

Alternatives to Guardianship

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Preface

There is no question asked more often by the parents of a disabled child than, “What will happen to my son or daughter when I am no longer around?”

The combination of love, fear and concern as a child approaches adulthood often has parents questioning whether or not they should pursue legal guardianship. This parental inner struggle is made even more difficult by the lack of information available regarding what a guardianship can and can't do. In fact, most people have many misconceptions about what a guardianship really is... and isn't. This article will offer parents, teachers and support providers information they don't typically receive about guardianship. In addition, it will offer students and families alternatives that can allow families to remain respectfully involved in their children's lives as they transition into adulthood.

Reality and Myth

First and foremost, it is essential that parents know that the best protection for their child and their child's future is a caring involved family, and a network of community connections. With these two things in place, aided by appropriate estate planning, parents can truly achieve some peace of mind as both they and their child with a disability age. This same peace of mind cannot be achieved merely with a legal peace of paper, which in reality offers a mostly false sense of security, and provides for an unnecessary amount of control.

Why is it a “false” sense of security? Typically, parents and others believe that a legal guardianship document can prevent bad things from happening, can insure good things will happen, and will fix things that go wrong. Unfortunately, none of these commonly held beliefs are true. Even when people have guardians, they can be abused, exploited and hurt by others. Just like any of us, they can be physically hurt by friends or strangers, they can be hit by a car, they can choose the wrong foods, destination and friends. Further, having a legal guardian doesn't guarantee receiving needed services and/or supports, nor does it assure a great job or enough money. If something bad does happen, or if the hoped for good things do not occur, a guardianship document is not the one and only way to attempt to “fix” things, seek recourse or provide advocacy.

The best and most respectful way to minimize harm, increase the prospect of a quality life and provide advocacy is not the removal of someone's rights. We often hear the term “giving someone a guardian,” making guardianship sound like some benevolent act, or the presentation of a gift. In reality, “giving someone a guardian” means taking away their rights. In guardianship, some or all of a person's rights are taken away and given to a third person. If someone has a full (plenary) guardian, they don't have the right to choose their own clothes, leisure activities, friends or even food. Another person has the legal right to tell them what they can and can't wear, what movie they can see, with whom they can associate, and

how many times a week they may eat potato chips. The reality of a guardianship is actually the opposite of what we as Americans have historically said we cherish. We have long and fervently believed that our personal protections lie in having and exercising our rights, not losing them, or having them taken away. We hold individual rights and the control of our lives very dear. That being true, it becomes difficult, if not hypocritical, if we seek to justify guardianship by saying we want to “protect” our children. How can we protect them by removing their rights, the very things we go to war to maintain for ourselves? Doesn't it make more sense, in the alternative, to partner our strength and rights with those of our sons and daughters and, thus, have an increased joint power, rather than a diminished singular one?

Alternatives

How then can students and adults with disabilities partner with others to exercise joint power? There are a number of ways. The least intrusive is simply by being connected and present. Go to meetings and planning sessions, and participate together. Family members and friends, by their very presence and advocacy, can assure that a person with a disability has every opportunity to communicate, is treated respectfully, and that professionals focus on supporting a person's dreams and on recognizing and nurturing a person's strengths, not deficits.

When access to records, and routine invitations to meetings are important, an adult person with a disability can empower a family member or friend to participate by signing a “Release of Information” or “Advocacy Authorization” (samples follow). Any of us can sign a “Medical Power of Attorney” that allows another to advocate on our behalf, give and receive information, and, in certain appropriately limited situations, actually make our medical decisions for us. This is another tool that persons with disabilities can use as well to partner with others while retaining all their legal rights.

Another great tool for partnering with persons with disabilities is the use of the “person-centered planning” concept. This can be utilized in transition planning, job development/self employment and delivery of services from the Development Disabilities, Mental Health, or other systems. Briefly, the person planning process might contain the following steps/components:

1. First, the individual chooses who to invite. Typically this will be those with whom the person feels a connection- family, friends, clergy, neighbors, co-workers, teachers, etc. The more people participating, who are NOT paid to be in someone's life, the better.
2. Everyone meets in a comfortable, non-institutional setting (preferably with food), and, assisted by a facilitator, shares the person's strengths and dreams for the future. Everyone contributes, and family members are always surprised at some of the new things even they find out. Also refreshing, is having many different perspectives help to produce a picture of a whole person who is the sum of many parts, rather than a limited picture of a single part.
3. An action plan and timetable are developed which address how to deal with any real or perceived barriers to achieving the dream. Everyone leaves with one or more tasks, and a time to reunite to monitor progress.

This person-centered method accomplishes several things. First, a network of naturally connected friends and family assure that a person doesn't make decisions in a vacuum, or worse, have all decisions made "in their best interest" by paid service providers. Secondly, it assures that tasks and support are shared by a number of people so no one person has the weight of another's happiness entirely on their shoulders. Third, it permits the person and everyone else to be thoroughly conscious of the person's strengths and gifts and dreams and humanity, all of which increase the likelihood of inclusion. The person-centered approach is a very natural way to partner with someone to work toward and then achieve their dreams.

What If...?

There are many "what if...?" questions asked by families. For instance, I have often heard, "Shouldn't I become my son's guardian, just in case?"

