Future Planning Resource Guide for Families and Adults with Developmental Disabilities in Illinois

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This Resource Guide was made possible through a grant from the Illinois Council on Developmental Disabilities and a grant from the National Institute on Disability and Rehabilitation Research (NIDRR) that supports the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD).

In 1999 the RRTCADD at the University of Illinois at Chicago and the CARC began a collaboration to support families and individuals with developmental disabilities in future planning. Our interests primarily focused on aging families. Research done by the University of Illinois at Chicago indicates that over 60% of individuals with developmental disabilities currently live at home with family caregivers and 25% of these caregivers are over the age of 60. Furthermore, these numbers are likely to increase due to at least three trends: the aging of the “baby boom” generation, long waiting lists for residential supports, and advances in quality healthcare that have increased the life span of individuals with developmental disabilities. Planning for the future is an important task faced by families, covering many areas.

Our project began with a series of workshops that provided information on legal/financial planning and accessing services in Illinois. Over 100 families attended these workshops, and over the course of the next year and a half we worked with approximately 40 families on a monthly basis to discuss future planning. Shortly after the project started, one father told us the service system is so complicated, such a maze, that “you need a road map” to navigate the system. He was absolutely right! As we searched for information, it became obvious that there are few centralized places where families can turn to for the information they need. There are bits of information here and bits there. Where do you start? We were fortunate. We turned to the experts: families and individuals with disabilities.

Through the wisdom of families and individuals with disabilities the resource guide developed. We framed parts of the guide in terms of questions that families frequently ask. Focus groups with families helped develop the topic areas which represent an array of issues which families may need to consider. They also gave us feedback on the format of the guide so that it is user friendly. Rather than just listing a series of phone numbers, we included descriptions and information on the process of accessing services. Finally, we included anecdotes from families and individuals with developmental disabilities to provide a voice of experience, share helpful tips, and provide encouragement and support to other families.

Although we developed the guide working mainly with aging caregivers and individuals with disabilities in the metro Chicago area, resources to use throughout the state are included. Resources such as transportation and recreation supports vary widely from one location to another; however, the guide can give ideas and suggestions of where to seek local services; we are not
endorsing any recreation programs listed. We included internet resources due to the abundance of information available through this medium. We also included addresses and phone numbers for each resource.

The guide and project would not have been possible without the assistance of many individuals and agencies, families and persons with disabilities, to whom we give thanks.

Marilyn Allen (Ray Graham Association), Nancy Brown (Family Support Network), Shu-Pi Chen (SRCA), Bill and Betty Christian (Clearbrook), Charlotte Cronin (Family Support Network), Paul Crutchfield (Illinois Department on Aging), Gloria Curtin (El-Valor), Mary Ann Ehlert (Ehlert Financial Group, Inc), Francine Gill (Habilitative System), Glen Hedman (IDHD/UIC/Assistive Technology Unit), Sheila Ryan Henry (SRCA), Susan Kaufman (Clearbrook), Joanne Lee (RRTCADD), Josephine Llorente (RRTCADD), Sheila Lullo (Clearbrook), Nancy Luther (Ray Graham Association), Jim and Rosemary Martin (Clearbrook), Tia Nelis (RRTCADD), Tony Paulauski (Arc of Illinois), Amy Peterson (Clearbrook), Brian Rubin (Brian Rubin & Associates), Andrew Ryal (IDHS/ODD), Deborah Satterfield (CARC), Joyce Strong (CARC), Theresa Varnet (Attorney), Ann Cameron Williams (RRTCADD), David Wricks (People First of Illinois), Kristen Zarling (Clearbrook). Also, the ARC of Iroquois County, Aspire, Clearbrook, Cornerstone, Illinois Council on Developmental Disabilities, and Trinity Services

A special thanks to Guadelupe Reyes and Lita Spak, two deceased members of the project’s Steering Committee, who shared a passion and dedication to persons with disabilities living vital lives in their communities.

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Overview of Service System in Illinois

Illinois Department of Human Services, Office of Developmental
Disabilities

The primary system of services for individuals with developmental disabilities is the Department of Human Services (DHS), Office of Developmental Disabilities (ODD). The DHS Office of Developmental Disabilities sets the budget and allocates money for services and contracts. The ODD has divided the state into different geographic networks with over 400 service providers to provide services across Illinois. Each network has a facilitator. See page 9 for a list of networks and facilitators. Facilitators are key persons in their area to assist in coordinating and overseeing services.

