

## Self-Determination in Relation to Having or Not Having a Legal Guardian: Case Studies of Two School-Aged Young Adults with Developmental Disabilities

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*Abstract: IDEA mandates that all rights accorded to parents transfer to students when they reach the age of majority, unless their competence is questioned. Using case studies, this research examined the concern that when competence is challenged, guardian appointments may occur, thus negatively impacting the self-determination of school-aged young adults who have developmental disabilities. The assumption that a young adult who had a full legal guardian would exhibit fewer, if any, self-determination skills in comparisons to a peer who did not have a legal guardian was investigated. Findings include (a) values, beliefs, and knowledge impact guardian roles, and (b) more research is needed to determine the impact IDEA age of majority and transfer of rights mandates are having on families as well as school, law, and agency service providers' interpretations and actions.*

The importance of developing self-determination related attributes in youth and young adults with disabilities is emphasized in legislation (e.g., IDEA; Rehabilitation Act Amendments of 1992 and 1998), as well as in an abundance of literature (e.g., Algozzine, Browder, Karvonen, Test, & Wood, 2001; Test, Fowler, Brewer, & Wood, 2005). In addition, there is a growing body of research which is providing evidence that self-determination does positively impact employment outcomes (Wehmeyer & Palmer, 2003); post secondary education (Field, Sarver, & Shaw, 2003); and overall quality of life (Wehmeyer & Schwartz, 1997). Despite the efforts directed toward promoting and increasing self-determination of youth and young adults with disabilities such that they can communicate their preferences, interests, and advocate for themselves, little is known about how self-determination is being impacted at the time students reach the age of majority, and become legally responsible for their decisions and actions. When a student reaches the age of majority, IDEA mandates

that all the rights accorded to the parents are to transfer to the student unless the student is determined to be incompetent by State law, or considered unable to provide informed consent with respect to educational programming. When competence is in question, States are responsible for establishing procedures for appointing an individual (e.g., parent) to represent the educational interests of the student [614(d)(1)(A)VIII].

To date, there is no known investigation that examines the procedures States have established to address the mandate, who is determining competence, how it is being determined, and what criteria is being used to determine it. Concern has been raised that when students are reaching the age of majority, and their competence is questioned, guardian appointments might be unnecessarily sought (Millar, 2007, 2003; Millar & Renzaglia, 2002). As it applies to adults, guardianship is a process when a judge appoints someone (a guardian) to make decisions for and handle the affairs of another (a ward) who is believed "partially" or "totally" incompetent (Bulcroft, Kielkopf, & Tripp, 1991; Lisi, Burns, & Lussenden, 1994). Dependent on a court order, guardians can assume complete or limited control over decisions related to the ward's residence, educational services, voca-

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tional training, medical treatment, and participation in contracts (Lisi et al.).

It is important to emphasize that legislation, which is created by each state, has differing levels and scope of guardianship. It might be expected, therefore, that individuals who exhibit few if any self-determination skills would need a full (plenary) guardian to make the majority or all decisions for their ward, in contrast to individuals displaying some self-determination skills who would be appointed a limited guardian to make decisions on specific issues (e.g., financial decisions) (Stancliffe, Abery, Springborg, & Elkin, 2000). It may also be expected that an individual who does not need or have a guardian exhibits self-determination skills. Essentially, individuals who have a full or partial guardian could be perceived as having no or limited capability to provide informed consent or to exercise control over their life in comparison to persons without guardians (Abery & Stancliffe, 1996).

Interestingly, the research on the extent to which guardian appointments impact self-determination is limited, and in many instances dated. In one topic related study, Lindsey and Luckasson (1991) suggested that service providers frequently allowed or encouraged family members to make decisions as if they were the guardian for an individual with a disability who did not legally have one appointed. This suggests that some equate disability with incompetence and limited ability. In another study, Lindsey (1994) evaluated 69 adults, who had developmental disabilities capacity to give informed consent to community residential placements. In this study, it was found that there were no significant differences regarding the ability to give informed consent between individuals who either had or did not have a court appointed guardian. This brings to question the need of legal guardian appointments. In a more recent study, Stancliffe, et al. (2000) attempted to compare self-determination competencies demonstrated by adults with disabilities by using results from self-determination related scales completed by residential agency care providers. Stancliffe et al. anticipated that adults with disabilities who had no guardian would be perceived as exhibiting more self-determination competencies and control over their lives in comparison to

their peers who had guardians. Findings revealed that the level of personal control exhibited by 76 adults (ages ranging between 20.8 to 71.7, with the average age of 37.3,  $sd = 11.6$ ; full IQ mean scores ranging from 42.3 to 62.6) who did not have guardians were perceived by agency personnel as higher than those individuals who had either partial or full guardians. The authors concluded that their findings "provide objective evidence that individuals with less restrictive substitute decision-making arrangements actually do exercise greater control over their lives." (p. 417). Given the findings of the studies noted above, it is clear that more research is necessary that examines the complexity of guardianship.

