

## **Guardianship: Its Role in the Transition Process for Students with Developmental Disabilities**

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*Abstract: The purpose of this qualitative study was to explore: (a) the underlying beliefs of those involved in determining the need for guardianship for young adults with developmental disabilities, (b) the overarching frameworks or theories that might explain some of the more predominate beliefs, and (c) the relationship of transition assessment, transition planning, self-determination, and age of majority to the guardianship process. The authors found that planning for guardianship was separated from the transition planning process and that full guardianship had become the set path for every student in the educational program. The authors made the following recommendations: (a) schools must begin with the assumption that each individual has the potential to lead his/her own life—from there supports in areas of need can be developed; (b) both the transition planning and guardianship process should be based upon an ongoing assessment of the student's strengths, needs, preferences, and interests; (c) schools must recognize students as emerging young adults, and prepare them to assume a variety of adult roles by helping them develop and practice self-determination skills; (d) the transfer of rights at age of majority should be seen as a key point in the transition process; and (e) in working to prepare students for adult life, instructional and support staff need to be aware of the wide variety of alternatives to and options within the guardianship process.*

Even though guardianship is a profound decision with serious implications both for and about the person labeled as having a developmental disability, the concept of guardianship has received little emphasis in the literature of the special education field. It seems logical that the determination of the need for guardianship should be made based upon an ongoing assessment of the student's strengths, needs, preferences, and interests, as part of the transition planning process. Identifying the supports needed by the student as he/she makes the transition to adulthood should be incorporated into the transition planning process, so that less intrusive alternatives to guardianship may be possible. Training in self-

determination should also provide skills that will assist the individual in taking control of his/her adult life, and advocate for these supports. The transfer of rights at age of majority is an ideal time for decisions regarding guardianship to be made.

### *Studies on Guardianship*

The majority of research on guardianship has focused on the concerns of elderly people (Bulcroft, Kielkopf, & Tripp, 1991; Iris, 1988; O'Sullivan & Hoffman, 1995; Peters, Schmidt, & Miller, 1985). In particular, these studies have focused mainly on the abuses of and difficulties in monitoring guardianship (e.g., Bulcroft et al.; Kritzer, Dicks, & Abrahamson, 1993; O'Sullivan & Hoffman; Peters et al.). A number of authors have undertaken an analysis of court records of guardianship hearings for elderly persons. Analyses of court records in Florida (Peters et al.), Ohio and Washington (Bulcroft et al.), Wisconsin (Kritzer et al.), and Maryland (O'Sullivan & Hoffman) identified several similar concerns. These concerns included: (a) the questionable validity

The authors express their appreciation to Dr. Deborah J. Gallagher for her active role in the design and implementation of this study and to Crystal Stokes for her editorial assistance during the final stages of manuscript preparation. Correspondence concerning this manuscript should be addressed to: Patricia L. Sitlington, Department of Special Education, Schindler Education Center 154, University of Northern Iowa, Cedar Falls, IA 50614-0601. Email: Patricia.Sitlington@uni.edu

of the assessment or rigor used in determining incompetency; (b) late notifications to alleged wards; (c) lack of participation of (or even the presence of) the alleged ward; (d) inadequate independent counsel to serve the alleged ward; (e) the frequent assignment of a full guardian when a partial or limited guardianship may have sufficed; and (f) a lack of monitoring of annual reports filed by guardians (both low numbers of reports filed and the failure to notify or sanction guardians who failed to file an annual report).

*Guardianship and individuals with disabilities.* Concerns have also been raised regarding the use of guardianship for individuals with disabilities (e.g., Endicott, 1988; Hoyle & Harris, 2001; Pepper, 1989), and possible alternatives to guardianship have been proposed (Pierangelo & Crane, 1997; Racino, 1993; Wilber, 1991). As Stancliffe, Abery, Springborg, and Elkin (2000) pointed out, "One of the dangers of guardianship is that it can easily go beyond protecting rights and seriously interfere with self-determination if guardians exercise control in areas where persons could make their own decisions or engage in collaborative decision-making with support from significant others" (p. 409).

Stancliff et al. (2000) examined levels of personal control exercised by 76 adults with mental disabilities, as related to their guardianship status. They found that individuals with no guardian exercised more personal control over their lives than did those with a limited guardian. Similarly, those with a limited guardian exercised more personal control than participants with a full guardian. These significant differences remained, even when controlling for competency in self-determination.

Millar and Renzaglia (2002) conducted an in-depth analysis of 221 court records of guardianship hearings for young adults between the ages of 17 and 29 with a disability who were living in one of nine counties in Michigan. They found the following: (a) 120 full guardians and 101 partial/limited guardians were appointed, but distinctions between the powers of these two guardianship types were often found to be minimal; (b) the wards' primary disability was most often reported as "mental impairment"; (c) over 50% of the wards in the sample were 18 years of

age; and (d) over 90% of the young adults were still in public schools at the time the petition was filed. In addition, petitions were most often filed by family members of the wards (74.7%), usually the mother. Mothers were the ones typically appointed as legal guardians.

Millar (2003) extended the findings of Millar and Renzaglia (2002) using the same court files to ask additional questions. She found the following reasons for petitions for guardianship: to make all decisions (37.1%), ward is not capable of making informed decisions (33%), specific tasks which the ward is unable to perform (13.5%), to assist the ward with decision making and specific daily living tasks (16.3%), and none given (1.8%). Millar also found the alleged ward was present at the hearing 86.8% of the time. If the individual were not present, the reason offered was that attendance would subject the individual to serious physical and/or emotional harm.

In addition, Millar (2003) found that evaluations tended to use standardized and norm-referenced intelligence tests. In all 221 court decisions, the judges stated that "clear and convincing evidence" was provided and that the ward was an individual with a developmental disability and required a guardian. Of the 105 full guardians, 88.2 % had appointments for an indefinite term. Of the 101 limited guardians, 97% had durations of five years, the legal limit in the state. Thirty-three percent of the wards indicated no preference as to whom they believed should be appointed guardian; thirty-two percent indicated the same preference as their petitioner did.