The DHS office of Developmental Disabilities contracts with Pre-Admission Screening (PAS) agencies that approve individuals for services and link individuals to service providers. The PAS agencies act as agents of the state. Contact with the state, with the PAS agencies and/or DHS networks is important for families, to make their needs known.

<table>
<thead>
<tr>
<th>Network</th>
<th>Area</th>
<th>Facilitator</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chicago North Network</td>
<td>Northern Half of Chicago</td>
<td>Dave Voytanic</td>
<td>(312) 814-4282</td>
</tr>
<tr>
<td>Chicago South Network</td>
<td>Southern Half of Chicago</td>
<td>Andrew Ryal</td>
<td>(312) 814-2786</td>
</tr>
<tr>
<td>----------------------------------------</td>
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<td>----------------</td>
</tr>
<tr>
<td>North Suburban Network</td>
<td>Part of Cook County and McHenry, Lake, Kane, DuPage, and Kendall Counties</td>
<td>Ed McManus</td>
<td>(312) 814-5981</td>
</tr>
<tr>
<td>South Suburban Network</td>
<td>Part of Cook County and Will, Grundy, and Kankakee Counties</td>
<td>Phil Gibboney</td>
<td>(312) 814-2723</td>
</tr>
<tr>
<td>Northwest Network</td>
<td>Boone, Carroll, DeKalb, Jo Davies, Lee, Ogle, Stephenson, Winnebago, and Whiteside Counties</td>
<td>Kevin Byrd</td>
<td>(217) 524-2521</td>
</tr>
<tr>
<td>Central Network</td>
<td>Adams, Brown, Calhoun, Cass, Christian, Coles, Clark, Cumberland, DeWitt, Douglas, Edgar, Effingham, Green, Hancock, Jersey, Logan, Macon, Macoupin, Mason, Menard, Pike, Montgomery, Morgan, Moultrie, Sangamon, Schuyler, Shelby, and Scott Counties</td>
<td>Monica Heatherton</td>
<td>(217) 524-2517</td>
</tr>
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Pre-Admission Screening (PAS) and Independent Service Coordination Agents for the Office of Developmental Disabilities

The DHS Office of Developmental Disabilities contracts with agencies called PAS (Pre-Admission Screening) and Independent Service Coordination Agents.
Independent Service Coordination provides information, referral and coordination of services including assessment of service needs, development of service plans, arrangement for service delivery, advocacy with service provider(s) and follow up.

Typically, PAS agencies are the first point of contact for individuals with developmental disabilities and their families in search of services. PAS agents determine eligibility for Medicaid - reimbursed services. They then link individuals with developmental disabilities and families with available services and agencies providing services.

PAS agencies are agents of the state. As such, if you disagree with a determination or denial of services, you are entitled to due process, meaning that an appeal process exists. Obtain a copy of the determination in writing and ask for a copy of their policy and appeal process. Be persistent.

Another important thing to remember is that unlike most states, Illinois does not keep an official waiting list for services. This can be confusing for families, because service providers sometimes keep their own waiting lists. State agencies do not have knowledge of families on these waiting lists. If you are not receiving needed services, it is important to make sure that you contact your Network Facilitator to let him/her know of your need. This is particularly important if the individual with a developmental disability is residing with an aging caregiver. Therefore, contact your Network Facilitator and also consider making your elected state representative aware of needs that are not being met. Again, be persistent.

