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## Guardianship Alternatives: Their Use Affirms Self-Determination of Individuals with Intellectual Disabilities

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*Abstract:* This article was written with the purpose of informing educators, agency service providers, family members, stakeholders, researchers in the field of transition, and individuals with intellectual disabilities themselves, of the guardianship alternatives that can be used, hence negating the need for a legal guardian. Guardianship refers to the legal procedure when a judge appoints a person (a guardian) to make some or all decisions for another adult (a ward). It is a legally documented association between a guardian and a ward as a result of the court determining that the adult ward is either totally or partially incapable of making decisions with regard to: (a) self-care, (b) financial management issues, (c) medical and health care, (d) home and community living, as well as, (e) safety, civil or legal matters. Summarized in this article are: a description of guardianship and how it disaffirms self-determination, the guardianship legal process, a review of related research, and perhaps most importantly guardianship alternatives. This information aims to serve as a resource to stakeholders as a student who has an intellectual disability approaches or has reached the age of majority with respect to educational planning in the academic areas and functional life skills, and when the student may be in jeopardy of losing all or some civil and legal rights as an adult due to a perception that he or she is in need of a guardian.

### The Importance of Using Guardianship Alternatives

When a student reaches the age of majority the Individuals with Disabilities Education Improvement Act (IDEA) mandates under Section 615 (m) that all rights accorded to 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 (IDEA 2004, Section B [614(d)(1)(A)VIII]). It is when a student reaches, or has reached, the age of majority that the issue of guardianship is often raised, and specifically during Individualized Educational Programming (IEP) meetings (Millar,

2007, 2008). Briefly, guardianship refers to the legal procedure when the judge appoints a person (a guardian) to make some or all decisions for another (a ward or respondent). It is a legally documented association between an adult and a minor child, and also a legally recognized relationship between an adult and an adult who has been determined by the court to be either totally or partially incapable of making all or some decisions regarding his or her life (Millar & Renzaglia, 2002; Moye & Naik, 2011). This second situation, adult and adult, is the focus of this article.

It is important that family members, educators, agency service personnel, members of the community, as well as the individual who has a disability, understand that parents do not automatically remain guardians of their adult son or daughter because of a disability, and that only a court order can appoint a guardian for someone who is 18 years of age or older, dependent upon the state's determination of 'age of majority' (Millar & Renzaglia, 2002). It is also important for stakeholders to understand that guardianship is not necessary for every individual with a disability,

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and if used, should be considered as a last resort (Moye & Naik, 2011). Guardianship is associated with the internal conflict that people have as they seek to protect a person from harm or from making bad decisions, but also want to ensure that the individual is autonomous and learns from decisions made (Moye, Butz, Marson, & Wood, 2007). In order to make informed decisions about whether to seek a guardian appointment of an adult aged individual with an intellectual disability, it is necessary to have some knowledge of the different kinds of guardianship and of the terminology used by the legal system, and perhaps more important guardianship alternatives that preserve the rights of individuals facing guardianship.

The following are summarized in this article: a description of guardianship as it relates to adults who have intellectual disabilities and how it disaffirms self-determination, the guardianship legal process, a review of related research, and perhaps most importantly a comprehensive list of guardianship alternatives specific to adult individuals who have an intellectual disability. The article aims to serve as a resource for stakeholders as students with intellectual disabilities approach or have reached the age of majority, with the goal that the information will inform educational planning with respect to academic areas and functional life skills. The information is also presented so that when students' competence is questioned and they may be in jeopardy of losing all or some civil and legal rights, less intrusive and restrictive options are known, hence, avoiding unnecessary guardianship appointments. It is also hoped that this information will create further interest such that empirical large scale studies are conducted that address the issue of guardianship and its disconnect with self-determination and the extent to which guardianship alternatives impact the quality of adult life for individuals who have an intellectual disability.

#### *Guardianship Disaffirms Self-Determination*

Self-determination is a construct that reflects the principle that all individuals should be treated with dignity and respect, and have the right to direct their own lives (Heller et al., 2011; Wehmeyer, 2005). Teaching and pro-

moting the development and demonstration of self-determination related actions and skills of students with disabilities is considered to be a 'best practice' and is a result of the ever growing body of research that provides evidence that self-determination does positively impact life outcomes (Konrad, Fowler, Walker, Test, & Wood, 2007; Wehmeyer et al., 2007; Wehmeyer, & Palmer, 2003; Wehmeyer, Palmer, Lee, Williams-Diehm, & Hogren, 2011). Within the past two decades research has shown that the ability and opportunity to be self-determined has positively impacted students with disabilities gaining access to general education (Lee, Wehmeyer, Palmer, Soukup, & Little, 2008; Lee, Wehmeyer, Soukup, & Palmer, 2010), financial independence, independent living, as well as employment and postsecondary education participation (Getzel, & Thoma, 2008; Wehmeyer & Palmer, 2003). Scholars in disability studies assert that self-determined individuals with intellectual disabilities that exit the P-12 system are more likely, in comparison to their counterparts, to live independently or with minimal supports and be employed in positions which pay higher wages and provide benefits (Wehmeyer & Palmer, 2003).