Based upon these findings, Millar (2003) suggested: (a) changes in the way evaluations are performed, to include evaluation of adult daily living skills (including decision making) on an ongoing basis throughout the guardianship term; (b) education for attorneys and judges in the area of disability, with an emphasis on the fact that persons with disabilities can and do lead quality adult lives when given the appropriate support; (c) education for families and educators related to the guardianship process and ramifications of guardianship imposition, well before the student reaches the age of majority; (d) increased participation of the alleged ward in the guardianship hearing; and (e) the selection and monitoring of

guardians who are knowledgeable about community resources, housing options, accounting, and public benefits for their wards.

Within almost all of the previously discussed studies there are similar difficulties: (a) problems in the assessment of incompetency, (b) inadequate due process procedures, (c) assignment of too high a level of guardianship (full when limited would have sufficed), and (d) poor monitoring of guardianships once assigned. Researchers are unsure, however, as to why these difficulties seem so widespread.

While these studies are interesting and useful, they fail to provide insight into the beliefs and attitudes of those involved in the process and how those beliefs and attitudes shaped the guardianship process. Also missing from these studies is the voice and beliefs of individuals with disabilities, those most affected by the guardianship process. Additionally, no studies have looked at the impact of the school system, or specifically, special education, on guardianship for young adults with disabilities. Within the schools, transition planning, mandated by law, is designed to prepare students for all of the adult roles they will assume. Discussion about guardianship, with the potential for the removal of rights and decision-making powers from the individual, should occur within the framework of four closely related concepts—(a) transition assessment, (b) transition planning, (c) self-determination, and (d) transfer of rights at the age of majority (Flower, 1994; Hoyle & Harris, 2001).

### **The Guardianship Process**

To fully understand the results of this study, it is important to understand the guardianship and transition processes.

#### *Our State's Guardianship Process*

Guardianship, including the process, terms and definitions used, varies by state. In the state in which this study was conducted, a guardian is defined as a “person appointed by the court to have the custody of the person of the ward” (Iowa Administrative Code; IAC§633.3(20)). A conservator is defined as a “person appointed by the court to have custody and care of the property of a ward”

(IAC§633.3(23)). “Ward” refers to the individual who has been assigned a guardian. Additionally, there are two types of guardianships – full guardianship and partial guardianship. Full guardians have all rights allowed by law over their ward, while partial guardians have specific rights over their ward as assigned by the judge during the court hearing (IAC§633). We will first review our state’s legal process regarding guardianship, followed by the process regarding conservatorship.

*Legal process for guardianship.* The legal process for obtaining guardianship in the state takes the following steps. First, an individual files a petition for guardianship (IAC§633.552). The petitioner (who is not necessarily the proposed guardian) can be anyone. The petitioner files a document that lists the alleged ward and his/her contact information, as well as the proposed guardian and his/her contact information. (“Alleged ward” is the legal term used in our state to refer to a person who has not yet been assigned a guardian but for whom a guardianship petition has been filed.)

After a petition is filed, notice is sent to the alleged ward (IAC§633.554)). The notice must inform the alleged ward that a petition has been filed on his/her behalf requesting a guardian, that he/she is entitled to representation, and of the rights that could possibly be taken away from him/her if assigned a guardian. Second, the court determines if the alleged ward needs a lawyer. The court can assign counsel if the alleged ward is incapable of voicing the need or if the alleged ward is indigent (the attorney fees, unless the alleged ward is deemed indigent, are paid for by the alleged ward) (IAC§633.561 and IAC§633.673). The lawyer’s obligations are described in the state’s code (IAC§633.561(4)). He/she must advise the alleged ward of the proceedings, must advise the alleged ward of his/her rights, must “personally interview” the alleged ward, and must file a report saying he/she has done these three things.

A hearing with a judge is the third step. The burden of proof is on the petitioner for an initial assignment (IAC§633.551). The lawyer for the petitioner must first “prove by clear and convincing evidence” that the alleged ward is indeed incompetent (IAC§633.556(1)). Incompetency is determined by

looking at whether the person has: (a) “a decision-making capacity which is so impaired that the person is unable to care for the person’s personal safety or to attend to or provide for necessities for the person such as food, shelter, clothing, or medical care” or (b) “a decision-making capacity which is so impaired that the person is unable to make, communicate, or carry out important decisions concerning the person’s financial affairs” (IAC§633.3(23)).

Next, there is a determination as to who will be the guardian. The only requirements are that the guardian be a “qualified and suitable person who is willing to serve in that capacity” (IAC§633.559). The rights that will be subsumed by the guardian are then identified. The court is to first consider a limited guardianship. There are, however, no specific definitions of “limited guardianship” contained within the state’s code. Limited/Partial guardians have only certain rights granted. Full/Plenary guardians have all rights allowed a guardian. These rights are divided into two categories: those that the guardian can do only with court approval and those that the guardian can do at his/her own discretion (IAC§633.635).

With court approval, the guardian may change the ward’s residency to a more restrictive one, arrange for elective surgery or non-emergency medical treatment, and consent to the withholding/withdrawal of life-sustaining procedures. Without court approval, the guardian may decide where the ward will live; select his/her educational program; choose the individual’s clothes, furniture, vehicle and other personal effects; determine what professional care and counseling might be needed; and make any other decisions specified by the court in the initial hearing.

*Legal process for conservatorship.* As mentioned previously, while guardians have rights over the person, conservators have rights over the property. Conservators “have a right to, and shall take, possession of all the real and personal property of the ward” (IAC§633.640). They have the responsibilities of protecting, preserving, and investing the ward’s assets (IAC§633.641). Powers of the conservator are broken down similarly to those of a guardian—with and without court approval. With court approval, the conserva-

tor may invest funds, execute leases, make payments (to the ward, to agencies providing services, to the guardian, to anyone who has custody of the ward), and carry out any other duties specified by the court (IAC§633.647). Without court approval, the conservator may collect income, defend or sue for the ward, sell/transfer personal property, vote in proxy at corporate meetings, and receive property for the ward (IAC§633.646).

