

National Down Syndrome Congress

Guardianship and Students with Down Syndrome A Brief for Families and Policymakers

The National Down Syndrome Congress (NDSC) is the country's oldest national organization for people with Down syndrome, their families, and the professionals who work with them. We provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome, and work to create a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome.



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CONGRESS

Introduction

As students with Down syndrome approach the age of 18, parents, families and the student themselves begin to plan their next steps. The transition from school and special education services to life after high school is a critical juncture in the life of a student with Down syndrome and their family. Unfortunately, this transition can sometimes be derailed in rather significant ways when students, families, educators and administrators begin making decisions about the need for guardianship with incorrect and/or incomplete information.

In our work, we continue to see a pattern in which caregivers are told that they must obtain guardianship (1), without meaningful consideration of less restrictive options, in order to remain involved in their loved one's education. This pattern builds off previous work establishing what is known as the "school-to-guardianship phenomenon" (2) roughly described as school personnel questioning the competency of students with disabilities, and parents seeking to become the legal guardian of their young adult children during the transfer-of-rights juncture in the special education process where educational rights transfer from parents to student when they turn 18. Furthermore, we have seen a state legislature take it upon themselves to require that Individualized Education Programs (IEPs) for certain students contain information and instruction on certain legal rights and responsibilities that transfer to students at the age of 18 and requires such information to include ways in which a student may provide informed consent to allow their parent to continue to participate in their educational decisions (3). This brief intends to demystify what is and is not necessary for families to remain involved in their loved one's educational career without unnecessarily obtaining guardianship (4). We must better ensure families and students with Down syndrome have all the appropriate information at their disposal to make a decision and policymakers must help ensure that guardianship is not unnecessarily imposed when less restrictive options are available and appropriate.

Telling Their Story

“When our daughter approached 18, our school provided us with information about obtaining guardianship, our area intermediary school district hosted a presentation on guardianship and the attorney we visited, upon learning our daughter has Down syndrome assumed we had come seeking a plan for guardianship. There is little awareness or resources to plan for alternatives to guardianship outside the community of disability rights advocates. When my daughter turned 18, it took time to find the resources we needed to put together an alternative plan, but she now has a plan that includes a power of attorney, trust and other supports that ensure she maintains her rights while getting the support she desires.” - Parent from Michigan

Current Law and Policy

The Individuals with Disabilities Education Act (IDEA) (5) is the federal law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. **The term “guardianship” appears sparingly in the IDEA law and regulations and does not appear at all in sections regarding the transfer of rights at age 18.** The IDEA regulations do however speak on the transfer of parental rights as a student approaches the age of majority (6). IDEA Regulation Sec.7 300.520 (7) “Transfer of parental rights at age of majority” states that once the child reaches the age of majority all IDEA rights transfer from the parent to the child except if the child has been determined incompetent under State law. In other words, a student with Down syndrome who receives services under the IDEA will assume all of the rights previously enjoyed by their parents under the IDEA once they reach the age of majority.

Sec. 300.520 also includes a “Special rule” provision which accounts for students who have reached the age of majority and have not been determined incompetent under State law but who do not have the ability to provide informed consent with respect to their special education services (8). The regulation includes a special rule which says that a State must establish procedures for appointing the parent of a child with a disability, or, if the parent is not available, another appropriate individual, to represent the educational interests of the child if the child is determined not to have the ability to provide informed consent with respect to the child’s educational program (9).

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In other words, the regulation requires, that schools allow either the student's parents or another representative to provide informed consent for the purposes of the student's education even if the student has reached the age of majority and is not legally incompetent under State law, but for whatever reason cannot provide informed consent themselves. **From an IDEA perspective, we find no statutory or regulatory basis for schools to require guardianship in order for families to remain involved in their loved one's education. We argue that the regulation grants appropriate flexibility for alternatives to guardianship such as providing informed consent.**

Current Law and Policy

In August 2020, the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS) published updates to "A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities, August 2020" (10) which includes a section titled, "Parental Consent, Age of Majority, Supported Decision-making and Guardianship". While the section is generally a restatement of the IDEA regulations, **the guidance clearly states "A student need not be placed under guardianship in order for his or her family to remain involved in educational decisions. Guardianship places significant restrictions on the rights of an individual.** Students and parents are urged to consider information about less restrictive alternatives." The guidance goes onto other alternatives:

- If State law permits parental rights under the IDEA to transfer to a student who has reached the age of majority, that student can become the educational rights holder who invites family members to participate in the IEP meeting. If the adult student does not want to have that role, he or she can execute a power of attorney authorizing a family member to be the educational decision-maker. Alternatively, if a student prefers not to execute a power of attorney, a supported decision-making arrangement can be established consistent with applicable State procedures, in which the parents (or other representatives) assist the student in making decisions. Unlike under guardianship, the student remains an autonomous decision-maker in all aspects of his or her life.

