



The Rural Institute Transition Projects

E-News

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A Quarterly Newsletter Produced by the Rural Institute Transition Projects

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Introduction

Guardianship – to pursue it or not - is one of the most complicated and emotion-laden questions parents of children with disabilities face. In this issue of the Transition Projects E-News, we present alternatives to guardianship for your consideration. We begin with a discussion of the realities and myths of guardianship, as well as concrete ideas about alternatives, from Marsha Katz. Our hope is that Marsha's piece will start you thinking about other ways to meet the ongoing safety and support needs of individuals with disabilities. We finish with Kathie Snow's "How..." article (reprinted with her permission) to inspire your creative thinking about how you can actually implement alternatives to guardianship.

Alternatives to Guardianship

By Marsha Katz

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 piece 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,

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Resources

University of Montana's Rural Institute Transition Projects
<http://ruralinstitute.umt.edu/transition/>

Parents, Let's Unite for Kids (PLUK)
<http://www.pluk.org/>

Montana Council on Developmental Disabilities
<http://www.mtcdd.org/>

Administration on Developmental Disabilities Youth Information, Training and Resource Centers
<http://www.addyc.org>

"Alternatives to Guardianship" Web Conference Archive (12/3/07)
<http://ruralinstitute.umt.edu/transition/trainingcalend.asp>

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Alternative to Guardianship, cont.

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 a 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.

- ⇒ Guardianship is NOT a magic shield that can protect people from bad things happening
- ⇒ Guardianship is not needed to redress wrongs that do occur
- ⇒ Typically, families of persons with developmental disabilities are motivated to seek guardianship because they love and wish to "protect" their family member
- ⇒ All guardians are not created equal



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." 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 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

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Resources

10 Legal Myths About Advance Medical Directives by Charles P. Sabatino, J.D.

<http://www.abanet.org/aging/publications/docs/10legalmythsarticle.pdf>

A Good Life: For You and Your Relative with a Disability
<http://agoodlife.org/>

Michigan Revocable Grantor Trusts, Second Edition
Chapter 12: Amenities Trusts for Individuals with Developmental Disabilities or Mental Illness by Joshua R. Fink and Joel S. Welber
<http://www.arcmi.org/Amenities%20Trusts%20for%20Individuals%20with%20Disabilities%20Joel%20Welber.doc>

Center for Self-Determination
<http://www.self-determination.com/articles/index.html>

Eliminating the Pervasiveness of Guardianship by Dohn Hoyle
http://www.e-epg.info/newsroom/files/eliminating_pervasiveness.pdf



Alternatives to Guardianship, cont.

planning, job development/self-employment and delivery of services from the Developmental Disabilities, Mental Health, or other systems. Briefly, the person-centered planning process might contain the following steps/components:

1. First, the individual chooses whom 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 helps 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?"

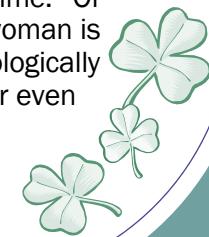
A family's best chance at long term peace of mind is helping to facilitate friendships and connections to people in the community who are not paid to be in their child's life.

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 (i.e., is not biologically sterile), and is actually sexually active, or even interested in sex.

Sometimes the prospect of sterilization can actually be overkill by parents who

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Alternatives to Guardianship, cont.

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 or 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.



Follow-Up Questions from 12/3/07 Web Conference "Alternatives to Guardianship" Responses Provided by Marsha Katz

1. Is the "Advocacy Authorization" good only for individuals with disabilities or can it be used with elderly people also?

The Advocacy Authorization could be used with anyone. A younger person who has no disability, but who is very shy and uncomfortable asserting him/herself might use the form to assure that service/health providers, etc. exchange information with and listen to advocacy from a particular friend or relative. It is a simple document that provides authorization for a person of your choosing to be involved with you in decision making about your life. It is a little different than a "Release of Information," although a Release of Information could be customized so you could also authorize a person of your choosing to act as your partner and advocate with various service providers and governmental entities.

2. Are the forms for "Guardianship" universal across the United States or are they state-based?

The legal requirements and process for guardianship vary from state to state, although there is much that all the states have in common. Some states also use different terms, or have different levels/forms of guardianship than do other states.

There may be some forms that are "universal"....meaning that they would cover the bases in all states, but you are always better off with forms that are specifically designed to conform to your individual state laws. These forms should be readily available at no cost from the Clerk's Office of the court that handles estates and guardianship in your state or community.