*Fulfilling the guardianship/conservatorship role.* After the hearing and assignment of a guardian, the guardian is responsible for filing three types of reports (IAC§633.669). The initial report is to be filed within 60 days. From then on, reports are to be filed annually. A final report must be filed when guardianship is terminated (for any reason). Conservators have slightly different requirements, but the same type and frequency of reports (IAC§633.670 and IAC§633.671).

Hearings may be held to modify or terminate guardianship/conservatorship. The burden of proof rests on the guardian if he/she requests termination or modification (IAC§633.551). If the ward requests termination/modification, the ward must first “make a prima facie showing of some decision-making capacity”; then the burden rests on the guardian to prove that the ward is incompetent (IAC§633.551). Changes may include adding additional restrictions, removing restrictions, or terminating the guardianship.

#### *Alternatives to Full Guardianship*

Because guardianship is a powerful legal control, many alternatives to guardianship are available. Often, these alternatives to guardianship offer monitoring and assistance to individuals with disabilities, but do not require that they define themselves as “incompetent,” nor that they give up their role in the decision-making process.

Typically, these alternatives can be grouped by type of service. These services include assistance in financial, educational, vocational, and/or daily living matters. Financial services may consist of: (a) a representative payee, a designated person who can receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) payments for a person with a disability to assist the individual

in budgeting and spending; (b) a special needs trust, a fund created to insure that an inheritance goes to the person designated (if this person has a disability) and the assignment of a trustee to help with money management; (c) joint bank accounts (Pierangelo & Crane, 1997), an account that would allow a second individual to assist the individual with a disability with banking and budgeting; and (d) daily money management services (Wilber, 1991), where a non-profit organization assists with financial affairs.

Educational services consist of educational power of attorney (P. Ehrenman, personal communication, November 14, 2001), a document that allows parents to retain the rights to make educational decisions beyond the age of majority. Vocational services typically consist of supported employment, a program to provide on-the-job support to an individual with a disability through the use of natural supports (supports occurring in the environment) or external supports, often using the support services of adult providers (Butterworth, Hagner, Kiernan, & Schalock, 1996).

Supported living services are also available, ranging from living in a group home to one's own apartment or home, with supports provided by adult service providers, as needed. Some services have multiple functions, including power of attorney, a document that allows an individual appointed by the person with a disability to make decisions in one or more areas of adult life. This role can also be terminated by the individual with a disability.

Additionally, within the state's code, it is specified that a limited or partial guardianship should first be considered (IAC§633.560), before consideration of a full or plenary guardianship. Because limited/partial guardianships have fewer rights over the ward and because these rights are based on specific, focused needs of the ward, as determined in the court hearing, limited/partial guardianships are considered to be somewhat less restrictive and are therefore to be considered before full guardianships.

### **Transition to Adult Life**

The Individuals with Disabilities Education Improvement Act (IDEA 2004) mandates individualized transition planning for move-

ment to all areas of adult life. The definition for transition services in IDEA 2004 is a coordinated set of activities for a child with a disability that:

- is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education; vocational education; integrated employment (including supported employment); continuing and adult education; adult services; independent living or community participation; and [602(34)(A)]
- is based on the individual child's needs, taking into account the child's strengths, preferences and interests. [602(34)(B)]

IDEA 2004 requires that a student's IEP be updated annually at age 16 to address the following:

- appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills;
- transition services needed to assist the student in reaching these goals, including the student's course of study (e.g., career and technology education, college preparation courses)
- a statement that the student has been informed of the rights (if any) that will transfer to him or her on reaching the age of majority—no later than one year before reaching the age of majority under State law.

The entire thrust behind transition services is the preparation of young adults with disabilities for the variety of emerging adult roles they will assume, with all the rights and responsibilities accorded to an adult. There are four major concepts that are a key part of the transition planning process: (a) transition assessment, (b) transition planning, (c) self-determination, and (d) transfer of rights at age of majority.

### *Transition Assessment*

IDEA 2004 clearly provides a mandate for including transition assessment in the IEP process. Transition assessment is an integral part of the educational process for students with disabilities during the secondary school years and serves as the foundation for planning for adult roles. Transition assessment encompasses age-appropriate methods to assist students in identifying individual needs, strengths, preferences, and interests and in obtaining information on future living, work, and education environments.

Sitlington, Neubert, Begun, Lombard, and Leconte (2007) defined transition assessment as follows:

Transition assessment is an ongoing process of collecting information on the student's strengths, needs, preferences, and interests as they relate to the demands of current and future living, learning, and working environments. This process should begin in middle school and continue until the student graduates or exits high school. Information from this process should be used to drive the IEP and transition planning process and to develop the Summary of Performance document detailing the student's academic and functional performance and postsecondary goals. (pp. 2–3)

### *Transition Planning*

As stated in IDEA 2004, transition planning is individualized and is based upon the "student's needs, taking into account the student's strengths, preferences, and interests" (20 U.S.C § 1401 (30)(B)). A focus on preparation for and transition to a successful adult life can be seen throughout transition planning and education, which should begin as soon as the student enters the school system (Sitlington & Clark, 2006).

The skill and knowledge domains under the concept of transition are broad. Sitlington and Clark (2006) identified the following nine skill and knowledge domains: communication and academic performance skills; self-determination; interpersonal relationship skills; integrated community participation skills; health and fitness skills; independent/interdependent daily living skills; leisure and rec-

reation skills; employment skills; and further education and training skills.

Transition strives to prepare students for the wide variety of adult roles they may assume. Therefore, the goal or outcome of the process of transition should be a high quality of life (Halpern, 1993). This long-term planning process brings together the student, family, school, outside agencies, and others to plan for and to prepare students for the variety of roles they may assume as adults, including such roles as worker, student, parent, friend, and citizen.

Within this broad focus on transition, there are many issues to consider. In terms of assuming adult roles, it is important for the student to be prepared to accept the responsibilities that come with adulthood. These responsibilities include the demands upon individuals to act autonomously and to self-advocate, as well as to assume the legal rights that are given at the age of majority.

