

“I Never Put it Together”: The Disconnect Between Self-Determination and Guardianship - Implications for Practice

Dorothy Squatrito Millar
Saginaw Valley State University

Abstract: IDEA mandates that students be responsible for their educational programming once they reach the age of majority, and are considered competent. Guardianship is often raised when student competence is questioned. Six focus groups were conducted to gather information regarding the extent to which participants understood guardianship and its alternatives, and how these related to self-determination. Two groups consisted of young adults with disabilities; Group 1 had legal guardians. Parents were also focus group participants; the last two groups consisted of special educators. Data suggested that the majority of participants (a) perceived they exhibited/promoted self-determination; (b) did not recognize a disconnect between self-determination and guardianship; and (c) had limited understanding of guardianship and its alternatives. Implications for practice are discussed.

In the recently reauthorized Individuals with Disabilities Education Act several changes from the 1997 amendments with regard to the transition from school to adulthood were presented. Changes include (a) procedures for reevaluations [614(a)(2)], (b) requirements for summary of performances for students whose eligibility under IDEA terminates due to graduation or has exceeded the age for free public schooling under state law [614(c)(5)(B)], and (c) a switch as to when transition services must be addressed, which is now age 16 as opposed to 14 [614(d)(1)(A)VII]. One area that did not see a change was the section in relation to the transfer of parental rights at the age of majority [614(d)(1)(A)VII]. Specifically, IDEA states that when a student reaches the age of majority under State law, all rights accorded to parents are to transfer to students. The special rule under Section 615 (m) procedural safeguards states that this right of transfer is to occur for all students with disabilities, unless the student is determined to be incompetent by State law, or has not been determined incompetent by State law, but

considered unable to provide informed consent with respect to educational programming. In these cases, the State is to establish procedures for appointing the parent, or some individual, to represent the educational interests of the student when the student is eligible to receive services under IDEA, section B [614(d)(1)(A)VIII].

To date, no known comprehensive or small study has investigated how States and local schools districts are responding to this mandate. Michigan, as an example, has addressed the mandate on the Individualized Educational Program (IEP) form by including an item such as “Parental Rights and Age of Majority (check all applicable): (a) if the student will be age 17 during this IEP, the student was informed of parental rights that will transfer to him or her at age 18; (b) if the student has turned age 18 the student and parent were informed of the parental rights that transferred to the student at age 18 including the right to invite a support person(s) such as parents, other family members, advocate, or friend; (c) the student has turned age 18 and there is a guardian established by court order. The guardian is ___; and (d) the student has turned age 18 and has appointed a legally designated representative (e.g., power-of-attorney, trustee). The representative is ___”(Michigan Department of Education, Section I-2, 2005). Furthermore, the

Correspondence concerning this article should be addressed to Dorothy Squatrito Millar, Saginaw Valley State University, College of Education, 7400 Bay Road, University Center, MI 48710. Email: dmmillar@svsu.edu

State's IEP manual presents "Guardianship issues (e.g., independence, decision-making, partial guardianships as appropriate) can be addressed in the student's secondary education career in the IEP under Transition services (e.g., Courses of study, Adult living, Daily living)" (Michigan Department of Education, Section 1-2). Although an IEP manual may suggest that 'age of majority' should be an ongoing educational topic for the student well before the student becomes of legal age (Michigan Department of Education, Section 1-2), statements such as this may be interpreted that guardian appointments should be considered.

Briefly, guardianship is a legal process, governed by individual state law as opposed to unifying federal law, by which a court appoints someone (a guardian) to have the authority to make decisions for another (a ward or respondent) who has been determined to be either totally or partially incompetent (Leary, 1997; Lisi, Burns, & Lussenden, 1994). As a result, the ward may lose many legal and civil rights. The potential ramifications of a guardian appointment can be enormous, therefore, it has been argued that alternatives should be explored (Iris, 1986; Lisi et al.). Alternatives to guardianship include youth and young adults collaborating with (a) family and friends; (b) representative payees; and (c) agency case managers (Lisi et al.; Sullivan, 1986). Trusts, specialized checking accounts, power of attorney and protective orders are additional guardianship alternatives that can be explored (Lisi et al.; Pierangelo & Giuliani, 2004; Sullivan). Table 1 presents more information on guardianship alternatives.

