

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

Module 3: Mental and Behavioral Health

References

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, McDougale 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, McDougale 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/>

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/>
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/fpsyt.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>

The Pennsylvania Developmental Disabilities Council is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$3,025,222.00 with 100 percent funding by ACL/HHS. Council efforts are those of the grantee and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

Copyright © 2025 Thomas Jefferson University and Pennsylvania Developmental Disabilities Council. Permission to reprint, copy and distribute this work is granted provided that it is reproduced as a whole, distributed at no more than actual cost, and displays this copyright notice. Any other reproduction is strictly prohibited.