Following is a map, followed by a list of the PAS agencies, to illustrate their geographic responsibility.
<table>
<thead>
<tr>
<th>Region</th>
<th>Service Coordination</th>
<th>Address</th>
<th>Phone</th>
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<tbody>
<tr>
<td>Central</td>
<td>Central Illinois Service Access, Inc.</td>
<td>1491 Valle Vista Blvd. #C Pekin, IL 61554</td>
<td>(309) 347-7202</td>
</tr>
<tr>
<td>Central</td>
<td>Prairieiland Services Coordination</td>
<td>132 S. Water Street #610 Decatur, IL 62523</td>
<td>(217) 424-0766</td>
</tr>
<tr>
<td>Central</td>
<td>Great Rivers Service Coordination</td>
<td>901 S. Morton Avenue Jacksonville, IL 62650</td>
<td>(217) 243-2330</td>
</tr>
<tr>
<td>Central</td>
<td>Macoupin/Montgomery Service Coordination</td>
<td>P.O. Box 267 Litchfield, IL 62056</td>
<td>(217) 324-6600</td>
</tr>
<tr>
<td>Central</td>
<td>West Central Service</td>
<td>WCU Building Room 820 Quincy, IL 63301</td>
<td>(217) 285-5227</td>
</tr>
<tr>
<td>North Central</td>
<td>Western Illinois Service Coordination</td>
<td>446 N. Lafayette Suite 4, Box 104 Macomb, IL 61455</td>
<td>(309) 833-1621</td>
</tr>
<tr>
<td>North Central</td>
<td>CSO of Rock Island and Mercer Counties</td>
<td>5447 Third Avenue Moline, IL 61265</td>
<td>(309) 58736-1260</td>
</tr>
<tr>
<td>North Central</td>
<td>Livingston County 708 Board</td>
<td>P.O. Box 504 Pontiac, IL 61764</td>
<td>(815) 844-7708</td>
</tr>
<tr>
<td>North Central</td>
<td>Champaign County Regional Planning Commission</td>
<td>1776 E. Washington, Box 339 Urbana, IL 61801</td>
<td>(217) 328-3313</td>
</tr>
<tr>
<td>Northwest</td>
<td>Access Services Northern Illinois</td>
<td>7339 Forest Hill Road Loves Park, IL 61111</td>
<td>(815) 282-8824</td>
</tr>
<tr>
<td>Southern</td>
<td>Southern Illinois Case Coordination Services, Inc.</td>
<td>220 E. 2nd Street Suite B Centralia, IL 62801</td>
<td>(800) 828-7422</td>
</tr>
<tr>
<td>Southern</td>
<td>DD Services of Metro East</td>
<td>928 S. 95th Street Belleville, IL 62223</td>
<td>(618) 236-7957</td>
</tr>
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### North Suburban

<table>
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<th>Region</th>
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<tr>
<td>North Suburban</td>
<td>Options and Advocacy for McHenry County Inc.</td>
<td>333 Commerce Drive Suite 800 Crystal Lake, IL 60014</td>
<td>(815) 477-4720</td>
</tr>
<tr>
<td>North Suburban</td>
<td>Suburban Access Satellite Office</td>
<td>10215 Roosevelt Road Westchester, IL 60154</td>
<td>(708) 338-9800</td>
</tr>
</tbody>
</table>
In addition to the DHS Office of Developmental Disabilities, the Illinois Department on Aging can provide services for aging caregivers and individuals with disabilities.

The Illinois Department on Aging is made up of 13 Area Agencies on Aging. The Department on Aging distributes money to the area agencies that then contract with many community-based social service agencies to directly serve older individuals. Many services, ranging from information and assistance, transportation, legal services, health screenings, counseling, recreation, education to housing assistance are offered through local senior centers. To find out about services in your local area, contact your Area Agency on Aging. A list with contact information is provided on the following page.

Some of the services offered by the Illinois Department on Aging are highlighted throughout this guide. The Department on Aging produces an excellent resource guide that discusses additional programs in more detail. Copies of these guides and additional assistance can be obtained by calling the Illinois Department on Aging Senior HelpLine at 1-800-252-8966 (v/tty) 8:30 am to 5:00 pm weekdays or 1-800-279-0400 after hours and weekends or by
visiting www.il.state.il.us/aging/