Interestingly, guardianship has been in existence for hundreds of years (Lisi et al., 1994), however, research on the topic and its related issues are sparse. Two recent studies are considered to be the first that investigated guardianship in relation to young adults who have developmental disabilities. By reviewing over 220 guardianship court files, Millar and Renzaglia (2002) and Millar (2003) found that main reasons why guardians were appointed included that young adults were perceived as having limited or no ability to make decisions, and youth were reaching the age of majority. More interesting, it was revealed that guardianship appointments did not necessarily resolve the areas of concern presented to the courts. Although

information regarding alternatives used prior to the filing of a petition was hoped for, such information obtained from the files was limited as no specific questions regarding the use of alternatives were found on guardianship petitions. These two studies, like the few others that examined guardianship in relation to the elderly (Iris, 1989; Lisi et al.) raised questions about the views of members of the judicial system, community service organizations, and family members with respect to alternatives. Importantly, it was pointed out that there is a need for research that includes formal participatory research methods in which key stakeholders provide in-depth experience-based perspectives.

This study is a response to this call as it includes perspectives from three key stakeholders: (a) young adults with disabilities who either have or do not have a legal, court appointed guardian; (b) parents of young adults who have disabilities; and (c) educators who work with young adults and their parents. It is the first known study that explores issues surrounding the age of majority, transfer of rights, self-determination, guardianship decisions, and guardianship alternatives. Focus groups were used as little is known about these areas. In addition, an aim of this investigation was to develop interest into and direction for future research. With the growing trend of encouraging students to be self-determined, it is crucial that educators, families and agency personnel understand what guardianship entails. Specifically, they need to examine the extent to which self-determination efforts are potentially being undermined by guardian appointments.

Method

Participants and District

Participant selection was purposeful such that six homogenous groups could be created. A mid-west regional school district, from which participants were selected, had a reputation at the state and local level for providing quality school-to-adulthood transition services. The district, comprised of a diverse student population, in addition to having several high schools, had a regional facility (transition/vocational center) such that students with disabilities, aged 18 and older, could continue their education and focus on transition issues. Participants were nomi-

TABLE 1

Overview of Guardianship Alternatives

Guardianship alternatives exist that can be used alone or in combination to meet the needs of an individual.

<i>Family and friends</i>	Family and friends can be consulted for advice when decisions need to be made. Potential options, consequences, advantages and risks can be explored.
<i>Trust funds</i>	Trusts are legal devices, which if properly drawn up, will not jeopardize eligibility of governmental benefits. As interests accrue, a trustee can purchase services and items not covered by government benefits. Due to varying types of trusts and roles trustees can assume, it is essential that an attorney familiar with governmental benefits be involved in designing the trust, in collaboration with parents, such that the terms of the trust can be delineated.
<i>Specialized bank account</i>	Banks can arrange specialized checking and saving accounts to meet individual needs, including cosigners, ceiling limits, and pour-over accounts.
<i>Power of attorney</i>	A power of attorney is a document by which any 'competent' individual can authorize someone else to make decisions on their behalf. The person given the power of attorney has only the power(s) that are specified by the individual, and may only be used if the individual understands completely what it is that he or she is authorizing another person to be responsible for. Power of attorneys can be privately written, without legal involvement.
<i>Representative payee</i>	A representative payee is a person who is appointed by the agency administering funds, such as Social Security Administration, to receive and manage federal benefits for another individual. The payee must maintain records of all expenditures made on behalf of the person with a disability and report such expenditures to the funding agency. The court system is not needed to establish a representative payee, rather applications must be made to the funding agency to be appointed a representative payee.
<i>Case management services</i>	Ideally, case management services view the person's life in its entirety; being aware of the person's strengths and needs and the assistance necessary to help the person live as independently as possible. The case manager works with the person, in collaboration with significant others, to identify and arrange services, and then monitors them.

