



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

Module 1: Communication, Common Sense, and Nuance: Care of Patients with Intellectual and Developmental Disabilities (IDD)

Additional Resources

Thank you for engaging with the content in Module 1 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.

<u>AASPIRE Healthcare Toolkit</u> – 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.

<u>Adapt Healthlink Training Program</u> – A 20-minute video that was created to fill in gaps in education on providing quality healthcare to people with IDD.

<u>Adult Down Syndrome Center</u> – Resources for providing care for adults with Down syndrome, as well as connections to community events and programs.

<u>Appendix Focus Group Moderator's Guide</u> – A guide from a focus group that goes over questions for providers to consider when providing healthcare to people with IDD.

<u>Approaches to Care and General Considerations</u> – 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.

<u>Dear Everybody Campaign</u> – This is a movement to end stigma and eliminate bias against people with disabilities. It contains videos and printable resources.

<u>Disability Etiquette</u> – A document from the United Spinal Association that contains tips on interacting with people with varied disabilities.

<u>Disability Voices United</u> – This statewide organization is led by and for individuals with disabilities and supports advocacy efforts for disability.





<u>Do2Learn</u> – A visual schedule creator. This can be used to make visuals for a provider visit or office.

<u>Docs with Disabilities Inclusive Learning</u> – Education for physicians focused on disability policy and procedures to help build inclusive educational environments in health care.

<u>Got Transition</u> – An organization which aims to support youth and young adults moving from pediatric to adult care.

<u>Home Modifications Toolkit</u> – This resource from USC provides tools to help increase accessibility in the home for individuals with disabilities and older adults.

<u>Hospital Passport</u> – 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.

<u>IntellectAbility Resources</u>- Webpage that provides resources and articles to provide effective care to people with intellectual disabilities.

<u>Mid-Atlantic ADA Center</u> – Provides guidance, information, and training on the ADA for businesses, government entities, organizations, and individuals.

<u>Modernizing Health Care to Improve Physical Accessibility</u> – This resource is from CMS and provides information of common barriers and ways to adapt the physical environment at a health facility.

<u>Parent to Parent Pennsylvania</u> – A PA organization connecting parents of children and adults with disabilities who have had similar journeys. The Southeast Regional Coordinator is Jennifer Bulson (<u>jbulson@parenttoparent.org</u>)

<u>Patient – Centered Outcomes Research Institute</u>- Paper on health disparities for Black and Hispanic children with Down Syndrome.

<u>Patient-Centered Outcomes Research Insitute Module</u>- Medical Provider Module: Disseminating Patient-Centered Outcomes Research Results about Disabilities to Black and Hispanic Parents.

<u>Pediatric to Adult Care Transitions Initiative</u> – A toolkit to facilitate more effective transitions for young adults from pediatric to adult care.

Pediatric Tool Kit for Social Communication- Create an account to use their tool kit

<u>Practical Recommendations for Enhancing the Care of Patients with Disability</u> – 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.

<u>Resources for Integrated Care</u> – This organization supports resources for managing Medicare and Medicaid plans.

<u>Upstate Medical University-</u> Web-based continuing education that has three modules that provides education and recommendations for care of patients with disabilities.

<u>Vanderbilt Toolkit</u> – A site which contains many resources related to the care of patients with IDD including general issues, physical health, and mental health.

Ableism

<u>Barriers to Health Care for People with Disabilities-</u> A chart that goes over the barriers to health care.

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.

<u>NPR People with Disabilities Fear Pandemic Will Worsen Medical Biases</u> – Article discussing disabled people's concerns about healthcare during COVID-19.

Autism

AASPIRE- Above

<u>Living Our Lives Through Letters-</u> Youtube video from a person who identifies as a non speaking person with autism and uses Spelling to Communicate.

<u>Screening for Autism Spectrum Disorder in the Primary Care office</u>- Article that goes over what ASD is and signs for primary care to observe.

Resource Guide for Autism- Powerpoint that goes of Autism, services and various resources

Down Syndrome





<u>Down Syndrome Medical Interest Group Speaker Series</u>- Has a 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

<u>National Down Syndrome Society 321go!</u>- The program to promote a healthy lifestyle has program guide, fitness kit and other resources.

<u>National Down Syndrome Society Women's Health-</u> A guide that goes over Women's Health and Down Syndrome, including cases, resources and visual supports.

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

Mental Health

<u>Human Services Inc</u>- Provides a variety of services including outpatient clinical services and community support programs.

Transitions Psychiatric Rehabilitation Program Referral-

Transitions Brochure

<u>Mental Health First Aid</u> - 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.

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