### *Self-Determination*

In recent years there has been a major focus on the concept of self-determination for all young adults with disabilities, but particularly individuals with developmental disabilities. The term "self-determination" attempts to encompass the themes of choice, control, and personally meaningful success for individuals with disabilities (Field, Martin, Miller, Ward, & Wehmeyer, 1998b). For students to transition successfully, it is critical for them to develop the skills considered under the concept of self-determination. However, studies focusing on the self-determination of individuals with disabilities indicate that adults with disabilities, particularly those with developmental disabilities, have low levels of self-determination (Wehmeyer & Metzler, 1995).

Many authors have defined self-determination. Field, Martin, Miller, Ward, and Wehmeyer (1998a) summarized these definitions as follows:

Self-determination is a combination of skills, knowledge, and beliefs that enable a person to engage in goal directed, self-regulated, autonomous behavior. An understanding of one's strength and limitations together with a belief in oneself as capable

and effective are essential to self-determination. When acting based on these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults. (p. 2)

Research is steadily mounting suggesting that enhanced self-determination may play a role in improving adult outcomes for students with disabilities, including employment status (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997) and participation in postsecondary education (Field, Sarver, & Shaw, 2003). As a result, promoting students' self-determination is now an important component of recommended practices in the transition of youth with disabilities to adult life (Council for Exceptional Children, 2003; Field & Hoffman, 2002; Field et al., 1998b).

Models act to guide the development of curricula and instructional strategies, thus acting as an overarching framework for more concrete instruction and facilitation of self-determination (Field, 1996). Several professionals have developed models outlining instruction in self-determination (Abery, 1994; Field & Hoffman, 1994; 1996; Halpern, Herr, Doren, & Wolf, 2000; Wehmeyer, 1992; 1997; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). Most recently, Test, Fowler, Wood, Brewer, and Eddy (2005) developed a conceptual framework of self-advocacy, a concept closely associated with self-determination. This framework, based upon a comprehensive review of the literature, included the components of knowledge of self, knowledge of rights, communication, and leadership.

Wehmeyer and Schalock (2001) also offered what they termed "essential characteristics" of self-determined behavior: (a) choice-making skills; (b) decision-making skills; (c) problem-solving skills; (d) goal-setting and attainment skills; (e) independence, risk-taking, and safety skills; (f) self-observation, evaluation, and reinforcement skills; (g) self-instruction skills; (h) self-advocacy and leadership skills; (i) internal locus of control; (j) positive attributions of efficacy and outcome expectancy; (k) self-awareness; and (l) self-knowledge.

We will refer to self-determination as an individual's autonomy and voice. While this may indeed simplify the concept when com-

pared to other authors' definitions, it clarifies the meaning and allows for discussion of the need for self-determination for all people, including those with developmental disabilities.

As transition planning occurs, it is necessary to attempt to develop and nurture an individual's level of self-determination so that he/she is able to fulfill adult roles, exercising one's autonomy and voicing one's opinions. Students must be taught and given the opportunity to exercise skills related to self-determination (Wehmeyer & Schalock, 2001). This preparation for the assumption of adult roles must be planned for through the transition process. Within this process, the transfer of rights at the age of majority, as well as the related need to act in a self-determining way, need to be addressed.

#### *Age of Majority and Transfer of Rights*

The term age of majority refers to "the age at which an individual is no longer considered a minor and, as such, becomes legally able to exercise rights accorded to adults in that state or province" (Lindsey, Wehmeyer, Guy, & Martin, 2001, p. 3). The legal rights attained at the age of majority would allow individuals, including those with developmental disabilities, to express their voice, to have power with that voice, and to have autonomy. In essence, this transfer of rights is a necessary part of transition planning as youth assume adult roles and act in a self-determining way.

Thirty-three of the forty states that responded to a survey conducted by the National Association of State Directors of Special Education (NASDE, 1999) indicated that the age of majority in their state, which is when the transfer of rights occurs, was 18. IDEA 2004 requires that students with disabilities and their parents are made aware of the transfer of rights at least a year before the student reaches the age of majority. Individuals who have reached the age of majority, regardless of their disability label, are considered to have the rights accorded to an adult in that state, unless the individual has been declared legally incompetent (Lindsey et al., 2001).

In their position statement on the age of majority and individuals with mental disabilities, the Council of Exceptional Children's Division on Mental Retardation and Develop-

ment Disabilities cited their concern that the discussion regarding age of majority required by IDEA may “lead to a circumstance where parents and family members will feel compelled to obtain guardianship or other legal decision-making status over their son or daughter when they might not otherwise do so” (Lindsey et al., 2001, p. 13). They also clarified that the way in which the school handles this notification of the transfer of rights will affect this possibility.

The legal basis for the personal choice and control emphasized within the concept of self-determination comes through the transfer of rights that occurs at the age of majority. “Transfer of rights” refers to the shift of responsibility from parent to child upon attaining the age of majority. This transfer of rights occurs for young adults with disabilities just as it occurs for those without disabilities. Upon attaining the age of majority, the individual is viewed in the eyes of the law as an adult, capable of making and responsible for his/her own decisions (Lindsey et al., 2001).

### *Transition and Guardianship*

To assure that students are prepared to assume the diverse duties of adulthood, careful and thorough transition planning, with a broad-based focus, is essential. For students with disabilities, this transition planning is mandated. Guardianship, which may be abused, can work against the goals of transition planning. In attempting to understand how guardianship and transition are related, it is important to understand that, for students with disabilities, the transition planning process undergirds the movement from school to adult life. A seminal time or moment in this transition is at the age of majority when the transfer of rights occurs. It is essential that ongoing transition planning has led up to this moment. Part of this transition process is the development of such life-long skills as self-determination, which provides students with voice and autonomy. As mandated by IDEA 2004, the transition planning process must be based upon transition assessment.

A major part of this transition is the development of needed supports to allow students to act as self-determining adults. These supports will be individual to each student, and,

for some, might include a form of guardianship or an alternative to guardianship. It is here that the connections between guardianship and transition are established. Each individual student will have a variety of needs upon entering the adult world.

