

## RESOURCE LIST

### “Options for Decision-Making Support When My Child Turns 18”

November 18, 2020

#### Forms

- Example of HIPAA release form (Maryland State Bar Association Health Law Section), available at
  - [https://cdn.laruta.io/app/uploads/sites/7/legacyFiles/uploadedFiles/MSBA/Member\\_Groups/Sections/Health\\_Law/model\\_authorization\\_form\\_health.pdf](https://cdn.laruta.io/app/uploads/sites/7/legacyFiles/uploadedFiles/MSBA/Member_Groups/Sections/Health_Law/model_authorization_form_health.pdf)
- Example of FERPA release form (Maryland State Department of Education), available in Appendix C at:
  - <http://marylandpublicschools.org/about/Documents/DSFSS/SSSP/TechnicalAssistanceGuide.pdf>
- State of Maryland Office of the Attorney General, “A Guide to Maryland Law on Health Care Decisions (Forms Included)” (August 2019), available at:
  - <https://www.marylandattorneygeneral.gov/health%20policy%20documents/adirective.pdf>
  - Includes a “Maryland Advance Directive” form (for informational purposes only)
- Mental Health Association of Maryland, “Advance Directives: Adult Resources,” available at:
  - <https://www.mhamd.org/information-and-help/adults/advance-directives/>
  - Includes a link to a “Advance Directive for Mental Health Treatment” form (for informational purposes only)

#### Laws and Regulations

- Americans with Disabilities Act, 42 U.S. Code §§ 12101 et seq., available at:
  - <https://www.ada.gov/>
- Adult Guardianship Statute:
  - Md. Code. Ann. Est. & Trusts 13-101-222; 13-704 to -908; 13.5-101-504
    - Available at: <https://law.justia.com/codes/maryland/2019/estates-and-trusts/title-13/>
  - Md. Code. Ann. Family Law 14-401-404
    - Available at: <https://law.justia.com/codes/maryland/2019/family-law/title-14/>
- Nondiscrimination in Access to Anatomical Gifts and Organ Transplantation, Md. Code Ann., Health-Gen. §§ 20-1601 to 20-1606, available at:
  - <https://law.justia.com/codes/maryland/2015/article-ghq/title-20/subtitle-16/>
  - Recognizes supported decision-making within the context of organ transplantation
- Transfer of Rights at the Age of Majority, Md. Code Ann. Ed. § 8-412.1, available at:
  - <https://law.justia.com/codes/maryland/2019/education/division-ii/title-8/subtitle-4/sect-8-412-1/>

#### On-Line Resources, Guides and Webinars

- Joan O’Sullivan, ed. Virginia Rowthorn and Ellen A. Callegary, “Guardianship and Its Alternatives: A Handbook on Maryland Law” (2011), available at:
  - <https://www.disabilityrightsmd.org/wp-content/uploads/2011/12/Guardianship-Handbook-2011.pdf>
  - Please note that this is a 2011 edition. Maryland law may have changed since then. This guide is being provided for informational purposes only.

- Autistic Self Advocacy Network, “Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding and Accommodations (October 2017), *available at*:
  - <https://autisticadvocacy.org/2017/10/everybody-communicates-our-new-toolkit-on-communication-supports/>
- Jenny Hatch Justice Project Web Portal, *available at*:
  - [www.JennyHatchJusticeProject.org](http://www.JennyHatchJusticeProject.org)
- National Community of Practice Supporting Families-LifeCourse Toolkit, Charting the Lifecourse: Tool for Exploring Decision Making Supports (formerly The Stoplight Tool), *available at*:
  - <https://www.lifecoursetools.com/planning/>
- Parent to Parent USA, Supported Decision Making, *available at*:
  - <https://www.p2pusa.org/sdm/>
- National Resource Center for SDM Website ([www.SupportedDecisionMaking.org](http://www.SupportedDecisionMaking.org)):
  - “In Your State” webpage for Maryland: <http://www.supporteddecisionmaking.org/state-review/maryland>
  - Archived Webinars on SDM: <http://www.supporteddecisionmaking.org/education> (certificates of attendance not available)
  - SDM Toolkit Compilation, including sample guides: <http://www.supporteddecisionmaking.org/resource-type/toolkit>
  - Other NRC-SDM Resources: <http://www.supporteddecisionmaking.org/content/resource-library>
- U.S. Department of Education, Office of Special Education and Rehabilitative Services, “A Transition Guide to Post-Secondary Education and Employment Services for Students and Youth with Disabilities (rev. August 2020), *available at*:
  - <https://sites.ed.gov/idea/idea-files/policy-guidance-transition-guide-postsecondary-education-employment-students-youth-disabilities-august-2020/>
  - Recognizes supported decision-making and less-restrictive alternatives to guardianship in education.

