

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

All references across the four-part learning series are contained within this document. Items are organized by the module and section where they appear within the learning materials.

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

Section 1 – What is disability

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
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\).](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/jncn.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 – Health disparities and IDD

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://specialsmilesltd.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 – Caring for patients with IDD

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, Haverkamp 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://thearcpa.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/>

Module 2: Patient and Caregiver Community Supports and Resources

Section 1 – Transitions and service delivery through childhood

1. Department of Education Commonwealth of Pennsylvania. Early Intervention. Accessed April 8, 2025. <https://www.pa.gov/agencies/education/programs-and-services/instruction/early-learning/early-intervention.html>
2. Educational & Developmental Intervention Services. The Early Intervention Process. Accessed April 8, 2025. <https://www.edis.army.mil/Early-Intervention-Process/>
3. Special Education FAPE and One to One Support Obligations for Students with Disabilities. Department of Education. Commonwealth of Pennsylvania. Accessed April 8, 2025. <https://www.pa.gov/agencies/education/resources/policies-acts-and-laws/basic-education-circulars-becs/federal-code/special-education-fape-and-one-to-one-support-obligations-for-students-with-disabilities.html>
4. Latham PH. FAPE at a glance. Understood for All. 2019. Accessed April 8, 2025. <https://www.understood.org/en/articles/at-a-glance-free-and-appropriate-public-education>
5. Department of Education Commonwealth of Pennsylvania. Department of Education. Accessed April 8, 2025. <https://www.pa.gov/agencies/education.html>
6. Clancy CL. *Change in Age of Eligibility for Free and Appropriate Public Education*. Pennsylvania Department of Education; 2023.
7. Department of Human Services Commonwealth of Pennsylvania. Home and Community Based Services. Accessed April 8, 2025. <https://www.pa.gov/agencies/dhs/resources/home-community-based-services-hcbs>
8. PA Inclusive. PA Inclusive. Accessed April 8, 2025. <https://www.painclusive.org/>

9. Employment First for Individuals with Disabilities. Department of Labor and Industry. Commonwealth of Pennsylvania. Accessed April 8, 2025. <https://www.pa.gov/agencies/dli/programs-services/disability-and-vocational-rehabilitation/employment/employment-first-for-individuals-with-disabilities.html>
10. Parent Education & Advocacy Leadership (PEAL) Center. 2025. Accessed June 12, 2025. <https://www.pealcenter.org/>
11. BrainSTEPS. BrainSTEPS Strategies Teaching Educators, Parents, & Students. Accessed April 8, 2025. <https://brainsteps.net/home/>

Section 2 – The waiver system

1. Disability Rights PA. Medicaid waivers for people with Intellectual Disabilities or Autism. *Disability Rights PA*. March 2018.
2. Department of Human Services Commonwealth of Pennsylvania. Overview of Pennsylvania’s 1915(c) Waivers Appendix A. Pennsylvania’s Statewide Transition Plan. Accessed April 8, 2025. <https://www.pa.gov/content/dam/copapwp-pagov/en/dhs/documents/services/assistance/documents/hcbs-stp/Appendix-A-Overview-of-Pennsylvania-Waivers.pdf>
3. Department of Human Services Commonwealth of Pennsylvania. Waiver Information. Accessed April 8, 2025. <https://www.pa.gov/agencies/dhs/resources/medicaid/waivers.html>
4. Department of Human Services Commonwealth of Pennsylvania. Community HealthChoices (CHC) Providers. Accessed April 8, 2025. <https://www.pa.gov/agencies/dhs/resources/medicaid/chc/chc-providers.html>
5. Department of Human Services Commonwealth of Pennsylvania. OCDEL Information. Accessed April 8, 2025. <https://www.pa.gov/agencies/dhs/departments-offices/ocdel-info.html>
6. Department of Human Services Commonwealth of Pennsylvania. ECM Services/Supports Coordinator Organizations. Accessed April 8, 2025. <https://www.pa.gov/agencies/dhs/resources/ecm/ecm-stakeholders/ecm-services-supports-coordinator-organizations.html>
7. Disability Rights PA. Medicaid Waivers for People with Intellectual Disabilities or Autism. April 25, 2018. Accessed April 7, 2025. https://www.disabilityrightspa.org/wp-content/uploads/2018/04/Medicaid-Waivers-for-People-with-Intellectual-Disabilities-or-Autism_ID2_04.25.2022.pdf
8. Department of Human Services Commonwealth of Pennsylvania. Prioritization of Urgency of Need for Services (PUNS). Accessed April 8, 2025.

