

FEATURE ARTICLES

Turning Off the School-to-Guardianship Pipeline

Incorporating Supported Decision-Making Into Special Education

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Abstract: Despite studies showing that students who have more self-determination—those who make more decisions and have more control over their lives—have more successful educational experiences and adult lives, research and scholarship document the existence of a “School-to-Guardianship Pipeline.” There, educational professionals recommend that parents seek guardianship over their children with disabilities, without explaining or exploring other options that may preserve or build their self-determination. This article documents the importance of self-determination to life and educational outcomes for people with disabilities, and summarizes research showing how overbroad and undue guardianship—guardianships that remove more rights than necessary or that remove rights from someone who is able to exercise them independently or with support—can decrease quality of life. Then, the authors show how Supported Decision-Making can serve as an alternative to guardianship and a way to enhance self-determination, and recommend ways to incorporate supported

“[I]F STUDENTS WITH DISABILITIES ARE SUPPORTED TO HAVE MORE OPPORTUNITIES TO MAKE MORE SELF-DETERMINED DECISIONS ABOUT THEIR OWN EDUCATION AND LIVES, THEY CAN GAIN THE SKILLS THEY NEED TO AVOID OVERBROAD AND UNDUE GUARDIANSHIP - GUARDIANSHIPS THAT REMOVE MORE RIGHTS THAN NECESSARY OR REMOVE RIGHTS FROM SOMEONE WHO IS ABLE TO EXERCISE THEM INDEPENDENT OR WITH SUPPORT - AND MAXIMIZE THEIR QUALITY OF LIFE”

decision-making into special education supports and services.

Keywords: special education, self-determination, guardianship, supported decision-making, independent living

Introduction

As high school students approach graduation, their soon-to-be adult lives, with all the potential and problems faced by teenagers since time immemorial, lie tantalizingly and terrifyingly before them. For students without disabilities, this is a time to make plans for college and careers, and to think about internships and independence. But for many students with disabilities and their families, this can be a frustrating time of trying to secure supports, find funding, and wondering whether they can, or ever will, live independently (Martinis et al., 2019).

When students receiving special education services reach the age of majority, educational professionals often urge their parents to seek guardianship over them, without explaining or exploring other alternatives (Jameson et al., 2015). Because of this “School to

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Guardianship Pipeline” (Martinis, 2023; National Council on Disability, 2019), young adults with disabilities all too often lose the legal right to make basic life decisions—who to date or marry, whether to work, and what kind of services, supports, and medical care to receive—although less-restrictive alternatives, such as *Supported Decision-Making* (SDM), may empower them to make those choices and live as independently as possible (Martinis, 2014).

In this article, we argue that guardianship (called “conservatorship” in some states), when it is unnecessary, can be harmful and prevent people with disabilities from becoming fully included and contributing members of society. However, if students with disabilities are supported to have more opportunities to make more self-determined decisions about their own education and lives, they can gain the skills they need to avoid *overbroad and undue guardianship*—guardianships that remove more rights than necessary or that remove rights from someone who is able to exercise them independently or with support (Hatch et al., 2015)—and maximize their quality of life. The section, “The Importance of Self-Determination,” will summarize the importance of self-determination to students and adults with disabilities, including how self-determination is correlated with enhanced quality of life. The section, “The Dangers of Overbroad and Undue Guardianship,” will document the potential harms of overbroad or undue guardianship. The section, “Supported Decision-Making as an Alternative to Guardianship and a Way to Enhance Self-Determination and Quality of Life” will discuss SDM and how it may serve as an effective, less-restrictive alternative to guardianship and a way to enhance self-determination and quality of life. Finally, the section, “Incorporating Supported Decision-Making Into Special Education Supports and Services” will offer recommendations for ways parents, advocates, and educational professionals may incorporate SDM into special education supports and services.