The supports in place to meet these needs may include natural supports, those available to all in the adult world, or may be more formal and planned by those involved in the transition process. Regardless of the type of actual support, those that are planned should be as non-intrusive as possible, allowing the individual with a disability to retain as much independence and autonomy as possible (Wehman, Revell, & Brooke, 2003). For some individuals with developmental disabilities, guardianship may be seen as a necessary support. However, before opting to declare a young adult legally incompetent and removing certain rights, all other options and alternatives should first be considered.

### *Purpose of Study*

Very little research could be found on the issue of guardianship for young adults with disabilities, particularly as it relates to the process of planning for the transition to adult life. In particular, no studies could be located that focused on the values, perspectives, and sociological frameworks of those directly involved in the guardianship process - individuals with disabilities, their families, teachers, support staff from intermediate units, and lawyers. The purpose of this study was to explore: (a) the underlying beliefs of those involved in determining the need for guardianship for one young adult with mental disabilities, (b) the overarching frameworks or theories that might explain some of the more predominate beliefs, and (c) the relationship of transition assessment, transition planning, self-determination, and age of majority to the guardianship process.

### **Method**

In order to understand guardianship, the beliefs of those involved in the process and the relationship of this process to planning for the transition to adult life, we undertook a qualitative study, focusing on the beliefs of those

involved in the guardianship process for one young man.

### *Selection of Qualitative Methodology*

We chose to explore guardianship using a qualitative methodology, because there are so many complex issues imbedded within the topic. Often, related to these complex issues are responses that would be considered optimal in their social acceptability. In exploring the topic, we wanted to reach beyond these more socially acceptable responses in an attempt to understand what ideas and understandings inform and motivate people who are involved in the guardianship process. We wanted to understand the way a small group of inter-related people view the complex issue of guardianship.

The letter and the spirit of a law often differ somewhat from the actual practice of the law; we attempted to delve into this issue as well. The spirit of laws pertaining to guardianship attempt to limit guardianship orders as much as possible and offer the alleged ward a voice; the letter of the law indicates that the alleged ward is to have his/her own council and receive notification of all legal action being taken. It was important to understand how people negotiate the difference between how a law is put into practice and what the spirit of a law intends.

### *Participants*

Purposeful sampling (Glesne, 1999) was employed to obtain information from individuals who had been involved in the guardianship process in some way or another. The guardianship process is likely to include some or all of the following individuals: those with disabilities, their families, teachers, intermediate education unit staff (if applicable), and lawyers who have worked with individuals with developmental disabilities. The intermediate education unit staff member who is head of a parent education project located a family, the Smiths (a pseudonym), who had recently gone through the guardianship process with their son, Evan, who has a developmental disability. From the Smiths we branched out, speaking with a current teacher, the intermediate education unit staff who were involved in

the student's education, and the lawyer who was employed by the family.

*Evan and his family.* The Smiths, a family of four, live in a rural area of a midwestern state. Larry (Evan's father) works at a tractor implement factory in a city about 40 minutes from their home; Connie (Evan's mother) works in the same city's county courthouse. Katie, 22, and Evan, 20, both live at home with their parents.

Important to this study on guardianship, and something that will certainly be asked, is the question, "Can Evan make it on his own?" This question, which is asked about many individuals, with and without disabilities, is difficult to answer. Evan does indeed have significant problems in all academic areas. He reads and writes poorly. He has well-developed social skills and excellent manners. Though his opportunities to practice his decision-making skills have been limited, both by his young age and by the protective blanket that surrounds him, he is aware of his likes and dislikes and makes choices regarding his day-to-day life with much success. It is our opinion that Evan will need various supports throughout his life. What these supports should consist of, however, should be determined by Evan, his family, and those who support him, based upon his future education, opportunities for growth, and personal freedom.

*The school and intermediate education unit staff.* Evan's current teacher and two intermediate education unit staff, both of whom work primarily at Evan's school, Lakewood, acted as participants. Evan's teacher, Laura Jenson, is in her third year of teaching; she has taught Evan for the past two years. Before teaching, she worked in a group home setting and currently works part time for another adult service provider supervising employees with disabilities. Bonnie Potter has been a social worker for the intermediate education unit for 27 years; she has spent the last 15-16 years at Lakewood. John Pitts, the intermediate education unit school psychologist, has been a school psychologist at Lakewood his entire career, for 24 years. Before working at Lakewood, he worked with individuals with severe and profound disabilities in an institution setting.

Lakewood is a school run by the intermediate education unit for students with disabili-

ties. Typically, individuals served at Lakewood tend to have more significant developmental disabilities. The school and its grounds house all needed facilities, including a cafeteria, a gym, a swimming pool, accessible bathrooms, a "life skills" area, and classrooms. Many opportunities are provided for experiences in the community, including exploration and training experiences in community businesses.

The school population is low, allowing for classrooms of 5-8 students. Students range in age from 2-21 years and are typically grouped in classrooms by age and the perceived severity of their disability. It is not atypical for a student to spend his/her entire educational career at Lakewood. Almost all school staff know each student and their family members by name; the resulting environment is warm and protective. Families of the students placed at Lakewood are very loyal and have lobbied for the school's continued existence. From casual discussion with family members, it appears that families of students feel the school offers their students a safe, protected environment where the students are among other individuals with developmental disabilities.

*The lawyer.* Geoff Ryder acted as the Smiths' lawyer for the guardianship proceedings. He has been in practice for the past 25 years, and while he has received no specific training on working with individuals with disabilities, he estimated that he has been involved in two to three guardianship proceedings a year since he began his career.

#### *Data Collection*

Data collection focused on three sources of information: interviews, archival records, and field observations. All data were collected by the lead author. Interviews took place with all of the participants identified in the previous section. A primary interview was scheduled at the convenience of the participant. Follow-up interviews to clarify statements or request additional data were used as necessary. Archival data collection focused mainly on court documents and material used by intermediate education unit staff; field observations were also used to gain a clearer picture.