<https://www.pa.gov/agencies/dhs/resources/intellectual-disabilities-autism/intellectual-disabilities-services/puns.html>

9. PA Waiting List Campaign. Finalized PUNS as of December 31, 2024. Accessed April 8, 2025. <https://pawaitinglistcampaign.org/wp-content/uploads/2025/02/PUNS-12-31-2024.pdf>

10. Department of Labor and Industry Commonwealth of Pennsylvania. Office of Vocational Rehabilitation. Accessed April 8, 2025. <https://www.pa.gov/agencies/dli/resources/forms-and-documents/office-of-vocational-rehabilitation.html>

11. Pennsylvania Assistive Technology Foundation. Pennsylvania Assistive Technology Foundation. Accessed April 8, 2025. <https://patf.us/>

12. Social Security Administration. Benefits for Children with Disabilities. 2025;(05-10026).

Section 3 – The role of providers

1. Gerhard RC. Power of Attorney vs. Guardianship in Pennsylvania. Accessed April 8, 2025. <https://www.paelderlaw.net/power-of-attorney-vs-guardianship-in-pennsylvania/>

2. National Resource Center for Supported Decision Making. Supported Decision Making. Accessed April 8, 2025. <https://supporteddecisionmaking.org/>

3. Special Olympics. Special Olympics Pennsylvania. Accessed April 8, 2025. <https://specialolympicspa.org/>

4. YMCA of the USA. Find Your Y. Accessed April 8, 2025. <https://www.ymca.org/find-your-y>

5. iCan Shine. Accessed June 12, 2025. <https://icanshine.org/>

6. Pennsylvania Center for Adapted Sports. Accessed June 12, 2025. <https://centeronline.com/>

7. USOPC | Find A Club - Pennsylvania. Accessed June 12, 2025. <https://www.usopc.org/paralympic-sport-development/getting-started/find-a-club/pennsylvania>

8. Jefferson Health Rehabilitative Medicine. Wheelchair Sports. Accessed April 8, 2025. <https://www.jeffersonhealth.org/clinical-specialties/rehabilitation-medicine/specialty-rehabilitation-services/wheelchair-sports>

9. PALS Programs. Accessed April 8, 2025. <http://www.palsprograms.org>

10. Carousel Connections. Accessed April 8, 2025. <http://www.carouselconnections.com>

11. Easterseals Camp Growing Green. Accessed April 8, 2025. <https://www.easterseals.com/esep/programs-and-services/camping-recreation/growing-green.html>

12. PA Vent Camp. Accessed April 8, 2025. <https://www.paventcamp.org/>
13. Variety the Children's Charity. Variety Club. Accessed April 8, 2025. <http://varietyphila.org>
11. Health Promotion Council. Family Services. Accessed April 8, 2025. <https://www.hpcpa.org/programs-services/family-services>

Module 3: Mental and Behavioral Health

Section 1: Behavioral health and IDD

1. Lineberry S, Bogenschutz M, Broda M, Dinora P, Prohn S, West A. Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities. *Community Ment Health J.* 2023;59(6):1119-1128. doi:10.1007/s10597-023-01091-4
2. Humphries L, Michael D, Hassiotis A. Schizophrenia and Related Psychoses in People with Intellectual Disability. In: *Oxford Textbook of the Psychiatry of Intellectual Disability.* Oxford University Press; 2020:91-104. doi:10.1093/med/9780198794585.003.0010
3. Lin L, Stamm K, Conroy J, Assefa M. Survey of Health Service Psychologists. American Psychological Association; 2022. <https://www.apa.org/workforce/publications/health-service-psychologists-survey/full-technical-report.pdf>
4. Cree RA, Okoro CA, Zack MM, Carbone E. Frequent Mental Distress Among Adults, by Disability Status, Disability Type, and Selected Characteristics - United States, 2018. *MMWR Morb Mortal Wkly Rep.* 2020;69(36):1238-1243. doi:10.15585/mmwr.mm6936a2
5. Manter MA, Birtwell KB, Bath J, et al. Pharmacological treatment in autism: a proposal for guidelines on common co-occurring psychiatric symptoms. *BMC Med.* 2025;23(1):11. doi:10.1186/s12916-024-03814-0
6. Palumbo ML, McDougle CJ. Pharmacotherapy of Down syndrome. *Expert Opin Pharmacother.* 2018;19(17):1875-1889. doi:10.1080/14656566.2018.1529167
7. LeClerc S, Easley D. Pharmacological therapies for autism spectrum disorder: a review. *P T.* 2015;40(6):389-397.
8. Doyle CA, McDougle CJ. Pharmacologic treatments for the behavioral symptoms associated with autism spectrum disorders across the lifespan. *Dialogues Clin Neurosci.* 2012;14(3):263-279. doi:10.31887/DCNS.2012.14.3/cdoyle
9. Stafford CF, Sanchez-Lara PA. Impact of Genetic and Genomic Testing on the Clinical Management of Patients with Autism Spectrum Disorder. *Genes.* 2022;13(4). doi:10.3390/genes13040585
10. Phelan-McDermid Syndrome Foundation. What is Phelan-McDermid syndrome? 2024. Accessed April 17, 2025. <https://pmsf.org/about-pms/>

