

The Arc of Nebraska presents

A GUIDE FOR SIBLINGS

Considerations in Planning
for a Sibling with a Disability



The
Arc
of Nebraska

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For over 50 years, The Arc of Nebraska, a non profit advocacy organization, has been committed to helping children and adults with disabilities secure opportunities to choose and realize their goals of where they learn, live, work and play.

The Arc of Nebraska is comprised of a state office and 18 local county chapters statewide with over 2400 members. We are affiliated with The Arc of The United States, the world's largest community based organization of and for persons with intellectual and developmental disabilities.

The Arc of Nebraska provides information and action on statewide issues for people with developmental disabilities, provides family advocacy, legislative lobbying, systems advocacy in regulations, policies and practices including special education, developmental disability support and Medicaid, referrals and a lending library, the annual Senatorial Appreciation Dinner, local chapter support, and a website with resource links.

The Local county chapters of The Arc of Nebraska provide a wide variety of services and information for persons with intellectual and developmental disabilities and their families.

Developmental disabilities include but are not limited to autism, cerebral palsy, epilepsy, Down Syndrome, mental retardation, and Prader-Willi syndrome.

Local County Chapters include

The Arc of Adams-Clay	The Arc of Norfolk
The Arc of Buffalo County	The Arc of Omaha
The Arc of Central Nebraska	The Arc of Platte County
ARC-Cheyenne	The Arc of Platte Valley
The Arc of Colfax County	The Arc of Sarpy
The Arc of Custer County	Arc-Saunders
The Arc of Elkhorn Valley	The Arc of Seward County
The Arc of Hamilton-Merrick	The Arc of Southeast
The Arc of Lincoln/Lancaster County	The Arc of Southwest

Published April 2009

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INTRODUCTION

My sister Jolene was born in 1962 when I was three years old. She had two older brothers as well, Mike and Dave. Shortly after she was born, Jolene was diagnosed with severe mental retardation and Down Syndrome. She lived at home and we all helped with her care. As we all got older, Mike, Dave and I all moved out of the house. Jolene stayed in the house with our mother. I remember frequently asking Mom if she thought Jolene might like to live somewhere else also. She always thought that Jolene should live at home with her. Through the years, we would all help in providing back up support for Mom in the care of Jolene. I would sometimes ask her if she had plans in place for the care of Jolene after she was gone. She would always tell me that she had it "taken care of." My mother passed away in 1995 when I was 36 and Jolene was 33. At the time I had a newborn and a husband and as it turned out very limited knowledge of the services available for my sister and even how to go about finding them. Although we had all contributed over the years to help my mother take care of Jolene, it turned out we knew nothing at all about the legalities of making sure my sister had the best services and supports available to her.

In my search for information I have found that most is directed at parents not siblings. Siblings that suddenly find themselves planning for the well being of a sibling with a developmental disability can be overwhelmed and confused on where to go and what to do. I urge all parents to have an open and honest discussion with their children on what they already have in place for their sibling and what they would like to see in place after they are gone. However, I realize from personal experience that this does not always happen. This sibling guide is meant to address both situations and hopefully help the sibling without a disability assume the role of caregiver and advocate in a positive way.

There are several things a family in which there is a person with a disability needs to attend to while the parent is alive:

- *Who will make decisions on behalf of your sibling after your parent is gone?*
- *What needs to be done to make sure that you, the sibling who is the decision maker, has the legal authority after your sibling with a disability reaches adulthood?*
- *What services are available to your sibling so that he/she receives an appropriate job or day program?*
- *How can your parent/sibling decision maker make sure that the sibling has a place to live that can meet their needs in a safe environment?*
- *How can your family make sure that your sibling has their supplemental, personal, and recreational needs met?*
- *What steps can your parents take now to make sure that services for your sibling are available or continue without interruption when the need arises?*
- *How can your parents provide financial security for your sibling without jeopardizing access to important services and benefits?*

Whether or not your parent has addressed these issues, the responsibility for advocating for your sibling may transfer to you after your parent is gone or no longer able to take care of these issues themselves.