The Importance of Self-Determination

Self-determination involves “acting as the causal agent in one’s life” (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015, p. 258). People exercise self-determination when making major and minor decisions that affect and empower them to direct their everyday lives (e.g., Blanck & Martinis, 2015; Shogren & Raley, 2022). Research and scholarship have repeatedly documented that people with disabilities who exercise greater self-determination have better life outcomes: they are more likely to be independent, employed, active members of their communities, and safer (e.g., Hickson et al., 2015; Khemka, 2000; Khemka et al., 2005; McDougall et al., 2010; Powers et al., 2012; Wehmeyer & Schwartz, 1997).

Self-determination is also critically important for students with disabilities. Studies show that those who receive supports and services designed to enhance their self-determination are better at communicating their needs, advocating for themselves, evaluating and adjusting their performance, and solving problems (Shogren, Hicks, et al., 2020). Students with more opportunities to make self-determined decisions are also more

likely to live in their communities, be employed, and report higher goal attainment (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015; Shogren et al., 2021). Because of this, experts have identified self-determination as the ultimate goal of special education programs and recommended that schools provide supports and services that build self-determination and decision-making skills (Shogren & Raley, 2023).

The Dangers of Overbroad and Undue Guardianship

Guardianship is a legal process where a court appoints one person to make some or all decisions for another. Thus, guardianship, by definition, limits or removes the self-determination of the person whose decision-making rights are removed. Although there are times when guardianship is appropriate (e.g., Blanck & Martinis, 2015), when people are ordered into overbroad or undue guardianship, the resulting loss of self-determination can have negative impacts on their quality of life (Martinis & Blanck, 2019). Decades of studies find that people with disabilities denied opportunities to make self-determined decisions both feel and function worse (e.g., Deci, 1975; Jones & Berglass, 1978; Shogren & Raley, 2022). Consequently, ordering people with disabilities into guardianship and removing their legal right to make decisions may actually worsen “the negative behaviors and symptoms that led to the . . . proceeding in the first place” (Blanck & Martinis, 2015, p. 26).

Accordingly, research and scholarship find that overbroad and undue guardianship may cause a “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010, p. 354). People ordered into such guardianship can suffer “marginalization and isolation from mainstream society” (Salzman, 2011, p. 293). For example, when people lose the right to make medical decisions, they “may get little information about [their] condition or treatment options” (Salzman, 2011, p. 293). Similarly, people denied the legal right to make financial decisions may “become[] gradually disengaged from the management of those finances as well as the interactions with others involved in that management—banking, shopping, financial planning . . . even giving gifts to loved ones” (Salzman, 2011, p. 291). In addition, removing a person’s right to make relationship choices can “isolate the individual by explicitly depriving [the person] the right to make certain social decisions regarding how or with whom he will spend time” (National Council on Disability, 2019; Salzman, 2011, p. 291). More opportunities to make decisions, aligned with self-determination, has also been found to increase positive outcomes (Shogren, Hicks, et al., 2020).

SDM as an Alternative to Guardianship and a Way to Enhance Self-Determination and Quality of Life

SDM is a judicially and legislatively recognized decision-making methodology that empowers people with disabilities to

make their own decisions with the support of people they choose, instead of having their legal right to make decisions removed through guardianship (Blanck & Martinis, 2015; Shogren, Wehmeyer, et al., 2019). While there is no “one-size-fits-all” model of SDM, it generally occurs when people choose and work with friends, family members, and/or professionals who help them understand the situations and choices they face, so they may make their own decisions (Dinerstein, 2012; Quality Trust for Individuals with Disabilities, 2014). People with and without disabilities use SDM to make simple and complex life choices (Peterson et al., 2022).