#### *Guardianship Types and Scope*

Guardianship stands in sharp contrast to self-determination. Guardianship refers to the legal procedure where the judge appoints a person (a guardian) to make some or all decisions for another (a ward or respondent). In most states, there are two main types of guardianship appointments where the guardian duties pertain to the person or to the estate. A guardian of the person generally indicates that an individual who is appointed by the court has the legal rights and powers to make everyday life decisions for the adult ward (Lisi, Burns, & Lussenden, 1994; Moye & Naik, 2011). Essentially, the guardian may have all the authority of the court to decide where the ward will live, where the ward will receive an education and might work, as well as how the ward can spend free time, including vacationing settings. The guardian would also be responsible for the type of routine and basic health care the ward would or would not receive. A guardian of the property or estate

typically refers to an individual (sometimes referred to as a fiduciary) who is authorized by a court to assume responsibility for the management of all or some of the ward's funds and property (Lisi et al., 1994; Moye & Naik, 2011). A guardianship of this type may indicate that a guardian has the court's authorization to receive monies due the ward (e.g. Social Security Income - SSI), to decide how much money the ward should have access to and how often, how the ward can spend it, how to manage the ward's money (savings, budgeting, paying bills, opening/closing accounts), and decide on other issues related to money and property (Bulcroft, Kielkopf, & Tripp, 1991; Lisi et al., 1994). In some situations, it may be that a guardian becomes responsible for both the person and the estate (Leary, 1997; Lisi et al., 1994).

A guardianship can also be declared as plenary (total or full) or partial (limited) (Leary, 1997; Moye et al., 2007). Plenary guardians are authorized by the court to make all decisions for the ward, and typically do not expire, lasting throughout the ward's life. A partial guardian, in comparison, refers to when the judge specifies which rights the ward retains and which are removed and under the authority of the guardian. The intent of a partial guardianship is to have the ward keep as many rights as possible (Moye & Naik, 2011). Dependent on the court ruling, a partial guardianship will have a time limit. For example, a ward may have a partial guardian for financial reasons which expire at the end of five years (Millar, 2003; Millar & Renzaglia, 2002). Once the appointment expires, a petition and the entire legal process would need to begin again if a guardian continues to be perceived as a need.

Guardians make critical decisions (as well as what can be considered minor decisions such as what to wear or eat) for a ward when he or she has been deemed incapacitated. The Uniform Guardianship and Protective Proceedings Act (UGPPA) describes incapacitated as an individual unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care (National Conference of Commissioners of Uniform State Laws: Uniform Guardianship

and Protective Proceedings Act, 1997). The areas of which a ward may no longer have rights include: (a) signing a contract, (b) consenting to or preventing any medical intervention, (c) traveling, (d) spending money, (e) changing residential arrangements, (f) bringing any court actions, and (g) making changes in educational or vocational programs (Millar 2009; Moye & Naik, 2011). The UGPPA recommends that prior to a guardianship related court order that all less restrictive alternatives to guardianship be explored and if or when issued, that partial (limited) guardians be used with the aim of fostering autonomy and maintaining opportunities for the ward to make independent choices (Quinn, 2004).

### **Overview of the Guardianship Legal Process**

Although there are no federal laws regarding guardianship, there is the Uniform Guardianship and Protective Proceedings Act (UGPPA) that makes recommendations regarding what States could do as they evaluate and reform their guardianship related statutes. The UGPPA, which was last revised in 1997, is a comprehensive act addressing all aspects of guardianships and protective proceedings for both minors and adults (National Conference of Commissioners of Uniform State Laws: Uniform Guardianship and Protective Proceedings Act, 1997). A majority of the states follow all or sections of the guidelines set forth by the UGPPA and the typical legal guardianship process is described below (Moye et al., 2007).

#### *Legal Process*

As previously shared, there are no federal mandates regarding guardianship procedures; however, states do tend to use similar processes (Moye et al., 2007). It is essential that when guardianship of an adult individual who has an intellectual disability is under consideration that specific state laws, statutes, and proceedings be explored. Prior to any guardianship consideration, however, less restrictive alternatives should be rigorously investigated.

*Petition and adjoining document.* A series of steps occur prior to a guardian being appointed with the first step typically involving the filing of a form, often referred to as a petition, where an official request is made to

the court that a judge appoints a guardian for an individual, referred to as an 'alleged ward' (Leary, 1997). Dependent on the state, petition forms will vary and some are available online (e.g., Petition for Guardian of a Minor, Petition for Guardian of an Incapacitated Adult) or at the registrar at the court house. Personnel at the court house should clarify which form is needed when it comes to requesting that an adult individual with an intellectual disability have legal a guardian appointed (Leary, 1997). There is the potential that a petition form could be filed prior to the individual reaching the age of majority and in this situation, it is most likely that an adult petition form should be used. If a minor form was filed with the court, the form would be obsolete when the individual turned 18 or the state's age of majority. Filing is done by the person (petitioner) who completes and then submits the form to the court. A petition can be completed and filed by any person including a parent, family member, friend, or agency representative but cannot be completed by a court clerk. A clerk can distribute forms and explain the court process, but may not provide legal advice or assist with a form being completed (Leary, 1997; Lisi et al., 1994). Petitioners can decide if they want an attorney to represent them, however, in most situations there are no provisions in law that require petitioners to be represented by legal counsel (Millar, 2003). Petition forms used for a guardian of the person or of the estate, for full (plenary) or limited (partial) are often the same, and can be filed at a court (usually a probate court) by the petitioner in the city or town where the alleged ward lives (Leary, 1997). Cost of filing a petition, however, will vary by location.