<table>
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<tr>
<th>Area</th>
<th>Agency</th>
<th>Address</th>
<th>Phone (Website)</th>
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<tr>
<td>1</td>
<td>Northwestern Illinois AAA</td>
<td>2576 Charles Street Rockford, IL 61108</td>
<td>(815) 226-4901</td>
</tr>
<tr>
<td>2</td>
<td>Northern Illinois AAA</td>
<td>P.O. Box 809 Kankakee, IL 60901</td>
<td>(815) 939-0727 <a href="http://www.ageguide.org.">www.ageguide.org.</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Field Office) 245 W. Roosevelt Road Building, Suites 41-43 West Chicago, IL 60185</td>
<td>(630) 293-5990 (800) 322-1051 <a href="http://www.wiaaa.org">www.wiaaa.org</a></td>
</tr>
<tr>
<td>3</td>
<td>Western Illinois AAA</td>
<td>729 34th Avenue Rock Island, IL 61201</td>
<td>(309) 793-6800 (800) 322-1051 <a href="http://www.wiaaa.org">www.wiaaa.org</a></td>
</tr>
<tr>
<td>4</td>
<td>Central Illinois AAA, Inc.</td>
<td>700 Hamilton Blvd., Room 300 Peoria, IL 61603-3617</td>
<td>(309) 674-2071</td>
</tr>
<tr>
<td>5</td>
<td>East Central Illinois AAA, Inc.</td>
<td>1003 Maple Hill Road Bloomington, IL 61704-9327</td>
<td>(309) 829-2065 (800) 888-4456 <a href="http://www.eiaaa.org">www.eiaaa.org</a></td>
</tr>
<tr>
<td>6</td>
<td>West Central Illinois AAA</td>
<td>P.O. Box 428 Quincy, IL 62306</td>
<td>(217) 223-7904 (800) 252-9027 (V/TTY)</td>
</tr>
<tr>
<td>7</td>
<td>Project LIFE AAA, Inc.</td>
<td>2141 W. White Oakes Drive Suite C Springfield, IL 62704-6495</td>
<td>(217) 787-9234 (800) 252-2918 <a href="http://www.seniorsprojectlife.org">www.seniorsprojectlife.org</a></td>
</tr>
<tr>
<td>8</td>
<td>Southwestern Illinois AAA</td>
<td>2365 Country Road Belleville, IL 62221</td>
<td>(618) 222-2561 (800) 326-3221</td>
</tr>
<tr>
<td>9</td>
<td>Midland AAA</td>
<td>P.O. Box 1420 Centralla, IL 62801</td>
<td>(618) 532-1853</td>
</tr>
<tr>
<td>10</td>
<td>Southeastern Illinois AAA, Inc.</td>
<td>516 Market Street Mt. Carmel, IL 62863</td>
<td>(618) 262-2306 (800) 635-8544</td>
</tr>
<tr>
<td>11</td>
<td>Egyptian AAA, Inc.</td>
<td>200 E. Plaza Drive Carterville, IL 62918</td>
<td>(618) 985-8311 (888) 895-3306 <a href="http://www.egyptianaaa.org">www.egyptianaaa.org</a></td>
</tr>
<tr>
<td>12</td>
<td>Chicago Department on Aging</td>
<td>30 N. LaSalle Suite 2320 Chicago, IL 60602-2586</td>
<td>(312) 744-4016 (312) 744-6777 (TTY) <a href="http://www.cityofchicago.org/Aging">www.cityofchicago.org/Aging</a></td>
</tr>
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</table>
Legal and Financial Planning

Planning for the future is an important but difficult process for families with relatives who have developmental disabilities. One of the most complex areas of future planning involves legal and financial issues. Although we may realize the importance of planning for the future, it is difficult to contemplate our own mortality. Families who need to ensure the safety of a relative with a developmental disability find planning even more difficult. The complexity of legal and financial planning makes planning easy to put off, but it is one of the most crucial ways to promote the future safety and security of the individual with a disability. Two areas are covered in this section: 1) estate planning, 2) guardianship and less restrictive alternatives.

Proper estate planning must be done on an individual basis and requires a knowledgeable attorney who has experience with estate planning for individuals with developmental disabilities. Attorneys must be aware of how to protect government benefits and support services. Misinformation or inadequate estate plans could jeopardize an individual’s future benefits and services. Attorney fees are also a major barrier for many families, but often the fees truly pay for themselves in the long run by ensuring that any money intended to be left to a relative with a disability goes to them for their future. Whether you are younger or older, wealthy or, like most of us - not so wealthy, estate planning is important. General estate planning information and resources for attorneys are provided in this section.

Guardianship is also a complex issue for families. Families want to ensure that their relative with a disability is safe and their rights are protected. However, the decision on whether guardianship is needed must also be made on an individual basis taking into consideration many factors including the capacity of the individual to make informed decisions and specific situational factors.

GUARDIANSHIP

Guardianship is a legal means of protection; sometimes a guardianship is absolutely needed to protect an individual’s rights. However, guardianship also limits an individual’s rights to autonomy in making decisions. Competency to make decisions varies for all of us in different life areas. For example, an individual with a disability may be able to make a decision about where they would like to work, but the same individual may not be able to make an informed decision about the risks and benefits
of a medical procedure. Therefore, different levels or types of guardianship may be appropriate. There are less restrictive alternatives to guardianship that may be more appropriate in assisting/safeguarding the person.

What types of Guardianship are there?