Note. Adapted from Pierangelo and Giuliani (2004), Sullivan (1986), and Wood et al. (1991).

nated by the district special education coordinator or high school department chair. Criteria for participation of young adults included that they: (a) had the same special education eligibility label of "moderately cognitively impaired" based on results from IQ assessments, adaptive behavior scores, and onset of the disability; (b) reached the age of majority (18 years old); (c) were eligible for agency support (e.g., vocational rehabilitation, social security income, Medicaid, department of mental health - services of people with developmental disabilities); (d) had high level of parental involvement; and (e) were able to verbally communicate in an interview forum. The goal was to have at least 10 students nominated for participation who were to be their own legal guardian, having a letter of intent from parents that guardian appointments would not occur; and at least 10 students where parents

were appointed as their legal guardians. Parents of these individuals also had to be willing to participate in focus groups. Finally, special educators who worked with students aged 17 and older and were considered by district standards to be well versed in transition services, were selected for participation.

In total, six focus groups were conducted. Focus Group 1 was comprised of six young adults with moderate cognitive developmental disabilities who had legal guardians (a parent) appointed by the courts. Within this group: (a) three students were male and three were female; (b) three were Caucasian, one was Black, one was Hispanic and one was Indian from India; and (c) their ages ranged between 19 and 22. The second group consisted of seven young adults with developmental disabilities who did not have a court appointed

guardian. Of these seven: (a) three were male and four were female; (b) four were Caucasian, two were Black, and one was Hispanic; and (c) ages ranged between 20 and 22. Groups 3 and 4 consisted of parents, five (one father and four mothers) and six (one father and five mothers) respectively, of the young adults in Groups 1 and 2. Group 3 parents were also plenary (full) guardians of the adult children in Group 1. For each parent group, one parent of the student groups was unable to attend the focus group meetings. The final two Groups, 5 and 6, were comprised of special educators who had taught special education for at least five years. Group 5 educators, seven in total (five females and 2 males), worked at the transition/vocational center with young adults 18+ years of age; Group 6, ten (eight females and two males), were special educators at high school settings.

It is important to note that the author relied on self-reporting, supported by the special education coordinator or department chair, on determining the group formation. Interestingly, this participant selection was an enlightening process. For example, regarding the composition of Group 1, 10 parents believed that they were their child's legal guardian. Four of these individuals, however, did not have the proper documentation. One of these parents stated "He is disabled-I'm his parent-I don't need a judge to tell me I'm his guardian." Three other parents had similar responses and were surprised to learn from the director that guardianship is a legal, court, process. These parents and their adult children did not participate in the focus groups.

Procedure

Focus groups, commonly used in the business and marketing arenas, were selected for this educational study as they provided an avenue to obtain comprehensive, in-depth diverse perspectives from key stakeholders in areas not previously investigated, guardianship and self-determination issues. In this study, the key stakeholders were young adults with disabilities who reached the age of majority, their parents and educators. As with most focus groups, the aim in this study was to form groups comprised of individuals who shared a common experience, and learn from them

(Vaughn, Schumm, & Sinagub, 1996). Although it is difficult to generalize the findings of focus groups, the method was selected so that complete and in-depth understanding of perceptions from multiple viewpoints could be obtained (Vaughn et al.), and perhaps more importantly, launch interest into and direction of future research.

Prior to each focus group, every participant received consent forms (and for Group 1 assent forms) and a list of the focus group questions. The intent of presenting the questions ahead of time was to establish a sense of trust between investigator and participants. All focus groups were held in a district administration conference room, a central location to all participants. The author of the study facilitated each focus group and an assistant recorded responses. At the beginning of each session, ground rules for the focus group were presented. Main rules included that (a) there were no right or wrong answers, (b) what was said was to stay among the participants, and (c) everyone was encouraged to speak freely such that each question could be comfortably and adequately discussed. The school administrator stayed with each group to ensure everyone felt at ease, then left once the ground rules were established. Each meeting lasted between 60-90 minutes and sample questions posed to each group can be found in Table 2. Following the focus groups, each participant was offered a gift certificate of \$25 as a way to acknowledge their participation. All meetings were audio-taped and then completely transcribed.

