

**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)**

**References**

**Section 1**

1. Stillman MD, Ankam N, Mallow M, Capron M, Williams S. A survey of internal and family medicine residents: Assessment of disability-specific education and knowledge. *Disabil Health J*. 2021 Apr;14(2):101011. doi: 10.1016/j.dhjo.2020.101011
2. Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of disabilities and health care access by disability status and type among adults - United States, 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67(32):882-887. doi:10.15585/mmwr.mm6732a3
3. Conceptual Models of Disability | PM&R Knowledge Now. Accessed March 20, 2025. <https://now.aapmr.org/conceptual-models-of-disability/>
4. Center for Disease Control and Prevention. The ICF: An Overview. September 10, 2001. Accessed March 18, 2025. [https://www.cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf)
5. Vanderbilt Health. Home - Health Care for Adults with Intellectual and Developmental Disabilities. Health Care for Adults with Intellectual and Developmental Disabilities, Toolkit for Primary Care Providers. 2023. Accessed March 20, 2025. <https://iddtoolkit.vkcsites.org/>
6. Cerebral Palsy. National Institute of Neurological Disorders and Stroke. Accessed March 20, 2025. <https://www.ninds.nih.gov/health-information/disorders/cerebral-palsy>
7. Autism Resource Institute. What is autism? Autism.org. Accessed March 21, 2025. <https://autism.org/what-is-autism/>
8. National Down Syndrome Society. About Down Syndrome. National Down Syndrome Society (NDSS). Accessed March 20, 2025. <https://ndss.org/about>
9. Fragile X 101. The Three Fragile X Disorders. The National Fragile X Association. Accessed March 20, 2025. <https://fragilex.org/understanding-fragile-x/fragile-x-101/>
10. Spina Bifida Association. What is Spina Bifida? Resources and Prevention - Spina Bifida Association. Accessed March 20, 2025. <https://www.spinabifidaassociation.org/what-is-spina-bifida/>
11. Understanding Fetal Alcohol Spectrum Disorders. National Institute on Alcohol Abuse and Alcoholism (NIAAA). Accessed March 20, 2025.

<https://www.niaaa.nih.gov/publications/brochures-and-fact-sheets/understanding-fetal-alcohol-spectrum-disorders#:~:text=What%20Are%20Fetal%20Alcohol%20Spectrum,known%20as%20prenatal%20alcohol%20exposure>).

12. National Down Syndrome Society. Resources. National Down Syndrome Society (NDSS). Accessed March 20, 2025. <https://ndss.org/resources?topical=24>

13. Lee K, Cascella M, Marwaha R. Intellectual Disability. In: *StatPearls*. StatPearls Publishing; 2025.

14. Global report on health equity for persons with disabilities: executive summary. Geneva: World Health Organization; 2022. CC BY-NC-SA 3.0 IGO.

15. Iezzoni LI, Rao SR, Agaronnik ND, El-Jawahri A. Cross-Sectional Analysis of the Associations Between Four Common Cancers and Disability. *J Natl Compr Canc Netw*. 2020;18(8):1031-1044. doi:10.6004/jnccn.2020.7551

16. CAR Autism Roadmap at Childrens Hospital of Philadelphia Research Institute. Diagnostic Criteria for Autism Spectrum Disorder in the DSM-5. Accessed March 20, 2025. <https://www.research.chop.edu/car-autism-roadmap/diagnostic-criteria-for-autism-spectrum-disorder-in-the-dsm-5>

17. Autistic Self Advocacy Network. Accessed March 20, 2025. <https://autisticadvocacy.org/>

18. Profound Autism Alliance. Accessed March 20, 2025. <https://www.profoundautism.org/>

19. PAAutism.org, an ASERT Autism Resource Guide. Accessed March 20, 2025. <https://paautism.org/>

20. Association for Autism and Neurodiversity. Accessed March 20, 2025. <https://aane.org/>

21. Raymaker DM, McDonald KE, Ashkenazy E, et al. Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism*. 2017;21(8):972-984. doi:10.1177/1362361316661261

22. Bowen CN, Havercamp SM, Karpiak Bowen S, Nye G. A call to action: Preparing a disability-competent health care workforce. *Disabil Health J*. 2020;13(4):100941. doi:10.1016/j.dhjo.2020.100941

23. Iezzoni LI, Rao SR, Ressler J, et al. Physicians' perceptions of people with disability and their health care. *Health Aff (Millwood)*. 2021;40(2):297-306. doi:10.1377/hlthaff.2020.01452