• **Guardianship of the Person**
  Full Guardianship of the Person has traditionally been the most common type of guardianship applied to individuals with developmental disabilities. This covers most decisions in the person’s everyday life. The guardian makes informed decisions about where the individual lives, where the individual works, and medical care. The guardian also supervises the care, comfort, personal items, educational/vocational, and social/recreational needs of the individual. If no guardian of the estate is awarded, the guardian of the person can assist with managing the funds of the individual.

  If a separate guardian of the estate (finances, property, assets) is awarded, the guardian of the person may request funds for the individual’s needs. However, the purpose of a guardian of the person is typically to make informed decisions and provide supervision, rather than manage money. There are limitations in the authority of the appointed guardians to provide consent for extraordinary interventions. These include: decisions about aversive behavior programs, sterilization, withholding of medical treatment that poses a substantial risk to life, and withdrawal of life-prolonging treatment. Decisions in such areas must be approved by the court.

• **Guardianship of the Estate**
  Guardianship of the Estate (or finances, property, assets) is a form of guardianship that is applied to individuals who are unable to manage their finances. A Guardian of the Estate is not frequently needed since eligibility for most government benefits requires the individual with a disability to keep their assets low. The court does not require the appointment of a Guardian of the Estate if assets are below $10,000. If an individual has substantial sources income other than benefit checks or other assets of property, Guardianship of the Estate may be considered to avoid the potential for financial exploitation.

  The Guardian of the Estate is required by the court to keep a detailed accounting of the individual’s finances and to file this annually with the court. It may be recommended that the Guardian of the Estate and the Guardian of the Person be different representatives to provide a system of checks and balances and to avoid conflicts of interest.

• **Limited Guardianship**
Full Guardianship of the Person is no longer the only form of Guardianship of the Person. Changes in the law now allow for Limited Guardianships that are a less restrictive alternative. The duties of the guardian are specified and limited to a certain area. For example, the individual may need a “Limited Medical Guardian” to assist only with medical decisions or a “Limited Placement Guardian” to assist with decisions about placement. The guardian only assists with decisions in the specified area where the individual may not have the capacity and potential risks from poor decision making are greater. For example, signing a permission slip to go on an outing poses different risks than signing a consent for psychotropic medication with potential harmful side effects. The benefit of a Limited Guardianship is that the rights of the individual with the disability to make decisions in other areas of their life remains, empowering them to make as many of their own decisions as possible.

**Important legal terms used after a type of guardianship has been appointed.**

**Short Term Guardian:** a person appointed by the guardian while they are away (e.g., while on vacation or in the hospital) to act as guardian during their absence or incapacitation. This is done without going to court via a notarized document. **Stand-By Guardian:** someone the guardian nominates to act as guardian in the event they become unable to act (e.g., mentally unable). This would ideally also be the person who would become **Successor Guardian**. **Successor Guardian:** person who becomes legal guardian in the event of the death of the acting guardian. The legal appointment of a Stand-By or Successor Guardian requires a court proceeding and appointment of the new guardian upon incapacity to act or upon death. It is important for the guardian, especially for aging guardians, to nominate and document the individual who they desire to take their place as guardian so it is clear to the court.

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**What Less Restrictive Alternatives are there to Legal Guardianship?**

- **Durable Power of Attorney for Health Care**
  This is a legal document in which a competent adult (one who has not had a form of legal guardianship appointed) over 18 years of age called the principle, appoints another individual, called an agent, to act on his or her behalf to make health care decisions. The agent can assist the individual if they become incompetent or need assistance in making or voicing decisions. The document must be written and notarized. Template Power of Attorney forms are available. It may also be helpful to have supporting documentation that the individual (principle) is competent to designate an agent. Often this can take the place of a full or limited
Guardianship of the Person. This provides a means to make health care decisions for someone requiring assistance in that life area. The Power of Attorney for Health Care goes into effect when signed and can be terminated at any time by either of the parties.

- **Durable Power of Attorney for Advocacy**
  This is a legal document similar to a Power of Attorney for Health Care but covers broader advocacy needs. It is also signed by a competent adult and designates an agent to assist the individual in making or voicing decisions. A form can be drafted that specifies what areas and assistance the individual may need advocacy. It can serve as a form of protection, allowing the agent to ensure that the individual understands and is capable of making decisions and providing consent. Like the Power of Attorney for Health Care, the individual retains the rights of a competent adult but receives needed assistance in making decisions.

