Why Does an 18 Year Old With Disabilities Need a Guardian?

by Mary Denise Cahill and Robert H. Farley, Jr.

hen we hold our monthly seminars at the Naperville 95th Street Library for parents of children with disabilities, we are frequently asked: "Do I really need guardianship over my 18-year-old child with disabilities?" "Is that the only answer for a youngster turning 18, who is under a disability?" "Will I become

"There are many reasons why parents need to go to the expense of obtaining guardianship for an 18-year-old with disabilities even if the child resides at home..."

liable for my child's bills and misconduct if I am his guardian?"

The answers are not easy and rarely do we have time to reply to all the questions a parent may ask or give as much detail as we would like. For those of you who do not concentrate on Special Education or Disabilities Law, the question may arise in your practice all the same. This article may help you answer such questions if a client asks them of you.

WHAT IS A GUARDIAN-SHIP?

Guardianship for a disabled adult provides a method by which concerned family members (or other responsible adults) can assume the burden of decision making for a person who is not fully able to manage his person or estate.¹

The Illinois Guardians for Disabled Adults Act ² does not, however, simply authorize the family to "take over" for someone they are concerned about. Section 5/11a-3 of the Act permits the court to adjudge a person disabled and thereafter appoint a Guardian of the Estate, a Guardian of the Person or both. Within that authority the court must "customize" the guardianship to deprive the person with the disability of as little of his freedom and autonomy as possible.

Usually, a person who needs a guardian of his person is adjudged to need a full guardianship of the person. A guardianship of the person refers to the authority of the guardian to make decisions concerning the personal and physical care of the person with the disability, including healthcare decisions and living arrangements. Guardianship of the estate refers to the authority of the guardian to handle money and property, to pay bills and conduct other financial transactions for the disabled. It is often in such cases that the court will "customize" the guardianship. This is especially so with a young person who may have some cognitive impairment that delayed understanding of how money works, but who may be able to catch on with some guidance. The court might require the guardian to come up with a budget that gives the disabled individual some control or participation in his finances. For instance, one of us recently represented a family in a case in which a guard-



Mary Denise Cahill is the owner of Cahill & Associates. Her firm concentrates its practice in the area of school law, spe-

cial education law, disability rights law, and estate planning for families with special needs issues. Prior to going into private practice, Ms. Cahill worked as an attorney for the Chicago Board of Education. Ms. Cahill is a frequent presenter to parent support groups such as CHADD, as well as school district sponsored support groups. She is an adjunct professor of law at IIT Chicago Kent College of Law where she teaches Legal Writing and an adjunct professor at Benedictine University (Illinois) where she teaches School Law. Ms. Cahill received both her B.S. and her J.D. from Loyola University of Chicago.

Robert H. Farley, Jr., has provided legal representation to individuals with disabilities for over twenty years in a variety of areas, including special needs trusts. estate planning, adult services, special education and guardianship. He was the lead attorney in Bruggeman v. Blagoevich, 324 F.3d 906 (7th Cir. 2003) which held that developmentally disabled persons are entitled to sue the State of Illinois under the Americans for Disability Act (ADA) to receive funding for services in the least restrictive setting (community settings as opposed to institutional settings). He has received from the "The Arc of Illinois" the "President's Award - For Outstanding Legal Advocacy On Behalf of People With Developmental Disabilities In Illinois." He has published legal information to assist families who have a disabled person at www.farley1.com His office is in Naperville.

ianship of the estate was established so that a concerned nephew could fend off a city that wanted to condemn the home of an elderly uncle who hoarded all kinds of flotsam and jetsam. The nephew was given authority to negotiate with the city, hire a company to clean out the house, hire a pest control company, etc. But control over the uncle's checkbook was specifically withheld from the nephew. He was permitted only to monitor it online by having his uncle's password information. The uncle still remained responsible for actually paying all these contractors, and he did so (grudgingly).

With young adults, the court will often permit the adult to have some pocket money, e.g., if the young adult has a source of funds from a family trust. The courts can be very creative in balancing the need for supervision with the need to let a young adult continue to learn to be independent (if there is potential there).

