

What Is Known About Schools' Transfer of Rights Practices for Students With Intellectual and Developmental Disabilities

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Abstract

We performed a scoping review of literature on schools' transfer of rights practices under the Individuals with Disabilities Education Act (IDEA) with respect to students with intellectual and developmental disabilities. The review found only limited empirical evidence of how IDEA transfer of rights policies are implemented in schools and affect students and parents. We found a substantial disconnect between this limited empirical evidence and generalizations about school practice made in recent literature that is not empirically based. In addition, we found some misunderstanding of relevant federal policy and little attention to variation in states' policies and schools' practices. Further research is needed to understand the intersection of relevant public policy, school practice, and student postsecondary education, employment, and independent living outcomes.

Keywords

intellectual disability, schools, transfer of rights, transition

Under the Individuals with Disabilities Education Act (IDEA), states can receive federal funding to provide special education and related services to students with disabilities ages 3 to 21, inclusive (20 U.S.C. § 1411(h)). As a result, many states have opted to provide IDEA services to students who have become adults under their states' laws (Government Accountability Office, 2019). When these students reach their state's age of majority, the IDEA rights that their parents have exercised on their behalf may transfer to them, depending on their states' laws or policies (20 U.S.C. § 1415(m)). Since 1997, the IDEA has expressly allowed states to decide whether to permit parental rights transfers (Publ. L. No. 105-17, § 615(m)). However, it does not allow states to transfer parental rights to adult students "determined to be incompetent" (20 U.S.C. § 1415(m)(1)). The IDEA also requires that schools notify both parents and students of the transfer of rights at least 1 year before a transfer may occur (20 U.S.C. § 1414(d)(1)(A)(i)(VIII)(cc)). IDEA parental rights generally transfer to adult students in 46 states, the District of Columbia, and Puerto Rico, but not in Maryland, Nebraska, New York, and Pennsylvania (Smith & Stein, 2022).

Currently, there is concern among disability rights advocates that schools' transfer of rights practices lead parents to seek legal guardianship of their children with intellectual and developmental disabilities (IDD; Center for Public Representation [CPR], n.d.). The National

Institutes of Health (2021) defines intellectual disability as starting "any time before a child turns 18 . . . characterized by differences with both intellectual functioning or intelligence, which include the ability to learn, reason, problem solve and other skills; and adaptive behavior, which includes everyday social and life skills." It defines developmental disabilities as a "broader category of often lifelong challenges that can be intellectual, physical or both." Advocates' concerns stem from the potential negative impact of guardianship on mental health outcomes (Winick, 1995; Wright, 2010), rates of community-based employment and independent living (Bradley et al., 2019), and self-determination (Kanter, 2015; Raley et al., 2020). The latter has been shown to have a positive relationship with student postsecondary outcomes (Powers et al., 2012; Shogren et al., 2015; Wehmeyer & Schwartz, 1997, 1998).

Though states' guardianship laws vary, generally a court will grant guardianship if an adult is proven unable to make independent decisions about personal or financial matters

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due to IDD or another condition affecting the adult's cognitive functioning. Guardianship orders give parents, caregivers, or other persons the legal authority to exercise either some or many important rights on behalf of adults with IDD. These may include the rights to vote, marry, contract, manage finances, direct services, and consent to health care (National Council on Disability [NCD], 2018). Although in practice guardians may wield their authority benignly, guardianships can create significant legal barriers for adults with IDD who wish to make their own life decisions. For example, guardianships have prevented some adults with IDD from using cell phones, choosing where to live, seeing friends and family, and spending their own money ("Toxic Conservatorships: The Need for Reform," 2021). Consequently, policymakers and civil society organizations are increasingly encouraging parents and caregivers to consider alternatives to guardianship that allow adults with IDD to retain their rights and exercise greater control over their lives (NCD, 2019).