Further, when considering IDEA, and the impact guardian appointments may or may not have on the rights of individuals, it is clear that research in the area of guardianship and its impact on self-determination is needed, particularly with respect to school-aged adults who have disabilities. Interestingly, the relationship has been rarely been examined. Within the last 10 years, Millar, and colleague, (Millar & Renzaglia, 2002; Millar, 2003) conducted studies that investigated guardianship in relation to young adults who had developmental disabilities that were in the transition phase of their education. By reviewing over 220 guardianship court files, it was found that guardians, as stated on court petition forms most often completed by parents, were needed because the student (a) reached the age of majority (18 years of age), and (b) had limited or no ability to make decisions. It was also found that the evidence used to "prove" "incompetence" was unclear, and that in 100% of the cases a guardian (most often a parent) was appointed. Review of annual reports submitted to courts by guardians found that the majority of wards' "conditions" of "having limited or no capacity to make decisions" reportedly remained unchanged following guardian appointments.

In a related investigation, Millar (2007) conducted focus groups with secondary special education teachers, parents (both who were legal guardians and who were not), and young adults with disabilities (both who had legal guardians and who did not) to determine their knowledge of guardianship and self-determination. It was learned that the par-

ticipants (a) believed 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. Another finding was that when asked how families first learned about guardianship, students and parents shared that it was at an IEP. They shared that a teacher asked “Do you have a guardian?” when it came to that section on the IEP form. From that point, parents went to court because they thought they were supposed to do it and began the guardianship proceedings without truly understanding what guardian appointments entailed. Parents also reported that they found it devastating to state their son or daughter was incompetent to make decisions. In hindsight, these parents questioned whether a guardian was actually needed.

Based on a review of guardianship and self-determination literature, it was learned that there has not been a study that addressed why some school-aged young adults with developmental disabilities do not have a guardian appointed, while others do. This current study, therefore, builds on the previous work as it provides an understanding of the experiences students and families encounter at the time students with developmental disabilities reach the age of majority and guardianship is considered. In addition, a purpose of this study was to examine why or why not parents elected to become guardians, as well as examine expectations that those with a full guardian were less likely to be self-determined and experience personal control than those with no guardian. Ultimately, it was hoped that through a case study approach, an in-depth view to guardianship and self-determination would lead to increased awareness as to what guardianship is really about, and the extent to which a guardian impacts a young adult’s life. This is the first known study that explores how families, with young adults with similar educational experiences and special education school labels, came to very different conclusions about guardianship when they attended an Individualized Education Program meeting (IEP) and it was time for the parents’ rights to potentially transfer to their adult child.

## Method

### *Participants and Settings*

Kevin and Jack, both 21 years of age, were purposively identified for this study as they both (a) had the special education eligibility label of “moderately cognitively impaired” based on results from IQ assessments, adaptive behavior scores, and onset of the disability; (b) were over the age of 18; (c) were eligible for services including vocational rehabilitation, social security income, Medicaid, Department of Mental Health - Services of People with Developmental Disabilities (DMH); and (d) had high levels of parental involvement. One essential criteria was that one individual (Jack) had a full (plenary) guardian, while one (Kevin) did not.

The two young men lived in the same community, attended the same high school, and had the same teachers throughout most of their schooling. Essentially, these two young men had grown up together, via their special education, since the age of four. The suburban community where Kevin and Jack lived had a population of over 40,000. The high school enrollment approximated 500, where 90% of the student body was Caucasian. The school district had a solid reputation for preparing students for college, and also had a reputation across the region and state for promoting supported community living and job experiences for individuals who had developmental disabilities. The school’s curriculum emphasis was on the expanded development of Kevin’s and Jack’s life skills (e.g., cooking, cleaning, money use) and vocational training. Particular emphasis was placed on teaching them to further develop their self-advocacy and other related self-determination skills. At the time the study began, both were in their last year of public schooling where they attended school for two to three hours a day, then were in the community – either working or recreating.

Both young men, and their parents, had opportunities for becoming aware of the various transition services available during and after high school graduation. Opportunities to explore various jobs, options, and agency services were available to Kevin and Jack, as they were for all students who received special

education services. Despite these similarities, each young man and their parents responded differently to the age of majority and transfer of rights issues. One family, Kevin's, secured a house, obtained agency support, and were adamant that no legal guardian be appointed. Another family, Jack's, chose a different path. By family choice, the young man had no agency services and lived with his parents, who were also his legal guardians.

For Kevin, Mary his mother shared the majority of information from the parental point of view. Although Kevin's father was involved in his son's life, Mary stated "Oh, I can speak for him." Mary was initially contacted by the district's transition coordinator about the study, then introduced to the author. Mary was immediately agreeable to participate in the study and gave the author the names and phone numbers of people to contact to set up times to meet with Kevin. A total of six individuals, in addition to Kevin, were interviewed who included: Mary (his mom), his dad, and the school Transition Coordinator. Kevin had a case manager through the Department of Mental Health - Services for People with Developmental Disabilities (DMH) whose job was to make sure Kevin had the supports he needed. The case manager, Tyler (Kevin's personal care assistant funded by DMH), and Simon (Kevin's job coach who's position was funded in part by the school and vocational rehabilitation) were also study participants.

In Jack's situation, the father granted the family participation in the study, however, made it clear that both he and his wife would attend interviews together. In all, four individuals, in addition to Jack were interviewed: his mom, dad, employer, and the school transition coordinator.

The transition coordinator for the district was contacted by the author, following the advice of the district director of special education, and given the participant criteria, who then helped identify participants. As a point of reference, the transition coordinator worked with the participants for a three year period, and had the responsibilities of being a teacher and work study coordinator. This individual was also responsible for arranging presentations throughout the school year on various topics, including social security, and living arrangement options.