What follows is a guide to finding answers and helping in the planning for the future for both parents and siblings.

ADVANCE DIRECTIVES & SUBSTITUTED JUDGMENT

One of the first things to do after your parent is no longer able to make decisions for your sibling with a disability is to address the legal issues giving you, the decision maker, the power to make decisions for your sibling. When one person needs help making decisions about their care or property from another, this is called "Substituted Judgment." The best type of substituted judgment allows your sibling as much independence as possible.

The age of majority in Nebraska is 19 years of age. In the eyes of the law, once a person reaches the age of 19 they are permitted to make their own decisions. If a person at age 19 is unable to make their own decisions due to a developmental disability, it may be necessary to take legal action to establish you as the decision maker sibling. Most parents will have this taken care of while they are alive, but it is important to know what type of substituted judgment they have established and that unless you are also named as a decision maker, you will have to establish yourself separately after your parent is no longer able to make the decisions.

The types of substituted judgment are listed in order from least restrictive to the most restrictive.

Representative Payee- This is a person appointed by the Social Security Administration (SSA) to handle your sibling's benefits if they are not able to do so. When your parents are no longer alive, it is important to notify the SSA and to request that you be appointed the Representative Payee for your sibling if they are not able to handle their Social Security Benefits themselves.

Protective Payee- This is similar to a Representative Payee except that the assignment is made by The Nebraska Department of Health & Human Services. In this case, you manage public assistance payments that your sibling receives from the state of Nebraska.

Advance Directives- These are used to inform others of your sibling's choices for medical treatment. Your parents' may have written directives that can be very helpful to you. However, if this was not set up before your parents' death or your sibling's health or choices have changed, it is important to put the directives in writing. Some common directives include, but are not limited to:

- *A Living Will*- This is a written statement created by your sibling stating the type of medical care they would like to receive in the event of a terminal illness or becoming permanently incapacitated.
- *Power of Attorney for Healthcare*- This document is written on behalf of your sibling. It gives you, or another person the ability to make decisions related to healthcare for your sibling. This would enable the decision maker to give and receive medical information about your sibling to help make medical decisions on their behalf.

Power of Attorney (POA)- This is a legal document that authorizes one person to act on behalf of another. There are two types of POA's: limited or general. A limited POA only allows you to act on very specific matters usually for a specific amount of time. A general POA allows you to act on a wide variety of matters. Powers of attorney however do not allow you to act in regard to assets held by your sibling.

Durable Power of Attorney- This is like a power of attorney. It can become effective in two different ways depending on how it is written. Some durable powers of attorney will allow you to keep making decisions for your sibling even if a doctor determines that they are unable to make decisions for themselves. Other durable powers of attorney will not become effective until a doctor determines that they cannot make decisions for themselves. It will be important to note what kind of power of attorney document your sibling has in place.

Many of the options listed above give your sibling the freedom to make their own choices regarding a lot of different issues. However, if your sibling is not able to make these decisions, a more appropriate choice may be:

Conservatorship- Under a conservatorship you are appointed by the court to manage the estate of your sibling. A conservator usually only has decision making power over property, money or other assets.

Guardianship- The last option to be considered is guardianship. This is also a court appointed position and gives you legal authority to be the decision maker for most of your sibling's personal needs. Guardianship is usually considered when a person cannot make or communicate decisions themselves. It is important to note that limited guardianship should be used if possible. If your sibling is able to make some decisions, guardianship should be limited to only those decisions that your sibling cannot make for him or herself.

It is important to note that according to Nebraska Probate Code, anyone appointed to a Guardianship or Conservatorship is required to take

a class which provides detailed information for persons serving as a Guardian or Conservator. These classes are held in various parts of the state and are taught by The University of Nebraska Lincoln Extension. They will explain the duties of your position and show you the various forms that are required to be filed annually with the court. For more information-www.supremecourt.ne.gov/Guardian.