Generally, a petition form requires information about the alleged ward including a full name, address, date of birth, closest living relative, description that approximates the alleged ward's estate, as well as, annual income and source. The type and scope of the guardianship being requested must also be stated on the petition, along with a basis regarding why a guardianship is perceived as required and a description of the nature and extent of the alleged ward's intellectual disability (Millar, 2003; Moye & Naik, 2011). Sections on the petition form allow for petitioners to specify

areas of concern, as well as sections where they can recommend what rights the alleged ward should be keep or have removed. Petitioners are to state their association with the alleged ward, their interest in the matter, and recommend who they believe should be appointed guardian. Petitioners can recommend themselves to become the guardian (Leary, 1997). Adjoining the petition must be a document that provides results of evaluations that are to address the nature of the alleged ward's disability and information pertaining to the alleged ward's mental, physical, social abilities, as well as the adaptive behavior (Leary, 1997; Moye & Naik, 2011). Recommendations from the evaluator regarding the need, type, and scope of guardianship are also expected to be included in the document (Moye & Naik, 2011; Moye et al., 2007) and there is evidence that suggests that the assessments are not based on functional life skills, but rather, standardized psychological assessments (Millar, 2008; Moye, Butz, Marson, & Wood, 2007; Moye & Naik, 2011).

*Proceedings.* After the petition is filed, a court date is set and a notice of the hearing occurs. If the alleged ward does not have an attorney, the court will appoint one. Because of the gravity of having a guardian appointed and the potential loss of rights, it is essential that the attorney has training and experience working with individuals who have intellectual disabilities (Millar, 2003). During the court hearing, which is a formal proceeding, all witnesses are sworn in and the petitioner (and attorney, if applicable) may make a brief presentation to the court to describe why a guardianship appointment is being requested. The alleged ward has the right to object the petition or request that the guardian role be limited and specific.

*Judge's decision.* At a minimum, a judge will make a decision based on whether the alleged ward meets a legal definition of incompetent or incapacitated and if the suggested guardian is an appropriate individual to assume the duties. If the court finds 'clear and convincing evidence,' a full/plenary guardian will most likely be appointed (Millar, 2003; Millar & Renzaglia, 2002). 'Clear and convincing evidence' is a legal phrase that indicates that there was a substantial amount of evidence that a person needs a guardian (Moye & Naik,

2011). If it is found that the alleged ward is only partially without capacity to care for him or herself, then the court may appoint a partial guardian, but not a plenary guardian (Moye & Naik, 2011). To summarize, a judge can either approve or deny the appointment as presented in the petition, or modify the decree, giving more or less authority to the guardian. It is not uncommon that court hearings are short in length. Millar (2003) found that hearings on average lasted seven minutes and that judges appointed a guardian each time.

*Decree.* When a judge determines that a guardian is needed for an adult ward, a guardianship decree will be signed by applicable parties (e.g., judge). An order should then be issued that specifies that a person (a ward) meets the legal requirements of needing a guardian and who said guardian is. This order may be referred to as “Letter of Guardianship” or “Letter of Authority” and should specify the guardian’s responsibilities (Millar, 2003).

*Following the decision.* It is expected that guardians will to adhere to the court’s rules, while not going beyond their authority. Guardians, when making decisions that are to be in the best interest of the ward, should be in constant communication with the ward, as well as, seriously take into consideration the individual’s preferences. ‘Best interest’ refers to a decision that most people would think is the right or best choice, therefore, decisions made by a guardian may not necessarily be agreeable or liked by the ward (Hurme, 1991, 1998). In addition to interacting with the ward and making decisions, guardians are required to complete a report, on an annual basis, regarding the ward’s overall status (Hurme, 1991, 1998). It is possible that a guardian can be removed, modified, and possibly replaced should there be questions regarding the appropriateness of an appointment, however, it is difficult to have guardianship revoked (Moye et al., 2007).

*Guardian qualifications.* Dependent upon court orders, a guardian will obtain control over all or some of the decisions for a ward. With such responsibilities, however, there are no uniform requirements regarding who can become a guardian. Essentially any adult thought to be competent may become a legal guardian (Hurme, 1991, 1998). In most situations involving persons who have an intellec-

tual disability, a parent or family member becomes a guardian (Millar & Renzaglia, 2002). There are times, however, when an individual does not have a family member or friend willing to or able to take on the role of a guardian. Should this circumstance be encountered, a court might order a public guardian. A public guardian is an agency or director of an agency that can serve as a guardian. Public guardians often have several ‘wards’ and concerns have been raised that the quality of services and advocacy may be questionable (Hurme, 1998). Before an actual appointment, judges are expected to discuss with the alleged ward about the petition and preference as to who the person should be appointed guardian (Hurme, 1991, 1998; Millar, 2003; Millar & Renzaglia, 2002).