### *Data Collection*

Several methods and data sources were utilized to collect, elaborate and verify information. Main data collection methods were the use of open-ended and semi-structured interviews with participants (via telephone or in person) and on-site observations. Documents and records (e.g., Individualized Education Programs, evaluation reports, and student performance data provided by the transition coordinator) were also reviewed.

Based on the recommendation of the transition coordinator, the author conducted the first interviews with the parents by telephone. Initial phone calls to parents lasted no more than 30 minutes, during which the purpose of the study was reiterated and arrangements for further interaction were made. A request for background information was also made such that the author could review documents related to health, school, employment and non-related school activities (e.g., recreation/leisure, social activities). It was also shared by the author why their adult child was selected for participation. Subsequent interviews lasted between 30 minutes to 2 hours, and were tape recorded and transcribed for data analysis purposes by either the author or an assistant. Sample questions posed to parents, and other participants, included: (a) what type of curriculum was emphasized at the school (e.g., life skills, academics, self-determination skills)?; (b) when did they first learn about guardianship with regard to their son?; (c) what experiences did they have that related to guardianship?; and (d) what type of transition information was provided by the schools, in particular to self-determination, guardianship, and guardianship alternatives? Throughout the study, questions were modified, and responses were clarified regarding the above noted topics.

On-site observations occurred approximately two to seven times a month (ranging from one to three hours per observation) over a ten month period that began in late August (the beginning of a school calendar) and ended in early July. Observations occurred at the young adults' home, school, place of employment, and various community settings the young adults frequented (e.g., mall, community recreation center, fast food restaurant).

Field notes were used to document the observations. During most observations, the author attempted to minimize impacting or influencing daily routines, and in most situations, stood or sat back from the student, having minimal direct interaction with others. There were times, however, when the author did interact with the student and other participants to clarify what was observed.

### *Analysis*

Data analysis began immediately following the first interviews by reviewing the tape transcripts. Initially the framework, or outline, for determining themes was the responses to questions (e.g., when did you first learn about guardianship?). Specifically, under each question that was used somewhat as a header, responses were sorted and categorized first regarding Kevin and then Jack. Following transcript review, observation field notes were then added to the interview data. The author and the assistant who transcribed interviews, separately reviewed at least 20% of randomly selected passages and field notes to establish inter-coder reliability. Reliability was high (over 85%), however, after the addition of field note observations, it was decided that the question/response approach framework for determining themes was not adequately reflecting the issues the students and their parents encountered. That is, the framework seemed to fragment the findings. Therefore, individual case studies were created, with two main themes, "Kevin: It takes a Village" and "Jack: It takes a Family." Documents (e.g., school records) were used to confirm and supplement the information collected during interviews and observations.

The initial case studies were shared with the young men and their parents (members checking) so that they could review and confirm the information. Following their review, and with little requested revision (nothing of content, rather grammatical concerns), the final case studies were completed. Prolonged engagement in the environments students frequented occurred, as did triangulation of data and members checking on the analysis of interviews and observational field notes, to ensure authenticity and credibility (Bogdan & Bilken, 1998; Lincoln & Guba, 1985). In the

subsequent section, each case study is presented. Kevin did not have a legal guardian, and Jack's father was his legal guardian.

### **Case Studies**

#### *Kevin: It Takes a Village*

At the time the study began, Kevin was a 6 foot tall 21 year old Caucasian male who appeared physically fit. When he was born, there were no apparent signs that he had a disability, and it was not until the age of three that his parents noticed delays, and began an early intervention program sponsored by the school district and family advocacy organization. By age nine, Kevin was found by a school psychologist to have an IQ and an adaptive behavior score that placed him in the "trainable mentally impaired" school category. As an adult, Kevin continued to lack verbal communication skills that most same aged peers had, however, he did communicate his feelings verbally, as well as behaviorally. On occasion, Kevin reportedly was "aggressive" and struck others. Such actions were interpreted by his parents, school personnel, and personal assistants as his way of communicating that he "does not like what was going on." The transition coordinator stated "In a sense, his behavior shows his attempt to be self-determined." Even with his limited verbal ability, he was able to understand questions and express responses. On occasion during observations, Kevin appeared sleepy, and according to his personal assistant this was "most likely due to his medications" that were to help mediate his manic or aggressive behaviors.

*Home.* Kevin lived in his own home that his parents, Mary and Joe, bought for him when he turned 18 years of age, while he was still enrolled in the public school system. "We used his money - well what was to be his college money - to buy the house." His two bedroom house was selected such that it was within the city limits and near various retail and community options. Kevin's home was located near a community recreation center where he walked (with support from his assistants) and enjoyed playing basketball, swimming, and taking karate lessons. Although he could take the public transportation to various locales, his assistants often opted to drive him around.

“Its easier for me to take him than wait for the bus” said one assistant.

Kevin depended on the assistance from others to help him with cooking, cleaning, dressing and accomplishing many other daily living tasks. Personal assistants from community service agencies came in and out of Kevin’s home between 7:00 a.m. and 11:00 p.m. each day. A two-way intercom system was installed in the home so that Kevin’s nightly actions could be monitored from 11:00 p.m. until 7:00 a.m. That is, a person employed by a human service agency monitored Kevin such that if he got out of bed, he would be reminded via a speaker to go back to his bedroom. Kevin received SSI (monthly income via Social Security Administration) and Medicaid, and because of this, he was eligible for services from DMH, who took care of all the housecleaning, meal preparation, shopping, errands and laundry. Support was also offered when it came to bathing, dressing, and taking medication.

