

Deafblind Focus

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A Vision and a Voice 10 Years of Advocacy

This is a reprint of an article by Sheri Stanger, President NFADB, from the NFADB News From Advocates For Deaf-Blind newsletter.

I'm often asked what is so different and special about the National Family Association for Deaf-Blind. The obvious answers come easily - we are the largest national network of families focusing on issues surrounding deaf-blindness. We adhere to our philosophy that

"Individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community."

We provide training, information and support to families, family groups and professionals. We collaborate with national projects and support national policies to benefit people who are deaf-blind.

As clear as these answers may seem, we still question our effectiveness and our goals for the future of our organization. To develop and offer families the support they need are necessities for our group as we move forward into our second decade. We must take stock of our priorities, our structure and the needs of families and never stray from our mission. We must have vision. We must be heard.

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Under the Magnifying Glass: Guardianship

The following article was written by Margaret Gilbride, Esquire. She is a former educator who has worked in the disability field as an advocate for full inclusion for nearly 15 years. During this time, she has presented at numerous state-wide and national conferences on a variety of disability issues. She is currently employed by the Indiana Institute on Disability and Community to provide training and technical support in the areas of community living and careers.

Warning: **Guardianship Under Construction**

The late United States Congressman Claude Pepper (D-FL), a leader in championing the rights of older people and other vulnerable groups, said the following when considering the effects of guardianship on the lives of people with disabilities (here called "the ward"):

"The typical ward has fewer rights than the typical convicted felon—they no longer receive money or pay their bills. They cannot marry or divorce. By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty (Abuses to Guardianship, 1987)."

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Under the Magnifying Glass: Guardianship

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Guardianship is a complex issue made more so in light of the facts that we as a society prize our independence and we as parents find our sons and daughters (and ourselves) part of a disability rights movement that demands for its members self-advocacy, self-determination and authentic interdependence.

Oftentimes guardianships are obtained merely as a routine course of action with little thought to the long-term implications for the young adult deemed “incapacitated”. Guardianships for persons with developmental disabilities are unquestionably easy to obtain but difficult to terminate. Ask the woman in her 30s who is unable to marry the man she loves because her legal guardian, her brother, will not give permission. She knows what she wants and she states it clearly. Her brother believes he knows what is best for her and so she cannot marry. Her brother has a faulty but common notion of the role of the guardian: to do what he thinks is best for his sister. The actual role is to ensure that the voice of his sister is heard. Too often the means of legally ensuring a person’s rights are protected becomes the means of legally curtailing those rights.

There are certainly times when there is genuine concern that an individual lacks sufficient understanding or capacity to make or communicate consent (agreement) either totally, partially or temporarily regarding his/her person or property (or both). There also are times when the only answer to a serious or potentially dangerous problem is to pursue guardianship. It is just wise to be fully informed as to what guardianship means and what its alternatives are so you can best determine if no better way exists to assure your child’s basic needs are met and that his/her property is protected for his/her benefit.

Guardianship and Person-Centered Planning

One of the five outcomes of person-centered planning developed by John O’Brien is **choice** which he defines to be “the experience of autonomy both in small everyday matters and in large life-defining matters.” Without a concerted focus on choice-making skills throughout their lives, children with disabilities will become adults who are passive and without voice or the ability to escape undesired outcomes in their lives. The more practice and participation children with disabilities have in decision-making across their lifespan, the better prepared they and their families will be when the appropriateness of guardianship and its alternatives is to be explored.

Essentially, the test for determining the “need” for guardianship is the ability of the person to (1) make decisions, and (2) communicate decisions once they are made. Making eccentric, ill-advised or periodic poor choices is not the test. On the contrary, it is the inability to engage in decision-making in the first place that is critical. The fact that a person has a disability, even a cognitive disability, does not indicate automatic need for guardianship. Practical questions to ask prior to limiting the legal rights and responsibilities automatically afforded a child who reaches age 18 include:

- Does this person understand the decision to be made?
- Does this person understand the options available?
- Does this person understand the consequences of each option?
- Does this person have the ability to inform appropriate parties once the decision has been made?

Because people with disabilities (all people) have different areas of strength and needs for support, there exists a variety of guardianships and guardianship alternatives from which the most appropriate and least restrictive can be selected. Because it is important to get advice applicable to the unique circumstances of your family, this newsletter is not meant to serve as anything other

than a brief introduction to these options. The intent of this newsletter is merely to inform; not advise.

What Guardianship Is (Technically)

Parents of children with disabilities often assume that they continue to be their child's legal guardian during their lifetime; however, by law, a child who reaches age 18 is presumed competent (able) to make decisions unless otherwise adjudicated (declared) by a judge.