- **Durable Power of Attorney for Property**
  Similar to the other Powers of Attorney, this is a legal document in which a competent adult designates an agent to manage their financial affairs. There are benefits and drawbacks to this option. Benefits are that the individual remains competent and court involvement (appointment of a Guardian of the Estate or Property, which can be costly and intrusive) is avoided. A drawback is that since the individual remains competent, he/she can enter contracts that may not be in his/her best interests. Like the other Powers of Attorney, the agreement can be terminated at any time by either parties.

- **Representative Payee**
  A Representative Payee is an individual named to manage the funds of an individual with a disability who receives government benefits from Social Security or the Veteran’s Administration. This individual also assists with maintaining benefits by reporting to Social Security. The individual with a disability still makes their personal decisions, but the Representative Payee has some authority to assist with managing money received from benefit checks. Family members may wish to act as Representative Payee, but many agencies or outside organizations may also serve as payee.

- **Joint Bank Accounts**
  Most banks can assist with creating a bank account to facilitate money management. For example, benefit checks can be directly deposited, certain bills can be automatically paid, and “spending money” can be automatically and regularly sent to the individual with a disability from their account. A joint bank account can help an individual manage their money and prevent excessive expenditures. To provide a check and balance, a joint bank account can be set up where one or both parties need to sign for banking.
• **Mental Health Treatment Preferences Act**  
This act authorizes an individual to execute a “Declaration” about future mental health treatment. It is written by a competent adult and signed by two witnesses, and goes into effect if the individual is later found to be incapable of making mental health decisions, by two physicians or a judge. It is useful for persons who have a history of mental illness for it can allow the individual to give instructions regarding psychotropic medication, electroconvulsive treatment, or admissions to a mental health facility. The individual can designate another person to make mental health treatment decisions or ensure the declaration is followed.

• **Health Care Surrogate Act & Living Wills**  
In addition to Durable Powers of Attorney for Health Care, these are also referred to as “Advanced Directives.” They express a person’s wishes to health care providers while they are still competent in case they become unable to make their wishes known at a later time due to health problems. The **Health Care Surrogate Act** authorizes a competent adult, or surrogate decision maker under some circumstances to make decisions. This is an option when there is no guardianship established. If there is a guardianship established, the court may require notification and permission. A **Living Will** is a document to be made concerning end of life care.

**Does an individual need a Legal Guardian?**

Guardianship is an area where families frequently have many questions and often the information they receive is unclear. The critical thing to remember is that the need for guardianship should be assessed on an individual basis - considering factors such as the capacity of the individual, their supports to make informed decisions, and situation specific circumstances that may require a guardian. Therefore, there are no general answers to the question of need for guardianship that applies to all families. Families seeking information on assessments of an individual’s functional skills, to help determine if guardianship is needed should inquire with current or former providers of service (e.g. schools or day programs).

Once a child turns 18, he or she is legally their own guardian. Guardianship must be appointed by a county probate court. The court makes the ultimate decision to appoint a guardian, and once guardianship is granted the court stays involved. It is very difficult to reverse a guardianship once it is awarded, because it requires presenting proof to the court than an individual who was “incompetent” is now “competent” to make decisions in their life.

**How do I Apply for Guardianship?**
Legal Guardianship is appointed through the probate court for the county in which the individual with a disability resides. First, a “petition” for guardianship has to be filed by the court. It should specify the type of guardianship sought. This is the application for guardianship and forms can be obtained by the county probate court.

A “medical report,” completed by licensed physician within 3 months of the date of petition, must also be filed with the court. This report states the physician’s evaluation and opinion regarding the guardianship. When the petition is filed a date is set for the hearing. After the petition is filed, the court will serve a “summons” to the individual with a disability; close relatives will also be served with a notice of the petition. A “guardian ad litem” may be appointed to represent the individual with a disability. The petitioner can ask the court to waive the appointment of a guardian ad litem in some circumstances, which can reduce associated fees and costs of the guardianship proceeding. Also, some courts may waive court costs if the petitioner shows proof of financial hardship. Generally, courts costs range around $100 - $150, excluding attorney’s fees.

At the hearing the judge, or appointed magistrate, will consider the need for guardianship and make a decision. The individual with a disability and the petitioner should be present. In some cases, a judge may appoint an attorney for the individual with a disability if the individual disagrees with the guardianship. The court can award a plenary (or full) guardianship of the person and/or estate. Or the court can award a limited guardianship, but individual courts and judges vary in their openness to limited guardianships.