### **Review of the Guardianship Related Literature**

A review of the literature was conducted using the Educational Resources Information Center (ERIC) and Wilsons Omni Select electronic databases between the dates 1980 through 2012 for two purposes: to determine what empirical studies have been conducted related to guardianship; and what less restrictive alternatives to guardianship have been recommended, with specific reference to adult individuals who have an intellectual disability. The search start date of 1980 was determined to be the main decade when a number of state studies on guardianship practices regarding the elderly were published. In the course of the search, it was found that limited empirically based literature was available, specifically in reference to adult individuals with intellectual disabilities, regarding how and why guardianships were imposed, and the extent to which guardianship alternatives were used prior to an appointment. Although there are limitations to the extant literature, the information is enlightening, specifically with respect to how guardianship disaffirms self-determination.

#### *Related Literature – Specific to the Elderly*

During the literature review search, 13 studies specific to the elderly were obtained and reviewed. These studies examined the character-

istics of the individuals involved in the process (Bulcroft et al., 1991; Friedman & Senage, 1988; Lisi et al., 1994). Individual state guardianship practices were also investigated and included: California (Friedman & Senage, 1988), Florida (Peters, Schmidt, & Miller, 1985), Illinois (Iris, 1986; 1989), Maryland (O'Sullivan & Hoffman, 1995), Missouri (Bulcroft et al., 1991), New York (Spring, Dubler & Garginlo, 1990), Ohio (Bulcroft et al., 1991), Virginia (Virginia Department of Social Services, 1988), Washington (Bulcroft et al., 1991), and Wisconsin (Kritzer & Dicks, 1992). One recent study by Moye et al., (2007) examined the evaluations used to determine capacity in adult cases in the states of Pennsylvania, Massachusetts, and Colorado. In this study it was found that a description of the individual's values and preferences were rarely recognized in capacity evaluations and that the use of functional assessments was limited. Two studies were found that addressed the use of alternatives to guardianship (Iris, 1986; Lisi et al., 1994). In 1987, the Associated Press (AP) investigated 2,200 guardianship files from all 50 states and the District of Columbia to develop a portrait of elderly wards and the guardianship process (Associated Press, 1987). During the early 1990s, the National Center for Social Gerontology explored guardianship practices of ten states (Lisi et al., 1994; The Center for Social Gerontology, 1990, 1994).

Based on review of the available studies, it is clear that the guardianship information that does exist which is specific to the elderly, although quite valuable in many respects, does have one or more of the following restrictions: (a) unsystematic manner of collecting and analyzing data, (b) information gathered focused attention solely on the abuses or misuses of the guardianship system; and (c) information obtained was reflective of what was occurring at one locale versus what was occurring across the state. Information was also found to be dated as practices and laws had changed since the study had been conducted.

#### *Related Literature – Specific to Individuals who have Intellectual Disabilities*

Research specific to youth and young adults who have disabilities is sparser than that found

regarding the elderly. Two of the first studies that addressed this issue were conducted by Millar (2003) and colleague (Millar & Renzaglia, 2002). These two studies involved a review of guardianship court files by using a stratified sampling approach across the state of Michigan. The files were exclusively of young adults with intellectual disabilities, ages between 18 and 26, who had legal guardians appointed. It was found that court petitions were most often completed by parents who claimed that their adult children needed a guardian because the student had a disability, reached the age of majority, and/or had limited to no ability to make sound decisions. Due to the limited file information and court forms, information pertaining to the use and effectiveness of guardianship alternatives was not able to be determined. Additional findings included that evidence (assessment results) used to determine competence was unclear, but predominately standardized and academically focused assessments, comparable to the Moye et al., (2007) study that focused on the elderly. The authors of these two studies also observed that the majority of guardians found the wards' "conditions" of "having limited or no capacity to make decisions" remained unchanged following guardian appointments. This last finding is important since, as reported in the Mental Health Code Act 258 mandates found in the Michigan Compiled Laws Annotated (MCLA), guardians are to support the ward in the development of maximum self-reliance and independence (MCLA, 330.1602; 330.1631). To emphasize the magnitude of guardian appointments, once they are declared, the removal and modification of it is virtually improbable (unless the judge specifies an expiration date).

Using qualitative methods, Millar further investigated this area and conducted two related studies (Millar, 2008; Millar, 2007). One study involved the facilitation of focus groups where young adults with disabilities (both who had legal guardians and who did not), their parents, and secondary teachers were questioned about their knowledge of self-determination, as well as, guardianship and its alternatives. Two main common findings across groups were that participants had limited understanding of the guardianship process and

that they did not realize the extent to which guardianship contradicted their efforts to promote/exhibit self-determination related skills. It was also found that students and parents first learned about guardianship at an IEP when a meeting member (usually a teacher) asked "Do you have a guardian?" when it came to that section on the IEP form. Following the IEP meeting, several parents went to court because they thought becoming their child's legal guardian was something they were expected to do, even though they did not have a clear understanding of what guardian appointments entailed (Millar, 2007).