Although guardianship may have profound impacts on the lives of adults with IDD, reliable, nationwide data on guardianship appointments for young adults with IDD is limited (Wood, 2006). Several studies and analyses have attempted to estimate their number and proportion and suggest that significant numbers of young adults with IDD reaching their states' age of majority have guardians appointed to them at that time (Millar, 2003; Millar & Renzaglia, 2002; NCD, 2019; Texas Office of Court Administration, 2004). At the same time, other data indicate wide state-to-state variation in guardianship rates among adults with IDD (Bradley et al., 2019).

Preparing students for postsecondary education, employment, and independent living is a key goal of the IDEA that may be affected by the way in which school personnel discuss the transfer of rights with students and parents. These discussions could encourage students and parents to choose guardianship or an alternative. They may also affect students' self-image or parental expectations for students in ways that influence student postsecondary education outcomes (National Alliance for Secondary Education and Transition, 2005). This scoping literature review was the first step of an endeavor, funded by the U.S. Department of Education, to design a testable intervention in schools' transfer of rights practices that supports positive postsecondary outcomes for students. As such, it is designed to identify existing knowledge about school transfer of rights practices and their effects on students' postsecondary outcomes as reflected in both peer-reviewed and non-peer-reviewed literature.

Method

We selected scoping literature review methodology to map a wide range of literature on a broad set of questions

(Arksey & O'Malley, 2005) relevant to an area with emerging evidence (Levac et al., 2010). Daudt et al. (2013), Sarrami-Foroushani et al. (2015), and Tricco et al. (2016) recommend this approach to identify key research areas relevant to policy change. We were seeking to address a set of related research questions about an area in which evidence is just emerging. The scarcity of evidence of school transfer of rights practices, and our goal of informing the development of an intervention to guide these practices, required that we include non-peer-reviewed literature and not limit the scope of our search by media type. We wanted to include literature authored by and available to stakeholders in our subject area, including school administrators, teachers, policymakers, parents, students, and advocates for people with IDD.

We followed the six stages of a scoping review described by Arksey and O'Malley (2005), Daudt et al. (2013) and Levac et al. (2010). They were (1) identifying the research questions; (2) identifying relevant literature; (3) selecting literature; (4) charting; (5) collating, summarizing, and reporting results; and (6) expert consultation.

Stage 1: Identifying Research Questions

We identified four research questions to guide the review:

Research Question 1 (RQ1): How does empirical research address school practices concerning transfer of rights, guardianship, and alternatives?

Research Question 2 (RQ2): How common is it for special educators to discuss the need for guardianship or alternative decision-making supports with parents and students with IDD? How often are these discussions conducted as part of the transfer of rights notification?

Research Question 3 (RQ3): What is known about variation in relevant state-level policy and practice? What is known about within-state district-level diversity in implementation of state policy?

Research Question 4 (RQ4): How does the literature consider the relationship between school transfer of rights practices and student postsecondary education, employment, and independent living?

Stage 2: Identifying Relevant Literature

For inclusion in the initial sample, literature had to address transfer of rights, guardianship or alternatives for transition-age students receiving special education, and/or state or district-level policies and practices for these processes in educational settings in the United States. The 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. Insufficient resources led us to exclude two types of

literature from the review: state and district-level guidance for school staff and state-focused guidance for parents written by non-profit organizations. We lacked the resources to collect and analyze this abundant literature across all U.S. jurisdictions.

Databases and search engines included Academic One File, Academic Search Complete and Premier, ERIC, HeinOnline, JSTOR, LexisNexis, Medline, ProQuest Central, PsychINFO, Science.gov, SocIndex, WorldCat, and customized searches on Google and Google Scholar. Our search terms always included “transfer of rights” or “guardianship,” or “alternatives to guardianship.” We paired these terms with words that would limit results of the search to transitioning students with IDD and school practices. These refining terms included “students with disabilities,” “youth,” “special education,” “intellectual disability,” “transition,” and “schools.” We systematically mined the reference lists of literature adhering to the search criteria for additional resources. We excluded sources that did not include any discussion of schools.