Coding

Transcribed information was analyzed in two phases. Phase 1 occurred once the focus group meeting tapes were transcribed. As a foundation for determining themes, data were categorized using the focus group questions as an outline. That is, data for students (Groups 1 and 2), parents (Groups 3 and 4), and educators (Groups 5 and 6) were sorted by group make-up, under each focus group question. Per each group session, at least 25% of the transcripts, randomly selected passages, were coded by two individuals, the author and an assistant. When inter-coder reliability was established at 85% (or higher) the remaining

TABLE 2

Focus Group Questions

Common key questions across focus groups.

- 1) What is the first thing that comes to mind when you hear the term guardian?
- 2) How does someone 18 years of age and older get a guardian?
- 3) What are your experiences, if any, with someone who is of legal age and has a guardian?
- 4) What, if any, guardianship alternatives are you aware of, and how did they work?
- 5) What type of curriculum does your school emphasize? (academics, life-skills, self-determination skills)
- 6) Where did you first learn about guardianship as it relates to adults?

transcripts were coded by the author. Discrepancies were discussed between coders until 100% agreement could be reached. Phase 2 of the analysis was performed by the author. In this phase, a content analysis was completed such that issues and concerns were sorted into main and sub-themes that went beyond the focus group questions. Key words, sentence sections, and complete sentences from the focus groups were used as units of analysis, which were sorted and grouped. Once all main and sub-themes were coded, data were organized to allow for comparisons between groups, as well as to previous research findings. Unique responses are presented as they are considered to be new contributions to the literature.

Results

Interestingly, findings revealed that there were more common responses and issues across the three groups (students, parents and educators) than differences. Therefore, common results across the three groups are presented first, followed by unique group findings. Regarding student responses, it has been cautioned that the validity of responses by individuals with cognitive impairments during interviews may be threatened by a number of biases (Heal & Sigelman, 1995), including acquiescence, the disposition to agree or answer

“yes” regardless of the question asked. Therefore, the validity of an interview response from persons with cognitive impairments is dependent on how they are asked, and/or the format of the question. With this knowledge, questions were carefully phrased during student focus groups to circumvent potential acquiescence bias.

Common Findings Across Groups

Guardian defined. When asked “What is the first thing that comes to mind when you hear the term guardian?” Six students, five parents and seven educators reported that they saw a guardian as someone who “protects” or “takes care of” another. One of these educators stated “I view a guardian as someone who is legally and morally bound to seek and ensure the best interests of another person.” On the other hand, five students, six parents and four educators envisioned “someone who takes over” or “is in charge of” someone. Three teachers indicated that they thought of someone who is responsible for children (under 18) who may or may not be a biological parent; two said “someone who assists someone” and one person said “not really sure.”

When asked whether differences existed between parents and guardians for adults, students with guardians, their parents and a supermajority of educators thought there were no differences. Seven educators, however, thought the motivation may be different as suggested in this statement: “Both parent and guardian should be doing everything possible to ensure that the needs of another person are met; however, a parent usually does so out of love for their child and a guardian doesn’t necessarily have to love their charge.” In response, one educator added:

When a student is of legal age, their parent relinquishes the power to make decisions for them. Legal age adults have the legal right to make their own decisions that will affect their future. The term “guardian” implies that the legal age adult is unable to make decisions and therefore is unable to. Their guardian will determine whether or not they seek employment, where to live, and even whether or not they might seek additional education or training.”

The remaining students stated that parents might be “bossier than a guardian” but they, like their parents, thought parents would be there to help out when needed.