Section 2: Supporting patients and caregivers

11. Anderson L, Hewitt A, Pettingell S, Lulinski A, Taylor M, Reagan J. Family & Individual Needs for Disability Supports (FINDS) Community Report. The Arc; 2018.
12. Got Transition. For Parents and Caregivers. Accessed May 8, 2025. <https://gottransition.org/parents-caregivers/>
13. Got Transition. Youth & Young Adults. Accessed May 8, 2025. <https://gottransition.org/youth-and-young-adults/>
14. Ontario Caregiver Organization. Caring for the mental health of caregivers [Video]. YouTube. <https://www.youtube.com/watch?v=f3ywtOOINQw>. Published August 6, 2019. Accessed May 5, 2025.
15. Barratt M, Lewis P, Duckworth N, et al. Parental Experiences of Quality of Life When Caring for Their Children with Intellectual Disability: A Meta-Aggregation Systematic Review. *J Appl Res Intellect Disabil*. 2025;38(1):e70005. doi:10.1111/jar.70005
16. The Global Tracheostomy Collaborative. Join the GTC. Accessed April 22, 2025. <https://members.globaltrach.org/join-us>
17. Association for Autism and Neurodiversity. Support Groups. Accessed April 22, 2025. <https://aane.org/services-programs/group-services/support-groups-community-connection/>
18. Parents Helping Parents. Parents of Adults with Developmental Disabilities. Accessed April 22, 2025. <https://www.php.com/parents-of-adults-with-developmental-disabilities/>
19. Department of Human Services, Commonwealth of Pennsylvania. Adult Protective Services. Accessed April 15, 2025. <https://www.pa.gov/agencies/dhs/report-abuse/adult-protective-services.html>
20. Smart911. Accessed May 8, 2025. <https://smart911.com/>
21. National Task Group on Intellectual Disabilities and Dementia Practices. Caregiver and Family Support Programs for ID and Dementia. Accessed May 8, 2025. <https://www.the-ntg.org/family-caregivers>
22. Perkins EA. My Health Passport for Hospital/Clinic Visits. Florida Center for Inclusive Communities. 2011. Accessed May 8, 2025. <https://www.poac.net/resources/my-health-passport/>

Section 3: Emerging trends and diagnoses

23. Silva EA da, Medeiros WMB, Torro N, et al. Cannabis and cannabinoid use in autism spectrum disorder: a systematic review. *Trends Psychiatry Psychother*. 2022;44:e20200149. doi:10.47626/2237-6089-2020-0149