We limited our search to resources published between 1997 and the time at which we conducted the search. The year 1997 is when the IDEA first expressly allowed states to decide whether to permit parental rights to transfer to adult students. We ended the search for literature on July 31, 2020. The Stage 2 literature search yielded 113 sources to advance to Stage 3.

Stage 3: Literature Selection

We selected literature into the study if it substantially addressed at least one of the study’s research questions. At least two researchers evaluated each piece of literature found in the search against this criterion. If they both agreed that the literature addressed at least one research question, they presented their recommendation for inclusion to the full group of five researchers, which then rendered decisions, through consensus, on whether to select literature into the study.

Stage 4: Charting

The charting process consisted of recording key information about each resource selected into the study (Arksey & O’Malley, 2005). The charting rubric included year of publication, research question(s) addressed, literature type, primary empirical data (y/n), and academic/practice field.

Stage 5: Collating, Summarizing, and Reporting Results

We engaged in qualitative thematic analysis of the literature in addition to charting. To do so, we uploaded the literature into ATLAS.ti v.9 (2020), a program for qualitative data analysis. This software allowed researchers to work together

to explore the literature and identify patterns and themes across the documents pertinent to each of the research questions (O’Neill et al., 2018). Five researchers agreed on a common set of a priori codes derived from the research questions and used them to code each resource. These a priori codes included “empirical research,” “school transfer of rights practice,” “school discussion of guardianship or alternatives,” “variation in state-level policy,” “district-level variation,” and “impact of transfer of rights notification on students/parents/student postsecondary outcomes.” At least two researchers coded each resource. Researchers used code reports generated by ATLAS.ti to engage in thematic analysis to describe the literature addressing each research question. During this process, researchers suggested, discussed, and reached consensus on additional inductively developed codes.

Stage 6: Expert Consultation

Researchers consulted with the project advisory board in a virtual meeting during the literature search. The advisory board consisted of a transition coordinator, researchers and administrators specializing in transition of students with IDD and alternatives to guardianship, a secondary student with IDD, parents of individuals with IDD, and an attorney specializing in working with individuals with IDD. Researchers described methods to members of the advisory board and asked for their suggestions. Specifically, researchers asked advisory board members if they could recommend additional databases and search terms. The board contributed additional search terms, but these suggestions did not yield additional sources that met selection criteria.

Results

Our selection process yielded 29 sources that were substantially responsive to at least one of our four research questions.

Empirical Research About School Practices

Although we cast a wide net, our search identified only six sources that were publications of original, empirically derived information about school practices concerning the transfer of IDEA rights, guardianship, and alternatives to guardianship (see Table 1). Only two of these publications present studies that directly investigate how schools notify parents and students about transfer of rights (MacLeod, 2017; Payne-Christiansen & Sitlington, 2008). Three provide data on schools as a source of information to families on guardianship and alternatives (Brill, 2017; Jameson et al., 2015; Pell, 2019), and two examine school staff’s knowledge of guardianship and alternatives (Millar, 2007; Payne-Christiansen & Sitlington, 2008).

Table 1. Sources Reporting Original Empirical Investigation of School Practice.