*Work.* Kevin’s jobs were mostly seasonal. During the fall and winter seasons, he worked at the community center doing janitorial and maintenance work. During the spring and summer months, he had a lawn maintenance and moving service in which he worked 20 hours a week. Throughout the year, he was scheduled to work at least 10 hours a week at a restaurant, clearing landscape or shoveling snow. The school district, in partnership with vocational rehabilitation services, sponsored a job coach, which Kevin and his parents interviewed and helped hire.

*School.* Prior to the afternoon work schedule, Kevin, under the supervision of his assistants, walked to school most mornings. For a two to three hour period at school, he worked on daily living activities (e.g., cooking, cleaning, recreating) in a simulated apartment, designed in a classroom. During the blocked time, Kevin had a semi-structured schedule where, during each half hour to 45 minute period, he was given a choice as to what he would like to do. As an example, between 9 and 9:30 a.m., recreation time, he could chose to play a card or board game. In addition to learning games, an aim was for Kevin to further develop his social and self-determination skills. Recreation and social interaction skills, like other daily living skills, were areas noted

on Kevin’s IEP, and data were collected in an effort to monitor his progress.

*Family values - no legal guardian appointed.* Mary and Joe, both retired, visited with their son regularly, at least once a week. Kevin fished and boated with his Dad and went to the mall and restaurants with his Mom. His parents also stayed in close contact with Kevin’s assistants and monitored his money. His older brother by two years, Peter, did not live in the state, however, he kept in contact with Kevin. Two months into the study, when the author phoned Mary to arrange an observation, she quickly interjected:

Boy do I have something to tell you about guardianship! We are at a ragged edge with this guardianship thing. I just got a phone call from the special education administrator. He said that Kevin was in an assault situation at school. He told me he couldn’t tell me anything more because I was not Kevin’s legal guardian - that because Kevin was his own guardian, he could not disclose any details of what occurred – He also went on to say that Kevin would not understand a report that detailed the situation and therefore would not give him the report either. This person had no right to make the determination of Kevin’s competence.

Mary volunteered regularly at a community family advocacy organization as a consultant to and an advocate for people with disabilities and their family members with regard to special education, community agency connections, social security income and other issues, including guardianship. Mary stated that she wanted Kevin, her son, to remain an individual who maintained all of his basic rights. Through her association with the family advocacy organization and school sponsored family transition topic nights, she learned that she could write a ‘letter of intent.’ A letter of intent is a document written by parents that describes the son’s or daughter’s history, current status and hopes for the future (Pierangelo & Giuliani, 2004). Although the document is not a legal one, judges and other parties can refer to the letter for guidance in understanding the wishes of the parents in regard to their son or daughter. Content areas of the letter can vary: including religion, sib-

ling information, medical history and care, recreation/leisure activities, financial information, employment and education. The letter Kevin's parents wrote stated that: (a) it was their intention that Kevin always be his own guardian; (b) if Kevin was ever involved with the court system in any way and his parents were unavailable, incapacitated, or deceased, he was to have the services of an attorney, not a court appointed attorney, working on his behalf; (c) either his parents or his trust would be responsible for the costs of an attorney, especially should there be guardianship issues, and (d) if an extreme emergency a guardian is deemed necessary, his brother Peter was to be appointed, however, should he be deceased, an individual approved by the family advocacy organization [NAME OF ORGANIZATION] was to be appointed.

Clearly, Mary strongly believed that Kevin should remain his own guardian. The letter of intent she and her husband wrote was copied and presented to all family members and organizations (e.g., agency case managers, school personnel) Kevin worked with and was also posted on the refrigerator in Kevin's home for easy access. "No one likes to be called or say that they are dumb, incompetent or incapacitated" which is something that does occur at a guardianship appointment hearing. She indicated that there are a number of ways in which Kevin, and other people who have disabilities, can have the support needed when making decisions, without having a legal guardian appointed. The alternatives for Kevin included the support of his family, friends, and agency support personnel; utilization of person-centered planning; and trusts. At one time, his parents were his representative payee, however, they opted to discontinue this as they no longer wanted to write out reports regarding his finances.

*Guardian defined.* To reiterate, having a guardian appointed means that an individual can no longer legally make decisions on his or her own behalf. Someone else does the decision making for them. Kevin did not have a court appointed guardian. Because Kevin had difficulty verbally sharing information, observations across environments occurred in order to get a sense of the decisions he made. At the school setting, it was clear that efforts were made for him to learn how to communicate

his wishes. In other environments, however, such efforts were not observed. Specifically, Kevin and Tyler (a personal assistant) were observed at Kevin's home and at the food court in local mall, near a fast food restaurant. On a daily basis during breakfast at Kevin's home Tyler made omelets and sausage for Kevin. Tyler was asked by the author if Kevin ever told him what he wanted to eat and if he ever helped prepare the food. It was observed in school that he was being taught how to prepare and cook simple foods (e.g., cereal and toast). Tyler shared "Well, I was a cook in the service, and I like to cook, so I pretty much spoil him and make him things. Most of his other staff makes him oatmeal." Kevin wiped his mouth with a napkin whenever Tyler told him to do so. After breakfast, Tyler placed clothes on Kevin's bed. Kevin was not observed picking out his clothes nor asked what he would like to wear.