Guardianship, then, is a legally instituted relationship established between an eligible adult or qualified charitable organization (as "guardian"), and an individual declared by a court to be an incapacitated person (the "protected person"), in which the guardian is empowered to make decisions on behalf of the protected person.

IC 29-3-1-7.5

Incapacitated person

Sec. 7.5 "Incapacitated person" means an individual who:

- (1) cannot be located upon reasonable inquiry;
- (2) is unable:
 - (A) to manage in whole or in part the individual's property;
 - (B) to provide self-care; or
 - (C) both; because of insanity, mental illness, mental deficiency, physical illness, infirmity, habitual drunkenness, excessive use of drugs, incarceration, confinement, detention, duress, fraud, undue influence of others to the individual, or other incapacity; or
- (3) has a developmental disability (as defined in IC 12-7-2-61).

Types of Guardianship

There are several types of guardianships for which an eligible adult may petition (ask) the court. Attorneys are not uniform in their fee structures and the cost for an uncontested (not argued against) guardianship of the person may range from several hundred to several thousand dollars. When initially contacting an attorney, ask for an estimate of fees as well as court costs.

Guardianship of the Person

The guardian, not the individual, makes decisions such as where the protected person will live, what medical treatments/he will receive, who his/her doctors will be, with whom s/he should associate, or where s/he should travel. **All decisions affecting everyday life are made by the guardian.** For example: a protected person in this situation would not be able to access Vocational Rehabilitation services for job placement unless the guardian approved.

Guardianship of the Property

The guardian, not the individual, makes decisions about how, where, or when to spend the person's money or how to administer her/his property. The guardian typically collects all money due the person and from that pays her/his bills and buys her necessities. Typically a two-year accounting is required. With this type of guardianship, only decisions regarding money and property are made by the guardian—all other decisions are made by the individual. For example: an individual would be able to access Vocational Rehabilitation services for job placement but his/her check would be directly deposited into an account managed by the guardian so as to assure necessities were paid for first.

Full Guardianship

Both of the above. **Guardian makes all decisions affecting both everyday life and financial/property related administration.**

Limited Guardianship

Gives authority over the protected person only for the listed actions, the individual retains decision-making responsibilities which s/he is capable of exercising, yet has guardianship assistance with respect to matters in which there is a need for a substitute decision-maker. **An order of limited guardianship must include the specific duties and powers of the guardian and the legal disabilities of the protected person.** For example, the protected person may have all decision-making rights and responsibilities except

for making purchases over five hundred dollars.

Standards for Guardians

A guardian:

- should be guided by the wishes of the protected person to the greatest extent possible, consulting with him/her about all options and decisions.
- should make decisions in a way that protects the civil rights and liberties of the person and maximizes opportunities for growth, independence and self-reliance.
- should operate with the highest degree of trust and loyalty.
- should make choices toward least restrictive alternatives.
- should adhere to the duty of operating only with informed consent.
- should manage property (real and personal) with competence and by reasonable standard.
- should seek termination or limitation of guardianship whenever indicated.

Alternatives to Guardianships

There are many reasons why parents look to guardianship alternatives. Some do so because they realize that any form of guardianship entangles the court in the life of their child as well as their own and by its nature takes away from their child the control of his/her life that they have tried over the years to impart. Some look to alternatives because they recognize that for their child's situation, guardianship would take away far more rights than are necessary to solve the problem at hand and conveys too strong a message to their child and others of **inability**. Some other reasons include that pursuit of guardianship can create antagonism, lead to complications or cost more than they wish to spend.

A sampling of alternatives used by parents are

listed below. Some can be done without the assistance of an attorney, although it is always advisable (even if you use your own legal software package) to at least have an attorney review the document for legal and procedural accuracies.

- A document is signed by the child **designating an advocate** without whom s/he won't make major decisions.
- The parents are identified as **payee** to receive checks (such as those from Social Security) "in lieu of" the child.
- The child assigns the parent with **Power of Attorney for Financial Affairs** so they can handle all financial matters as "the attorney in fact".
- The child assigns the parent with a **Limited Power of Attorney** wherein the document lists the specific actions that they as "the attorney in fact" has the right to make on behalf of the individual.
- The child assigns the parents with **Healthcare Power of Attorney** authorizing them as "attorney in fact" to accept or refuse healthcare in accordance with the individual's wishes. This also would allow them to access records, choose providers, and to admit or release the child from chosen healthcare facilities.

