Overview

Under the *Individuals with Disabilities Education Act (IDEA)*, eligible students with disabilities may receive special education and related services through age 22. Although the age of majority, which is when students gain important rights and become adults in the eyes of the law, varies from state to state, in all states the age of majority comes before age 22. As a result, many students with disabilities reach the age of majority while they are receiving services under the IDEA.

When students with disabilities who receive special education services reach their state’s age of majority, the IDEA rights that parents have exercised on their children’s behalf may transfer to the students, depending on states’ laws or policies. Since 1997, the IDEA has allowed states to decide whether to permit parental rights transfers. States’ transfer of rights rules vary. For example, Maryland, Nebraska, New York, and Pennsylvania generally do not transfer parental IDEA rights to students when they become adults.

Some researchers and advocates are concerned that states’ transfer of rights rules and practices may cause parents or other caregivers to seek guardianship unnecessarily. This is because the IDEA does not allow states to transfer parental rights to students for whom courts have appointed legal guardians. Thus, some parents or caregivers who wish to continue exercising parental rights under the IDEA on behalf of adult students with disabilities may incorrectly believe that guardianship is the only way to prevent IDEA parental rights from transferring.

With funding from the US Department of Education’s Institute of Education Sciences, the Institute for Community Inclusion (ICI) at the University of Massachusetts, Boston, together with Massachusetts Advocates Standing Strong (MASS), the Self Advocacy Association of New York State (SANYS), and consultants from the Harvard Law School Project on Disability, have conducted a scoping literature review to explore the wide range of resources related to the transfer of IDEA rights for students with disabilities.

The findings of our literature review will be published elsewhere, including on the [https://gator.communityinclusion.org/](https://gator.communityinclusion.org/)

Our literature search covered a broad range of literature types, including peer-reviewed journals, gray literature and reports, websites, books, and guidance for parents and professionals. We excluded two types of literature from our review:

1. state- and district-level guidance for school staff, parents, and other stakeholders authored by education agencies
2. state- and district-level guidance for school staff, parents, and other stakeholders authored by non-profit organizations

However, we included literature and videos targeting transition-age youth in New York and Massachusetts on transfer of rights, guardianship, and alternatives to guardianship that were collected by MASS and SANYS researchers. You will find the sources we collected during our literature review in the following list, which groups sources under six headings: (1) empirical research, (2) law and policy analysis, (3) professional resources, (4) parent resources, (5) self-advocacy materials, and (6) general resources.
(1) Empirical Research

What do NCI data reveal about the guardianship status of people with IDD?

*Brady, A. M., Burke, M. M., Landon, T., & Oertle, K. (2019)*

Guardianship and the potential of supported decision-making with individuals with disabilities. Research and Practice for Persons with Severe Disabilities, 40(1), 36-51

*MacLeod, K. (2017)*
“I should have big dreams”: A qualitative case study on alternatives to guardianship. Education and Training in Autism and Developmental Disabilities, 52(2), 194-207

*Millar, D. S.*

- (2009). Comparison of transition-related IEP content for young adults with disabilities who do or do not have a legal guardian. Education and Training in Developmental Disabilities, 44(2), 151-167

Factors affecting guardianship practices for young adults with disabilities. Exceptional Children, 68(4), 465-484

Guardianship: Its role in the transition process for students with developmental disabilities. Education and Training in Developmental Disabilities,43(1), 3-19

*Pell, E. (2019)*
Supported Decision-Making New York: Evaluation report of an intentional pilot

*Plotner, A. J. & Walters, C. B. (2021)*
Perceptions of district- and school-level special education leaders on guardianship and adult decision-making support. Journal of Disability Policy Studies, 1-11
(2) Law and Policy Analysis

Cannon, Y. Z. (2011)
Who’s the boss?: The need for thoughtful identification of the client(s) in special education cases. Journal of Gender, Social Policy & the Law, 20(1). 1-79

Growing up with disabilities: Education law and the transition to adulthood. Disability Studies Quarterly, 20(4)

Is guardianship reform enough? Next steps in policy reforms to promote self-determination among people with disabilities. Journal of International Aging Law & Policy, 8, 177-210

Glen, K. B. (2017)
Piloting personhood: Reflections from the first year of a supported decision-making project. Cardozo Law Review, 39, 495-519


Guardianship for young adults with disabilities as a violation of the purpose of the Individuals with Disabilities Education Improvement Act. Journal of International Aging Law & Policy, 8. 1-68

Understanding the gap between law and practice: Barriers and alternatives to tailoring adult guardianship orders. Buffalo Public Interest Law Journal, 36, 155-215

National Council on Disability
(2018). Beyond guardianship: Toward alternatives that promote greater self-determination for people with disabilities
• (2019). Turning rights into reality: How Guardianship and alternatives impact the autonomy of people with intellectual and developmental disabilities

Pringles, C. I. (2011)
Throwing a lifesaver without going overboard: Considering alternatives to guardianship. Vermont Bar Journal, 37-Spring, 21-23

Age of majority and alternatives to guardianship: A necessary amendment to the Individuals with Disabilities Education Improvement Act of 2004. Journal of Disability Policy Studies, 1-11


Saltzman, J. C. & Hughes, B. S. (2005)
Planning with special needs youth upon reaching majority: Education and other powers of attorney. NAELA Journal, 1(1), 41-57