In related work using case studies, Millar (2008) explored how two families with young adults with similar educational experiences and special education school labels, came to different decisions about guardianship after they attended an IEP meeting when it was time for the parents' rights to potentially transfer to their adult child. One student had a legal guardian and one did not. Interestingly, it was learned that the young man who went through the court process and had a full (plenary) legal guardian appointment made several decisions at his residence and place of employment; whereas the other student who did not have legal guardian had limited control over day-to-day decisions. Actions, values, and beliefs of others (e.g., parents, educators, service providers) impacted the extent to which the young men controlled aspects of their life.

Approaching the issue of guardianship from a different venue, Millar (2009) systematically compared de-identified individualized educational program (IEP) content of adult students with moderate or severe developmental and intellectual disabilities who had or did not have a legal guardian across the following areas: (a) post-secondary goals related to training, education, employment, and independent living; (b) transition services used to meet those goals including course of study, review of objectives, and agency connections; and (c) student participation in educational planning. It was found that students with guardians were more likely to earn a certificate of completion, and wanted to remain living with their families, in comparison to students without guardians who were more likely to earn a diploma, and wanted to live on

their own. Differences regarding emphasis of objectives related to employment, transportation and self-care were observed. In addition, differences were observed regarding teaching self-determination related skills; students without guardians had more objectives than those with.

Comparable to the issues surrounding the research specific to the elderly, more research is needed with regard to how guardianship related issues are being addressed during the school years, prior to and after a student with an intellectual disability reaches the age of majority. The research that does exist specific to this student group is informative but has actually generated more questions. Future research, at a minimum, should address on a large scale: (1) To what extent are school personnel learning about self-determination and how guardianship alternatives, along with promotion and instruction related to self-determination, being addressed in their preparation programs and ongoing professional learning experiences?; (2) To what extent are adult students having guardians appointed (as such data are not clear according to Millar & Renzaglia, 2002) and why, and how are educational assessment and programming decisions addressing the guardianship issue?; (3) When students complete their schooling, is the guardianship status being monitored? That is, what is the likelihood that guardian appointments occur after the age of 21 when public schooling ends and the reliance on agency services increases?; and (4) To what extent are guardianship alternatives being used as a result of quality assessments and evaluations related to determining capacity, and to what extent are the alternatives effective? Even though more questions than answers have been gained by reviewing the extant guardianship related literature, the need for more knowledge about and use of guardianship alternatives is clear (Millar, 2008, 2009; Moye & Naik, 2011).

### **Guardianship Alternatives**

In actuality, most individuals who have moderate and severe intellectual disabilities are capable of making choices and decisions, and can manage their life with support and guidance from others. Whether performing daily



living tasks, or making medical decisions, most people, if they have a disability or not, tend to discuss issues with family members, friends, or trusted and supportive individuals. A family member, friend, or neighbor could assist with explaining potential benefits and risks when making a particular decision with regard to cooking, hygiene, health care, safety, relationships, money issues, and other everyday living areas. When there is a support system in place there is essentially no need for a guardian.

#### *Daily Living Concerns and Alternatives*

Concern that an individual with an intellectual disability may not be able to safely live in a home alone is a frequently reported rationale for why a guardian would be needed (Iris, 1986; Lisi et al., 1998; Millar, 2003, 2008; Millar & Renzaglia, 2002; O'Sullivan, 1998). When drilling down to what the specific areas of concern are with regard to living safely in a home, the issues may not seem insurmountable. One example that may lead to a perceived need for a guardian regards safety with respect using a gas stove and oven. Not only are gas fumes an issue, but so too are fire concerns. To eliminate the specific concerns, the stove could be removed and a microwave be installed. Another option would be to have in-home help services work with the individual to prepare meals, with a rule to only use the stove or oven when there is someone to cook with. In addition, the gas stove and oven could be replaced with an electric option (O'Sullivan, 1998). When a concern is specific, and then alternatives are explored and successfully implemented, no court involvement or guardian would be needed.

The authorization of medical treatment is one of the most common reasons why people file for guardianship, as there may be concerns that the individual with a disability is unable to understand or provide informed consent for a recommended treatment (Iris, 1986; Lisi et al., 1994; Millar, 2008; Millar & Renzaglia, 2002; O'Sullivan, 1998). In emergency situations, most hospitals will ask the patient (with or without disabilities) 'who is the next of kin?' and in most situations this is a spouse or a parent. When these people are not accessible, siblings or other relatives will be contacted and viewed as next of kin. With

regard to non-emergency medical treatments, physicians and others in the medical profession must have the un-coerced informed consent of a patient prior to delivering care. Informed consent refers to a patient having an understanding of the anticipated benefits and potential risks, including side effects, associated with the treatment. If an individual with a disability does not understand the information provided by the physician, the physician must obtain informed consent from another person, such as a family member or friend, who can serve as a health care agent or surrogate decision-maker. If a family member or friend can assist the individual who has a disability to move forward with and agree to a needed treatment, there is no necessity to petition for guardianship (Millar, 2003, 2008; O'Sullivan, 1998). In extreme situations, a temporary or emergency guardian could be appointed for a specific reason and for a limited amount of time. Table 1 provides a description of additional guardianship alternatives with regard to concerns of a person living taking care of everyday living needs and responsibilities including community participation, safety, health, and medical needs.