If the guardianship is awarded, the guardian is required to take an “oath” to perform the duties of the guardian as specified in the order. At the time of the hearing, the proposed guardian should indicate a “successor guardian” in the case of the guardian’s death. If Guardianship of the Estate is awarded, the guardian may be required to post a surety bond, which acts as a premium to give assurance that the guardian is acting in the person’s best interest. The judge may allow a guardian to post a personal bond or go through an insurance company to post the bond. The value of the bond is typically dependent on the value of the person’s assets, (generally 1½ to 2 times the value of the estate).

Your county may ask the guardian must make an “annual accounting” to the court. The report asks about the person’s current mental, physical and social conditions (e.g., any changes in where the person lives or activities from the previous year). The guardian has responsibilities to fill; at any time if the individual with a disability feels their guardian is not performing their duties, they can petition the court to remove the guardian.

**What is an OBRA 93 Payback Trust?**

In 1993, President Clinton signed into law a new tax/budget Act, the Omnibus Budget Reconciliation Act, known as OBRA-93. In this document are provisions in which parents can properly plan for the future of their child with a disability.

It is important not to confuse an “OBRA 93 Payback Trust” with a Special Needs Trust. An OBRA 93 Payback Trust does not take the place of a special needs trust, but it is a “safety net” if an individual with a disability suddenly receives an inheritance that might disqualify them for government benefits under Medicaid for having assets over $2,000. Before 1993, money would have to be “spent down” to a level under the $2,000 within a short time frame. OBRA 93 allows the money to be placed in an irrevocable “OBRA 93 Payback Trust.” This is similar to a special needs trust in that money can be designated for things not covered by government benefits and services and provide for the long term needs of the individual. When the person with a disability passes away, the state is entitled to receive any money that is still in the trust for services that were provided.

What is a Special Needs Trust?

There are many different ways families may choose to leave money for the future of their relative with a disability. But, directly leaving money to the relative can jeopardize their entitlement to government benefits and services.

Many programs for people with developmental disabilities are provided through the federal Medicaid program and the state, with eligibility based in part on the assets of the individual with a disability. Receiving a “lump sum” of funds through an inheritance may make them ineligible or may require that the money is “spent down” in a relatively short time period, leaving little money for their long-term future needs. Inheritance is directed through a will. If an individual dies without a will, the state determines who is entitled to the estate, so money is often inherited by a relative with a disability in this way.

To avoid this, families were traditionally given advice to “disinherit” their relative with a disability. Sometimes, instead of leaving money directly to the individual with a disability, families may leave money to a sibling or other trusted relative, with the understanding that they will provide for the relative with a disability. However, this may pose unintended problems for even the most trusted other relative.

One attorney encountered an example in her legal practice when a client’s son was denied financial aid for college because of the money that was being held in their account for the provision of the relative with a disability. There are also things we don’t like to consider such as family feuds over money, divorce, or if something should happen to the trusted other relative. All of these things could risk the money not making it to the relative with a disability.
To avoid such problems families often wish to set up a trust fund. However, this is complicated and requires a specific type of trust fund called a “special needs trust” or private supplemental needs trust. The wording must be careful so that money is not spent on things that should be covered by government benefits and services (often these include room and board, support staff, or day programs). If money is directed towards these things then the state can make a claim for “reimbursement,” and the money can disappear very quickly.

So what does a special needs trust provide? Simply put, it covers all the “extras” - all of the numerous things that government programs do not provide. For example, think about recreational activities or personal items your relative may desire in the future. Sometimes these things are big and sometimes they are little. They are things that make a tremendous difference in the quality of life of the relative with a disability, but are not covered by government programs.

Special needs trusts are set up in advance by a lawyer. Money can be placed in a special needs trust at any time by relatives or placed in the trust through a will, when a relative passes away. A trustee, who oversees the allocation of money from the trust, also needs to be designated. It takes a knowledgeable attorney to draft a proper special needs trust. Fees could range from about $500 - $1,000 (depending on if other services are provided like a will or powers of attorney). Some attorneys offer payment plans.

A trustee oversees the fund and disburses money. However, it is critical that the trustee and the attorney setting up the trust are experienced with laws relating to government benefits so that the individual with a disability does not become disqualified. Funds remaining in the trust often the beneficiary’s death will be distributed based on the original document creating the trust.