Guardianship process. When asked, “How does someone get a guardian if they are of legal age?”, all students and their parents knew that it involved the courts. Six of the 17 educators stated “I don’t (really) know.” The other educators stated that the court or a judge is involved, but only four educators seemed to fully grasp the legal process. One educator stated “Typically, if a parent feels that a student is unable to make their own decisions, then that parent would petition the court requesting that power be granted to them so that they may remain making decisions for that student.” In response, another educator added:

Someone has to petition the court and the court assigns one. I’m assuming there is a process, but do not know for sure what process if any investigates how fit the guardian is to serve. I believe if the parent wants some say in the process or expects one will be needed, it should be started before the 18th birthday. A person who is of legal age automatically becomes their own guardian unless someone petitions the court, regardless of competence. Information must be provided by the petitioner to the court, like medical documentation that show incompetence, like doctor’s statements and medical or psychiatric information. A probate judge is who decides and assigns a guardian if one is needed.

One of the six educators unsure of the guardianship process exclaimed, “Wow, I’m learning so much from being here [in the focus group].” In response, another educator said “I didn’t realize until now how much I didn’t know.”

Guardianship alternatives. Some groups (Groups 1, 3, 5, and 6) had limited awareness of alternatives to guardian appointments. These individuals did not recognize that instead of guardianship, family and friends could be consulted for advice when decisions needed to be made. In Groups 3, 5 and 6 many participants openly wondered whether they may have acted differently, regarding the

IEP section which discusses age of majority, had they known then all the information that was being discussed during the focus group. Groups 2 and 4 were aware of several alternatives, the main being family and friends, power of attorneys and representative payees. Five of the seven students in Group 2 had specialized checking accounts. Two of these five students shared “I can’t write checks. My mom writes it out for me. It is in both of our names – we both have to sign the check,” and “My sister can help me too when we go shopping, she writes the check and has me sign it at the bottom.” Another student from this group said “I believe my mom is my power of attorney. That means she’ll help me make money decisions-doctor, dentist, school decisions, things like that. Yeh, I am pretty sure my mom is my power of attorney.” The mother of this student confirmed that she did have power of attorney to make medical decisions, but stated she has not needed to use it.

District curriculum emphasis. All groups of participants were asked what they perceived to be the district’s emphasis on the transition process, teaching life-skills, in addition to self-determination and self-advocacy skills. Here, the majority of teachers indicated that as a whole, the district did not emphasize these areas, rather they perceived that specific teachers at specific grade levels (secondary) were emphasizing them. Not surprisingly, 100% of the educators in Group 5 stated their school was dedicated to the transition process, teaching life, and self-determination skills. They also had a curriculum that focused on students’ abilities to make choices, set goals, and engage in problem-solving. The district, all 17 educators stated, had its main emphasis on academics and high test scores on the state assessment. Only the educators in Group 5 indicated that they addressed guardianship to a limited extent, and the others all stated that this was not addressed beyond the checklist item found on the IEP.

All students in the two groups stated that they were involved in their educational program planning (including the IEP), and received year long self-determination skills training. To check for student understanding of self-determination, students were requested to give examples of how they were self-determined. One student shared that “We talk about human rights and

legal rights – I voted.” “Yeh” another student stated “They teach us to say what we want – but they don’t always listen.” Finally, one student said, “We get to talk at our IEPs if we want – tell them what we want and stuff.” Essentially, the students all perceived that they exhibited self-determination, and parents and educators perceived they promoted students doing this. All groups, however, did not view guardianship as being in opposition to self-determination. No one recognized the disconnect. One educator shared “I never put it together—until now.” Another teacher said, “I just saw the IEP check area, ‘a guardian has been appointed by law’, responded, and moved on to the next part of the IEP.”

Final thoughts. The advice offered by all three groups was similar: be involved, be informed, stay current, listen, collaborate, and encourage children/students to advocate for themselves. One parent, who was a guardian of a student in Group 1 shared “Students can still make mistakes, even when they have a guardian; for parents, guardianship is more of an assurance that we still have a say in our child’s life.” Another parent in the group stated “Some students get taken advantage of and a guardian may help, not sure.” Interestingly, two teachers shared that even though they want their students to self-advocate, “students aren’t really allowed to make choices and are taught helplessness.” Students on the other hand said “We are adults. They need to accept that,” “they need to listen,” and “they [teachers and parents] should put themselves in our shoes sometime.”