#### *Money Management Concerns and Alternatives*

The inability to manage money and property is yet another frequently cited reason for why an individual is in need of a legal guardian (Iris, 1986; Lisi et al., 1994; Millar, 2003, 2008; Millar & Renzaglia, 2002; O'Sullivan, 1998). Although the majority of individuals with disabilities manage their money to some extent, there are times when someone may not understand specifically how to budget, or what it means to use credit or debit cards. It may also be the case that someone spends money on questionable items, and has insufficient funds for necessities. Fortunately, several supports and services exist that may make a guardian unnecessary; including consultation with family members, friends, and other trusted people. Credit unions and banks also have a number of services (e.g., debit or credit cards, limited checking accounts, direct deposits), representative payees, power of attorney, and trusts that can be accessed to diminish the need for a guardian appointment. See Table 2

**TABLE 1**

**Potential Guardianship Alternatives – Daily Living**

<i>Everyday Living Tasks and Responsibilities</i>	
Supportive and trusted individuals (e.g., family, friend)	<ul style="list-style-type: none"> <li>● Support and assist with explaining potential benefits and risks when making decisions with regard to money management, cooking, hygiene, health care, safety, relationships, and everyday living issues.</li> </ul>
In-home care services (e.g., nurse, therapist, dietician)	<ul style="list-style-type: none"> <li>● Assist with support to ensure that medications are taken as prescribed and that other medical related needs are addressed (e.g., diabetes monitoring, catheter use).</li> <li>● Assist with everyday responsibilities (e.g., grooming, shopping, meals, cleaning, transportation).</li> <li>● Provide therapy in home (e.g., physical, occupational, speech therapy).</li> </ul>
Case management services	<ul style="list-style-type: none"> <li>● Coordinate services across agencies with the aim of ensuring that the individual with a disability remains as self-sufficient as possible.</li> <li>● Services may be provided by the department of human services, community mental health, or other organizations (e.g., vocational rehabilitation, advocacy organizations).</li> </ul>
Free or reduced price meals, food, and prescription delivery from community agency services	<ul style="list-style-type: none"> <li>● Deliver free or reduced price meals to individuals who are unable to cook or have difficulty with cooking.</li> <li>● Deliver prescription medications by mail or by delivery directly to their home.</li> </ul>
Free or reduced price transportation services	<ul style="list-style-type: none"> <li>● Taxi vouchers, van services, and mass transportation services could be coordinated to help meet appointment needs of an individual when mobility and safety are concerns.</li> </ul>
Daily call services	<ul style="list-style-type: none"> <li>● Comparable to a neighbor checking in on a daily basis, some agencies have volunteers make daily calls to individuals to make sure that all is well.</li> </ul>
Utility companies (e.g., gas/electric providers, phone)	<ul style="list-style-type: none"> <li>● Establish an arrangement to notify a third party if an individual does not pay a utility bill on time.</li> </ul>
Home visit services	<ul style="list-style-type: none"> <li>● Volunteers make home visits to provide social contact when there is concern of limited or questionable networks.</li> <li>● Volunteers observe how the person is fairing and obtain help if needed.</li> </ul>
Medical release forms	<ul style="list-style-type: none"> <li>● Medical release forms authorize the extent to which private medical records can be shared and with whom.</li> <li>● Release forms do not allow others to consent on behalf of the individual for actual health or medical care and the authorization can be revoked at any time.</li> </ul>
Living will/Healthcare directive and surrogate decision-makers	<ul style="list-style-type: none"> <li>● Specify the type of medical treatment an individual wishes (or does not wish) to receive when the person is unable to communicate that information.</li> <li>● In situations when a directive is not in place, and the individual with a disability is not able to provide informed consent for medical treatment, a surrogate decision maker may be appointed to make decisions.</li> </ul>

for additional guardianship alternatives when there are concerns of an individual managing money and property. It is important to appreciate that everyone needs help at some time

and it is important to review the least restrictive supports that are readily available prior to petitioning for a restrictive guardian appointment.

TABLE 1—(Continued)

*Everyday Living Tasks and Responsibilities*

(Durable) power of attorney (DPA)	<ul style="list-style-type: none"><li>● A DPA, which can be revoked anytime, allows an individual to authorize another to assist with areas specified in a document (e.g., participate in IEP meetings and negotiate services, apply for and coordinate services from community agencies, challenge and appeal any denials or changes of benefits, how to manage money).</li><li>● Not all DPAs are recognized by all parties, therefore it is essential that organizations be contacted to determine if there are specific forms they will honor.</li></ul>
Technology – ‘Apps’	<ul style="list-style-type: none"><li>● Technology devices that have become available (e.g., smart phones, tablets) should be explored to determine how they can assist an individual with becoming and remaining independent.</li><li>● Applications (‘Apps’) may enable an individual to have recipes created to meet their needs (e.g., use picture and verbal instructions), timers to remind when to take medication, reminders to turn off the stove and lock the door, and budget money.</li><li>● The possibilities of how technology can aid an individual with an intellectual disability to be autonomous are endless.</li></ul>

*Note.* Alternatives adapted from Pieranglo & Giuliani (2004), Sullivan (1986), Wood, Dooley, & Karp (1991), Millar (2007), O’Sullivan (1998), and Jackins, (2010). Agency services will vary by county and state, therefore it is essential that availability of services be explored and that advocacy occurs for desired services.