Current Law and Policy

As you can see, the special rule in the IDEA regulations makes it very clear that if a student has not been deemed legally incompetent but does not have the ability to provide informed consent with respect to the student's educational program, the State must have procedures that provide alternatives to guardianship. The OSERS Transition Guide goes further and allows students to appoint someone else if the student does not want to be the education rights holder. In spite of these provisions, many States do not have these procedures in place and are therefore not properly implementing IDEA. This becomes an even bigger problem if a due process case is filed on a student's behalf, there is no guardianship, and the administrative body refuses to recognize the parent as having any authority to proceed on behalf of the student. We are aware of at least one appellate court that issued a decision that said the State department of education could not create these procedures until the State legislature put the IDEA special rule into State law. This case further muddies the water since State departments of education are required to follow federal law. As a result of this confusion and lack of implementation at the State level, it is imperative that the U.S. Department of Education take steps to ensure implementation of the IDEA special rule.

We believe more must be done to ensure that families and students know that guardianship is not a prerequisite for a student's family to remain involved in educational decisions. The U.S. Department of Education must do more to educate the field, including schools, districts, and states about both what is available to families under the IDEA regulations on this topic and less restrictive alternatives to guardianship including issuing clarifying sub-regulatory guidance.

Recommendations

I. Parents/Families and Students

A. Parents, families and students should become familiar with their state-supported decision-making landscape, power of attorney options, and guardianship laws prior to the age of majority and preferably as early as possible. See the following resource for more information about supported decision-making in your state: <https://supporteddecisionmaking.org/in-your-state/>

B. Caregivers should become familiar with less restrictive options to guardianship. A good resource to start with is the following resource from the U.S. Department of Justice: <https://www.justice.gov/elderjustice/less-restrictive-options>

C. While formal transition planning under IDEA must occur no later than age 16, transition planning, both within the formal IEP process and externally, can and should begin well before 16 and preferably in middle or elementary school. Parents/families and students should begin planning what vision they have for their student post-high school that takes into account a student's strengths, preferences, and interests (11). The earlier the planning begins, the less likely it is that a student will need to be funneled into guardianship since ideally a well-thought-out strength-based plan has been set and developed over a long period of time in school.

D. Set an expectation that establishing guardianship would be a "failure" without first fully and effectively considering all other least restrictive alternatives (12). Emphasize with the school that an important part of a successful education is teaching the student how to make good decisions and students cannot do that if they proactively have guardianships placed over them.

E. Ask your school about your state's procedure for appointing either a parent or another appropriate individual to represent the educational interests of the child if the child is determined not to have the ability to provide informed consent.

Recommendations

F. Learn more about your State's transfer-of-rights rules, including statutes, regulations, and policies here: <https://gator.communityinclusion.org/#states>

II. U.S. Department of Education

A. The National Council on Disability “Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities” report included several recommendations that should be enacted now. Specifically, we recommend the U.S. Department of Education act on the following:

- Issue regulations and/or guidance clarifying the requirements for states that they create an educational representative appointment option for adult students who cannot provide informed consent or do not want to be the decision-maker for their special education services, pursuant to IDEA (20 U.S.C. § 1415(m)(2)) and its regulations (34 C.F.R. § 300.520(b)). When such appointment is triggered by a parent’s request or an alleged certification of incapacity, states must require that: (1) less-restrictive options, such as educational powers of attorney or other voluntary delegation by the student are exhausted first; and (b) such appointments are easily challengeable by the students involved through, for example, a mere objection rather than by a due process hearing before an administrative law judge.
- Issue a “Dear Colleague” letter to all teacher education programs and vocational rehabilitation agencies urging them to cover the full range of decision-making options in their transition programming and instruction of accommodations for people with intellectual and developmental disabilities (ID/DD).
- Require that State Education Agencies develop tracking mechanisms to determine how decision-making rights are exercised by and/or for adult students in special education to assess and monitor the use of guardianship and alternatives by transition-age youth.