Because everyone makes decisions differently and needs different types of support at different times for different decisions, SDM is and should be an individualized process tailored to the person’s unique abilities, needs, and preferences (Shogren, Wehmeyer, et al., 2019; Shogren & Wehmeyer, 2015). Thus, SDM relationships may range from “purely informal supports we all enjoy as citizens when making decisions in our daily lives” (Carney, 2014, p. 46) to support from people who “speak with, rather than for, the individual with a disability” (Dinerstein, 2012, p. 10) to more formalized “micro-board[s]” and “circles of support” (Kohn et al., 2012, p. 1123). Through these and other SDM processes and relationships, people with disabilities can receive support, such as information about their situations, the choices available to them, and the potential benefits and harms of each possible choice (e.g., National Council on Disability, 2019; Salzman, 2011).

Research and scholarship document that people with disabilities can use (and have used) SDM to make everyday life decisions (Browning et al., 2021; Harding & Taşcioğlu, 2018), engage in social and romantic relationships (Boni-Saenz, 2015), and take part in and consent to health care (Browning et al., 2014; Enck, 2021; Kokanović et al., 2018; Sapolsky, 2017), legal representation (Gooding, et al., 2023), and medical and mental health assessments (Jayes, Austin, & Brown, 2022; Jayes, Palmer, & Enderby, 2022). Thus, empowering people to use SDM—including people with extremely limited cognitive capacity (Peterson et al., 2022)—is “compatible with, and may even promote, their overall well-being. By the same token, overriding someone’s decision(s) out of concern for their best interests can sometimes, ironically, reduce their overall well-being, in part by undermining whatever autonomy they have” (Veit et al., 2021, p. 22).

SDM is increasingly being recognized and adopted by courts, state legislatures, policymakers, and professionals across the United States as an effective and preferred alternative to guardianship (Martinis et al., 2023). For example, in 2013, Margaret “Jenny” Hatch, a woman with intellectual disability, became the first person to defeat, at trial, a petition to remove her legal right to make decisions because she uses SDM. At her trial, Jenny demonstrated that she has friends and supporters who help her understand, make, and communicate life choices that reflect her values, interests, and preferences and, therefore, does not need someone to make decisions for her (*Ross and Ross v. Hatch*, 2013). After her victory, Jenny was the subject of

national and international news, hailing her as a leader in the SDM movement (Vargas, 2013). Since then, Jenny has been living and working where and how she wants, using the SDM skills that she developed and practiced throughout her life (Vargas, 2019).

In the 10 years following Ms. Hatch’s victory, more than 20 states and the District of Columbia amended their guardianship laws to formally recognize SDM as an alternative to guardianship and courts across the country have either terminated guardianships or refused to order people into guardianship because they use SDM (Martinis et al., 2023). In addition, the U.S. Department of Health and Human Services (Blanck & Martinis, 2015), National Council on Disability (2019) and prominent private organizations, including the National Guardianship Association (2017), the Arc of the United States (2021), and the American Bar Association (2023) have advocated for increasing the use of SDM as an alternative to guardianship.

Research shows that using SDM as an alternative to overbroad and undue guardianship can improve people with disabilities’ quality of life. SDM is associated with self-determination because it empowers people to make their own decisions instead of having a guardian appointed to make decisions for them (Blanck & Martinis, 2015). Thus, using SDM may help people with disabilities “reap the benefits” of self-determination, including enhanced education, employment, and independent living (Blanck & Martinis, 2015, p. 31). Furthermore, a 2020 pilot study found that people with disabilities who used SDM improved their ability to make decisions, made objectively better decisions, and enhanced their quality of life (Martinis & Beadnell, 2021).

Incorporating SDM Into Special Education Supports and Services

The Individuals with Disabilities Education Act (2004; IDEA) sets forth the aim of special education:

to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living. (20 U.S.C. § 1400(d)(1)(A))

As mentioned, self-determination is linked with increased education, employment, and community living outcomes (e.g., Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015). Accordingly, researchers and experts have long recommended that schools provide special education supports and services designed to increase students’ self-determination and decision-making opportunities and skills (e.g., Shogren & Raley, 2023). Unfortunately, schools have historically failed to provide such supports and services (e.g., Raley et al., 2023). Indeed, studies find that parents are most likely to learn about guardianship and have guardianship recommended to them by educational

professionals (Jameson et al., 2015; National Council on Disability, 2019).