Author (date) [type]	Topical focus	Method: Sample	Findings on school practice
Brill (2017) [Organization journal]	Family perceptions of guardianship and alternatives	Survey: Staff of Parent to Parent USA and Family Voices organizations. <i>N</i> is unknown.	Majority hear that families are sometimes instructed by school personnel or health care providers to seek guardianship to secure eligibility for services
Jameson et al. (2015) [Peer-reviewed journal]	Prevalence of guardianship; information on guardianship and alternatives provided to families	Survey: Respondents (adults with IDD or their family) recruited through organizations advocating on behalf of people with IDD. <i>N</i> = 1,225	175 of 726 respondents indicate guardianship was first suggested to them by school personnel. Few respondents received training or education on guardianship or alternatives through school. Schools and other service providers rarely discussed alternatives to guardianship with respondents.
MacLeod (2017) [Peer-reviewed journal]	Beliefs underlying use of SDM; practices to support student self-determination and use of alternatives to guardianship	Participatory single case study with interviews: Young man with ID who utilizes SDM and transitioned to adult life without a guardian, his parents, educator from a public high school in Michigan, and friend.	Underlying beliefs include importance of engaging students with their communities and the value of decision-making supports. Practices include inclusive K-12 education, collaborative school transition practices, and SDM.
Millar (2007) [Peer-reviewed journal]	Extent to which young adults with IDD, parents, and special educators understand guardianship and alternatives and how they relate to self-determination	Focus groups: Six focus groups in a Midwestern regional school district with positive reputation for transition services, including 13 students with “moderate cognitive impairment” (6 under guardianship, 7 not), students’ parents, and 17 special educators.	Students, parents, and staff have only limited understanding of guardianship and alternatives and cannot see how they relate to self-determination.
Payne-Christiansen & Sitlington (2008) [Peer-reviewed journal]	Beliefs of those involved in determining need for guardianship; relationships among transition planning, self-determination, TOR notification, age of majority, and guardianship	Single case study consisting of interviews, record review, field observations: One young adult student with IDD who attends a segregated public school in Iowa for students ages 2–22 with significant disabilities, his family, and the staff and attorney that work with him and his family.	Preemptive belief in need to protect all people with disabilities with guardianship is in conflict with individualized transition planning. School staff use TOR notification to warn parents and the age of majority as a deadline.
Pell (2019) [Report]	Role of schools in advising on guardianship and alternatives	First-year process evaluation of a 5-year pilot project: Family members of 20 adults with IDD, and key staff and facilitators administering SDM pilot program in New York state.	Schools are among the most persuasive advisors on guardianship. Schools are effective in connecting students to SDM when there is long-term collaboration with SDM providers and understanding of potential benefits. Of families of 15 adults with IDD, 6 were recommended by school staff to seek guardianship.

Note. IDD = intellectual and developmental disabilities; SDM = supported decision-making; TOR = transfer of rights.

How Schools Notify Parents and Students of Transfer of Rights. Each of the two studies that collect empirical data on school administration of the transfer of rights notification investigates a single school and focuses on a specific student. Payne-Christiansen and Sitlington (2008) present a single case study of a young man with IDD in Iowa for whom a guardian had recently been appointed. He attended a public school for students between the ages of 2 and 22

years that only admits students with “more significant developmental disabilities” (p. 12). The study found that the school implemented the required transfer of rights notification as a “warning to parents” and treated the age of majority as a “deadline for obtaining guardianship” (p. 16). Researchers found that school staff “highlighted only the negatives” of a transfer of parental rights to students, leaving parents with a sense of “alarm and dread” (p. 16). In

addition, researchers noted that although the school's transition planning for students was individualized, school staff "preemptively" recommended guardianship to parents as the path for every student in the school (p. 17). The authors found that underlying this practice was a belief on the part of school staff that its students required the protection of guardianship in adulthood.

MacLeod (2017) presents a single case study of a young man with IDD who transitioned from a public high school in Michigan, did not have a guardian appointed, and was using supported decision-making. In this case, his teacher presented that:

guardianship was only briefly discussed during the annual review of his Individualized Education Program (IEP) during his senior year and only so that she could check a box on the IEP documenting that [. . .] she had informed Brian and his parents of the rights that would transfer to him at age 18 (p. 200).

The young man's parents said of their interactions with school staff, "guardianship just didn't come up" (p. 200). His IEP team did, however, "discuss at his IEP meeting [. . .] the many supports for decision-making and daily living [. . .] he needed," and included these types of supports in his IEP goals related to his plan to attend college (p. 200). MacLeod reports that underlying this approach is the teacher's belief that "students with complex needs [. . .] should be a part of their community," and her student would "need supports in order to be successful and interdependent" (p. 202).