Unique Group Findings

Students with guardians. The students in Group 1 first learned about guardianship at an IEP. A teacher at their IEP meeting said “Do you have a guardian?” From that point forward, their parents went to the court to file a guardianship petition. “I think my mom told me we had to go to court and there was paper work and stuff we had to fill out.” All students relayed that going to court was “scary” as they had no prior experience with the court system. One student shared that the judge said she needed a guardian because “maybe you could make the wrong decision and they [the guardians] will try to guide you where to go.

Like that’s not a good decision-try to make another one. Maybe they’ll help you with how to dress. Like that’s got a spot on it, or that’s wrinkled, go take it off, and put another one on. Things like that.” Another student added that having a guardian means “You have to do this thing they say and sometimes you don’t feel like doing it. I always listen to her [the guardian]- sometimes I don’t want to listen . . . Like she said you have to study now and I say no I don’t want to study, but I do anyway.” Another student stated that she and her guardian (her father) “Sometimes have disagreements but work it out.”

Parents. Across both groups of parents, it was clear that they had great concern for their adult children. They reported that they constantly worried about the decisions their children made or that they would be taken advantage of. Sample transcripts that reflect their concerns included: “He is just so trusting – I think he’d give his shirt away” and “I hate to say this, but I don’t want the schools to pull a fast one.” Their death, the parents’, was also a common concern across both groups. One person shared “the transition stuff – the schools basically are all gloom, doom, I’m gonna die soon – it is scary – who is gonna take care of my son when I’m gone?”

Interestingly, all five of the guardians in Group 3 stated that they obtained guardianship because, as one parent shared, “I thought I was supposed to do it.” Guardianship related information was sparse, and all five indicated that they did not believe they were really informed about the process until they went through it. All parents in this group found it difficult or “devastating” to say their child was either totally or partially incompetent. Even during the focus group, they questioned the need for guardian appointments, as they did not perceive they needed to “use the power” other than signing permission slips or IEP forms. Parents in Group 4 essentially had the attitude that “just because my daughter is slower than her brothers and sisters doesn’t mean she shouldn’t take responsibility for her actions or that she can’t decide things on her own.” And another parent from this group added “We all make mistakes, and we all need help sometime – but that doesn’t mean we need guardians.”

Educators. When asked how they learned about guardianship, most educators that had knowledge about guardianship, reported that they learned about it on-the-job. Some did, however, have personal family experiences. Two had learned about the issues from previous jobs (nursing home assistant). On-the-job training, however, was limited to the evening presentations created for families. Teachers could attend if they wanted. Of the teachers in the focus groups, two attended such presentations, but these were also the two who had an understanding of the process. In terms of formal teacher preparation, it was found that a supermajority (70% or more) learned about the transition process, strategies for teaching students self-determination and self-advocacy skills throughout their teacher preparation program. That is, the issues were discussed briefly across all of their special education courses. Guardianship and its alternatives, however, were not addressed for over 60% of educators. For those where guardianship was addressed, it occurred for no longer than 45 minutes in one class of one 15 week course. Lack of preparation was clear. Some educators speculated that the lack of preparation was due to the professors' limited knowledge, or concern that they would be perceived as giving out legal advice, hence guardianship was a topic best left un-discussed.

When asked about their experiences with guardians, the following situations were shared by teachers:

Doing permission slips – it is usually a big deal to get a permission slip signed if they are not their legal guardian - whereas other students are 18 and can sign it themselves.

This past year, I had a student who was almost 20 years old and her mother was her appointed guardian. Her mother made all, and I do mean all, decisions for her. My co-workers and I were so disturbed by the relationship. I had known the student for years and felt that she had extremely regressed in all aspects. The young lady that I was working with had always expressed a desire to pursue her education. Sadly, I know that my ex-student is continuing to remain at home with no tangible future in sight. I truly believe that it is her mother

that is unable to function independently of the student; not the other way around!