When determining which form of substituted judgment might be needed, it is important to remember that most, if not all of these require some sort of legal assistance. This should be obtained shortly after your sibling reaches the age of majority or immediately after your parents are no longer able to be the primary decision maker.

For help finding an attorney contact *The Nebraska State Bar Association*: www.nebar.com. Other resources for substituted judgment and advance directives that may be helpful include: *Nebraska Legal Aid*: www.nebls.com or *Nebraska Health and Human Services Unit on Aging*: www.dhhs.ne.gov/ags/agsindex.htm, *Nebraska Advocacy Services*: www.nebraskaadvocacyservices.org

SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME

It is important for you to know that most people with disabilities are entitled to some type of cash assistance from the Social Security Administration. There are two types of income separate from a job that your sibling with a disability may be receiving.

Supplemental Security Income (SSI)- This income is available to a person with a disability who is unable to maintain permanent employment and does not have resources above \$2000. Resources are considered to be either money or something owned that can be turned in to cash such as stocks, bonds, or savings accounts. There is also a monthly limit on how much they can receive in additional monthly income such as a part-time job or monetary gifts. If your sibling is 18 or under and living with your parents, the parental income is counted and generally the sibling does not qualify for SSI. After the age of 18 your parents' income and assets are not counted and your sibling will generally qualify for SSI benefits. However, it is important for you to know that your income and assets will not be counted towards your sibling's income or assets regardless of their age or where they live. SSI payments are based on the income and assets of your sibling. The payments will be adjusted yearly if the cost of living goes up. In Nebraska, a person who receives SSI payments will automatically qualify for Medicaid.

Social Security- These benefits are given to disabled dependents of a parent who collects Social Security benefits, or are benefits given to a disabled dependent when a parent dies. Generally, your sibling does not get both SSI and Social Security after a parent dies. Because Social Security is counted as income for SSI, and because Social Security benefits from the parents are usually higher, the Social Security office will generally reduce or eliminate the SSI benefits. Persons who get Social Security also receive Medicare. Even if SSI benefits are eliminated in favor of higher Social Security benefits, your sibling will still qualify for Medicaid as well as Medicare. This is important for you to know as many worry about the additional cost of healthcare for their brother or sister.

HEALTHCARE

Different options are available to cover any healthcare expenses that your sibling may incur. These options may include: private insurance, Medicaid, and/or Medicare.

Private Insurance- Your sibling may have their own private health insurance that they either purchase themselves or is provided to them by their employer.

Many people are confused by the difference between Medicaid and Medicare. This section will highlight the differences between the two.

Medicaid- This is a program that is run by each individual state, that in theory is designed to cover all medical expenses. Generally there are no or very low co-pays. Medicaid is designed to provide insurance to persons with low income and little or no resources. Eligibility is generally similar to that of Supplemental Security Income-low monthly income and resources under \$2000.

Medicare- This type of coverage is provided to persons age 65 and older, to Social Security Disability Income recipients, and to persons deemed "permanently disabled" by the Social Security Administration. Medicare is a federally run insurance program that helps to cover the costs of your sibling's healthcare. Medicare generally covers hospital care, physician services and a variety of therapies and other medical items. Prescription drug coverage is also available. Medicare has certain co-pays and deductibles. It is important to note that there are no income or resource tests for Medicare.

Generally when your parents die, your sibling may qualify for both Medicare and Medicaid so little or no expenses will be charged to you. One of the first things you should do upon becoming the legally responsible party is to check with your local Social Security office to see what benefits are available for your brother or sister. You can also access information online at www.socialsecurity.gov.

EDUCATION AND SERVICES

This section deals with education and supplemental services that are available to your sibling. Many siblings, when they become the decision maker, are not aware of the services available to their sibling. By taking advantage of the services available, you can greatly enhance your sibling's quality of life.

Special Education- Children with disabilities from birth to 21 are entitled to special education services through federally mandated programs in all states. Most siblings of a person with a developmental disability will most likely not assume responsibility for their sibling until they are past that age group. However, it is still a good idea to have a basic understanding of the programs available.