*Interviews.* The semi-structured interviews included both close-ended and open-ended

questions. The close-ended questions provided a general overview of participants' opinions, while the open-ended questions allowed a better understanding of the participants' attitudes, beliefs, and sociological frameworks. Interview questions focused on several areas, including general background, familiarity with the guardianship process, and beliefs. Questions on the participants' general background focused on demographic information and interactions with young adults with disabilities and young adults with disabilities who have guardians. Questions on the participants' involvement with guardianship focused on their role in the guardianship process and awareness of and attitudes toward the scope of guardianship powers available. Questions on the participants' beliefs focused on beliefs about the type of young adult with a disability who might need a guardian; beliefs on the role of the age of majority in precipitating the guardianship process; and attitudes toward the concept of self-determination.

All interviews took place at the convenience of the participant and each was tape-recorded with the participant's permission. Each interview was transcribed by the lead author. All interviews were coded to identify emergent themes throughout. Memos and notes were written while coding, to help clarify themes and issues identified by the participants.

*Archival data and field observations.* Through contact with participants, we were able to identify other individuals who had obtained guardianship of a young adult with a disability and who were willing to allow for the review of court documents of the guardianship proceedings. In addition to court documents, we were given other archival data in the form of informal handouts received by the participants from school and intermediate education unit staff. The main observations focused on Evan as he interacted with his family in their home.

#### *Self as Researcher*

Because of our interest in this topic, experiences, and past reading in this area, we brought to this study some pre-theoretical dispositions. We were concerned that not enough questions were being asked as people labeled as having a disability were having per-

sonal rights removed through guardianship. Removal of these rights appeared to occur with relative ease. As a result, we entered the study with some skepticism and concern regarding guardianship. We attempted, deliberately, to challenge our beliefs and our cognizance. Identification of these concerns allowed us to constantly evaluate and re-evaluate our interpretation of data, as well as alert readers to our dispositions.

### **The Smiths' Story**

We first met the Smith family at their home; Connie opened the door, explaining that Larry was still out working in the garage but would drop in shortly. Katie and Evan were sitting in the living room. Katie worked diligently, preparing materials for the day care by which she is employed. Evan and Connie had been watching the news in the living room. Evan joined us as Connie detailed his history.

Evan was born on November 2<sup>nd</sup>, five weeks early, and with serious complications. He was moved from the small, local hospital to a large university-affiliated hospital an hour away. There he was diagnosed with Pierre Robin Syndrome, which is characterized by such features as a large tongue, cleft pallet, and a small jaw. Evan underwent many surgeries, had a tracheotomy, and had a feeding tube inserted. When he finally was sent home almost a year later, he began early intervention with the local intermediate education unit, which provides support services. The staff members provided physical therapy for Evan and instruction for his parents. At the age of 2 1/2 he started preschool at Lakewood, a specialized school for children with disabilities administered through the intermediate education unit.

Shortly before Evan's 18<sup>th</sup> birthday, the Smiths contacted a lawyer in their county of residence and obtained guardianship and conservatorship over Evan. Lakewood recommends, even stresses, that all parents obtain guardianship and conservatorship over their sons/daughters with disabilities, so the Smiths opted to do so. Lakewood staff has on hand the names of two lawyers in the county who routinely file guardianship papers, but as the Smiths live in a different county, they located a lawyer on their own. The lawyer they con-

tacted recommended that the family apply for full guardianship and conservatorship of Evan so that there would be no additional costs to them if they decided they needed more power over aspects of his life. The \$150 fee was paid and the papers were filed. Then, because this lawyer and county choose to waive the court hearing in cases where the parents of a "special needs child" are the petitioners and proposed guardians/conservators for their son/daughter, the papers allowing Evan's parents to become his legal guardian were signed by the judge with no further discussion. The Smiths now file annually a brief form on Evan's whereabouts and well being to maintain guardianship, as well as a more detailed form accounting all his funds to maintain conservatorship.

### **Beliefs, Perspectives, and Sociological Frameworks of the Participants**

After an initial interview with the Smiths, the lead author interviewed Evan's teacher, intermediate education unit staff at Lakewood, and the Smiths' lawyer; she then returned for several interviews with the family. After speaking with these individuals, transcribing the interviews, making notes, and reading and re-reading the transcriptions and notes, we were able to identify several important themes recurrent in the data. First and foremost, as a whole, participants demonstrated few reservations or second thoughts when concluding that Evan and other students at Lakewood needed guardianship. Second, participants felt the need to protect Evan and other students and believed the way to do this was by pursuing guardianship. Third, participants lacked knowledge regarding alternatives to guardianship. Finally, the process in place for guardianship planning was separate from the students' transition planning. In the following sections, we elaborate on and substantiate this assessment.

#### *Preemptive Conclusion of Need for Guardianship*

A declaration of incompetence is the first major step in determining the need for a guardian. An implicit statement is made regarding a student's competency by advocating for or stating that there is a need for guardianship. It

is very important to look at how the determination of the need for guardianship, or a student's competency, are made.

Evan's placement at a segregated school for students with disabilities and his status as an individual with a disability undoubtedly contributed to his being viewed as "incompetent" and therefore in need of guardianship. John Pitts and Bonnie Potter felt that Evan's attendance at Lakewood, a segregated school for individuals with disabilities, was indicative of his lack of or level of competence.

If school staff, educated in working with students with disabilities, feel that placement in a certain school is enough to determine competence or need for guardianship, it is not surprising that other adults, with less training in working with students with disabilities, might draw similar conclusions. Geoff Ryder, the Smiths' lawyer, also concluded Evan was in need of guardianship. When asked how he had determined this, he responded, "Now this is when we have a special needs child – I rely more upon the parents. That's because normally they aren't going to go to the cost and the expense of this unless necessary." So, if a parent went to the time and expense to request guardianship for a "special needs" child, Ryder indicated that he would assume the young adult was incompetent and proceed with the guardianship.

Troublingly, Ryder also noted that in other guardianship cases, he may be called upon to act as a guardian ad litem for an alleged ward. In this case, he would determine competency and identify what actions he believed to be in the best interest of the alleged ward. In doing so, he stated that he would contact the alleged ward, meet them, and have a conversation. "A lot of times," he said, "they aren't able to communicate." In this statement, he was referring to an alleged ward's ability to communicate in a traditional sense, specifically, orally. He tied great importance to the ability to communicate orally. In referring to a particular case, he noted that, even though staff doctors at a state mental health institution had labeled a woman incompetent, he, from talking with her, knew that she "had a certain level of understanding" and judged her competent.