When a father came to visit our school for the first time he was under the impression that he was the guardian because his child had a disability. So at that point when we asked him for guardianship papers he was like - well what do you mean? I don't know what those are; I'm his guardian though. So immediately he wanted to know how to get guardianship. A lot of parents don't know the advantages and disadvantages of guardianship. They want a resource where they can contact and find out if they really want guardianship. I think a lot of them don't know much about it - they don't know they need to go to court, they don't know if they should or shouldn't.

Discussion and Implications

By using focus groups, this study is the first to examine the perspectives from three key stake-holders: (a) young adults with disabilities who either have or do not have a legal, court appointed guardian, (b) parents of young adults who have disabilities, and (c) educators who work with young adults and their parents regarding issues surrounding age of majority, transfer of rights, self-determination, guardianship decisions and alternatives. With the trend of encouraging students to be self-determined, it is crucial that educators and families examine the extent to which self-determination efforts are potentially being undermined by guardian appointments. Major findings from this study revealed that the majority of participants (a) perceived that they exhibited/promoted self-determination; (b) did not recognize a disconnect between self-determination and guardianship; and (c) had limited understanding of guardianship and its alternatives. As noted earlier, focus group findings should be considered more as discovery than conclusion (Vaughn et al., 1996). With this in mind, it is believed that the results of this study provide useful information for educators and families, and important implications for practice.

On-going transition awareness. This study worked with families in a district considered to have quality transition services. Even with this

reputation, findings from this study are consistent with those where parents believed they lacked the knowledge with respect to post-school issues (Chambers, Hughes, & Carter, 2004). While it was believed that the district worked with in this study had exemplary transition services in place, confusion, lack of information and disconnects were observed. This was evident during the selection of focus group participants, as several parents did not realize they were not legal guardians of their adult children. Parents and educators who did participate in the study also seemed to have questions, which may have occurred for variety of reasons – lack of preparation, fear of being sued if perceived as giving legal advice, fear of harm coming to students, or simple ignorance. The findings in this study are similar to those of Thorin, Yovanoff, and Irvine (1996). That is, the transition to adulthood is a challenging time for families of youth, including those who have disabilities. The parents of both groups in this study struggled with wanting to create opportunities for child's independence, while at the same time had concerns for their child's health and welfare (Thorin et al). Similarly, they had concerns that their child's life could include potential exploitation.

Educators and families must be offered a variety of approaches to discuss guardianship and its alternatives. Some individuals may prefer to receive newsletters (electronic or paper), whereas others may prefer to attend workshops. Other means for providing guardianship/alternatives information could include (a) providing workshops/presentations on transition issues for both families and educators, (b) connecting families with other families who have elected to go through the guardianship process and maybe more importantly with families who did not, and used alternatives, (c) arranging visitations with members of the judiciary such that differing worlds can learn from one another, (d) creating training videos and modules for people to check out, and (e) encouraging the use of person-centered planning, alternative exploration and mediation. Resources need to be available, and not just presented in one three hour class or workshop. Educator preparation programs may need to consider how much

emphasis has been placed on self-determination, guardianship and its alternatives.

Examining emphasis on self-determination. Self-determination has been (a) viewed as an educational outcome, (b) defined in relation to behaviors exhibited by an individual, and (c) realized by individuals throughout life-long learning, opportunities, and experiences (Wehmeyer, 1996). Much of the research that has been done on self-determination, however, has been directed toward students participating in their IEPs. In the group of students who participated in the focus groups, all students reported they attended, and several perceived they had major roles at their meetings. Teachers and parents also verified this and stated that they encouraged student involvement. These findings differ from those of Katsyannis, Zhang, Woodruff, and Dixon (2005) who studied data from the National Longitudinal Transition Study 2 (NLTS2), where professionals and educators did not necessarily act on their beliefs.