Guardianships and Their Alternatives—Just the Beginning

The question, "Should I or shouldn't I?" when asked about pursuit of guardianship for your child with a disability is only the beginning. The answer you come up with will not help when you ask the ultimate question, "What will happen to my child when I (we) am gone?" It is true that financial/estate planning for the secure future of your child with a disability can be a huge issue to address. Because of the laws/regulations determining eligibility for different entitlements, you must get a complete financial and legal picture of the impact on them different trusts, inheritance laws, home ownership and the like can have. These and other such long-term estate planning topics are beyond the scope of this newsletter.

A Vision and a Voice 10 Years of Advocacy

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At the risk of sounding cliché, I will quote Helen Keller:

**“Is there anything worse than being blind?
Yes, a man with sight and no vision.”**

This simple quote says a lot. As an organization that started out as a parent advisory group to HKNC only 10 years ago we need to look at our history to understand our current situation and where we are headed. Ten years ago a formal family organization did not exist, parents did not have a united voice and we were not organized to effectively influence legislation. We were individuals working hard to advocate for our children, yet having a difficult time sharing our successes and failures with other families. Parents needed to make a difference by being heard and NFADB was born.

Today we are much better off for having been around. Even though current legislation for IDEA is not ideal, it is better than it was. Deaf-blindness is written in the law and we have a family voice on the Deaf-Blind Coalition, which is also part of the Consortium of Citizens with Disabilities. The state deaf-blind projects have written into their RFPs that they must work with parents. That was not there in the past. We are included at conferences and asked to speak from our own personal expertise in parenting a child with deaf-blindness.

We are a special entity that is becoming part of a bigger picture. This is a process. It takes time, energy and commitment. We must not forget where we came from but we must have a vision for the future. I can't help but quote Helen again:

**“One can never consent to creep
when one feels an impulse to soar.”**

We know all our children can soar but are often held back by ineffective legislation, poorly trained and informed teachers, lack of financial resources and a myriad of other reasons.

We struggle with job training, job opportunities, travel arrangements and appropriate housing. This is our commonality. We all share these same problems and yet many of us persevere and encourage our children to live their lives to the fullest.

We put all of our energy and resources into helping our children soar. We have a daily struggle that very few people can understand. NFADB understands. All our volunteers share the same struggles and want to make a difference in our lives.

How can we lessen the struggles? We can share our hard-earned information with each other. We can support each other's efforts and we can make sure the professionals hear our concerns and we can lobby for change.

It sounds like a lot to do. It is. The road ahead is not easy but was paved by those who came before us and we salute them at our 10-year anniversary.

It is once again time to dream. To make sure our vision of success for our children, young or old, is heard.

We have a vision and a voice. Let's use it together!

We Need Your Help!

We need your help to keep our records up-to-date. If you or someone you know needs to change their address or would like to be added or removed from our mailing list, please fill out the form below and return it to the Indiana Deafblind Services Project, College of Education, Room 502, Indiana State University, Terre Haute, IN 47809 or contact us by email SharonBryan@indstate.edu

- Add me to your *Deafblind Focus* mailing list
- Remove me from your mailing list
- My info has changed. Please update records.
- I am a Parent
- I am a Service Provider

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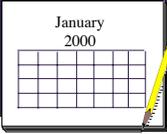
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Upcoming Events

The SELF Outreach Project

A six week online course is being offered this fall for anyone involved in the assessment and intervention of infants and toddlers. The course, funded by the U.S. Office of Special Education and Rehabilitative Services, provides information on self-regulation, sensory processing, temperament and social-emotional development. It is an opportunity to learn new information and practice new skills in a flexible environment. The course is free but there is a \$25 materials fee. Participants receive a certificate and OT/PT/SLP and Social Worker CEUs are available.

The project also is looking for people who are interested in becoming trainers in the SELF Process or want to use the SELF information and materials in their training activities. If you are interested, please contact Holly Harrison by email at hharriso@unm.edu.

Visit their website at:
<http://www.newassessment.org>
For information on the SELF Outreach Project, click on "SELF" on the left side bar. Information about the SELF Process can be accessed by clicking on "Models" on the right side bar.

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Free Technical Assistance Available

The Indiana Deafblind Services Project's staff and consultants work with children and youth, ages birth through 21, who are deafblind. along with their families and service providers. The goal of the project is to improve the quality of educational services available to Indiana's infants, toddlers, children and youth with dual sensory impairments. In order to achieve this goal, the project provides free technical assistance, training and support services. To request assistance, please contact the project at (800) 622-3035.

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Editors:

Karen Goehl, Project Director
Lisa Poff, Program Coordinator
Sharon Bryan, Administrative Specialist
Dr. William R. Littlejohn
Director of the Blumberg Center

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University



The Indiana Deafblind Services Project
BLUMBERG CENTER for Interdisciplinary
Studies in Special Education
School of Education 502
Indiana State University
Terre Haute, IN 47809
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