WHY IS IT APPOPRIATE TO SEEK GUARDIANSHIP FOR AN 18-YEAR OLD?

There are many reasons why parents need to go to the expense of obtaining guardianship for an 18-year-old with disabilities even if the child resides at home, still attends high school, and looks no different the day after his 18th birthday than the day before. Here are a few compelling reasons:

Ability to make decisions for and speak for the young adult to his healthcare providers and to have access to his medical records. Once a child turns 18 he is an adult. Before age 18, parents were expected to remain in the examining room with the doctor. After age 18, parents are often excluded from the examining room unless the child invites them to stay, because of HIPAA regula-

tions. Illinois law recognizes some exceptions (e.g., the decision to give or withhold life-sustaining treatment³), but for garden variety trips to the doctor, unless the child agrees, the parents stay out in the waiting room. Yet often a parent needs to tell the doctor or psychiatrist that the child is not taking his medication or is exhibiting symp-

"Not every child with a disability should automatically have a guardianship established at their 18th birthday."

toms at home that they are forgetting to tell the doctor about. In reality if a child is so low-functioning that he cannot communicate at all, healthcare providers would probably turn to the parents for guidance. But there are circumstances in which it is not obvious that a young adult is so disabled that his decision-making powers are impaired. Guardianship is a method of resolving the issue in advance of an emergency.

Many parents have been misinformed told that if their child has signed a Power of Attorney, a guardianship is not needed. However, in order for a Power of Attorney to be valid, the person granting or signing the power must have the legal capacity to fully understand the significance of what is being done and must fully to give another the power to make health or financial decisions. And, if that is the case, the adult child can just as easily revoke the power in the future.

Continued entitlement to Special Education services provided by his school district. Guardianship may be a necessity for an 18 year old who has a disability that prevents him or her from making decisions about his or her financial affairs, medical issues

or even education. In fact, many school districts positively brow beat parents into getting guardianship of their 18 year old because the federal and state law that mandates that these students receive a free appropriate public education (FAPE) also provides that unless the student has been declared disabled, all rights under the Individuals with Disabilities Improvement Act, of 2004, (IDEIA) transfer from the parents, to the students at age 18. For the child who is so clearly disabled that he functions, say, at the level of a two-year-old, there often is not an issue and the school district will treat the parents as the de facto guardians even if there has been no adjudication of disability by a Court.

But what if the child is not functioning at the level of a two-year old? What if he has Asberger's or ADHD or a communication disorder that makes it difficult to participate in a two-hour meeting with a roomful of his teachers? What if the school district administrators are trying to convince him to accept his diploma and leave high school at 18, when the law says he has four more years of eligibility for services?" He may need a guardian to argue that he needs transition services after high school.

In response to the many parents who have objected to being pushed aside as the decision maker once their child turned 18, the Illinois General Assembly has recently passed an amendment to the School Code providing that the rights transfer to the 18 year old unless the child has been adjudged disabled or the child has signed a Delegation of Rights form permitting his parents to make educational decisions for him.4 However, in the view of some, the law is flawed in that it only remains in effect for one year, whereas even a Power of Attorney for Property or Healthcare can remain in effect until revoked. It is further flawed in that it can be revoked at any time. Thus, the student who disagrees with what his parents want the school to provide for him can revoke his consent and exclude his parents from IEP (Individual Education Plan) meetings with the school. In the case of children with bipolar disorder, that might be exactly when the parents need to be making decisions for the student or negotiating with the school district on his behalf.

Preventing the young adult from being taken advantage of by unscrupulous people. Some young adults with disabilities are "gullible." They can be persuaded to sign leases, buy cars or apply for credit cards by others who appear to be their friends. One client was granted guardianship over her 18 year old son who had a low I.Q. Shortly thereafter, he was persuaded by some would-be friends to sign up for a credit card offer that came to the house. When the credit card came, the "friends" took him to a shopping center and they all ran up the credit card to its limit. The client was able to get all of the charges waived and the credit card cancelled because her son had been declared disabled and was not legally able to execute a contract.