24. Jawed B, Esposito JE, Pulcini R, et al. The Evolving Role of Cannabidiol-Rich Cannabis in People with Autism Spectrum Disorder: A Systematic Review. *Int J Mol Sci.* 2024;25(22). doi:10.3390/ijms252212453
25. Holdman R, Vigil D, Robinson K, Shah P, Contreras AE. Safety and Efficacy of Medical Cannabis in Autism Spectrum Disorder Compared with Commonly Used Medications. *Cannabis Cannabinoid Res.* August 24, 2021. doi:10.1089/can.2020.0154
26. Santoro JD, Patel L, Kammeyer R, et al. Assessment and diagnosis of down syndrome regression disorder: international expert consensus. *Front Neurol.* 2022;13:940175. doi:10.3389/fneur.2022.940175
27. Santoro JD, Filipink RA, Baumer NT, Bulova PD, Handen BL. Down syndrome regression disorder: updates and therapeutic advances. *Curr Opin Psychiatry.* 2023;36(2):96-103. doi:10.1097/YCO.0000000000000845
28. Children's Hospital of Los Angeles. A First Clinical Trial for Down Syndrome Regression Disorder. 2024. Accessed April 17, 2025. <https://www.chla.org/blog/experts/research-and-breakthroughs/first-clinical-trial-down-syndrome-regression-disorder>
29. Santoro JD, Partridge R, Tanna R, et al. Evidence of neuroinflammation and immunotherapy responsiveness in individuals with down syndrome regression disorder. *J Neurodev Disord.* 2022;14(1):35. doi:10.1186/s11689-022-09446-w
30. Connors MH, Sachdev PS, Colebatch JG, Taylor MS, Trollor J, Mohan A. Case report: Down syndrome regression disorder, catatonia, and psychiatric and immunomodulatory interventions. *Front Psychiatry.* 2024;15:1416736. doi:10.3389/fpsy.2024.1416736
31. Bonne S, Iftimovici A, Mircher C, et al. Down syndrome regression disorder, a case series: Clinical characterization and therapeutic approaches. *Front Neurosci.* 2023;17:1126973. doi:10.3389/fnins.2023.1126973
32. Santoro JD, Spinazzi NA, Filipink RA, et al. Immunotherapy responsiveness and risk of relapse in Down syndrome regression disorder. *Transl Psychiatry.* 2023;13(1):276. doi:10.1038/s41398-023-02579-z
33. Sweeney K. A Family Finds Hope for Down Syndrome Regression Disorder. Children's Hospital of Los Angeles. May 2, 2022. Accessed May 8, 2025. <https://www.chla.org/blog/patients/family-finds-hope-down-syndrome-regression-disorder>

Module 4: Working with Interdisciplinary Teams

Section 1: What makes an interdisciplinary team?

1. Bobbette N, Ouellette-Kuntz H, Tranmer J, Lysaght R, Ufholz L-A, Donnelly C. Adults with intellectual and developmental disabilities and interprofessional, team-based primary health care: a scoping review. *JBI Evid Synth.* 2020;18(7):1470-1514. doi:10.11124/JBISRIR-D-19-00200

2. Geese F, Schmitt K-U. Interprofessional Collaboration in Complex Patient Care Transition: A Qualitative Multi-Perspective Analysis. *Healthcare (Basel)*. 2023;11(3). doi:10.3390/healthcare11030359
3. Morgan J, Zavras AT. Oral health care for individuals with intellectual and developmental disabilities: A statewide model. *Spec Care Dentist*. 2024;44(6):1527-1534. doi:10.1111/scd.13046
4. American Physical Therapy Association. The Physical Therapy Profession. Presented at the: PT Moves Me, Provided by APTA; 2020. [physical-therapy-overview-high-early-college.pdf](#)
5. AOTA. What is Occupational Therapy? 2025. Accessed May 1, 2025. <https://www.aota.org/about/what-is-ot>
6. ASHA. Speech-Language Pathologists Job Description and Career Information. 2025. Accessed May 1, 2025. <https://www.asha.org/Students/Speech-Language-Pathologists/#:~:text=%EE%80%80Speech-language%20pathologists%EE%80%81>
7. Froymovich E. What's the Difference Between Rehabilitation and Habilitation? RSI Cares. December 29, 2020. Accessed May 1, 2025. <https://www.rsicare.com/whats-the-difference-between-rehabilitation-and-habilitation/>
8. Blaskowitz MG, Johnson KR, Bergfelt T, Mahoney WJ. Evidence to inform occupational therapy intervention with adults with intellectual disability: A scoping review. *Am J Occup Ther*. 2021;75(3). doi:10.5014/ajot.2021.043562
9. Friedman C, Feldner HA. Physical Therapy Services for People with Intellectual and Developmental Disabilities: The Role of Medicaid Home- and Community-Based Service Waivers. *Phys Ther*. 2018;98(10):844-854. doi:10.1093/ptj/pzy082
10. Terband H, Coppens-Hofman MC, Reffeltrath M, Maassen BAM. Effectiveness of speech therapy in adults with intellectual disabilities. *J Appl Res Intellect Disabil*. 2017;31(2):236-248. doi:10.1111/jar.12384
11. Epilepsy Foundation. A Seizure Safe Environment. *Epilepsy.com*. March 2021.