Recommendations

B. Issue a “Dear Colleague” letter to all State Education Agencies urging them to remind Local Education Agencies of their obligations under IDEA Regulation Sec. 300.520 “Transfer of parental rights at age of majority” with a specific emphasis on the part of the regulation which says that a State must establish procedures for appointing the parent of a child with a disability, or, if the parent is not available, another appropriate individual, to represent the educational interests of the child if the child is determined not to have the ability to provide informed consent with respect to the child’s educational program. The letter should also make clear that from an IDEA perspective, there is no statutory or regulatory basis for schools to require guardianship in order for families to remain involved in their loved one’s educational life and that current IDEA regulations grant appropriate flexibility for families and schools to explore alternatives to guardianship.

C. Issue a “Dear Colleague” letter urging State Education Agencies to encourage districts to begin transition services or pre-employment transition services for all youth with significant disabilities at or prior to age 14 (13).

III. Congress

A. Fund grants specifically designed to enhance protections for the rights of students with disabilities who are in, or at risk of, guardianship or conservatorship. The grants could be modeled after the U.S. Department of Health and Human Services, Administration for Community Living, Elder Justice Innovation Grants.

B. Pass the Guardianship Grant Flexibility Act (S. 1126) and the Guardianship Bill of Rights Act (S. 1148).

Acknowledgements

NDSC benefitted tremendously from an advisory committee that provided excellent work, needed knowledge, and important insights about guardianship and special education and the need for ensuring that guardianship is not recommended to families when less restrictive options are appropriate. We are grateful to the following individuals and their organizations:

- Selene A. Almazan, Esq, Legal Director, Council of Parent Attorneys and Advocates (COPAA)
- Mike Burgess, Director of Policy & Outreach, Disability Rights Center of Kansas
- Matthew S. Goodin, Esq, Goodin Law Office of Special Needs Planning, PLLC
- Rocky Nichols, M.P.A., Executive Director, Disability Rights Center of Kansas
- Derek Warden, J.D.,G.D.C.L.,LL.M.,S.J.D., New Orleans, Louisiana

Telling Their Story

“The bias towards guardianship is pervasive. There’s simply not enough information about Supported Decision Making.” - Parent/Family Member of an individual with Down syndrome from Texas

“More efforts around supported decision-making agreements (and educating families and professionals about them) would be a fantastic alternative to assuming all people with Down syndrome require a guardian.” - Parent/Family Member of an individual with Down syndrome from Washington

“For individuals with significant cognitive disabilities, there is usually an automatic default for full guardianship with no thought or intent to consider the least intrusive approach to assistance with decision-making. Our state has statutes for supported decision-making, but usually, this is not a consideration for individuals with Down syndrome. Schools are usually in a position to introduce the need for decision-making support to families and rarely have the necessary information/tools to help families think these decisions through. We need specific transition coordinators in our local school districts to support families. Usually, families are left on their own to figure this out.” - Parent/Family Member of an individual with Down syndrome from North Dakota

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“I am independent and when my parents and family become involved it is necessary to help me understand. My parents give me the ability to speak for myself when I am able.” - Craig Blackburn, Self-Advocate from Louisiana



Sources

- (1): Guardianship includes adult guardianship, conservatorship and any other corresponding terms used by a state or tribe.
- (2): See: https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf
- (3): See: <https://www.flsenate.gov/Session/Bill/2023/636>
- (4): The information provided in this brief does not, and is not intended to, constitute legal advice; instead, all information, content, and materials available in this brief are for general informational purposes only.
- (5): 20 U.S.C. § 1400 et. seq.
- (6): Age of majority is the age when children legally become adults. Each state sets the age of majority for young people in the state. In most states the age of majority is age 18. Source: <https://www.parentcenterhub.org/age-of-majority-parentguide>
- (7): 34 C.F.R. etc
- (8): See: <https://www.parentcenterhub.org/age-of-majority/>
- (9): 34 CFR § 300.520 - Transfer of parental rights at age of majority
- (10): U.S. Department of Education (Department), Office of Special Education and Rehabilitative Services, A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities, Washington, D.C., 2020. <https://sites.ed.gov/idea/files/postsecondary-transition-guide-august-2020.pdf>
- (11): Turning 18: What Parents & Teachers Need to Know; Massachusetts Advocates Standing Strong (MASS) and Self-Advocacy Association of New York State (SANYS): https://youth-voice.org/wp-content/uploads/2023/07/GATOR_tip-sheet-final.pdf
- (12): Committee of the State Board of Education in Kansas; Report 1 – Recommendations on improving the transition process for all students with disabilities: <file:///C:/Users/chuncharek/Downloads/Report%201%20Improving%20Transition%20for%20All%20Students%20Recommendations%20Final.pdf>
- (13): See: https://www.dol.gov/sites/dolgov/files/odep/topics/pdf/acicieid_final_report_9-8-16.pdf