As frightening as it may be to have someone take financial advantage of a young person with a disability, there are predators who will try to lure a person with disabilities away from home in order to take sexual advantage of them, as well. Once a child is 18, he or she is an adult and can leave the family home and live wherever they please. However, guardians have control over where their child lives and can seek the assistance of the police to force a third party to return the disabled adult to his guardians.

Protection in some encounters with the police. While having a guardian is not a "get out of jail free" card, it has some value. For example, in another misadventure, the young man mentioned

sets that must be invested, parents might be able to get by without obtaining guardianship of their 18 year old with disabilities. Nevertheless, it would be advisable that parents seek Guardianship of the

"Parents have the burden of persuading the court to appoint a guardian for their child. The parents may be correct in stating that their child is immature and lacks judgment, but a court will require some independent proof of that."

above was arrested for shoplifting. He did not want his mother to find out about it. One of his "friends" who was well acquainted with the system drove him over to the court house. He encountered a wet-behind-the-ears assistant state's attorney who negotiated him into a plea of guilty, a hefty fine and 50 hours of community service. The mother found out about it when her hairdresser mentioned seeing the guilty plea reported in the local newspaper. Since the young man was not capable of holding a job, none of the usual agencies would even consider letting him do his community service with them unless Mom came with him to supervise him. attorney was able to unravel that mess by arguing that the young man did not have the legal authority to negotiate a plea agreement which is basically a contract.5 The judge agreed and dismissed the charges out of compassion for the mother.

WHEN IS A GUARDIAN-SHIP NOT APPROPRIATE OR USEFUL?

Social security does not require a person with a disability to have a guardian. The Social Security Administration lets parents act as representative payees for persons with disabilities without the formality of a guardianship of the estate.⁶ If a child has no other as-

Person, to gain full access to medical records and have decision-making authority in the areas of healthcare and living arrangements.

If the child's disability is not severe enough, the court will not automatically grant guardianship to the parents unless the young adult agrees. Not every child with a disability should automatically have a guardianship established at their 18th birthday. Parents often assume that because their child has learning disabilities and qualifies for special education services, the court will appoint a guardian for the child. This is not true. Section 5/ 11a-2 of the Illinois Probate Act provides that only a person over 18 years old who is not fully able to manage his person or estate is a candidate for guardianship.7 Parents have the burden of persuading the court to appoint a guardian for their child. The parents may be correct in stating that their child is immature and lacks judgment, but a court will require some independent proof of that. The easy route to meeting that burden is to persuade the child to acquiesce to the guardianship. The hard route to meeting this burden is described below.

If the young adult is an unwilling participant, it is less likely that a court will impose the guardianship. As one judge said off the record, "Hell, my 18 year old has no common sense with money, either. Should she have a guardian?" Another factor signaling that petitioning for guardianship is not going to be a simple undertaking is when the child's physician refuses to sign the Physician's Report that must be either attached to the petition or submitted at the time of the hearing.8 When a child is immature or has learning disabilities, but still has the intellect to learn how to manage his money, make a doctor's appointment, and get a prescription filled, his pediatrician is not going to participate in having him declared a disabled adult. Many pediatricians will simply dodge the question by telling the parents that they should be requesting that the child's psychiatrist fill out the physician's report form.

Usually the treating psychiatrists are less "frightened" of the idea

of considering whether a young adult needs a guardian, but they may not be willing to fill out the Physician's Report solely upon their meetings with the young adult. They will want to back up their opinion with psychological testing. There are several sources for the psychological testing. The easiest source is the testing done by the young adult's school. If that is not current or complete, the psychiatrist will want to see recent testing by a private psychologist. The clinical testing will provide quantitative information such as the young adult's IQ, his scores on achievement tests, particularly scores regarding reading and calculations and other measures of skill levels.

Obtaining the Physician's Report is no assurance of order granting guardianship because, of course, the young adult has a right to contest the guardianship (and will be

so informed by the *guardian ad litem* the Court will appoint to advise him, possibly at the parents' expense^{9 10}). If the young adult tells the Court that he or she wishes to contest the guardianship, and requests a lawyer, the Court "shall" appoint one. If the young adult has no assets, the Court may direct the parents to pay for the court appointed attorney.

