

Transfer of Rights: How Parents, Families, and Caregivers of Youth with Intellectual and Developmental Disabilities Can Prepare for this Exciting Opportunity

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Introduction

For parents, families, and caregivers of youth with intellectual and developmental disabilities (IDD), reaching the age of majority is an important milestone. In most US states, the age of majority is when many legal rights parents have under the Individuals with Disabilities Education Act (IDEA) transfer to young adults.¹ The way that transfer of rights discussions between schools and families happen can differ from state to state and school to school. For some, conversations about transfer of rights begin at Individualized Education Program (IEP) or transition planning meetings; for others, this process begins with a written notification from the school when a student turns 17.

How and when you receive information about transfer of rights can potentially affect the decisions you make as your student moves through the transition process.

Parents reading this brief will learn:

- » what research shows about parents' and youths' transfer of rights discussions with schools
- » what you can do as parents and caregivers to take advantage of the transfer of rights process to position youth with IDD for better transition outcomes

Methods: How we collected information

We conducted a scoping literature review, which is a review of a wide range of sources using a broad set of guiding questions. We sought out research on:

- » what transfer of rights conversations are like
- » differences in discussing the transfer of rights by state or school district
- » recommendations for having conversations about transfer of rights
- » how transfer of rights processes can affect outcomes in the lives of people with IDD

We conducted this review as a first stage of the Guardianship Alternatives and Transfer of Rights (GATOR) project, funded by the Department of Education's Institute of Education Sciences. The GATOR project's goal is to develop and test an approach to the transfer of rights process in schools that supports positive outcomes for youth with IDD.

We reviewed 53 sources, including peer-reviewed journal articles, legal reviews, government and independent reports, organizational websites, books, manuals, expert opinions, and other resources available to individuals, families, and education professionals. We sorted through these sources to look for common themes and recommendations about the transfer of rights process.

Tips for parents, families, and caregivers



- 1. View transfer of rights as an opportunity.**
- 2. Use transition planning to build youths' decision-making skills.**
- 3. Practice decision-making with your youth early and often.**
- 4. Learn more about guardianship and alternatives.**
- 5. Consider guardianship only as a last resort.**

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FINDINGS: What we learned

“Transfer of rights” is linked to the concept of guardianship.

For states where parental rights transfer to adult students, the Individuals with Disabilities Education Act (IDEA) requires schools to notify both students and their parents at least one year before youths reach the state’s age of majority. IDEA requires that the transition planning processes begin before schools send the transfer of rights notice.² However, the transition planning processes do not necessarily prepare families to address guardianship, or alternatives to guardianship, before receiving this notice. Often, these school notices state that the youth will be authorized to make educational decisions instead of the parent, and that this transfer will occur unless a guardian is in place to take on these decisions. The literature says that the wording of such notices may create the impression that it is best to avoid transfer of rights and that the only option for doing so is guardianship.³

Be proactive and intentional as you prepare yourself and your youth for transfer of rights.

When conversations do take place, they are brief and oversimplified.

Families perceived transfer of rights discussions with special educators as short, and in some cases, off-hand or superficial. Although these conversations are brief, some evidence suggests that they can steer parents toward seeking guardianship, and even outline the specific steps for parents to follow to obtain guardianship. There was little evidence of discussion about long-term consequences of guardianship, or reasonable alternatives to guardianship.⁴

Families look to schools for guidance.

Many parents seek advice from special educators and other school professionals about planning their children’s future education. Advice from special educators and other school personnel can have important effects on how families view transfer of rights and weigh their options. The literature suggests that if schools recommend a certain transfer of rights option to families, or simply fail to mention other available options, this may make families more inclined to pursue one option over another.⁵

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Youth have limited involvement.

Transfer of rights discussions appear to take place frequently with only limited, if any, involvement of the youth themselves. Often schools present parents with options for navigating transfer of rights without mentioning the extent to which youth are or should be involved in choosing options. The limited youth involvement in transfer of rights discussions is evident in a review of the informational material available to educate stakeholders. Information on transfer of rights processes is widely available, but it is rarely designed or shared with youth with disabilities in mind.

RECOMMENDATIONS:

What you can do as parents, families, and caregivers

The sources we reviewed suggest five ways you can make the most of the transfer of rights process.

1. View Transfer of Rights as an Opportunity

You may receive information that presents the transfer of rights process as an event to be avoided. However, research recommends seeing it as an opportunity for youth with IDD to hone decision-making and leadership skills that will serve them well as adults.⁶ Use the transfer of rights process to educate your youth about their rights and responsibilities. Encourage your youth to take ownership of their IEP process. IEP teams can sometimes get caught up in what needs to be done and not make space for the youth to contribute their thoughts or make decisions.⁷ Participation in IEP meetings can be empowering and can teach youth valuable skills. Help your youth develop good working relationships with school personnel and other IEP team members so the team can communicate openly and inclusively about your youth's transition to adulthood.