Information regarding guardianship alternatives listed in Tables 1 and 2 were determined by reviewing the extant literature including Pieranglo and Giuliani (2004), Sullivan (1986), Wood, Dooley, and Karp (1991), Millar (2007, 2008), O’Sullivan (1998), Iris (1989), Lisi et al., 1994, and Jackins, (2010), in addition to the research articles previously summarized. As mentioned earlier, there are no empirical studies specific to the use of guardianship alternatives for young adults who have an intellectual disability and only a limited number have been conducted with the elderly. In addition, self-determination and longitudinal transition-related research have not specifically addressed how autonomy may be impacted by a legal guardian appointment or the effectiveness of guardianship alternatives.

### Discussion

Understanding what guardianship means and does to those involved is important for all professions that are service oriented and play a role in the educational, welfare and judicial

systems. It is also important that the individual who has the intellectual disability and their relatives and friends (in addition to the community at large) are educated to ensure that civil rights are not unnecessarily removed. Because of the seriousness of guardianship appointments and the potential loss of all civil and legal rights of an individual, the following are issues to consider when the student approaches or reaches the age of majority, and may be in jeopardy of have a guardian appointed.

#### *Promote Self-Determination While Being Cognizant of Guardianship Risks*

Family members and educators are responsible for helping a child transition into adulthood. Families can afford children opportunities to further develop their independent living skills in addition to helping them exhibit attributes associated with being self-determined. Educators teach academic content knowledge and skills in addition work with students as they further develop their self-determination related skills (Millar, 2009).

**TABLE 2**

**Potential Guardianship Alternatives – Money Management and Consumer Awareness**

<i>Managing Money and Consumer Awareness</i>	
Credit union and banking services	<ul style="list-style-type: none"> <li>● Provide services for individuals that may need assistance with money management. Brief descriptions of some options are provided in the table below.</li> </ul>
<ul style="list-style-type: none"> <li>● Direct deposit and payments</li> </ul>	<ul style="list-style-type: none"> <li>● An individual's regular income, or government benefits (e.g., SSI), could directly be deposited into an account.</li> <li>● Saves on unnecessary trips and removes the concern of a check being lost or stolen.</li> </ul>
<ul style="list-style-type: none"> <li>● Ceiling limits</li> </ul>	<ul style="list-style-type: none"> <li>● Refers to an account from which an individual can withdraw funds up to a specified limit (over the amount would make the transaction void).</li> </ul>
<ul style="list-style-type: none"> <li>● Pour-over accounts</li> </ul>	<ul style="list-style-type: none"> <li>● Refers to a separate account that has funds automatically transferred to the questioned account to maintain limited amounts of money;</li> </ul>
<ul style="list-style-type: none"> <li>● Joint accounts and Cosigner Prepaid cards</li> </ul>	<ul style="list-style-type: none"> <li>● Refer to an account where at least two people have access to the monies either to make a deposit or withdrawal. A cosigner account requires that at least two people, collectively, must sign documents in order to authorize withdrawals</li> </ul>
Credit and debit cards	<ul style="list-style-type: none"> <li>● Refers to reloadable cards that can be used as a money management tool to help individuals adhere to a budget.</li> <li>● When used with caution, credit and debit cards are also possible alternatives and if used properly can help an individual manage money.</li> </ul>
Representative payee	<ul style="list-style-type: none"> <li>● A person or entity (a representative payee) is appointed by an agency administering funds (e.g., Social Security or Veterans Administration) to assume the financial responsibilities of another.</li> <li>● The payee at a minimum is expected to maintain records and report all expenditures to the funding agency that were made on behalf of the individual with a disability.</li> <li>● Expenditures are to be used for basic needs including food, clothing, medical care, a place to live.</li> </ul>
Special needs individual trusts	<ul style="list-style-type: none"> <li>● Permits a person (the grantor) to have another, or an institution (a trustee), manage the property (e.g., home) and money (e.g., life insurance, cash) for the benefit of another person (a beneficiary).</li> <li>● When properly written, it is a document that may ensure that the individual with a disability would not own the contents of a trust, and that monies designated in the trust would not jeopardize eligibility of federal programs (e.g., Medicaid, SSI -Supplemental security income).</li> <li>● Trust monies are to supplement, and not supplant governmental benefits.</li> </ul>

Specific programs have been designed such that students, with support of the people in their lives, lead their educational planning meetings including: Steps to Self-Determination (Field & Hoffman, 1996): Whose Future is it, Anyway? A Student Directed Transition

Process (Wehmeyer et al., 2004); and the Self-Advocacy Strategy (Van Reusen, Bos, Schumaker, & Descheler, 1994). Although these programs are important, they can be enhanced if information pertaining to guardianship alternatives is addressed.