3. I am wondering if you could direct me to a legitimate resource for Power of Attorney Forms. Can this be done without the services of an attorney?

Power of Attorney forms are available in any office supply store, and on many web sites. Some web sites even offer the ability to include or exclude certain tasks you would want to authorize or not authorize another person to be able to perform on your behalf. These forms typically have a cost of a few dollars, or \$20, or possibly more if the situation is complicated, but all are likely to be much more affordable than an attorney. That said, when it comes to authorizing another person to make decisions about your life and finances, it may be well worth it to have the papers drawn up or at least reviewed by an attorney. If you do go the route of an office supply store, or a web site, note that there are a variety of Power of Attorney forms. Some cover medical situations, some cover finances, some are effective when executed and properly witnessed and notarized, some become effective in the case of disability. It is important to understand these differences, and assure you are using the right form for your situation and to meet your specific needs.

Save the Date

The first annual Montana Youth Transitions conference
will be held in Great Falls September 15-17, 2008.
Details will be provided as the conference takes shape.
Be sure to mark your calendars now and save the date!



Training Calendar

Web Conferences

The audio portion of the Web conferences can be accessed from any telephone and the video portion from a computer with Internet access. There is no cost for any of the sessions.

All sessions take place from 1:00pm - 2:30 pm Mountain Time.

Dec. 3 - Alternatives to Guardianship

Jan. 7 - Montana VR: Navigating the Transition from School to Work

Feb. 4 - Montana Youth Leadership Forum

Mar. 3 - Assistive Technology and the Transition Process: Part I

Apr. 7 - Assistive Technology and the Transition Process: Part II

May 5 - Montana's Disability Navigators

Jun. 2 - Independent Living Centers as a Resource to Youth in Transition

Aug. 4 - Self-Advocacy Skills for Transition-Age Youth

Session fliers and registration information will be sent to Montana Transition Listserv members. To join the Montana Transition Listserv, send your email address to Kim Brown at brown@ruralinstitute.umt.edu. Fliers may also be downloaded from the Transition Projects Web site as they become available.

Audio recordings of conferences that have already taken place may be downloaded from the Rural Institute Transition Projects and PLUK Web sites:

<http://ruralinstitute.umt.edu/transition>

<http://www.pluk.org>

Other Trainings

Third Annual Transition Seminar
June 18-20, 2008

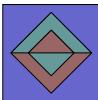
University of Montana, Missoula
mika.watanabe-taylor@umontana.edu

The International Conference on Self-Determination

May 27-29 2008
Detroit, Michigan

http://www.communitydrive.org/uploads/ICSD_Broch.pdf





Emerging Leader Perspective: An Interview with Connie Lewis by Kim Brown

Connie Lewis is the Project Liaison for the Montana Transition Training, Information and Resource Center (MT-TIRC), one of the Rural Institute's Transition Projects. Connie has worked at the Rural Institute for six years providing clerical and administrative support to the Training Department and the Transition Projects. She is the Vice President of the Missoula People First chapter, an Aktion Club member of the Kiwanis, on the Board of Directors of Very Special Arts (VSA) and a singer in the VSA choir. Connie has participated in advocacy classes at Summit Independent Living, and has experience as a consumer of Vocational Rehabilitation and Developmental Disabilities services. She used a Social Security Plan for Achieving Self Support (PASS) to purchase her own vehicle, and she lives independently in the condominium she owns.

Kim: Connie, do you remember the IEP (Individualized Education Program) meeting when you turned 18 and your rights were transferred from your parents to you? The time when you could start signing your own IEP forms?

Connie: Not really. I had been living in a group home for 1½ years at that point. I just remember being given a paper with lots of questions asking what I wanted to do after high school. I had all kinds of ideas racing through my head. I thought maybe I wanted to be a case worker but thought I'd have to go to college for seven years. My second thought was to become independent enough to work at my first job. I wanted to be in the community, not at the workshop where I ended up working for the first year after I graduated.

Kim: When you told your parents you wanted to live and work in the community, were they worried?

Connie: My dad was wondering about my finances.

Kim: Did your parents ever go to court to become your guardians?

Connie: No.

Kim: Do you have a protective payee for your Social Security benefits?

Connie: No, my Social Security checks are direct deposited into my account and I pay my own bills.

Kim: Does anyone help you make medical decisions?