Schwartz, B. D., Colwell, W., & Milsk, P. (2008)
Presumption of incompetence: The systematic assignment of guardianship within the transition process. Research and Practice for Persons with Severe Disabilities, 39(4) 319-328

Intellectual and developmental disability: Transition to adulthood and decision-making process. International Journal of Child Health and Human Development, 8(4), 517-527

Smith, M. S. & Stein, M. A. (2021)
Transfer of parental rights: The impact of section 615(m) of the Individuals with Disabilities Education Act. Drexel Law Review, forthcoming

Theodorou, E. J. (2018)
Supported decision-making in the Lone Star State. New York University Law Review, 93, 973-1013

(3) Professional Resources

Alar, N. & Hughes, B. S. (2009)
How and Why the Educational Power of Attorney Was Created

Alternatives to guardianship toolkit. University of Montana Rural Institute for Inclusive Communities

Clair, T., Gruhn, S., & Harris, S. (2000)
Transfer of rights: A special education technical assistance document. Oregon State Dept. of Education, Office of Special Education

Fuchs, T. (2018)
Interview with Jerri Davison & Charlie Walters [Interview]. Independent Living Research Utilization

Glen, K. B. (2019)
What judges need to know about supported decision-making, and why. Judges’ Journal, 58(26)

The comprehensive guide to special education law. Jessica Kingsley Publishers

Massachusetts transition timeline. [Chart]. University of Massachusetts Boston, Institute for Community Inclusion

Lindsey, P., Guy, B., Wehmeyer, M. L., & Martin, J. (2001)

Martinis, J. (2015)
“The right to make choices”: How vocational rehabilitation can help young adults with disabilities increase self-determination and avoid guardianship. Journal of Vocational Rehabilitation, 42(3), 221-227

Transition requirements: A guide for states, districts, schools, universities and families. National Center on Secondary Education and Transition & Institute on Community Integration, University of Minnesota
The WrightsLaw Way
(November 1, 2016) *Age of majority: TURNING 18*
(May 30, 2019) *Transfer of Parental Rights at Age of Majority*

*Brill, K. (2017)*
Supported decision-making and alternatives to guardianship by families.
*TASH Connections, 42(3), 33-35*

*Center for Parent Information & Resources (October, 2015)*
*Getting ready for when your teen reaches the age of majority: a parent's guide*

*deFur, S. H. (1999)*
*Transition Planning: A Team Effort.* National Information Center for Children and Youth with Disabilities

*Disability Law Center (2012)*
*A Transition Services Online Manual* (2nd ed.)

*Federation for Children with Special Needs & Massachusetts Department of Education. (2006)*
*A parent’s guide to special education*

*Federation for Children with Special Needs. (n.d.)*
*TIPS: Transition Information for Parents and Students with IEPs*

*Guardianship Alternatives and Transfer-of-Rights (2021)*


*Leuchovius, D. & Ziemke, B. (2019)*
*Consider the Alternatives: Decision-Making Options for Young Adults with Intellectual Disabilities.* Think College Insight Brief, 41

*Misilo, F. (2013)*
*Coming of Age in Massachusetts: A Legal Resource Guide* | 3rd Edition

*National Center on Secondary Education and Transition & PACER Center (2002)*
*Age of Majority: Preparing Your Child for Making Good Choices [Parent brief]*

*National Dissemination Center for Children with Disabilities. (2009)*
*Developing your child's IEP: A Parent's Guide*

*Newton Public Schools. (n.d.)*
*Age of majority*

*PACER Center. (2015)*
*Prepare your child for age of majority and transfer of rights*

*A transition guide to postsecondary education and employment for students and youth with disabilities*
(5) Self-Advocacy Materials

Advocates as Leaders. (2017)

Roadmap to Transition: A Handbook for Autistic Youth Transitioning to Adulthood

Autistic Self Advocacy Network. (2016)
The Right to Make Choices: International Laws and Decision-Making by People with Disabilities [Easy Read]

Disability Law Center (2012)
Self-Advocacy Materials: Alternatives to Guardianship and Guardianship

McCarty, J.
• (April 27, 2020). The Process of Terminating Guardianship (Using Supported Decision-Making) [Video]. YouTube
• (May 10, 2020). Why Supported Decision Making Matters and How to Get Started [Video]. YouTube
• (May 13, 2020). Supported decision making and guardianship termination. Self Advocacy Resource and Technical Assistance Center
• (May 13, 2020). Who’s in Charge Here? [PowerPoint]. Self Advocacy Resource and Technical Assistance Center
• (2020). Helpful resources to get started with Supported Decision Making [Handout]

(6) General Resources

Center for Public Representation (n.d.)
• Supported Decision-Making
• Supported Decision-Making and education

Institute for Community Inclusion (2022)
State-Specific Transfer-of-Rights Rules. Guardianship Alternatives and Transfer-of-Rights

Disability Rights Texas. (June 29, 2016)
Supported Decision-Making in Action: Dawn and Belinda’s Story [Video]. YouTube

Martinis, J. & Blanck, P. (2019)
Supported decision-making: From justice for Jenny to justice for all. Something Else Solutions Press

O’Hara, L. (2016, March 22)
Supported Decision-Making: Gabby’s Story [Video]. YouTube

Texas Office of Court Administration. (2004)
Texas guardianship cases: Improving court processes and monitoring practices in Texas courts

A call to society for supported decision-making: Theoretical and legal reasoning. Journal of Child and Family Studies, 28, 1803-18
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