Below is an example of the exchanges that occurred on Wednesday and Friday afternoons, when Kevin and Tyler regularly went to the local mall:

Tyler. "What do you want for lunch Kevin? Do you want a hamburger? One or two?"

Kevin raised two fingers to communicate his wishes.

Tyler. "What do you want to drink? Milk or coke?"

Kevin. "Coke."

Tyler. "No, let's have milk. I'll get you milk."

Tyler gave Kevin milk and himself a cola. Tyler indicated that he usually ordered Kevin's food for him. At one point, Tyler was asked by the author whether Kevin ever ordered his own food and the reply was "It is easier for me to do it." Tyler shared that he worked with Kevin for "about 2 years", and that he was just a few months older than Kevin. Essentially, both men had the same build (tall, lean and fit) and dressed similarly.

Tyler. "Kevin, take off your jacket" Kevin complied and took off the coat.

Regularly, it was observed that Tyler arranged Kevin's food on the table. After a few bites of his fries, Kevin asked Tyler about students and

teachers that they both knew at high school. Tyler shared that Kevin's recall of all his classmates and teachers impressed him. Following some discussions about school, Tyler unwrapped Kevin's cheeseburger. Kevin ate slowly, but interacted with both Tyler, and at times the author. When Tyler was done eating one burger, he asked Kevin "Do you want your second burger, or do you want to save it for later?" The response was "I want some now." Tyler, however, put the second burger in his coat pocket and said "No. Let's save it." The turnover rate for working with Kevin ran between 1 to 2 years. The longest time an attendant worked with Kevin was three years, on a part-time basis.

Simon was Kevin's job coach. Similar to what was observed at the mall and at Kevin's home, was also observed at the work place. Simon got the supplies Kevin needed to use to vacuum, mop floors and clean tables. When the transition coordinator was the job coach, an effort was made to provide the least amount of intrusion so that Kevin would become independent at the job site. Although Kevin did not ever become fully independent on the majority of steps he needed to do the job, he was independent at getting his supplies. Kevin's school job portfolio had a task analysis and data reflected Kevin's areas of being independent. When asked, Simon indicated that he was not concerned about the quality of Kevin's work because he would go behind him and complete the tasks when needed.

Mary indicated that on Mondays and Thursdays from 1:00 p.m. to 3:00 p.m., her son was scheduled to work at a restaurant to clean the landscaping and pick up trash. When observations were arranged to meet at the worksite, Kevin and Simon were at least 15 minutes late and on four occasions, Kevin did not show. Simon indicated that he, not necessarily Kevin, did not care for that job and so they did not go there on a regular basis. Such information was news to Mary when she asked how the observations were going. Mary worked with vocational rehabilitation counselor, DMH case manager and transition coordinator to ensure that Simon was helping Kevin become as independent as possible at the job sites.

### *Jack: It Takes a Family*

Jack, 21 years of age at the time the study began, and was planning to leave school at the end of the school year. He, like Kevin, began an early intervention program at the age of three. In fact, both young men were in the same early intervention program class, had similar IQ and adaptive behavior scores and the same special education school label. Unlike Kevin, Jack was noticeably small from the moment he was born. He was born two months pre-mature, had a brain tumor, and numerous medical scares throughout his life. He had a shunt initially placed when he was an infant. His parents could not recall the exact age of the first shunt, but they could recall that the shunt had to be replaced four times. Jack was also tube fed for the first year of his life.

Jack could have stayed associated with the schools until the age of 26 (state law), but Jack and his parents opted that he leave earlier as they felt he was not "benefiting from the curriculum." His mother shared "It was decided to leave school because he isn't progressing and there is no advantage to staying. He has reached his maximum at shopping, and all of the things that the kids do. The only thing we think we will miss is the social part." She shared that it would be difficult to keep her son busy and that they would try to get him to stay in contact with his friends, but that "it probably will be just too difficult." They planned to keep him socially involved with family functions and activities.

Jack was described by his parents, transition coordinator, and his employer as being "someone who is nice to be around as he is responsible" and "overall, a proper young gentleman." In terms of stature, Jack, a 21 year old blond hair, blue eyed man, was not quite four feet tall.

Father. We love being around him. He's very pleasant. We're very fortunate that we have him and that he is small—people think of him younger than he is. We see some people who are handicapped who don't look it, and it is harder for them because people expect a lot from them.

Mother. Jack is 21, but he is still my baby.

*Home.* Jack lived with his mother and father in a home that was located just outside the city limits. Deer and other wild life maneuvered through the family's 30 acres of land. In turn, the family, who had a long history in the area, continued to enjoy the animal activities. Although Jack and his parents attended presentations about living/housing options that existed in their community, they were satisfied and comfortable with maintaining their living situation. Jack indicated, as did his parents, that he was not in any rush to have a home away from his parents. Jack had his own room and spent time showing the author how he, with a little assistance from his mother, redecorated it. He picked out the blinds and carpet. He bought himself a rocking chair and cabinets for his room. He proudly showed the golf clubs he purchased. He played golf and went fishing with his dad, who was retired. Interestingly, Jack had his driver's permit and drove a car that had been accommodated by having the foot pedals extended so that his legs could control the gas and brakes. When asked by the author "Can you tell me about how you learned to drive?" Jack's response was "I wanted to drive. My Dad said you gotta take a class. I took a class." He drove himself to work "sometimes", with his father by his side, and to a city that was about 20 minutes from where he lived. Surprisingly, given his calm demeanor, Jack's taste in music was hard rock, which he listened to often. He had his own T.V., his own phone and he frequently took his parents out to lunch and dinner. His parents stated that Jack knew how to use his money "cautiously and wisely."