When the section on age of majority and transfer of rights on the IEP form was discussed, however, focus group participants failed to recognize that guardianship contradicted their efforts to promote self-determination. Unlike findings by Wehmeyer, Agran, and Hughes (2000), teachers in this study were familiar with self-determination and felt it was important to teach. Wehmeyer et al. found teachers in their study questioned whether students would benefit from instruction and a minority of teachers they surveyed indicated that self-determination issues were addressed on IEPs. The teachers in this study, however, took the Wehmeyer et al. quote to heart "The fact that someone may not become completely independent in his or her decision-making does not mean that he or she cannot become less dependent or more involved in decisions that impact his or her life." (p. 65). These teachers and parents, as verified by students, also invested heavily in preparing students for participation in the transition process across the students' life-span, instead of simply preparing students for one or two school meetings. Similar investment was not found in other studies such as the one conducted by Thoma, Rogan, and Baker (2001). In this work, individuals often sought to ensure that self-determination efforts were

sustained beyond the confines of the IEP. Even with this, however, they did not fully appreciate the disconnect between self-determination and guardianship.

Considering mediation. In addition to the alternatives presented in Table 1, mediation is a form of intervention that may help an individual with disabilities remain autonomous and prevent unnecessary guardian appointments (Special Committee on Aging, United States Senate, 1993; Wood, Dooley, & Karp, 1991). Mediation is a process that involves communication and negotiation between parties such that options can be discussed and mutually acceptable plans for action can be established. It is also a time where people can learn from one another on topics that may not ordinarily be addressed in educational planning (Devlieger & Trach, 1999; Mueller, Engiles, & Peter, 2003). IDEA requires that states offer mediation whenever due process hearings are requested in an effort to resolve disagreements about educational programming. Not only are parents involved in mediation, but it has been suggested that students should fully participate in mediations regarding the educational services they receive (Mueller et al., 2003). Application of mediation for young adults with developmental disabilities in relation to transfer of rights, guardianship and use of alternatives, however, has not been previously presented. Prior to the student reaching the age of majority, it is possible that mediation regarding guardianship would be beneficial. Benefits to students could include (a) maintaining their legal and civil rights, (b) learning how to address issues in a constructive manner, (c) appreciating that people can have differing points of view, and (d) exhibiting their self-determination skills. Should it be determined that mediation would assist with guardianship decisions, it is essential that a mediator be found who has the skills and knowledge regarding the judicial system, disability and collaboration. The mediation process is time consuming and at this time, there are no data available suggesting whether mediation has helped a situation with regard to young adults with disabilities and guardianship issues indefinitely, or if the petitioner went to court following the mediation activities. Mediation, however, is a viable option for not only guardian prevention, but for other

life issues as well (Special Committee on Aging, United States Senate; Wood et al.).

Limitations

Although this study provides important new information, its format presents many limitations. For example, in the selection of participants for the focus groups it is possible that the participants were not truly representative, hence restricting the ability to generalize these findings to other families and teachers. Future research should include a larger number of individuals to minimize the influence of factors unique to these participants. Another concern is that information was gained from participants based on self-reporting. Although confirmation of perceptions were somewhat addressed by asking similar questions to all three groups of participants, direct observation to determine the extent to which responses could be confirmed would have made the results more credible.

Future Research

One purpose of focus groups is to develop directions for future research. Based on the results of these focus groups, major findings included that the majority of participants (a) perceived that they exhibited/promoted self-determination; (b) did not recognize a disconnect between self-determination and guardianship; and (c) had limited understanding of guardianship and its alternatives. Hence, more research in these areas is needed. Perhaps a nationwide longitudinal study could add questions about how guardianship and its alternatives are being handled as there is no comprehensive data base that addresses these issues. A related area to investigate is the extent to which IDEA and IEP forms are being interpreted as promoting guardian appointments. We also must learn what school personnel are saying, if anything, to families about these areas.

Summary

Involvement of students in the transition process is critical, as is the collaboration between families and school personnel. By determining the student's and family's expectations,

knowledge, and concerns, transition services can be better aligned with their values and needs. Although there is merit to discussing transition-to-adulthood issues such as employment goals, residential living situations and recreation/social options during educational planning meetings, guardianship and its alternatives also need to be discussed. Such information should be given well before a student reaches the age of majority. In order to effectively deliver transition services, all parties involved need to have information about guardianship and, perhaps more importantly, its alternatives. Communication and collaboration are key to helping youth become and remain autonomous adults.

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