All infants or children who show signs of a developmental disability will be examined by a doctor who will give a written determination of the type of disability a child has. The law requires that each child must receive a program that meets their individual needs. Schools must develop annually an Individual Education Program, or IEP, that outlines the services to be provided. Schools and physicians are required to provide extensive documentation outlining the needs and goals of the sibling. This information can be very helpful to the sibling who later assumes responsibility. Parents should be encouraged to keep this information safe and secure and to discuss with the siblings where this information is kept. For more information about special education, you may wish to consult the following resources:

PTI-Nebraska: www.pti-nebraska.org

Nebraska Advocacy Services:
www.nebraskaadvocacyservices.org

Nebraska Department of Education: www.nde.state.ne.us

Adult Services- Once your sibling reaches the age of 21, they are no longer entitled to receive federally mandated special education services. There are many options available to your sibling and it is important that you have a basic idea of these programs to help determine what the best option is. It is also important to keep in mind that there is a waiting list for many of the services, so it is necessary to apply early. Ideally, families should ensure that these services are in place before graduation.

Day Services- Upon graduation from high school, families and your sibling must decide what the best option for your sibling is. Some of these options may include: competitive employment, job coaching and support services to support employment in the community, sheltered workshops, or provider based day programs.

- *Competitive Employment-* Employment that is secured by your sibling.
- *Job Coaching and Support Services-* This program will provide your sibling with a job coach and help them secure a job in the community. The job coach will help your sibling learn various skills such as applying for a job, filling out an application, and assisting them on the job for a period of time.
- *Sheltered Workshop-* A workplace that provides a supportive environment where persons with a disability can acquire job skills and vocational experience.
- *Provider Based Day Program-* A place that is run by a provider of community based services where your sibling can participate in various vocational activities.

Residential Services- Many parents believe that it is in the best interests of your sibling to live at home. However, upon the death or incapacitation of one or both parents, the situation can change. Many of us are unable to take on the added responsibility of caring for our sibling due to our own family or job commitments. It is important that you and your parents have this conversation to decide what choices should be made available to your sibling at the appropriate time. Since waiting lists, many several years or longer exist, it is important that you encourage your parents to seek assignment to the appropriate waiting list category to avoid a crisis upon the death or incapacitation of one or both parents. By doing so this can increase the options available to your sibling when they need residential services. The types of residential services include:

- *Independent Living*- This can be an ideal living situation for your sibling if they are able to make their own decisions and prefer to live on their own with minimal outside assistance. If your sibling only needs help with financial matters, for example balancing their checkbook, or only needs periodic support this is the type of living situation that should be considered.
- *Community Supports Program (CSP)* - This is a set of community based services and supports funded through the Nebraska Division of Developmental Disabilities. This program offers funding to assist persons in their everyday living. This gives your sibling more choices of services and providers. The CSP does not provide the usual habilitation services and are generally appropriate for persons who desire to live with their family or in their own home.
- *Adult Family Home*- This is a safe home provided in a family type setting for adults who require minimal supervision. This setting is limited to no more than three adults. This setting may be appropriate for siblings who receive day services or who are employed and need minimal assistance in meal preparation and daily living skills. This enables your sibling to remain as independent as possible while being in a safe, secure environment.
- *Respite*- This is temporary and occasional personal assistance to family members who provide continuous support and care. This service is provided when the sibling lives at home with family.
- *Supervised Apartment or Home*- This is an apartment or home where a person with a disability may live with several roommates. Staffing is based on how much assistance each person needs. Many people who live in this type of setting share household chores and meal preparation. They are also provided opportunities for actively participating in the community. If a person goes to work or receives day services, a staff person may come to assist someone at night with various duties and may possibly provide support overnight as well.
- *ICF/MR*- Intermediate Care Facility for people with mental retardation. This is a private or state run institution that provides habilitation and health services.