*Work.* Jack had a part-time paying job at a nursing home that he could keep upon school completion. His tasks involved providing fresh ice water to the residences and he reportedly liked it there. Jack was observed at the nursing home at which he worked three times a week. No assistance from vocational rehabilitation services or a specialized job coach were needed, nor desired by Jack or his parents.

*Family values – a legal guardian appointed.* When Jack was just about to turn 18, his parents filed a petition to become the legal guardian of their son. Jack's father began the discussion:

One of the things you asked about was for us to talk about guardianship and I've been thinking. I think you can break it down into two areas: one with the people who are more reliant on the government and SSI; and maybe people that can make it on their own and don't rely on the government. When you look at the people who don't rely on the government, such as ourselves, the advantage we find with a guardianship is we have authority and can make changes in Jack's yearly investments, the things that he does, and the things he buys. Now if you were not in the position that we are, I think the role of the guardian may change. Not sure exactly how. The difficulty that we have in trying to give you an assessment as to whether guardianship is a good thing-is that we've never been challenged on anything or had any problems because we take care of things ourselves, so it is difficult to give you plusses and minuses.

Unlike Kevin and his parents, Jack and his parents did not want any of the human service agencies involved in their lives. They did not get SSI or Medicaid, and did not wish to have Jack surrounded by personal care attendants. "Taking care of Jack is the family's responsibility. Not the governments, or anyone else's." When Jack's parents were asked how they learned about guardianship, his father stated:

Through the schools. It was through the transition coordinator that we found out. Something that I thought was most effective about the school program was the transition coordinator gave the parents information. Then us, the parents, could decide what we want: to take care of ourselves; or try to share those responsibilities. The reason the flag went up for us about guardianship is because of the medical situation. If we were in another city or state or something, they may not deliver medical attention to Jack. An attorney gave us advice one way. My brother is also involved with a handicapped child, as is our sister-in-law. They advised us against guardianship. We looked at it as what we felt that was best for our son. But again, we don't really know the plusses and minuses of it because we haven't been challenged. We felt that we had to have the

ability to make decisions in the medical area and investment area and just his general care. We felt much more qualified to make these decisions than to have the court make them. While Karen (mother) and I are both alive, we don't see any problems because the estate is very simple. In the future, there may be some problems and I'm not sure how guardianship might fit in. When we did this we had as many questions not to do it as we did to do it. Since we have done it, we think it's great because we haven't had any problems. However, like I said before, we haven't been challenged.

Jack's mother indicated that the only downside to being a guardian was that once a year they had to submit a form with the court, a responsibility they did not know about before they filed the petition. Both of Jack's parents indicated that the report had to be done in a timely manner and that from their view point it was an extremely confusing form. For the first two years, they had the report sent back to them three times, as it was not acceptable by the court.

They just needed to know what you've spent on him in the last year, and let them know if he's comfortable. That part is extremely easy. Where we've had trouble is trying to reconcile accounts from one year to the next, and carrying things forward with the trust we have set up.

Jack's parents indicated that they "felt bad that the court had to come back" to them to find out or have to ask for more information as to the balance from one year to the next. "We feel somewhat knowledgeable in this area seeing that we've been in business for a good part of our lives, involved with finance. We got thinking, if we've gotten in trouble with this, imagine the other people."

Jack's parents believe that "the Judge's court has been simply outstanding." This is their experience:

Author. You found an attorney that you felt comfortable to go through the process with?

Mother. Yes, we have our own attorney.

Author. Can you tell me what happened in the court?

Father. Well it was fantastic. The judge got Jack up on the judge's bench and let him take the gavel. It was very personal. We know the Judge very well.

Mother. Jack sat with his attorney.

Author. Separate from yours?

Father. Yes. So we had our attorney and then another for Jack to make sure that he was defended. I think that was a good thing. We wanted to make sure that he was represented by someone other than his guardian. I think it is required by the court. The attorney tried to help explain what he was getting into. If he was comfortable with us as guardians. Very deep questions.

Mother. Simple though. Jack would answer "yes" or "no." It was a great experience for him . . . different though . . . in the attorney's office, and in the court room.

Author: Did Jack testify in court?

Mother. Not really. He just had to say "yes or no." The questions were very simple. The judge has a very soft spot for children and would probably treat any child very special.

Jack's father encouraged him to participate in conversations. "Tell about when we went to the Judge's court. What happened there? Remember when we went to the court room?" Jack said "Oh yeah, I met with my judge, and he said what do you want me to do for you? And I said I want my Dad, and he said, court is adjourned and stuff like that." To remember the details of what occurred three years ago was a challenge for Jack, but he did recall the main events. These parents and their 21 year old adult son viewed their experience with the court as "positive."