Connie: I make all my own medical appointments. Last year I had surgery and I made the arrangements myself. My friend Nancy drove me home after the surgery. I learned how to make appointments by

listening to my mom on the phone when I was living at home. Sometimes I don't ask doctors very many questions so I need more information. I talk to my parents and they give me ideas about what to go back and ask the doctor. My parents are pretty comfortable with me taking care of my medical appointments.

Kim: Do you have any trusts set up in your name?

Connie: Not that I know about.

Kim: There is a lot to learn when young people move out on their own for the first time. Who has provided you supports along the way?

Connie: My DD case manager, my friend Nancy, and I ask my parents for help when I need it.

Kim: You work in the community, own your own home, have a pet cat, drive a car you purchased, are in a romantic relationship, and travel by yourself for vacations. What are some of your dreams for your future?

Connie: I want to buy a full house (not just a condominium), get married, and travel to Switzerland.

Kim: There are lots of young people out there with big dreams like yours, but maybe their parents are afraid of them living on their own and making adult decisions independently. If you could talk to these kids and their parents, what would you say?

Connie: Parents can be very overprotective. At times this is not really helpful. I wanted to get away from this when I was young. I wanted my parents to learn a lesson so sometimes I'd take off on my own and walk to the store. I'm not sure what will happen when my parents pass away, though. Maybe my brother or sister will try to act like my parents. I don't want this! Families need to talk about things like that.

When I finally moved out and was living in an apartment with a roommate, my parents used to come to my apartment every Saturday. I didn't really want them there every Saturday. I wanted my space.

Parents should protect their kids a little but be careful not to overprotect them. Young people need to learn and grow from their mistakes.



How?

is the Question

Revolutionary Common Sense by Kathie Snow
www.disabilityisnatural.com

"No, not yet—you can't be in general ed classes, be involved in the community, have a job, live on our own or [fill-in-the-blank]... because you can't walk, talk, read at grade level, wipe your own behind, cook, behave, and/or [fill-in-the-blank]. You're just not ready, the teacher/employer/community isn't ready, we don't do that here, and/or it just won't work..."

These and a myriad of similar statements create an inviolate wall of separation—an attitudinal barrier—which results in segregation, isolation, and loss of opportunities for children and adults with disabilities. We seem to be stuck in the muck, *unable or unwilling* to wriggle free and find *creative solutions* to ensure people with disabilities are included in all aspects of our society and are living real lives.

If we have been *unwilling*, we should have the integrity to state our position honestly—to admit that we are, indeed, unwilling—rather than spew a variety of excuses, including “blaming” the person with a disability. Honesty is always better than little white lies, half-truths, exaggerations, or deception. And while such honesty may generate frustration, sadness, or anger in the person on the receiving end, it also allows that person to see things as they really are and to then move on, find other options, etc. (And those of us who are on the receiving end of “no” should learn to ask the nay-sayers: “Are you unwilling or unable?”

There *is* a difference!) In addition to admitting our unwillingness, we should also have the decency to acknowledge that our decisions may have contributed to negative consequences for a child or adult with a disability, and as moral human beings, we should assume our share of responsibility for the difficulties we may have caused in another’s life.

If we have been *willing*, but somehow *unable* to arrive at the right solution, perhaps it’s because our

creative juices have dried up, we’ve hit a seemingly insurmountable bump in the road, we think it will cost too much, and/or . . .

Either position—unwilling or unable—may also have been the result of limited vision, following old ways of thinking, or other attitudinal barriers. But asking “How?” can eliminate these barriers, opening our minds to a world of possibilities, for we begin seeing things in a whole new way!

- How can Stephen be successfully included in general education classes?
- How can Maria live in her own place?
- How can Eric participate in the Boy Scouts?
- How can John be an effective employee?
- How can Mrs. Thomas include a student with a disability in her high school classroom?
- How can Mr. Matthews ensure his place of business is accessible and welcoming for all employees?
- How can we find the money?

Asking “How?” in a classroom; on the job; at home; at a community activity; at an IEP, IHP, or other PP meeting; and/or in any other setting can

be the opening of a brainstorming session that can generate a flurry of great ideas. Assistive technology, supports, accommodations, or modifications might be

just the ticket to ensure a child or adult with a disability can be successful at school, in the community, on the job, or at home. More training, environmental alterations, using the expertise of people with disabilities/families, or other changes may be what’s needed by teachers, employers, leaders of community activities, and others.