Schools as a Source of Information to Families on Guardianship and Alternatives. Three publications (Brill, 2017; Jameson et al., 2015; Pell, 2019) present empirical evidence regarding schools as a source of information to families on guardianship and alternatives. Jameson et al. (2015) report on a survey of adults with IDD, or their families, from unidentified states, recruited through organizations advocating on behalf of people with IDD. Up to 175 of 726 (24.1%) respondents had guardianship first "suggested" to them by staff of the student's school (p. 42). Of 302 respondents who indicated they had received training or education related to guardianship, three said they had received the training or education from school personnel. Respondents indicated that the school personnel who provided information about guardianship most frequently discussed full guardianship and rarely discussed other options.

Brill (2017) administered a survey to staff of national Parent to Parent USA and Family Voices organizations and found that 65% of an unspecified number of respondents indicated that "families are sometimes instructed by school personnel or health care providers to seek guardianship in order to assure their children will be eligible for school and adult services" (pp. 34–35). Pell (2019) evaluated a

supported decision-making pilot project in New York State. The evaluation found that school staff, other parents of children with disabilities, and health care providers were the most persuasive recommenders of guardianship to the parents of 20 people with IDD. The evaluation also found that the most effective recruitment of people with IDD to supported decision-making occurred when program staff developed relationships with school administrators, teachers, and transition coordinators over time and engaged them in ongoing conversations about supported decision-making and its benefits.

School Staff Knowledge of Guardianship and Alternatives. Two empirical studies investigated school staff's knowledge of guardianship and alternatives. Selecting a U.S. Midwest regional school district with a reputation at the state and local levels for providing high-quality transition services, Millar (2007) used focus groups with 17 district staff considered by their district to be knowledgeable about transition services. She found their knowledge and understanding of guardianship and alternatives to be limited. Payne-Christiansen and Sitlington's (2008) case study of the student at an Iowa school for students with "more significant developmental disabilities" found that this student's teacher, social worker, and psychologist lacked knowledge of alternatives to guardianship.

Non-Empirical Characterizations of School Practice

Ten of the 29 sources we identified did not primarily present original empirical research or data analysis but did substantially characterize school practices concerning transfer of rights, guardianship, or alternatives to guardianship. These included two peer-reviewed journal articles (Raley et al., 2020; Rood et al., 2015); three law journal articles (Kanter, 2015; Lanier, 2019; Theodorou, 2018); two government reports (NCD, 2018, 2019); a website for self-advocates, parents, and advocates (CPR, n.d.); the transcript from an on-demand training posted on the Independent Living Research Utilization website (Fuchs, 2018); and a policy, research, and practice brief (Leuchovius & Ziemke, 2019). (Although the NCD [2018, 2019] reports include empirical data, their collection of data was not focused on school practice).

Several themes emerge from these sources. Seven sources note that special education staff commonly encourage parents to seek guardianship as their children approach the age of majority in school (CPR, n.d.; Kanter, 2015; Lanier, 2019; NCD, 2018, 2019; Rood et al., 2015; Theodorou, 2018). Six sources state that the transfer of rights notification prompts school staff to discuss guardianship with students' parents (Kanter, 2015; Leuchovius

& Ziemke, 2019; NCD, 2018, 2019; Raley et al., 2020; Theodorou, 2018). Three sources indicate that school staff, although discussing guardianship of students with parents, do not discuss alternatives to guardianship (Fuchs, 2018; Leuchovius & Ziemke, 2019; Rood et al., 2015). Three sources say that parents seek guardianship because it is recommended to them by school staff (Kanter, 2015; Raley et al., 2020; Rood et al., 2015). Additionally, four sources use the phrase “school-to-guardianship pipeline” to describe school practice (CPR, n.d.; NCD, 2018, 2019; Raley et al., 2020). NCD (2018) is the first source to include the phrase, and it describes the pipeline as a process in which school staff warn parents of the transfer of IDEA rights and suggest they seek guardianship as their child reaches the age of majority in order to continue to participate in their child’s education and to protect their child (p. 92).