Jack's parents were asked whether they had thought about a backup guardian, because a court determined need for a guardian stands over the ward, regardless if the guardian dies or decides to be relieved of guardianship duties and responsibilities. Jack's mother shared "He's (the father) the guardian and I'm the backup. You really have to think long term." The father added "What we've done is set that up with the trust. We have looked through that process so that 15-20 years from now, Jack would be taken care of . . . that's why we had an attorney for him to make sure everything was set up. Regardless of what people told us not to do, we got everything set up. That's why

we felt strongly that we needed information. So that's our view, and where we come from."

In addition to the courts monitoring yearly reports, Jack's mother shared that a court appointed social worker made annual visits to their home.

Mother. A social worker comes to the door very unexpectedly, and comes and checks on Jack . . . without any call ahead.

Father. Which I think is really, really neat. It is through the Judge's court room, that's how it's done. I think it's how the system is. It's in the law. I think it's written in there but I don't think people ever do it. I think we have one of the very few judges who ever does this. The visits are very spotty, there's not a pattern to it.

Mother. Yeah, there's no pattern to it. You just have a knock at the door and I had a woman one time and a man this last time. They just want to see Jack's bedroom.

*Guardian defined?* Jack, who legally had all his decision-making rights taken and given to his father, made decisions about preparing his work station, and deciding which patients at the nursing home needed water and who did not. The nursing home manager acknowledged his decision making ability and applauded it, frequently asking Jack to train other people. "He learned right away about who needed water and who did not. When he goes on vacation, he makes sure that a substitute is trained and is scheduled to cover for him. He does this all on his own. No supports or reminders."

During observations, Jack not only decided what he would do at work, but directed the author as well. He said, "Put your coat there, and follow me." He told the author that "If there is a yellow flag on the room, I am not to go in there because the person is sick. I just look in each room and check to see if someone wants water." Jack spoke to a few residents he stated that he liked to talk to. "I am patient with the people who think I am their son."

When shopping at the mall, Jack walked side by side his parents and they engaged in causal conversations.

Father. He pays for all his things.

Jack. I keep an eye on things and stuff like that.

Mother. He has a savings account.

Jack. Yeah, a savings account and ah, if I don't know what to do with it (money) I put it in the savings account and see how much I am saving.

Father. How many dollars do you always keep in your wallet for going to McDonald's?

Jack. Oh, a couple dollars.

Father. A little more than a couple (laughs).

Mother. Jack buys lunch for the family a lot.

Jack. Yes, I do.

Father. At the nursing home, he is making \$3,000 to \$5,000 per year and after two years he has really built up his nest egg.

Jack. I am making a lot of money. Ah, sometimes, if I see a nice shirt I'll buy it. I like looking in the mall store, to make sure stuffs a good deal.

## Discussion and Implications

The importance of promoting self-determination skills of youth and young adults with disabilities during the school years continues to be emphasized in legislation, literature, and research. It has even been suggested that an indicator of special education services success can be measured by the extent to which students with disabilities are the guiding force of their own lives (Agran, Blanchard, & Wehmeyer, 2000). For youth who are about to become adults, it is imperative to understand their, and their family members', values regarding self-determination. Grigal, Neubert, Moon, and Graham (2003) stated "Undoubtedly the success of self-determination depends on parents' views of its appropriateness and desirability." (p. 98). Although parent views are important, the success, as it was found in this study, depends heavily on the values of educators, service providers, and members of the judiciary (e.g., attorney, judge) who may work for and with families.

IDEA mandates that once students reach the age of majority, they will assume the rights once accorded to their parents, unless their competence is in question. A concern was raised that if competence was challenged, guardian appointments may occur, thus negatively impacting the self-determination of the

young adult. In addition to examining the impact of guardianship, it was anticipated that the young adults who participated in this study would affirm an assumption that a school-aged young adult with developmental disability who had full legal guardian appointed would exhibit few, if any, self-determination skills in comparison to a peer who did not have a guardian. Surprisingly, this was not the case. As a result, the findings of these case studies extend the research by providing the first examination of how guardians, legal or otherwise, impact the self-determination opportunities for school-aged young adults with developmental disabilities.

Despite the importance of family and teacher efforts to promote self-determination of young adults, other forces (e.g., school administrator, service providers) at times impeded them, as was seen with Kevin. This finding that a teacher (transition coordinator) actively promoted the development of students' self-determination skills contrasts the findings of the Wehmeyer, Agran, and Hughes (2000) and Katsyannis, Zhang, Woodruff, and Dixon (2005) studies where teachers realized the importance of self-determination skills, but did not necessarily teach them. A concern raised in this study, rather, is the disconnect observed between the school administrator's perception of Kevin's competence and the parents' values and teacher's role in helping the student demonstrate his abilities. It was almost as if the fact that Kevin had a developmental disability, the administrator assumed incompetence.

Turnbull and Turnbull (2001) suggested that individuals with developmental disabilities most likely will require ongoing support from others to experience a quality life. Unfortunately, in this study it appeared that Kevin and his parents would be challenged with building alliances that would enable Kevin to be self-determined. Although the transition coordinator and families are applauded for teaching self-determination skills, a need exists to work on such skill development within a larger context, beyond the school building. Teaching students self-determination skills (e.g., making choices) is important, but perhaps more important is ensuring significant others, including personal assistants from community agencies, acknowl-

edge and respect the students' communication.