2. Take Advantage of the IEP and Transition Planning Processes

Use the IEP and transition planning processes as part of your efforts to build youths' decision-making skills.⁸ Add goals to the IEP about how to make decisions. The IEP can also include goals about building a support network for students who have decision-making challenges.⁹ Use required evaluations to identify decision-making support needs to incorporate into your youth's IEP. Work with transition professionals to write a plan for your youth to continue to practice making their own decisions about their lives. You can also include a transition planning goal related to learning about decision-making arrangements, including guardianship and alternatives, so that your youth can be an informed participant in transfer of rights discussions.

3. Build Youths' Decision-making Skills

For transfer of rights to be a meaningful opportunity, practice decision-making with your youth early and often. The ability to make and be responsible for decisions is important for developing self-determination. Whenever possible, present your youth with big and small opportunities to make decisions, like what to cook for dinner, or what music to listen to in the car. Building confidence and decision-making skills takes time and practice. Step back and let your youth take control over some responsibilities, decisions, and consequences. Try to give them opportunities to succeed or fail. Gradually increase the level of difficulty of these decisions as youth get older, and talk about the pros and cons of these decisions with them. Help them identify other trusted people they can go to for advice about difficult decisions.¹⁰

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4. Learn More about Guardianship and Alternatives

If you and your youth prefer to avoid transfer of rights, consider learning about both the effects of guardianship and the range of alternatives that might achieve that goal. Review information from your state's designated Protection and Advocacy agency. Depending on your state's laws, options may include:

1. an educational power of attorney, which a youth can use to authorize you or someone else to make decisions about their education;
2. an assignment or delegation of rights form, which a youth can use to authorize you or someone else to make decisions about their education; or
3. an educational representative appointment, which can designate someone to make educational decisions for the youth if the youth is deemed unable to give informed consent.

In transfer of rights conversations, you and your youth may want to explore other guardianship alternatives that can help with decision-making outside of school:

1. a representative payeeship or power of attorney, which a youth can use to authorize you or someone else to manage earnings, benefits, and other finances;
2. a health care proxy or power of attorney, which a youth can use to designate you or someone else to make medical decisions if clinicians believe the youth is unable to do so; and
3. a supported decision-making agreement, which a youth can use to choose supporters to help with certain kinds of decisions in the ways the youth wants.¹¹

5. Use Guardianship Only As a Last Resort

Consider guardianship only as a last resort.¹² If you and your youth want to avoid transfer of IDEA rights, there are less restrictive options than guardianship for doing so. Guardianship has broad effects beyond educational decision-making that can make it an overly restrictive measure for the simple purpose of avoiding transfer of IDEA rights. Learn about the effects of guardianship, and youths' options for restoring their rights or modifying the guardianship later on. Review information from your state's designated Protection and Advocacy agency. If you and your youth believe that guardianship is appropriate, consider whether a partial or time-bound guardianship will address your decision-making concerns.

Conclusion

Transfer of rights discussions are often brief and school personnel may not be fully aware of all available options. For these reasons, conversations about transfer of rights may result in some parents, families, and caregivers seeking guardianship. Be proactive and intentional as you prepare yourself and your youth for transfer of rights. Use the transfer of rights process as a stepping stone toward an increasingly independent and self-determined transition to adulthood.

Endnotes

- 1 In general, IDEA parental rights do not transfer by default to adult students in Maryland, Nebraska, New York, and Pennsylvania. In Colorado, the state's general age of majority (18) is different from the educational age of majority (20).
- 2 Under the Individuals with Disabilities Education Act (IDEA) Section 300.320(b), the transition planning process is required to begin when the youth reaches the age of 16, or earlier if deemed appropriate in their Individualized Education Plan (IEP).
- 3 Alar, N. & Hughes, B. S. (2009) How and Why the Educational Power of Attorney Was Created. https://www2.waisman.wisc.edu/cedd//connections/pdfs/description_epoa_and_sample.pdf
- 4 Payne-Christiansen, E. M. & Sitlington, P. L. (2008). Guardianship: Its role in the transition process for students with developmental disabilities. *Education and Training in Developmental Disabilities*,43(1), 3-19. www.jstor.org/stable/23879740
- 5 Brill, K. (2017). Supported decision-making and alternatives to guardianship by families. *TASH Connections*, 42(3), 33-35.
- 6 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. <https://www.jstor.org/stable/26420390>
- 7 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. <https://www.jstor.org/stable/24233490>
- 8 Millar, D. S. (2013). Guardianship alternatives: Their use affirms self-determination of individuals with intellectual disabilities. *Education and Training in Autism and Developmental Disabilities*,48(3), 291-305. <https://www.jstor.org/stable/23880988>
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- 10 PACER Center. (2015). Prepare your child for age of majority and transfer of rights. <https://www.pacer.org/transition/resource-library/publications/NPC-19.pdf>
- 11 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.
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