In sum, a contested guardianship can be a costly undertaking. So once parents see that the young adult is vigorously opposing guardianship, it is time for a serious cost benefit analysis.

Guardianship will not automatically entitle a guardian to keep a young adult hospitalized or placed at a residential facility. One fallacy that parents bring with them to the attorney is the belief that if they get guardianship over their adult child, they will be able to sign him or her into a hospital like they did before the child turned 18. That is not the case. Without going into a long discussion of the mental health laws, suffice it to say, that mental health laws in Illinois support the thought that persons should not be "imprisoned" in a hospital for mental illness, and once they are stable, they will be released.

Even when young adults are students at a residential facility at their school district's expense, they can sign themselves out of the facility, with or without a guardianship. According to reports by our clients, these residential schools usually tell both the parents and the students that if the student signs himself out, he will not be permitted to return. The student would have to find another residential school to take him if he changed his mind and wanted to return to a residential setting.

Guardianship will not shield a young adult from seri-

DiGiovine, Hnilo Use Nov 07 page 27

West Group Use Dec 07 page 33

ous criminal liability. Parents also come to attorneys with the erroneous notion that if their child is declared disabled, the courts will not hold him or her accountable for violations of the law. That is not true. While, as noted above, guardianship can act as a shield in some minor issues (e.g., a plea of guilty to a charge of shoplifting), felonies and other serious misconduct fall into another category. The effect of guardianship on such serious misconduct is outside the scope of this article. Parents seeking advice in such situations, should be referred to criminal attorneys.

CONCLUSION

In sum, parents of children with disabilities who are approaching their 18th birthday should have a thorough discussion with their attorney to discuss the advisability of seeking guardianship of their child. Each situation is, of course,

unique. Sometimes guardianship is a top priority, sometimes it is a practical impossibility. Parents, in conjunction with an attorney who understands what the guardianship can and cannot do for them, should be able to make a decision that fits the needs of their family.

' Section 5.11a-2 of the Guardians for Disabled Adults Act defines a disabled person as "a person 18 years or older who (a) because of mental deterioration or physical incapacity is not fully able to manage his person or estate, or (b) is a person with mental illness or a person with a developmental disability and who because of his mental illness or developmental disability is not fully able to manage his person or estate, or (c) because of gambling, idleness, debauchery or excessive use of intoxicants or drugs, so spends or wastes his estate as to expose himself or his family to want or suffering." 755 ILCS 5/11a- 2

2 755 ILCS5/11a-1 et seq.

³ Illinois Health Care Surrogate Act, 755 ILCS 40/1 et seq.

+7)) ILCS 5/14-6.10

⁵ See. People v. Waid, 221 Ill 2d 464,

wherein the Illinois Supreme Court discussed with approval the case of Commonwealth v. DelVerde, 398 Mass. 299, 496 N.E.2d 1357 (1986) in which the Massachusetts Supreme Judicial Court held that a person adjudged incompetent to stand trial could not enter a plea of guilty as part of a plea bargain, even with the involvement of his guardian.

6 42 USC § 1383(a)(2)(A)(ii)(II)

7 755 ILCS 5/11a-2

8 Requirement that a Physician's Report be submitted with the Petition for Guardianship is found at 755 ILCS 5/11a-9.
9 Under Section 5/11a-10(a) of the Guardian for Disabled Adults Act, 755 ILCS 5/11a-10(a) the Guardian Ad Litem may be allowed reasonable compensation. Under Section 5/11a-10(c), if the ward (young adult) cannot pay the fees of the guardian ad litem, the court may direct the petitioners (his parents) to pay the fees.

See, In re Serafin, 272Ill. App. 3d 239, 649 N.E. 2d 972 (2d Dist., 1995) where the Court required the ward to pay the fees of the guardian ad litem, even though there was no permanent order of guardianship established, because the court found that she had the resources to pay the fees and they were reasonable.