These assumptions about the need for guardianship or incompetence appeared to be based on perceptions of disability, the

meaning of a school program placement, and the label of "special needs." No individual mentioned specific capabilities of Evan or of other students. Related to these assumptions of incompetence is the need to protect individuals viewed in this way.

### *Paternalism and the Related Push for Guardianship*

The Smiths have concerns for Evan, as all parents might for their child. They wonder what he will do when he grows up, when he will leave the house, and if he will be able to maintain and prosper on his own. Additionally, there are other concerns related to Evan's perceived ability to care for himself. Connie, his mom, admits, though, "it's going to be, I think, a bigger leap for me" to adjust to his growing up and leaving the house. The school, though, seems to have used these natural concerns of parents to strongly encourage the Smiths to obtain guardianship.

When asked why she had pursued guardianship, Connie cited Lakewood's emphasis on acquiring it and the importance they had placed on it. She added that she did have some fears for Evan. When asked to elaborate, she said she was concerned he might be "taken advantage of." These vague suggestions of what might occur to a young adult with a disability, if left without a guardian, were noted in several other interviews. Laura Jensen, Evan's teacher, stated the following in regards to what she might tell a parent during an IEP meeting:

A lot of parents ask, "Why would I want to be my student's or my child's guardian?" We just make suggestions, "If you do want to be your son's guardian a good reason would be so someone couldn't come along and take advantage of their money," which is a certain possibility. . .

Along similar lines, Potter, the school social worker, provided some concerns regarding a student's ability to protect or care for themselves.

Really, our kids are very gullible and can be taken advantage of easily and that's where we come from with the parents. Our kids can be talked into something very easily. Unfortunately there are people out there

who are not trustworthy, and when our kids leave here (Lakewood) they go to other programs, you know, or they go to group homes, or into the workforce and they can be talked into something that is illegal or they can be taken advantage of and if they are their own guardians, they can sign papers or get involved with something they don't understand if somebody talks them into it and then they are responsible for it if it's some illegal activity.

Each participant stressed the need to protect and look after Evan and other young adults with developmental disabilities. Evan and other students at Lakewood were considered unable to make decisions and/or choices or, if they were allowed to do so, these decisions or choices would result in negative consequences due to poor decision-making capacity. To protect Evan from this, guardianship was needed. While the paternalistic desire to protect and keep safe may stem from love and concern for Evan and other young adults with disabilities, it acts to hinder his development as an adult. He is not seen as an adult, but as an eternal child, forever to be looked after.

#### *Lack of Knowledge Regarding Alternatives to Guardianship*

No other alternatives to guardianship were discussed with parents. Staff had no knowledge of or was reticent to discuss the legal process behind guardianship or of any alternatives to guardianship. Initially in the interview with Jenson, Evan's teacher, she was very anxious and kept repeating that she was unsure she would be able to help us, as she knew very little about guardianship. Her role in the process at Lakewood is to refer students on to the intermediate education unit staff, the school psychologist, Pitts, or the school social worker, Potter. Jenson said she had no knowledge of the legal process that guardianship takes and that she relied on Pitts and Potter to provide information and resources to the parents of students at Lakewood.

When speaking with Potter, though, she admitted that she also had no knowledge of the legal process. Pitts also knew little; when asked if he had any idea of the process, he replied with a shrug and a shake of the head, "Not

really." So while Lakewood staff was unfamiliar with the legal process surrounding guardianship, they recommended it without discussing or exploring with parents possible alternatives to full guardianship. Though numerous and substantive, no alternatives were discussed by staff at Lakewood. It seems that any alternatives to full guardianship, even limited guardianship, were not discussed. These options could have been provided as part of the transition planning process.

#### *Separation of Planning for Guardianship from the Transition Planning Process*

Transition planning should be the driving force behind the movement from secondary school to adult roles. Without adequate transition planning, students leave school unprepared, and parents are left in even more uncertainty and worry about their child's future. At Lakewood, planning for guardianship has been separated from transition planning. The result is a push for guardianship for all students without consideration of other aspects of their adult life. The resulting situation is problematic and includes the use of a blanket policy towards one particular option (in this case, guardianship), the use of the notification of the transfer of rights as a warning to parents, and a lack of emphasis on or belief in self-determination.

In the first interview with staff working at Lakewood, the lead author spoke with Laura Jenson, Evan's classroom teacher. When asked if it is assumed that guardianship is appropriate for all the students at Lakewood, she responded, "Well, we leave that up to the parents to choose. We just, we just simply ask if they've started the process and recommend that they do if they want to." As you can see, Jenson states that this decision should be made by the family, but does note that Lakewood takes a more aggressive path, by recommending guardianship. The intermediate education unit staff were much more certain of the role that Lakewood should play, advocating clearly for any family with a student at the school to obtain guardianship. Bonnie Potter, the school social worker, made numerous statements to this effect, including "We feel guardianship is a real necessity for our kids here in the building." The school psycholo-

gist, John Pitts, felt similarly. "I would encourage," he said, "all parents that have students here (at Lakewood) to pursue this, to obtain guardianship so that, so that they don't run into any difficulties or problems on down the road if they don't."

The first dilemma is that while Lakewood staff, in their interviews, used words like "recommend" and "encourage," it appears that the role they play in this decision is much stronger than recommending and encouraging. Connie Smith, Evan's mom, went through the process. She said that different members of the school staff mentioned guardianship at every meeting she had with school staff for almost two years prior to Evan's 18<sup>th</sup> birthday, including parent-teacher conferences, annual reviews, three-year re-evaluations, and meetings about the work experience program. Connie noted that even after the family had obtained guardianship, school staff still verified that she had completed the process.