Reviewing the scenarios above, Stephen can be included in general ed classrooms if he’s provided

***It all depends on how we look at things,
and not how they are in themselves.***

Carl Jung

2 - "How?" is the Question

with certain assistive technology devices. Maria can live in her own place if she has some supports or accommodations in the kitchen and bathroom. Eric can participate in Boy Scouts if some of the activities are modified. John can be an effective employee if he has a couple of mentors he can call on for help. Mrs. Thomas can include a student with a disability if she works closely with the student, his parents, and the special ed department. Mr. Matthews can ensure his business is accessible by making some environmental changes. We can find the money by investigating grants and other funding sources, collaborating with community service groups, and/or spreading the word about what we need to all who will listen. While these are generalized examples, they *do* represent real-life experiences.

In my son's life, we never presumed the diagnosis of cerebral palsy was an automatic barrier to Benjamin's success. Instead, asking "How?" from the time he was very young helped us figure out what was needed to ensure Benjamin can lead a real life, successfully included in any arena: the neighborhood preschool; general ed classes; T-ball, karate, drama classes, and other community activities; and today, college. Other people with disabilities and families, in collaboration with caring and open-minded educators, day care providers, community leaders, etc., have done the same. But we're in the minority, as evidenced by the majority of children and adults with disabilities who are segregated in special programs and isolated from real-life experiences, with little hope of living a wonderful, ordinary life or achieving their dreams.

The dictionary on my computer defines "how" as "in what way or manner; by what means." Every

day, people who do not have disabilities ensure their own personal success, as well as the the success of their children, their families, their jobs/businesses, etc., by a variety of means, and it all begins with asking questions such as:

- How can we take that trip to Hawaii?
- How can we buy a new home?
- How can we afford college tuition?
- How can we increase sales?

Asking "How?" can turn dreams into realities. In these and similar situations we don't automatically eliminate the idea as unrealistic or impossible, nor we feel the need to justify or prove our case. So why do we impose such standards on people who happen to have disabilities?

Whether you've been unwilling or unable, examine your position and your motives. Are your actions the result of fear, apathy, laziness, or ignorance?

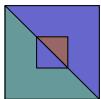
Or perhaps you're robotically following rules, policies and procedures, or conventional wisdom. If you're an educator, employer, or serve in any decision-making role, has a person with a disability or family member offered solutions, and you've pooh-poohed their ideas? Regardless of the "why" of one's actions, the outcomes are the same: segregation, isolation, loss of opportunities, and other less

than desirable outcomes for children and adults with disabilities. We all have the power to create positive change. Don't we also have an ethical responsibility to do so?

Ask "How?" with an open, creative mind. Look at the situation differently. Believe in possibilities. Then be astounded by the changes in your perceptions, attitudes, and actions—and celebrate the awesome improvements in the life of a child or adult with disability!

Sometimes the situation is only a problem because it is looked at in a certain way. Looked at in another way, the right course of action may be so obvious that the problem no longer exists.

Edward de Bono



Transition TIP

Start thinking EARLY about what supports your child might need to live, work, and play in the community if you were not available. Then think about how those support needs could be met.

1. Ask yourself, "What scares me the most when I think about the day when I'm not around to care for my daughter/son?" Write down your responses. For example, you might write:
 - a. I'm worried that a doctor might say she needs surgery or some other medical procedure and I won't be there to decide if it is really safe and in her best interest.
 - b. If he's able to live in an apartment with a roommate, I'm afraid he'll forget to pay his bills and wind up on the street.
 - c. What if our daughter runs out of money? We've heard we can jeopardize her Medicaid if we leave money to her in our will.
2. Brainstorm ways to address each of the concerns you have identified. Using the examples above:
 - a. Consider a Medical Power of Attorney to allow someone your daughter trusts and is comfortable with to advocate on her behalf and, in limited situations, make medical decisions for her.
 - b. Your son's SSI check and paychecks are already being direct deposited into his bank account; research whether his rent payments can be "auto-paid" (directly withdrawn and deposited into the property management company's account) each month.
 - c. Talk with a knowledgeable attorney about establishing an "amenities trust."
3. Develop a plan of action – this may involve things like researching certain options more thoroughly, talking to other families and individuals with disabilities about how they have addressed specific issues, meeting with an attorney, visiting reputable Web sites to learn more about alternatives to guardianship (see the "Resources" section of this newsletter), investigating local resources, etc. Above all, make sure the plan elements respect the wishes, dreams, desires, and rights of your son or daughter.
4. Implement the plan.



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