Many of the assertions these sources make about school practices strongly suggest generalization to the broader population of U.S. schools. However, these sources do not adequately support these themes with empirical evidence. Their characterizations are often qualified by imprecise or vague words such as “often,” “many,” or “frequently.” Some characterizations are not supported by citation, some are supported by citation to non-empirical sources, and some are supported by citation to empirical sources in ways that mischaracterize or omit context important to understanding their findings.

Schools Commonly Recommend Guardianship and Do Not Discuss Alternatives. Of the seven sources that portray school staff as commonly encouraging parents to seek guardianship of their children, CPR (n.d.) cites its practice-based experience of running supported decision-making pilots, providing training and technical assistance, and consulting with educators. However, Kanter (2015, p. 3) provides no citation in support of its statement that “many schools encourage parents to become legal guardians,” and Theodorou (2018, p. 28) cites non-empirical sources for a similar proposition: “transition counselors at schools often . . . tell parents they must obtain guardianship . . . to stay involved in their child’s education planning.” Similarly, the three sources stating that school staff generally do not present alternatives when they discuss guardianship with parents do not provide citations to support this generalization (Fuchs, 2018; Leuchovius & Ziemke, 2019; Rood et al., 2015).

Four sources provide empirical citations that do not adequately support the statement made or omit important context (Lanier, 2019; NCD, 2018, 2019; Rood et al., 2015). These sources generally interpret Jameson et al. (2015) or Millar (2003) to say either most schools recommend guardianship to parents or that schools are the most common recommender of guardianship to parents. However, Jameson

et al. actually show that a minority (24%) of respondents had guardianship first suggested to them by school staff. Moreover, the unit of analysis in the Jameson et al. study is individuals, and the survey results do not generalize to schools or school staff. Furthermore, none of these sources mentions that the proportion of the Jameson et al. survey respondents who had guardianship first suggested to them by school staff was closely followed by the proportions of respondents who said they had guardianship first suggested to them by adult or social service personnel (21–23%) or by a family friend or family member (22%). Sources citing Millar (2003) to support this generalization about school practice similarly overlook that the Millar (2003) study does not examine school practice.

Transfer of Rights Notification Prompts School Staff to Recommend Guardianship. Of the six sources that identify the transfer of rights notification as the event that leads school staff to recommend guardianship, two (Kanter, 2015; Leuchovius & Ziemke, 2019) do not provide supporting citation, while Theodorou (2018, pp. 1008–1009) and NCD (2019, p. 29) cite only non-empirical sources. The two others cite empirical sources that do not provide clear evidence for generalization. NCD (2018, p. 92) refers to Payne-Christiansen and Sitlington (2008), which provides evidence of this phenomenon in only one school. Raley et al. (2020, p. 2) cite Jameson et al. (2015), Payne-Christiansen and Sitlington (2008), Millar and Renzaglia (2002), and Millar (2007). However, the Jameson et al. survey does not ask respondents about transfer of rights notifications, Millar and Renzaglia (2002) do not examine school practice, and Millar (2007) does not contain an empirical finding on the transfer of rights notification.

Parents Seek Guardianship Because School Staff Recommend It. Raley et al. (2020, p. 2) cite Millar and Renzaglia (2002), Jameson et al. (2015), and Payne-Christiansen and Sitlington (2008) to support the hypothesis that “parents seek guardianship over their children because school professionals advise them to do so or inform them that they will lose the right to make education decisions for their children unless they obtain guardianship.” Although the Payne-Christiansen and Sitlington study does find that the two parents in its study sought guardianship of their son as a result of staff’s recommendations from their son’s school, this finding pertains to a single family; neither of the other cited studies explores why parents who sought guardianship of their children did so (Jameson et al., 2015; Millar & Renzaglia, 2002). Kanter (2015) and Rood et al. (2015) cite Millar (2007) in support of statements that parents seek guardianship because school professionals advise them to. However, Millar (2007) does not include this finding.