Lakewood staff also discussed, with Evan's family and with the lead author, their emphasis on the transfer of rights at the age of majority. This tenet was used by staff as a major push for guardianship. The age of 18, which is the age of majority in our state, became the deadline for the completion of the guardianship process. As Laura Jenson, Evan's teacher, stated, "18 years old is when we recommend they have it done, because when they turn 18, if it's not done by 18, that student is automatically in charge or is guardian of their finances and situations. . ." Bonnie Potter, the school social worker, discussed the concept in much the same way, saying things like, "Parents don't realize what it means when kids turn 18." Pitts, the school psychologist, also shared stories with parents about things that could happen if a student did not have a guardian at the age of 18, such as how they could buy a car or could move into their own apartment. The transfer of rights became a major reason why parents were encouraged to pursue guardianship. The transfer of rights and the powers that came with that were discussed in a way that highlighted only the negatives of this transfer, leaving the Smiths with a sense of alarm and dread. In essence, the notification of the transfer of rights was used as a warning and a further reminder of the need for guardianship.

The blanket policy towards guardianship and the questionable use of the transfer of rights tenet, when coupled with the aforementioned theme of lack of knowledge of alternatives, leads to the potential abuse of trust by Lakewood staff. Families often have longstanding relationships with the school and trust the input they receive from school staff. Evan's family, who have interacted with Lakewood staff since he was 2 1/2 years, are pleased with the school. Connie felt, in developing Evan's IEPs, that the school staff knew best. She stated, "Because they've worked with so many kids in the same category as him that they can say, 'well, you know, maybe this would be best for Evan.'" Connie and the family have been happy with the decisions made by Lakewood staff and feel that it is the best place for Evan. She trusts what staff at Lakewood think and relies on the staff for support and input in working with her son. If Lakewood staff is not representing the wide array of options available and are advocating for one decision, guardianship, there is the possibility for an abuse of trust to occur.

An underlying problem is that staff at Lakewood is unable to see their students as being or becoming self-determined individuals. As a result, with the guardianship discussion separated from transition planning and self-determination, we see these decisions being made for students and families, with their care and protection in mind, as opposed to with students and families.

Many of these problems stem from the fact that the issue of guardianship has been removed from the concept of self-determination and the transition process, which brings together the student, family, school, adult service providers, and others involved with the student. Instead, it is a blanket policy, covering all students at Lakewood. Alternatives are not discussed and are therefore not made available to parents. The wide variety of adult roles that the student may assume is not fully considered alongside the issue of guardianship. A consideration of self-determination and the assumption of the rights that are transferred at the age of majority are not present in the decision regarding guardianship.

## Discussion and Recommendations

Lakewood's preemptive conclusion regarding the need for guardianship for all students is problematic. The root of the problems surrounding the issue of guardianship at Lakewood is that the planning for guardianship is separated from the transition process. The result is that the student, family, school, adult service providers, and others are not making a fully-informed, well-planned group decision. Discussion of the individual student's strengths, needs, preferences, and interests in relation to the guardianship process has not occurred. Alternatives and options that may work for the student have not been discussed. Guardianship has not been considered in conjunction with the assumption of other adult roles. Full guardianship becomes a set path for every student, as opposed to a process, such as the transition process that is individualized for each student and family according to their needs and desires

Based upon our observations, we make the following recommendations related to the role of the guardianship process within the transition planning process. First, both the transition planning and guardianship processes should be based upon an ongoing assessment of the student's strengths, needs, preferences, and interests. This is a required component of the transition planning process (IDEA 2004). The transition assessment process is an ideal vehicle to identify the strengths, needs, preferences, and interests of the individual. The IEP team can then identify the supports and accommodations needed by the individual to transition to adult life. The Association for Persons with Severe Handicaps (TASH; 2003) in the TASH Resolution on Alternatives to Guardianship urged "the development and promotion of the use of accommodations and supports people need to make choices and decisions, to have their preferences recognized and honored, and to have their rights to self-determination protected." In this same resolution TASH committed to the promotion and use of alternatives to guardianship.

Second, schools must recognize students as emerging young adults, and prepare them to assume a variety of adult roles. Third, schools should prepare students for the assumption of

these adult roles by helping students develop and practice self-determination skills. Developing students' autonomy and voice will allow them to participate in their transition planning to a greater degree and will allow them to advocate for themselves in the future.

Fourth, the transfer of rights at age of majority should be seen as a key point in the transition process, rather than a warning, or perhaps even a threat. Lindsey et al. (2001) addressed this concern, offering a reminder that schools cannot make judgments on the competency of students and voicing a concern that notification of this transfer could lead parents towards guardianship. As they stated, if schools "adopt a philosophy of supporting students to become more self-determined and to become meaningful participants in the planning process" (p. 13), then notification will not act as a threat. They also noted that how schools address this will greatly affect parents' concerns. Millar and Renzaglia (2002) recommended that the IEP team could even tailor the IEP goals and objectives with the aim of preventing the imposition of guardianship.

Fifth, in working to prepare students for adult life, instructional and support staff need to be aware of the wide variety of alternatives to and options within guardianship. Knowledge of guardianship is necessary for all school officials, but especially if schools have a strong relationship with parents, and parents trust the input of school officials, as they do at Lakewood. School staff should be familiar with the legal proceedings and should educate themselves and families regarding possible alternatives; otherwise, full guardianship becomes the only option presented to families. Additionally, those outside the educational arena who interact with individuals with disabilities (i.e., lawyers) need education in these same areas.

Finally, the discussion regarding guardianship must be intertwined with the transition process, as this will help ensure that students, families, school staff, adult service providers, and others are considering all adult roles and all options to help the individual succeed within these varied adult roles. It seems logical that the determination of the need for guardianship should be made based upon an ongoing assessment of the student's strengths,

needs, preferences, and interests, as part of the transition planning process. Identifying the supports needed by the student as he/she makes the transition to adulthood should be incorporated into the transition planning process, so that less intrusive alternatives to guardianship may be possible. Training in self-determination should also provide skills that will assist the individual in taking control of his/her adult life, and advocate for these supports. The transfer of rights at age of majority is an ideal time for decisions regarding guardianship to be made.

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Received: 23 August 2006

Initial Acceptance: 13 October 2006

Final Acceptance: 15 February 2007