## Section 2

1. Sayles M. All About the Social Determinants of Health - American Association on Health and Disability. May 2, 2022. Accessed March 20, 2025. <https://aahd.us/2022/05/all-about-the-social-determinants-of-health/>
2. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev*. 2006;12(1):70-82. doi: 10.1002/mrdd.20098. PMID: 16435327.
3. Li H, Parish SL, Magana S, Morales MA. Racial and Ethnic Disparities in Perceived Barriers to Health Care Among U.S. Adults With Intellectual and Developmental Disabilities. *Intellect Dev Disabil*. 2021;59(1):84-94.
4. Johnson TJ, Winger DG, Hickey RW, et al. Comparison of physician implicit racial bias toward adults versus children. *Acad Pediatr*. 2017;17(2):120-126. doi:10.1016/j.acap.2016.08.010
5. Williamson HJ, Chico-Jarillo TM, Sasse S, et al. A Scoping Review of Health Research with Racially/Ethnically Minoritized Adults with Intellectual and Developmental Disabilities. *Dev Disabil Netw J*. 2023;3(2).
6. Sachse C, Jacob R. Optimizing dental care for adults with intellectual and developmental disabilities: challenges, strategies, and preventative approaches. *Cureus*. 2024;16(11):e72871. doi:10.7759/cureus.72871
7. Special Smiles, Comprehensive dental care for persons with special needs. 2023. Accessed March 20, 2025. <http://specialsmileslltd.com>
8. Landes SD. Disability Mortality Disparity: Risk Of Mortality For Disabled Adults Nearly Twice That For Nondisabled Adults, 2008-19. *Health Aff (Millwood)*. 2024;43(8):1128-1136. doi:10.1377/hlthaff.2023.01197
9. Jonathan Gleason, Wendy Ross, Alexander Fossi, Heather Blonsky, Jane Tobias, Mary Stephens. The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States. *New England Journal of Medicine (NEJM) Catalyst*, March 5, 2021; DOI: 10.1056/CAT.21.0051
10. Jett J, Fossi A, Blonsky H, et al. Retrospective review of the code status of individuals with Down syndrome during the COVID-19 era. *Am J Med Genet C Semin Med Genet*. 2024;196(1):e32080. doi:10.1002/ajmg.c.32080

### Section 3

1. Iezzoni LI, Rao SR, Ressler J, et al. Physicians' perceptions of people with disability and their health care. *Health Aff (Millwood)*. 2021;40(2):297-306. doi:10.1377/hlthaff.2020.01452

2. Stillman MD, Ankam N, Mallow M, Capron M, Williams S. A survey of internal and family medicine residents: Assessment of disability-specific education and knowledge. *Disabil Health J.* 2021;14(2):101011. doi:10.1016/j.dhjo.2020.101011
3. Bowen CN, Havercamp SM, Karpiak Bowen S, Nye G. A call to action: Preparing a disability-competent health care workforce. *Disabil Health J.* 2020;13(4):100941. doi:10.1016/j.dhjo.2020.100941
4. Skotko BG, Levine SP, Goldstein R. Self-perceptions from people with Down syndrome. *Am J Med Genet.* 2011;155(10):2360-2369. doi:10.1002/ajmg.a.34235
5. Iezzoni LI, Rao SR, Agaronnik ND, El-Jawahri A. Cross-Sectional Analysis of the Associations Between Four Common Cancers and Disability. *J Natl Compr Canc Netw.* 2020;18(8):1031-1044. doi:10.6004/jnccn.2020.755
6. Javaid A, Nakata V, Michael D. Diagnostic overshadowing in learning disability: think beyond the disability. *Prog Neurol Psychiatry.* 2019;23(2):8-10. doi:10.1002/pnp.531
7. Grier E, Abells D, Casson I, et al. Managing complexity in care of patients with intellectual and developmental disabilities: Natural fit for the family physician as an expert generalist. *Can Fam Physician.* 2018;64(Suppl 2):S15-S22.
8. Steinway C, Gable J, Jan S. *Preparing for Transition of Aging Youth with Complex Medical Conditions and Intellectual Disability.* PolicyLab at Children's Hospital of Philadelphia; 2017.
9. McAndrews DC. Guardianship vs. Power of Attorney. McAndrews, Mhealick, Connolly, Hulse, and Ryan P.C. 2022. Accessed March 20, 2025. <https://mcandrewslaw.com/publications-and-presentations/articles/guardianship-vs-power-of-attorney/>
10. Disability Rights PA. *Disability Rights Pennsylvania Chapter 10: Guardianship in Pennsylvania.* Disability Rights Pennsylvania; 2018.
11. The Center for Public Representation. About Supported Decision-Making. 2025. Accessed March 20, 2025. <https://supporteddecisions.org/about-supported-decision-making/>
12. Kripke C. Adults with Developmental Disabilities: A Comprehensive Approach to Medical Care. *J Am Board Fam Med.* 2018;97(10).
13. National Disability Rights Network. Protection and advocacy for people with disabilities. 2025. Accessed March 20, 2025. <https://www.ndrn.org/>
14. The Arc of Pennsylvania. Welcome to the Arc of Pennsylvania. 2024. Accessed March 20, 2025. <https://thearca.org/>
15. Special Olympics Resources. *How to Speak with People with Disabilities.* Special Olympics. N.D. <https://resources.specialolympics.org/marketing-and-communications/photos-and-videos/special-olympics-video-resources/how-to-speak-with-people-with-disabilities>. Accessed March 20, 2025

16. UCLA Health. Inclusive Health: Caring for Patients with Intellectual Disabilities [Video]. YouTube. <https://www.youtube.com/watch?v=ojQTz9FINt4>. Published May 28, 2020. Accessed March 20, 2025.

17. Pathfinders for Autism. Visual Supports for Hospital and Doctor Visits. 2020. Accessed March 20, 2025. <https://pathfindersforautism.org/articles/healthcare/visual-supports-for-hospital-visits/>

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