TABLE 2—(Continued)

*Managing Money and Consumer Awareness*

Special needs pooled trust	<ul style="list-style-type: none"> <li>● With this type of trust, which is often managed by advocacy groups, assets of an individual who has a disability are placed into a sub-account arranged within a larger trust program.</li> <li>● With the pooling of several sub-accounts, there is a potential increase in the principal for investment purposes.</li> </ul>
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*Note.* Alternatives adapted from Pieranglo & Giuliani (2004), Sullivan (1986), Wood, Dooley, & Karp (1991), Millar (2007), O’Sullivan (1998), and Jackins, (2010). Agency services will vary by county and by state, therefore it is essential that availability of services be explored and that advocacy occurs for desired services. Support from trusted individuals, DPAs, and tech (apps) as noted in Table 1 can also be applied to money issues. Due to the complexity of designing a trust, an attorney well versed in disability issues should be sought to avoid unexpected, and potentially negative, consequences. There are concerns that if monies or inheritance from a will are left directly given to the individual who receives governmental benefits that the individual may lose their eligibility to receive them and potentially need to reimburse the government for services rendered. Joint accounts may not be appropriate for representative payees and recipients. Under Social Security rules, the recipient is not to have independent access to a bank account. Only the representative payee should have access.

*Enhance Professional Preparation*

To ensure that individuals with disabilities are receiving due process, it is essential that members of service professions, including educators, agency personnel, social workers and members the judicial system, have an understanding of how to effectively interact with and represent individuals with intellectual disabilities. For example with lawyers, some states, as part of their instruction, require attorneys who handle guardianship cases to learn about issues that impact individuals with intellectual or developmental disabilities (Moye & Naik, 2011). Some is not enough. It is the responsibility of preparation programs (be it for educators, lawyers, judges, social workers, and other service providers) to ensure that professionals in preparation gain an understanding of: the nature of disabilities; strategies to prevent stereotypes; laws that address and protect the rights of individuals who have disabilities (e.g., Section 504, Americans with Disabilities Act, IDEA); the philosophy of inclusion, equal access and accommodations; and the complex community, state, and federal supports, resources and services systems (Millar, 2003; Millar & Renzaglia, 2002). Alternatives to guardianship that may be used by individuals with intellectual disabilities are perhaps one of the most important topics to emphasize in trainings across disciplines and

professions. The aim of the trainings clearly would be to ensure that members of the judicial system are prepared to address the needs of the individuals they serve. Because not all members of the judicial system have training, experience, or insight, individuals and their support network should be encouraged to work with attorneys who are well prepared to provide the best legal counsel for their client, if they have a disability or not.

*Apply and Evaluate Guardianship Alternative Use across Environments*

If guardianship alternatives are to be effectively evaluated, it is important that environments (e.g., in the home, community, place of employment) provide ample opportunities for them to be used. The transition planning process is one forum for identifying guardianship alternatives and to determine when they will be systematically implemented and evaluated. As students, family members, educators and service providers plan together, it is important that student autonomy and self-determination stay at the forefront. In addition, during the school years, there is somewhat of an inherent safety net should additional guardianship alternatives be explored. For example, if a student chooses to manage his or her check (either from work or Social Secu-

ity), and has lost the check between receiving it and taking it to a credit union or bank, an alternative to guardianship may be to have the employer directly deposit the check into an account or have a representative payee arrangement with Social Security Administration.

### Summary

Guardianship refers to the legal process where a court appoints someone to have the power to make all or some decisions for another who has been determined to lack total or partial capacity to make everyday living decisions. The end result is that a ward may lose many or all legal and civil rights and no longer have the opportunity to be a self-determined and autonomous adult citizen. Because of this potential loss of rights, disability advocates have argued that guardianship should not be used, or at the very least be considered as a last resort, and if ever imposed should be used to encourage the development of self-reliance and independence (Lisi et al., 1994; Moye & Naik, 2011).

For the past twenty years, literature and empirical studies have supported the notion that individuals with disabilities should and can be self-determined. Follow-up studies of individuals with disabilities, however, continue to indicate they lack the abilities and skills necessary to achieve a quality adult life comparable to their peers without disabilities (Katsyannis, Zhang, Woodruff, & Dixon, 2005). One area being studied that has promising results with regard to breaking the pattern of poor outcomes is to assist individuals with disabilities in becoming self-determined (Heller et al., 2011; Wehmeyer & Palmer, 2003).

Interestingly, for the past two decades there has been a change among the states to limit the use of guardianships and to support partial guardianships if ever appointed with the intent to preserve the ward's rights as much as possible. These are the same two decades when self-determination became emphasized in the special education literature; however, it has not specifically addressed the guardianship concern until recently (See studies conducted by Millar). Due to the limitations of the studies, more questions than answers have been gleaned.

The Individuals with Disabilities Education Act (IDEA) mandates that transition services be addressed beginning no later than age 16 and earlier, if appropriate. The purpose of the planning is to determine long range goals relative to the following outcomes: "postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and/or community participation" (20.U.S.C. 1401(a)(19)). Effective transition planning for youth and young adults with disabilities serves as the foundation from which all educational programs and activities should be developed and therefore should not be viewed as an add-on activity, nor is it something that just occurs in the final two years of secondary schooling. Rather, it is an integral component of the entire educational program. Because guardianship disaffirms self-determination, it is essential that during the school years all stakeholders continue to promote self-determination of youth and young adults with intellectual disabilities, and also be aware of the array of guardianship alternatives that exist to avoid unnecessary guardian appointments.

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