete with a supporter to better understand how to handle stressful situations.

[Transitions Psychiatric Rehabilitation Program Referral](#)

[Transitions Brochure](#)

PM&R

[American Academy of Physical Medicine and Rehabilitation](#)

Providing Medical Care to Individuals with IDD

[AASPIRE Healthcare Toolkit](#) – Website with information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on primary healthcare, or healthcare with a regular doctor.

[Adapt Healthlink Training Program](#) – A 20-minute video that was created to fill gaps in education on providing quality healthcare to people with IDD.

[Appendix Focus Group Moderator's Guide](#) – A guide from a focus group that goes over questions for providers to consider when providing healthcare to people with IDD.

[Approaches to Care and General Considerations](#) – A guide that goes over primary care guidelines, approaches to care, physical and mental health considerations for people with IDD.

[Baylor College of Medicine Intellectual and Developmental Disabilities Continuing Education](#) – Resources for continuing medical education credit related to medical treatment of individuals with IDD. Includes topics related to transition care, common physical health problems, and adapting visits to be more inclusive.

[Docs with Disabilities Inclusive Learning](#) – Education for physicians focused on disability policy and procedures to help build inclusive educational environments in health care.

[Gateway Resource](#) – Introductory resources in supporting individuals with IDD in healthcare.

[IntellectAbility Resources](#)- Webpage that provides resources and articles to provide effective care to people with intellectual disabilities.

[Modernizing Health Care to Improve Physical Accessibility](#) – This resource is from CMS and provides information about common barriers and ways to adapt the physical environment at a health facility.

Safety Tools

[Smart 911](#) – Individuals can register and provide health information to first responders ahead of an emergency.

[Health Passports](#) - Completed by an individual ahead of time, a health passport helps healthcare professionals know about health history, medication, preferences, and behavior needs prior to a provider visit or an emergency health situation.

Transition from Pediatric to Adult Care

[Got Transition](#) – An organization which aims to support youth and young adults moving from pediatric to adult care.

[Home Modifications Toolkit](#) – This resource from USC provides tools to help increase accessibility in the home for individuals with disabilities and older adults.

[Hospital Passport](#) – Individuals with disabilities and those who support them can fill out a health passport with their support needs, ways to best provide care and communication, and other information medical professionals should know prior to an emergency or hospital visit.

[Mid-Atlantic ADA Center](#) – Provides guidance, information, and training on the ADA for businesses, government entities, organizations, and individuals.

[Parent to Parent Pennsylvania](#) – A PA organization connecting parents of children and adults with disabilities who have had similar journeys.

[Patient –Centered Outcomes Research Institute](#)- Paper on health disparities for Black and Hispanic children with Down Syndrome.

[Patient-Centered Outcomes Research Insitute Module](#)- Medical Provider Module: Disseminating Patient-Centered Outcomes Research Results about Disabilities to Black and Hispanic Parents.

[Pediatic to Adult Care Transitions Initiative](#) – A toolkit to facilitate more effective transitions for young adults from pediatric to adult care.

[Pediatic Tool Kit for Social Communication](#)- Create an account to use their tool kit

[Practical Recommendations for Enhancing the Care of Patients with Disability](#) – From Upstate Medical University. Provides continuing education opportunities for physicians, nurses, and other health professionals that provide practical recommendations, tools, and strategies to help enhance care for patients with disabilities.

[Preparticipation Physical Exam, Upstate Medical University](#) – An interactive online module providing information for a provider who is completing a preparticipation physical for an adult patient with IDD. This is typically for Special Olympics, though it can be used for other recreational activities.

[Resources for Integrated Care](#) – This organization supports resources for managing Medicare and Medicaid plans.

[Upstate Medical University](#)- Web-based continuing education with three modules that provides education and recommendations for care of patients with disabilities.

[Vanderbilt Toolkit](#) – A site which contains many resources related to the care of patients with IDD including general issues, physical health, and mental health.

Recreation Opportunities

[Athletes Helping Athletes](#) - Inclusive sport opportunities for individuals with and without disabilities. Events focused on athletics and community engagement.

[Carousel Connections](#) - Carousel Connections offers a participant centered model for adults with disabilities to collaborate, connect, and engage with the community. Their programs are focused on job and skill building, independent living skills, and community involvement for individuals after they transition out of high school.

[Easter Seals](#) - Easter Seals provides a variety of therapeutic and recreational services for individuals with disabilities across the lifespan. They offer accessible camping and recreation for adults with disabilities, in addition to providing respite programs for caregivers and their families.

[iCan Bike](#) - This organization hosts weeklong programs to teach individuals with disabilities to ride bikes. Their programs are across the country.

[KultureCity](#) - Nationwide nonprofit focusing on increasing sensory accessibility in large public spaces. Partner with a variety of spaces like museums, sporting events, concerts, and others to increase sensory accessibility through sensory break spaces and to-go sensory bags.

[Magee Wellness Center](#) – A center related to Jefferson Magee Rehabilitation in Center City Philadelphia, located on the riverfront where individuals with disabilities can engage in fitness, recreation, and leisure opportunities. They offer monthly memberships and opportunities to engage with community members and staff.

[PA Vent Camp](#) - A summer camp for children and adults that use ventilation to breathe in Hummelstown, PA. This is a week-long camp that involves camp activities like zip-lining and crafts.

[PALS Programs](#) - PALS offers inclusive camp experiences where individuals with Down syndrome are paired 1-1 with a volunteer Peer. Camps take place on university campuses and are overnight, one-week long opportunities.

[Special Olympics PA](#) - Special Olympics serves over 15,000 athletes in Pennsylvania through a variety of sports and recreation during the year. Individual and team sports are offered to athletes by season, and individuals with disabilities are supported by volunteer coaches.

[Variety Club](#) - Variety offers many opportunities for children and young adults with disabilities ages 5-24 in the Delaware Valley area of Pennsylvania. During the summer, they offer day camps, overnight camps, and vocational camps for individuals to nurture independence and self-confidence.

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