Section 2: Supporting communication

12. Nagy L. It's Never Too Late to Communicate: Increasing Communication Access for Adults with Intellectual Disabilities and Autism. *Autism Spectrum News*. December 30, 2024. Accessed May 1, 2025. <https://autismspectrumnews.org/its-never-too-late-to-communicate-increasing-communication-access-for-adults-with-intellectual-disabilities-and-autism/>
13. Hartmann A, Sheldon E. How to be a respectful communication partner. *Assistive Wear*. Accessed May 28, 2025. <https://www.assistiveware.com/learn-aac/follow-their-lead-how-to-be-a-respectful-communication-partner>
14. OCALI. Assistive Technology Internet Modules. Accessed May 29, 2025. <https://atinternetmodules.org/>

15. Rackensperger T. Working with People with Complex Communication Needs. USSAAC. 2020. Accessed May 29, 2025. <https://ussaac.org/news/working-with-people-with-complex-communication-needs/>
16. I-ASC. Help for nonspeakers and their families. 2019. Accessed May 29, 2025. <https://i-asc.org/new-nonspeakers-families/>
17. Stewart J. Assistive Communication Tools and Technologies for Autistic Children. Today's Parent. August 30, 2024. Accessed May 29, 2025. <https://www.todayparent.com/family/special-needs/assistive-communication-for-autistic-children/>
18. Schlosser RW, Prabhu A. Interrogating neurotypical bias in facilitated communication, rapid prompting method, and spelling 2 communicate through a humanistic lens. *Curr Dev Disord Rep.* 2024;11(1):41-51. doi:10.1007/s40474-024-00296-w
19. American Speech-Language-Hearing Association. Position Statement, Rapid Prompting Method. ASHA. Accessed May 29, 2025. <https://www.asha.org/policy/PS2018-00351/#:~:text=It%20is%20the%20position%20of>
20. Cboard - AAC Communication Board. Accessed May 29, 2025. <https://app.cboard.io/>

Section 3: Physical medicine and rehabilitation

21. Physical Medicine & Rehabilitation. AAPM&R. Accessed May 29, 2025. <https://www.aapmr.org/about-physiatry/about-physical-medicine-rehabilitation>
22. Halsey G. The Primary Care-PM&R Collaboration Can Help Keep Patients Out of the OR. Patient Care Online. August 1, 2023. Accessed May 29, 2025. <https://www.patientcareonline.com/view/the-primary-care-pm-r-collaboration-can-help-keep-patients-out-of-the-or>
23. Finger N. What I wish other docs knew about PM&R. The DO. February 6, 2022. Accessed May 29, 2025. <https://thedo.osteopathic.org/columns/what-i-wish-other-doctors-knew-about-pmr/>
24. University of Southern California Leonard Davis School of Gerontology. Homemods.org. Homemods.org. 2025. Accessed May 29, 2025. <https://homemods.org/>
25. Advice & Support for Senior Caregivers. Aging in Place. Accessed May 29, 2025. <https://aginginplace.org/>
26. Visitability. National Council on Independent Living. Accessed May 29, 2025. <https://ncil.org/visitability/>
27. Liberty Home Solutions. Accessed May 29, 2025. <https://libertyhousingsolutionspa.com/>

28. Pennsylvania Assistive Technology Foundation. Pennsylvania Assistive Technology Foundation. Accessed April 8, 2025. <https://patf.us/>

29. SolutionBased. SB2 Tub Buddy. Accessed May 29, 2025. <https://solutionbased.com/products/sb2-tub-buddy>

30. FAWSsit. FAWSsit Showers. Accessed May 29, 2025. <https://shop.fawssit.com/>

31. Rifton. The Rifton HTS Hygiene & Toileting System. Accessed May 29, 2025. <https://www.rifton.com/products/hygiene-toileting-system>

Section 4: Putting it into practice

32. AADMD. American Academy of Developmental Medicine and Dentistry. Accessed May 29, 2025. <https://www.aadmd.org/>

33. AAIDD. American Association on Intellectual and Developmental Disabilities. Accessed May 29, 2025. <https://www.aaidd.org/>

34. DSMIG-USA. Down Syndrome Medical Interest Group. Accessed May 29, 2025. <https://www.dsmig-usa.org/>

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