If someone with a disability is in an accident, circumstances are not any different than they are for the rest of us. If a person is injured in a car crash, and is taken unconscious to the hospital emergency room, medical personnel are legally empowered to take any action necessary to save life or limb, regardless of the person's inability to consent. If the situation is not an emergency, but is nonetheless urgent, medical personnel typically ask next of kin for treatment permission, regardless of whether or not the person had a disability before the accident or urgent situation.

What if a written or verbal authorization is legally required for medical treatment, and someone is not able to give one, and there is no medical power of attorney in place? In such cases, a temporary guardian can be immediately appointed at any hour by the local judge on-call, and the judge can grant the temporary guardian only the power to sign the medical authorization. The procedure is the same whether or not a person has a disability, and a judge's order can be very narrowly defined so as to achieve authorization for needed treatment that lasts only until the person her/himself can resume exercising their own power of consent.

What If.....Scenario #2

"What if I want to have my daughter sterilized so she can't get pregnant?"

This is one concern that is often the real "hidden agenda" when parents seek guardianship. In many states, sterilization, like a heart transplant, is considered an "extraordinary procedure", and is not covered by a typical guardianship. In addition, if family and friends are concerned because a woman is "too cognitively disabled to care for herself", then perhaps more than pregnancy, people close to her need to worry about and guard against abuse. If sexual abuse of a very vulnerable person is prevented, then most likely, so will unwanted pregnancy be prevented. If a woman is able to engage in consensual sex with a partner of compatible ability (whether or not he passes muster with her family), then a more typical solution might be birth control, including methods like the underarm implants, which offers protection for months at a time. Of course, all of this is assuming that the woman is actually able to conceive (is not biological sterile), and is actually sexually active, or even interested in sex.

Sometimes the prospect of sterilization can actually be overkill by parents who want to assuage their parental fears. It does not address the more basic issues such as biological ability to conceive, interest in sex, having a partner, how to meet people, developing and maintaining healthy relationships, and how to say “NO” to unwanted touch. Unless a guardian is joined to a woman at the hip and can monitor her 24 hours a day, then guardianship alone cannot prevent abuse, exploitation or unwanted pregnancy or sexually transmitted diseases. If a woman is under her family’s watch 24 hours a day, then guardianship is unnecessary because there will be no opportunity for wanted, or unwanted sexual contact. A family’s best chance at long term peace of mind is helping to facilitate friendships and connections to people in the community who are not paid to be in their daughter’s life.

“What If....” scenario #3

“What if my son or daughter is pressured or enticed into signing a lifetime contract for new siding by some fast talking con man?”

First of all, since guardianship doesn’t come with a magic shield, your son or daughter might still be persuaded or coerced into signing something. It will just be unenforceable. Instead of guardianship, advocacy is an appropriate situational solution. All of us have 3 days within which we can withdraw our consent to any sales contract we may have signed. Beyond that time frame, a call by family, a friend, an advocate or attorney explaining the situation should result in voiding the contract by the issuing company. Most companies do not want their salespeople exploiting or taking advantage of vulnerable people. If your son or daughter does not own property and receives only SSI and/or SSDI, their benefits cannot be attached legally to satisfy a debt. The parents of adults with disabilities are also not responsible for any debts their children incur, unless, of course, they are co-signers. If all else fails, legal services or your state’s Protection and Advocacy agency can assist with legal help to explain in court how your son or daughter was exploited.

In all of these very common scenarios, guardianship is not able to prevent bad things from occurring. In addition, there are other ways available to deal with nearly all of the possibilities that are of great concern to parents, and which leave your son’s and daughter’s dignity and rights intact. Some of the possibilities for typical supports, available to everyone, or disability-specific supports that can provide support and serve as alternatives to guardianship include:

1. Supports Available to All of Us
 - A. Family and Friends
 - B. Circles of Support
 - C. Releases of Information; Advocacy Authorizations; Appointment of Personal Representative

2. Scheduled Checks and Alerts-Generic Community Assistance
 - A. Postal service checks
 - B. Unpaid utility bills/meter reader observations

C. Telephone reassurance programs

3. Generic and Disability Supports

- A. Food and prescription drug deliveries
- B. Meals on Wheels
- C. Home visitors and “Pets on Wheels”
- D. Service animals
- E. Transportation to medical and other appointments
- F. Personal Assistance/Home Health Services
- G. Home sharing/roommate
- H. Home and Community-based Services (HCBS) or other Medicaid Waiver

4. Legal Assistance Requested and/or Authorized by the Person

- A. Advance Directives/Protective Medical Decisions Document (PMDD)/Living Will
- B. Surrogate decision making/Health Care Proxy
- C. Durable Powers of Attorney

5. Assistance with Finances

- A. Banking services
- B. Joint ownership of bank accounts, or two-signature checks
- C. Authorization of a specific banking transaction
- D. Living and/or other Trusts (Amenities Trusts/OBRA Trusts)
- E. Representative Payee (appointed by Social Security for SSI/SSDI benefits)
- F. Conservatorship

6. Assistance Where We Live

- A. Case Management/Supports Coordination
- B. Senior Care/Adult Day Care
- C. Respite Care programs
- D. Continuing Care Retirement Communities
- E. Assisted Living facilities
- F. Group/Foster Care Homes

Utilizing a combination of the above alternatives, families have a full toolbox to help them stay involved with their son/daughter, assure respectful and meaningful support for their son/daughter, and protect their son's/daughter's rights.