Variation in Policy and Practice

Although the IDEA provides options to states regarding the transfer of rights to students when they reach their state's age of majority, the literature on school practices pays scant attention to variation in state rules or policy or whether or how administration of state rules and policy may vary across school districts, schools, or practitioners. Our review identified 20 sources that acknowledge, to at least some degree, variations among states or school districts in how transfer of rights discussions may occur. The majority of these (13 sources) refer only to differences in formal rules and policies (Cannon, 2011; Center for Parent Information & Resources, 2015; Clark & Lillie, 2000; Fuchs, 2018; Giuliani, 2012; Kanter, 2015; Martinis & Blanck, 2019; National Center on Secondary Education and Transition & PACER Center, 2002; National Dissemination Center for Children with Disabilities, 2009; PACER Center, 2015; Payne-Christiansen & Sitlington, 2008; Rebore & Zirkel, 2000; Saltzman & Hughes, 2005). Four note only differences in school practices (Glen, 2019; Leuchovius & Ziemke, 2019; Millar, 2007, 2009), and three refer to both policy and practice (Lindsey et al., 2001; NCD, 2019; Rood et al., 2015). All but two sources focus only on differences between states, rather than differences among school districts (Glen, 2019) or differences among both states and districts (Millar, 2009). Where differences among various states or districts are recognized, analysis is limited; descriptions generally lack breadth and depth and emphasize similarities while downplaying differences.

Also, several sources inaccurately describe the federal transfer of rights law. For example, Millar (2007, p. 119), Kanter (2015, p. 4), and NCD (2019, p. 29) indicate that the IDEA *requires* rights to transfer. In fact, the IDEA permits states to choose whether to transfer rights (20 U.S.C. § 1415(m)[1]).

Relationship Between School Transfer of Rights Practices and Students' Postsecondary Outcomes

The literature often assumes that the transfer of rights notification causes parents to seek guardianship and focuses on the effects of *guardianship*, not the transfer of rights notification, on student self-determination and transition outcomes. However, the causal relationship between the notification and parent decisions to seek guardianship is not empirically supported. None of the literature we reviewed describes other impacts of school transfer of rights practices on parents, and none discusses their impact on students.

Discussion

We found there is very little published empirical research on school practices concerning transfer of rights. There is a

body of non-empirical literature that asserts that it is common for school staff to discuss the need for guardianship of young adults with IDD with parents, in the context of transfer of rights notifications, or when the student approaches the age of majority. However, this assertion is not supported by the empirical literature that exists. In addition, there is little attention in the literature to policy and practice variation at state, district, or school levels. Finally, there is little attention in the literature to how school transfer of rights practices affect student postsecondary outcomes.

Exploration of the literature reveals how little empirical evidence is available on how transfer of rights policies play out in practice for students with IDD and their parents. Only two case studies (MacLeod, 2017; Payne-Christiansen & Sitlington, 2008) examine how school staff deliver transfer of rights notifications. Payne-Christiansen and Sitlington (2008, p. 12) explores the transfer of rights practice in only one public school in Iowa serving only students, ages 2 to 22, with "more significant developmental disabilities." MacLeod (2017) shows how parents and school staff worked together to maximize self-determination and develop supported decision-making practices for one student in a public high school in Michigan. Two studies, Millar (2007), of one U.S. Midwestern school district in an unidentified state, and Payne-Christiansen and Sitlington (2008), of one school in Iowa serving only students with "more significant developmental disabilities," examine knowledge of guardianship and alternatives among students with IDD, their parents, and school staff. Two empirical studies, Jameson et al. (2015) and Brill (2017), survey people with disabilities, their families, or people who work with parents, about information school personnel and others provide to parents and students about guardianship or alternatives. Although the Jameson et al. (2015) survey is national in scope, because it draws on the participation of people affiliated with a network of advocacy agencies, it is not designed to generalize to all people with IDD. Brill (2017) surveys nationwide staff of Parent to Parent USA and Family Voices but does not distinguish between what parents are told by school staff and what they are told by health care providers.