For more information about obtaining services, you may wish to contact the *Nebraska Division of Developmental Disability Services*: www.dhhs.ne.gov/Developmental_Disabilities

ESTATE PLANNING

Most parents want to leave assets to their children when they die. They may worry that if they do not leave anything to their child with a disability there will not be adequate resources to take care of them later in life. Your parents could also make decisions that have unintended consequences. For example, they could leave everything to you with verbal instructions to use part of the estate to care for your sibling. However, you are under no legal obligation to use this money on behalf of your sibling. This money can also be the subject of equitable distribution in the event you get divorced. This means that the money your parents have left for you to take care of your sibling can be considered an asset and be distributed to your spouse as part of a divorce settlement. Or your parents could leave assets directly to your sibling, which could affect your sibling's medical or monetary benefits, such as SSI or Medicaid.

The best way to ensure that your parents' wishes are fulfilled while protecting everyone involved is to set up what is called a *Special Needs Trust* or "SNT." The trust can be set up while your parent is still alive or immediately after your parent is gone. Family members use a SNT to hold assets for your sibling. It is important to note that at no time are the assets ever vested in your sibling's name as this could subject them to recovery by either State (Medicaid) or Federal (SSI) programs. There are three basic terms to keep in mind when creating a Special Needs Trust. A SNT begins with the money or property of your parents (settlor), being held by another (trustee), for the benefit of your sibling with a disability (beneficiary).

The settlor must very clearly indicate that the trust is to provide for the supplemental needs of the beneficiary. The law prohibits the use of the assets for "basic" needs such as food, clothing, or shelter.

The law allows the beneficiary access to these assets for non-essentials, while still allowing them to receive state and federal benefits for their basic needs. In this regard, it is necessary to set up the SNT to give the trustee discretionary power to provide for the supplemental needs of the beneficiary. The important thing to remember is that the

trust must be written so that the beneficiary cannot have any control over the trust.

It is equally important for the trustee to have a complete knowledge of the roles and responsibilities of their position. The trustee will need to review the beneficiary's needs periodically. The trustee has a duty to administer in good faith in accordance with the trusts terms and interests of your sibling. The trustee also must keep adequate records of the administration of the trust and submit them annually to the court.

The supplemental needs that are covered by the SNT can go a long way toward ensuring the happiness and greatly improving the quality of life of your sibling. These assets can be used to purchase non-essential items such as, stereos, TV's, movies, or even trips that your sibling may not otherwise be able to purchase with their government benefits.

It is important for you to enlist the help of an attorney who specializes in the creation and administration of a Special Needs Trust, as very specific language must be used in the document. To find an attorney who specializes in setting up a SNT you can contact the *Nebraska Bar Association*: www.nebar.com.

Living Trust/ Inheriting Property

The term "living" in a Living Trust means that the trust is made while the settlor, your parent, is alive. A Living Trust is often used to make sure that your sibling retains rights to their family home. If the Trustee is someone other than the beneficiary/sibling, this will not affect your siblings state or federal benefits. In general, if your sibling has no control over the property, it will not be counted against them as an asset. It is important to keep in mind that if there is possible rental income, that may be counted as income against your sibling. As in a Special Needs Trust, it is important to enlist the help of an attorney in setting up a Living Trust.

IMPORTANT INFORMATION

It is very important to have an open conversation with your parents regarding their wishes for your sibling. It is also important that you know where information is that will help in the transition process. During a conversation with your parents, it would be helpful to encourage them to put together a folder with the following information:

Name and phone number of Service Coordinator- This is the person, employed by the state, that helps organize and inform your sibling of the various services available.

Name and phone number of Primary Care Physician

Name and phone number of any attorneys that have been consulted

Social Security number of your sibling and parents

Medical Records including diagnosis of your sibling

Sibling's birth certificate

Listing of all bank accounts in your sibling's name

Health Insurance information

Names and phone numbers of all service providers

Any legal documents that relate to your sibling such as, Representative Payee documents, powers of attorney, guardianship, etc.