Therefore, to “turn off” the school-to-guardianship pipeline, students, parents, advocates, and educational professionals must collaborate and coordinate efforts to ensure that students with disabilities—particularly those at risk of guardianship—receive special education supports and services designed to enhance their self-determination and decision-making skills as early as possible and throughout their educational careers, including education and services designed to help them learn about and practice SDM. Following are recommendations for how SDM may be incorporated into special education supports and services.

Develop and Implement SDM Policies and Procedures

Families, advocates, and educational professionals should urge schools to develop and implement special education policies and procedures designed to encourage and enable students to learn about and practice self-determination and SDM. For example, the District of Columbia Public Schools (DCPS) teaches students from prekindergarten to build SDM relationships and use SDM to make educational and life decisions (Downing-Hosten, 2015). By doing so, DCPS makes SDM part of students’ everyday school lives. This helps them learn to use SDM from when they are young, when decisions are more simple, empowering them to develop and practice SDM techniques that they can call upon as they age and decisions become complex.

At the same time, DCPS works with families, encouraging them to support their children’s use of SDM and help their children build and use SDM networks (DCPS, Office of Specialized Instruction, n.d.-c; Downing-Hosten, 2015). As a result, families learn about the importance of self-determination and SDM and can help their children understand that there is nothing wrong with asking for and using support to make decisions. In addition, because parents are involved in their children’s SDM process, they may come to understand that their children can and do make their own decisions and be less likely to see guardianship as inevitable, decreasing the use of overbroad and undue guardianship.

Incorporating SDM into the Individualized Education Program Process

Assessing Self-Determination and Support Needs

Every year, as part of the Individualized Education Program (IEP), schools must review students’ “present levels of academic achievement and functional performance” (20 U.S.C. § 1414; 34 C.F.R. 300.304). Based, in part, on that assessment, schools must develop an IEP for students that meets the “needs that result from the child’s disability” (20 U.S.C. § 1414) and prepares them “for further education, employment, and independent living” (20 U.S.C. § 1400(d)(1)(A)). Given the correlation between self-determination and these important life outcomes, schools should, as a part of this process, review students’ self-determination and decision-making skills.

This review may be done using readily available and low-to-no cost tools. For example, “I’m Determined,” a project of the Virginia Department of Education, has developed checklists to help students, parents, and educators assess student self-determination and decision-making (Virginia Department of Education, n.d.). The checklists require the person to review and rate on a scale of 0 to 3 (with 3 being the highest rating) whether the student exercises self-determination, including whether students feel in control of their life; tell people what they want; make good choices; and have people in their lives who provide support to them. The student’s “scores” on the checklist should then be used to shape their supports and services. For example, if a student consistently scores a zero in areas related to decision-making, the IEP team should develop goals, objectives, and services designed to help the student learn about and use SDM.

Similarly, the Self-Determination Inventory (SDI; Shogren & Wehmeyer, 2017) is a validated measure of self-determination that is used by schools across the country to understand student self-determination and inform transition planning. It has been validated with adolescents aged 13 to 22 years (Shogren, Hicks, et al., 2020; Shogren, Little, et al., 2020; Shogren, Rifenbark, et al., 2020) with and without disabilities. The assessment is completed online, incorporating features of universal design and universal design for learning; ratings are made on a slider scale with anchors of *disagree* and *agree*; the computer system converts the ratings to scores ranging from 0 to 99 and generates an overall self-determination score, as well as scores for volitional action (Decide), agentic action (Act), and action-control beliefs (Believe). Validity evidence for the SDI: SR was provided with a sample of 4,500 youth with and without disabilities. Evidence has suggested strong reliability and validity of scores in measuring self-determination, and differentiation of scores based on disability and racial/ethnic groups with minoritized groups scoring lower (Shogren et al., 2018). Users get a report on their self-determination profile and tools to inform opportunities to build self-determination skills (University of Kansas, n.d.).