This review reveals that there is a disconnect between this limited empirical evidence and generalizations about school practice made in recent literature that is not empirically based. Many of the characterizations of school practice found in this literature are not supported by the empirical studies and analyses that precede them. These empirically unsupported characterizations include representations that school staff commonly advise parents to seek guardianship of their children as they approach the age of majority (e.g. Rood et al., 2015, p. 320); transfer of rights notification is the event that prompts school staff to discuss guardianship with parents (e.g. NCD, 2018, p. 92); schools are the most frequent source of guardianship referral (e.g. NCD, 2019,

p. 31); and parents seek guardianship because they are advised by school staff to do so (e.g. Kanter, 2015, p. 15).

Both the empirical and the non-empirical literature shed little light on whether school transfer of rights practices differ significantly in different places. In the few cases where variation among states is noted, there is most often a focus on state-level rules (e.g. Rebores & Zirkel, 2000, pp. 40–45). Variation in practices across states is less explored, and district-level variations in practice are virtually unexplored. In addition, there is a lack of clarity concerning federal transfer of rights policy and how it allows states' policies to vary (e.g. Millar, 2007, p. 119).

The literature does not describe ways in which transfer of rights discussions directly affect students and parents in ways that contribute to shaping students' postsecondary outcomes. Although several authors say the notification causes parents to seek guardianship (e.g. Raley et al., 2020), this is not substantiated in the published empirical literature. The findings from this review show there is ample room for researchers to explore the hypothesis that school transfer of rights conversations affect postsecondary outcomes for students. It is important to understand how schools can approach transfer of rights in ways that support preparation of students with IDD for postsecondary education, employment, and independent living.

Implications for Research, Policy, and Practice

Our review demonstrates a lack of clarity about this area of special education policy and practice that is potentially of great consequence to students' transition processes and outcomes—indeed, to the quality of their lives. The literature reflects a misunderstanding of federal transfer of rights statutory and regulatory provisions and often fails to acknowledge differences in state policies. There is insufficient empirical data on how these public policies are administered in schools. Is there significant variation at the district level, within districts, at the school level, or within schools, at the practitioner level? What shapes the practice of individual school staff who directly interact with students and their parents on these issues, and how do their practices affect students and parents? We lack adequate empirically based understanding of why parents choose guardianship or what alternatives they chose and why. We do not have sufficient empirical evidence of the impact of school transfer of rights practices on student transition outcomes.

The gaps in knowledge revealed in this review suggest the next steps for evolving school practice regarding transfer of rights to support positive transition outcomes for students. It is important to build accurate understanding of current federal policy on the transfer of rights, including the options available to states and how state policies vary. The

field can engage in empirical work to understand how these policies are implemented in schools, the influences that shape implementation at the level of direct service delivery, and how that delivery impacts the lives of parents and students in ways that contribute to shaping students' postsecondary outcomes. This knowledge can be used to develop interventions to support school staff, students, and parents in achieving the IDEA's goals of transitioning students to postsecondary education, employment, and independent living.

Limitations of the Study

The small sample of empirical literature published on our topic since 1997 did not allow us to conduct a systematic review or generalize from the literature to actual school practice. Also, project resource limitations led us to exclude two types of literature that otherwise met our Stage 2 search criteria: state- or district-level specific guidance documents for school staff and state-focused guidance documents for parents written by state and local governments or non-profit organizations. We did not have the resources to comprehensively review this literature across all U.S. jurisdictions.

Conclusion

The view expressed in the recent non-empirical literature—that schools' transfer of rights practices induce parents who would not otherwise do so to obtain guardianship—has outpaced understanding of the complex dynamics that inform the ways in which school staff work with students and parents and how that affects them. This review shows that the available empirical research does not support the emerging “school-to-guardianship pipeline” narrative. Generally, there is limited understanding of federal and state policies on the transfer of IDEA rights from parents to students, how those policies are administered, and how their administration affects students and parents. The field must address these knowledge gaps to undergird the design and evaluation of an intervention to strengthen schools' administration of transfer of IDEA rights in ways that support positive transition outcomes for students.

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