It has been argued that individuals with disabilities have had limited influence over their lives and conversely have had their lives unnecessarily controlled by others (Lisi et al.), and as a result, a cycle of dependency and less independence may be created. Kevin's parents made substantial effort to establish environments where their son could express and further develop his self-determination skills, however Kevin's expressions were stifled, even in his own home. This finding is in contrast to a study conducted by Wehmeyer, Kelchner, and Richards (1995) who found that adults with developmental disabilities who lived independently were more self-determined than individuals who lived in group homes. The findings from this study are more aligned with the results from the Wehmeyer and Metzler (1995) study where adults with developmental disabilities indicated that they had limited control over important life choices and decisions. Wehmeyer and Metzler concluded that people with developmental disabilities may be in environments that are overly structured or protective and do not place emphasis on opportunities to make meaningful choices and decisions and solve problems.

This study has also brought to light that 'guardian' may be interpreted in a variety of ways. If not having a guardian means an individual is living a life based on their values, preferences, and choices without external forces, Kevin had a guardian, and in fact several – they just were not court appointed. Many of the decisions he attempted to communicate (e.g., desire for a cola instead of milk), although not life critical, were not honored. For Jack, who had a legal guardian, it was clear to whom he interacted with that he made many decisions. Jack was exercising self-determination, even with the fact he had a legal guardian. The findings from this study for one individual, Jack, suggest that guardian appointments may not impact the day to day decision-making of some individuals. His parents admitted that they have not needed to use their legal authority, however, since they became legal guardians three years earlier. As a point of caution, Jack's situation may be exceptional in that he had a family network to support him which contrasts findings found in

literature, mostly to do with the elderly, where abuse and misuse of guardian powers were observed (Lisi et al., 1994).

Jack's situation further reflects the finding of a study conducted by Stancliffe et al. (2000) who found that some adults with guardians displayed self-determination competencies that were as good or better than others who had not been assigned a guardian. The authors suggested that perhaps the self-determination skills of some individuals steadily increased over time as a result of experiences. They also suggested that in these situations courts should reevaluate guardian appointments or responsibilities, and cautioned that if too much time is taken to reconsider guardian roles, then a ward's motivation to exhibit self-determination may decrease, or potentially deteriorate. It is possible for individuals to petition the court to modify or remove guardian appointments. An interesting finding about Jack's situation is that the parents were adamant about family taking care of family. Curiously, they did not seem to view the court's authority, annual reports they had to submit to the judge, or social worker home visits as intrusions.

It has been suggested that families need to have access to information to make informed choices regarding guardianship (Millar, 2003; Millar & Renzaglia, 2002). In addition to this information, each family has to have individualized support and guidance by school personnel. Although Jack's family believed they were informed, they had at times inaccurate or incomplete information. For example, medical issues, a main reason for filing a petition for their son, may have sufficiently been taken care of in different ways (e.g., 'next of kin,' 'power of attorney,' 'emergency/temporary guardianship). Alternatives could have been explored (see Millar, 2007 for potential alternatives), hence reducing the need for them to write reports for the courts, and unnecessarily limiting their son's legal rights. Because legal issues can be confusing and complex, it is essential that members of the judiciary (e.g., probate clerks who register guardian petitions, attorneys, judges) learn about self-determination initiatives and ways they too can support individuals with disabilities to remain autonomous. Perhaps members of the judiciary, either prior to or at the time

a petition for guardianship is filed with the courts, can work with families to ensure they understand what guardianship entails and its alternatives.

#### *Limitations and Future Research Ideas*

Although this study provides important new information, and used sound strategies for conducting quality case studies (e.g., prolonged observations, members checking, triangulation of data), there are limitations. For example, in the selection of participants, it is possible that they are not representative of students in similar situations, hence restricting the ability to generalize the findings. A case study approach was used, however, because exploration in this area of self-determination in relation to guardianship for young adults is new. It is anticipated that the lessons learned from this study will help with designing future research endeavors where larger numbers of individuals can have the opportunity to participate and have their voices heard.

In addition, this study has acted as a catalyst by raising several questions that could be addressed in future research initiatives. For example, how, if at all, has IDEA impacted the number of young adults having a guardian appointed? If a student's competence is a concern, then to what extent are IEP present level of functional performance statements, goals, and objectives addressing this concern? When educators and service providers learn of guardian appointments, does their respect for and actions toward the individual with the disability change, and if so how? Another question to investigate is how prevalent is it that families petition courts at the time a student becomes of legal age? Does the awareness that a young adult with a disability who has been appointed a guardian lead to that individual becoming less likely to attempt to demonstrate self-determination attributes, or was Jack's situation an exception? Other questions could relate to how often guardian appointments are modified or revoked if families realize that alternatives to guardian appointments can be used.

Awhile ago Halpern (1994) wrote "if the transition process is to be successful, it must begin with helping students to gain a sense of empowerment with respect to their own tran-

sition planning.” (p. 118). Although there has been improvement in supporting students in their role during their personal transition from school to post school environments, it is essential that legislation, school initiatives and service supports, honor and respect the individuals they serve, particularly if guardian appointments are a result of IDEA mandate interpretations.

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Received: 14 February 2007  
Initial Acceptance: 18 April 2007  
Final Acceptance: 14 July 2007