Developing Self-Determination Goals

After the IEP Team reviews the student’s present level of performance and educational abilities and needs, it creates the student’s IEP. The IEP must contain measurable goals and objectives, including “academic and functional goals” that are designed to help the student make academic progress and “meet each of the child’s other educational needs that result from the child’s disability” as well as educational and other services that will help the student “advance appropriately toward attaining those goals” (20 U.S.C. § 1414).

Accordingly, when students have support needs in self-determination and decision-making that need to be addressed to advance their progress toward “further education, employment, and independent living,” their IEPs should include goals and services designed to help them address, overcome, and build skills and abilities. Research shows that creating and implementing goals designed to enhance

self-determination results in students becoming more self-determined and improving their educational and nonschool skills and performance (Shogren, Burke, et al., 2019).

The IEP process is, by itself, an opportunity for students to develop and practice SDM. In the *Student-Led IEP*, students take on a leadership role and work with IEP team members to develop, implement, and monitor progress toward their goals and objectives. As students age and their self-determination and decision-making skills progress, their role and responsibility on the IEP Team increases: they may begin as young students simply by introducing themselves and progress to discussing their specific abilities and needs, identifying supports that do and do not work for them, suggesting and discussing specific goals and objectives, and, eventually, leading the meeting and working with the team to develop and agree to the final IEP (Virginia Department of Education, n.d.).

In that way, the student-led IEP empowers students with disabilities to practice self-determination and SDM in a safe, controlled setting (Martinis, 2014). Furthermore, research shows that students who led their IEP Teams gained self-confidence and were better able to advocate for themselves, work with adults, and assume more responsibility (Mason et al., 2004). The student-led IEP is also consistent with educational best practices, which call on schools to give students opportunities to develop and practice self-determination and decision-making skills (Wehmeyer & Gragoudas, 2004).

There is also a range of other research-based self-determination interventions (Burke et al., 2020). For example, the McGill Action Planning System (MAPS) stresses that students should play lead roles in developing and implementing their educational plans (Vandercook et al., 1989) and has been found to promote the development of IEPs based on student strengths (Elder et al., 2018). In MAPS, students work with adults and educational professionals to identify goals and develop plans to reach them that will ensure that they have maximum opportunities to be integrated into classrooms and activities with their same-age, nondisabled peers. MAPS planning sessions are recorded graphically, with key stakeholders present and participating. The participants discuss student issues and objectives and collaboratively develop a concrete plan and schedule follow-up meetings to assess progress and modify the plan as needed (Elder et al., 2018). Similarly, the Self-Determined Learning Model of Instruction (SDLMI; Shogren & Raley, 2023), described previously, provides an evidence-based approach in transition planning (National Technical Assistance Center on Transition, 2017) and actively involves students in setting goals for their future across a variety of life domains.

Transition Planning

Under IDEA, students must receive transition supports and services “beginning not later” than the year they turn 16 years of age and continuing until the end of the school year they turn 21 years of age (20 U.S.C. § 1414). Transition services are designed to facilitate the student’s “movement . . . to post school activities”

including “post-secondary education, integrated employment, [and] independent living.” The services must be based on the “individual child’s needs, taking into account the child’s strengths, preferences, and interests” and include “the development of post-school adult living objectives [and] acquisition of daily living skills” (20 U.S.C. §1401[34]).

Unfortunately, educational professionals frequently recommend that families seek guardianship during this period, often without discussing or exploring alternatives such as SDM (Jameson et al., 2015; National Council on Disability, 2019). One study found that a school district serving more than 1,000,000 students used IEP software that provided parents with information about guardianship, but not other alternatives (Millar, 2007). Another study found that schools had a standard practice of recommending guardianship for students with intellectual disabilities (Payne-Christiansen & Sitlington, 2008).