### **Other Resources on Supported Decision-Making in Health Care**

- Autistic Self Advocacy Network, “Transition to Adulthood: A Health Care Guide for Youth and Families” (2014), *available at*:
  - <http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf>
  - Includes worksheets for making an appointment, what to bring to a health care visit, describing symptoms, and what to do after the visit
- My Choice Kentucky, “Blood Draw Tool,” *available at*:
  - <http://www.mychoiceky.org/toolkit/>
  - Helps with having a plain language conversation with person, supporter, and doctor; Reminds doctors and supporters to allow time for processing; Published in multiple formats (cartoons and video) with instructions for patients, supporters, and health care providers
- The Arc of the U.S., “A Letter for My Doctors,” *available at*:
  - <https://thearc.org/wp-content/uploads/forchapters/Making-My-Own-Health-Care-Decisions-A-Letter-for-to-My-Doctors.pdf>
  - Helps people with disabilities describe how and when they want help making health care decisions
- Grace Raso & Nicole Newnham with Bread & Butter Films, “Gabby’s Story,” *available at*:
  - <https://withfoundation.org/healthcare-access-for-people-with-disabilities-special-hopes-video-shorts-tell-the-story/>
  - Includes conversations among a person with a disability, health advocate, and primary care provider.

- National Disability Rights Network, “Supported Decision Making and Health Care” website, available at:
  - <http://www.sdmmedicalcare.org/>
  - Includes video and FAQ sheets for medical and health care providers, people with disabilities, and their family friends, and advocates.
- American Civil Liberties Union et al, Video: Making Healthcare Choices: Perspectives of People with Disabilities, *available at*
  - <https://www.youtube.com/watch?v=QTyZrSC2I6U>

### **Right to Exceptions to COVID-19 Hospital Visitor Bans**

- CommunicationFIRST, “COVID-19 Communication Rights Toolkit,” available at:
  - <https://communicationfirst.org/covid-19/>
  - essential to the person’s care, communication, and equal access to treatment.
- Maryland Department of Disabilities and Department of Health: “Notice: Access to Support for Patients with Disabilities in Hospital Settings” (September 24, 2020)
  - [https://phpa.health.maryland.gov/Documents/2020.09.24.01\\_MDOD\\_MDH\\_Notice%20-%20Access to Healthcare Facilities.pdf](https://phpa.health.maryland.gov/Documents/2020.09.24.01_MDOD_MDH_Notice%20-%20Access%20to%20Healthcare%20Facilities.pdf)

### **Other PowerPoint Citations**

American Association on Intellectual and Developmental Disabilities, The Arc of the United States, and Chapters of The Arc. (2016). Autonomy, Decision-Making Supports, and Guardianship. Retrieved from: <https://www.aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship>.

Blanck P., & Martinis, J. G. (2015). The Right to Make Choices: The National Resource Center for Supported Decision-Making. *Inclusion* (3)1, 24-33.

Bradley, V., St. John, J., Bourne, M.L. (2019). National Core Indicators Data Brief: What Do NCI Data Reveal About the Guardianship Status of People with IDD? Retrieved from: [http://www.nationalcoreindicators.org/upload/core-indicators/ NCI\\_GuardianshipBrief\\_April2019\\_Final.pdf](http://www.nationalcoreindicators.org/upload/core-indicators/ NCI_GuardianshipBrief_April2019_Final.pdf)

Deci, E. (1975). *Intrinsic motivation*. New York: Plenum Press.

Dinerstein, R. (2012). Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision Making. *Human Rights Brief*, 19, 8-12.

Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse. *American Journal of Mental Retardation*, 110(3), 193-204.

King, S. (2019). Our Journey of Supported Decision-Making for Ryan, Impact Feature on Self-Determination and Supported Decision-Making (Vol. 32, No.1, 2019). Retrieved from: <https://publications.ici.umn.edu/impact/32-1/our-journey-of-supported-decision-making-for-ryan>

National Guardianship Association. (2016). Position Statement on Guardianship, Surrogate Decision-Making, and Supported Decision-Making. Retrieved from: [https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision\\_Making\\_PositionStatement.pdf](https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision_Making_PositionStatement.pdf).

- Powers, L.E., Geenen, S., Powers, J., Pommier-Satya, S., Turner, A., and Dalton, L. (2012). My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education. *Children and Youth Services Review* 34(11).
- Salzman, L. (2010). Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act. *University of Colorado Law Review* 81: 157-245.
- Salzman, L. (2011). New Perspectives on Guardians and Mental Illness: Guardianship for Persons with Mental Illness - A Legal and Appropriate Alternative? *Saint Louis University Journal of Health Law and Policy* 4: 279-329.
- Shogren, K.A., Wehmeyer, M.L., Palmer, S.B., Rifenburg, G.G., and Little, T.D. (2015). Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities. *The Journal of Special Education* 48(4): 256-267;
- Wehmeyer, M. and Palmer, S. (2003). Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination. *Education and Training in Developmental Disabilities* 38(2): 131-144.
- Wehmeyer, M., Palmer, S., Agran, M., Mithaug, D., & Martin, J. (2000). Promoting causal agency: The Self-Determined Learning Model of Instruction. *Exceptional Children*, 66(4), 439–453.
- Wehmeyer, M. and Schwartz, M. (1997). Self-Determination and Positive Adult Outcomes: A Follow-up Study of Youth with Mental Retardation or Learning Disabilities, *Exceptional Children*, 63(2): 245-255;
- Winick, B. (1995). The Side Effects of Incompetency Labeling and the Implications for Mental Health Law. *Psychology, Public Policy & Law*, 1(1), 6-42.
- Wright, J. (2010). Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA. *International Journal of Law and Psychiatry*, 33(5-6), 350-368. <http://dx.doi.org/10.1016/j.ijlp.2010.09.007>.