Copy of your parent's will

Multiple copies of parents Death Certificate

Encourage your parents to keep this information updated, preferably annually, as Service Coordinators, providers, etc. can change. Make sure that your parents let you know where this information is kept. It is helpful if this information is kept together all in one place. This enables you, who in some cases can suddenly become the decision maker, to quickly gather all the information.

HELPFUL RESOURCES

Answers4families-<http://answers4families.org>. Nebraska's support and information connection for families and professionals. 800-746-8420

TheArcLink-TheArcLink.org Provides resources that empower individuals with disabilities and their families to make sound choices about services that support their full participation in the community. 866-928-3090

The Arc of Nebraska- www.arc-nebraska.org-A non-profit organization dedicated to promoting the rights of persons with intellectual and developmental disabilities and their families. 402-475-4407

The Arc of the United States- www.thearc.org advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. 800-433-5255

Autism Society of Nebraska- www.autismnebraska.org. A support and advocacy group for individuals with autism and their families. 877-375-0120

Disability Info. Gov- www.disabilityinfo.gov. Federal Government website providing disability related information and services.

The Down Syndrome Association for Families (DSAF)- www.dsafnebraska.org. A Lincoln non-profit organization that provides support for individuals with Down syndrome, their families, friends, educators, and professionals who share in their lives. 402-421-1338

Medicaid Reference Desk- www.thedesk.info-Information about Medicaid for persons with disabilities. Enables you to click on your state for specific information.

Nebraska Advocacy Services- www.nebraskaadvocacyservices.org- a private, non-profit organization that works to protect and advocate for the rights of Nebraskans with significant physical or mental disabilities. 800-422-6691

Nebraska Department of Education- www.nde.state.ne.us. Contact NDE for information on special education services. 402-471-2295

Nebraska Department of Health and Human Services-
www.dhhs.ne.gov. Provides guidance to a variety of services that are available. 800-358-8802

Nebraska Division on Developmental Disabilities-
www.dhhs.ne.gov/Developmental_Disabilities and click on Overview of Community Based Services. For a listing of service providers in your area.

Nebraska Health and Human Services Unit on Aging-
www.dhhs.ne.gov/ags/agsindex.htm."To Promote the Dignity, Independence, & Freedom of Choice for Older Nebraskans" 800-942-7830

Nebraska Legal Aid- www.nebls.com. Promotes Justice, Dignity, Hope and Self-sufficiency through quality civil legal aid for those who have no where else to turn. 877-250-2016

Nebraska Legislature- www.nebraskalegislature.gov- Keep up to date with current and pending laws in the state of Nebraska.

The Nebraska State Bar Association- www.nebar.com. A source to help find specialized attorneys in your area. 800-927-0117

*Nebraska Statewide Respite Network-*http://nncf.unl.edu/family/grandparent-caregivers/changing-role/nebraska-statewide-respite-network. The purpose of the Nebraska Respite Network is to establish a statewide system for the coordination of respite resources that serve the life span. 1-866-737-7483

PTI Nebraska- www.pti-nebraska.org. A statewide resource for families of children with disabilities and special healthcare needs. 800-284-8520

Sibling Support Project- www.siblingsupport.org- Click on Sibling Leadership Networks White Papers for an excellent report on the role of siblings and upcoming federal legislation. 206-297-6368

Social Security Online- www.socialsecurity.gov-Provides answers to questions regarding what benefits are available and what questions to ask. 800-772-1213.

The Supreme Court of Nebraska- www.supremecourt.ne.gov/ Guardian. Provides information on guardian/conservatorships

Names and Phone Numbers

Service Coordinator

Primary Care Physician

Department of Health and Human Services

Residential Coordinator

Residential Staff

Vocational Coordinator

Vocational Staff

Employer

Attorney

The Arc of Nebraska

*Would Like to Thank the Following People for
Their Help in Putting this Handbook Together*

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This project is supported in part by the Nebraska Planning Council on Developmental Disabilities and the Federal Administration on Developmental Disabilities funds awarded to The Arc of Nebraska by the Nebraska Department of Health and Human Services.