The school-to-guardianship pipeline persists although studies show that students who receive transition services focused on building their self-determination are more likely to live independently, be employed, and make effective choices after they graduate (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015). Therefore, instead of reflexively recommending guardianship, schools should provide students with transition services and supports focused on building their self-determination and decision-making—“adult daily living skills” that are directly correlated with the transition goals of enhancing students’ education, employment, and independent living outcomes (e.g., Martinis, 2014).

There are several steps that parents, advocates, and educational professionals may take to ensure that students receive effective and appropriate transition services. First and foremost, students should be empowered to play a lead role in the transition planning process to ensure that their goals and services truly reflect their “strengths preferences, and interests,” and to empower them to exercise both self-determination and decision-making throughout the process (Martinis, 2014). The IEP Team should then meet regularly, with the student taking the lead, to determine whether the student is achieving their Transition goals and, if not, whether those goals and services should be modified (Waters et al., 2010).

Research supports this approach. For example, the SDLMI (Shogren & Raley, 2023) has students take the lead in setting their own goals and develop plans to meet them, with support from their teachers. They work with their teachers, families, and friends to evaluate progress and revise goals and methods as needed. When they identify barriers preventing them from reaching their goals, they identify and implement solutions, such as amending their goals and supports, and assess the results of their choices. A wide array of research has suggested the power of the SDLMI for enhancing student outcomes in transition planning, including students with the most complex support needs (Burke et al., 2020; Shogren et al., 2021), particularly when combined with other interventions using a tiered approach based on student needs

Students should also be encouraged to empower themselves to practice SDM throughout the transition process by identifying and working with a network of people they choose to help them make decisions and direct their lives (Shogren, Burke, et al., 2019). For example, DCPS makes SDM an integral part of transition planning for students receiving special education services in Washington, D.C. As DCPS students progress, they are provided with a self-advocacy course where they receive support to develop their decision-making skills and prepare “them to take an active role in their future.” DCPS professionals encourage students to “discuss their decisions with their parents” and others they trust and make decisions that “they feel best meet their needs” leading up to students beginning a formal “Supported Decision-Making process” in the ninth grade (DCPS, Office of Specialized Instruction, n.d.-c).

When students reach age 18 years, DCPS gives them an opportunity to create and execute an SDM Form, identifying people who will “make up their educational support network” and the areas where they want their support (DCPS, Office of Specialized Instruction, n.d.-b). For example, students may authorize members of their network to attend IEP team meetings, see school records, and provide input into their educational decisions, with the student remaining the final decision-maker (DCPS, n.d.-a).

Students should include service providers, employers, and others they trust to be part of their SDM network. Creating a broad network of trusted people and professionals will give them more control over the makeup of their Team and the meeting itself, helping them feel more comfortable participating in and leading their IEP process. The SDM network should also include family members and friends who will not only support the student but also provide insight into the student’s life and cultural experiences that may shape their transition goals and needs (e.g., deFur, 2002; Scott et al., 2021; Waters et al., 2010).

Conclusion

Turning off the school-to-guardianship pipeline will require parents, advocates, and educational professionals to commit to seeking and providing special education supports and services focused on building students’ self-determination and empowering students to use SDM to make their own decisions and direct their educational and adult goals and decisions. These skills are not only directly correlated with important quality of life outcomes, such as enhanced education, employment, and independent living (e.g., Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015) but are also the exact abilities that people with disabilities need to meet their needs and avoid overboard and undue guardianship (e.g., Hatch et al., 2015; Martinis & Blanck, 2019).

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Peter Blanck is University Professor at Syracuse University and Chairman of the Burton Blatt Institute at Syracuse University. He is a former member of the President’s Committee on Employment of People with Disabilities and a former Senior Fellow of the Annenberg Washington Program. Before teaching, Blanck practiced law at the Washington D.C. Firm Covington & Burling, and served as law clerk to the late Honorable Carl McGowan of the United States Court of Appeals for the D.C. Circuit.