**The Illinois Self Sufficiency Trust**

The Self Sufficiency Trust is a private statewide pooled trust which is available to families of individuals with disabilities to permit them to supplement current services and programs without jeopardizing their means tested entitlements. The Trust is available to Illinois residents who are mentally ill or developmentally disabled. The self sufficiency trust is family driven; with an individual Life Care Plan developed for each participant based on the priorities of that family. Any family member can contribute to the trust. Although assets are co-mingled, all returns on investments are credited proportionally to each “private trust.” The SST is governed by a volunteer Board of Trustees. Upon the death of a beneficiary, the balance of funds remaining in the account (but not more that 75%) are distributed at the direction of the donor.
A minimum of 10% remaining is transferred to the Charitable Trust of the Self Sufficiency Trust to be used to provide similar opportunities to low income persons with disabilities.

For more information on the Self Sufficiency Trust, contact:

Life’s Plan, Inc.
2801 Finley Road
Downer’s Grove, IL 60515
630-628-2355

What are the resources for finding an attorney?

When searching for an attorney to set up a Special Needs Trust or estate, it is critical to questions about their understanding of government benefits for individuals with disabilities. Find out if they have experience working with other families of individuals with disabilities and if they understand what a special needs trust is. Do not assume they know about special needs trusts, as most attorneys probably do not. There are however experienced attorneys across the state. To find attorneys in your area, contacting your local ARC, asking within your service agency, or asking other families are likely the best resources to finding a qualified attorney you can trust.

A resource to find attorneys in your area is the Illinois Bar Association through The Lawyer Finder Service. Participating attorneys agree to charge no more than $15 for the first half an hour of consultation. The service can be accessed through the Internet or by telephone; Contact:

• Illinois Bar Association
  Lawyer Finder Service
  (217) 525-5297
  www.illinoislawyerfinder.com

There may be resources for free or low cost legal assistance in your area. Law schools are a good resource. Some attorneys will provide pro bono assistance or charge on a sliding scale for families with limited income. Typically, it is easier to find assistance with guardianship than it is with special needs trusts.

The Chicago Bar Association provides this list of free or low costs legal assistance to families in the Chicago area:

• The Center for Disability and Elder Law
  710 N. Lakeshore Drive - 3rd Floor
  (3120 908-4463
May handle cases involving adult guardianship, special education, public accommodation, Social Security, employment discrimination and elder abuse.

- **Chicago Legal Clinic, Inc.**
  - Main offices
    - 2938 E. 91\textsuperscript{st} (South)
    - (773) 731-1762
  - Secondary offices
    - 1909 S. Ashland (Pilsen)
    - (312) 226-2669
    - 118 Central Street (Austin)
    - (312) 854-1610

Services vary at different offices but they may be able to assist with adult guardianship and special needs trusts. There is a $30 consultation fee and the additional fees are on a sliding scale based on income. Other resources include:

- **Guardianship and Advocacy Commission**
  - 620 N. LaSalle
  - (312) 793-5900
  - (312) 793-5937 (TTY)
  - (866) 724-8023 (National toll-free intake number)
  - Handles disability rights cases and may assist with adult guardianship and Social Security

- **Loyola University Community Law Center**
  - 1 E. Pearson - 2\textsuperscript{nd} Floor
  - (312) 915-7830
  - May handle guardianship and Social Security.

The Illinois Bar Association may be able to assist you with locating free or low cost legal assistance in your area.

- **Illinois Bar Association**
  - Illinois Bar Center
  - Springfield, IL 62701
  - (217) 525-1760
  - (312) 726-8776 (Chicago)
  - (800) 252-8909 (Toll Free within State)
  - [www.illinoisbar.org](http://www.illinoisbar.org)
What is a Letter of Intent?

A letter of intent is a non-legal document that contains important information about the individual with a disability, their family and their desires for the future. A letter of intent is important for several reasons: first, it can be used as a tool for families to think about the future. Second, it can document preferences and help communicate those preferences to other family members or other persons after the family caregiver may no longer be available. Lastly, the letter of intent can document history that is often lost and document knowledge of the person with a disability that only the family caregiver might know. A letter of intent can include family, medical, educational and vocational history. It can include information on financial arrangements, (e.g., special needs trusts), and legal plans (e.g., successor guardians). It can include the likes/dislikes of the individual with a disability, behavioral patterns, and best methods of communication. It should include desired plans for future residence or employment. It can include important contact persons and contact information of individuals involved in the life of the individual with a disability. It should be as creative and as detailed as families wish. A sample Letter of Intent is provided in the appendix.

Government Benefits

"Disability" under Social Security is defined as inability to work ("maintain substantial gainful employment") due to mental or physical impairment.

What is SSI (Supplemental Security Income)?

SSI is a “needs-based” program through the Social Security Administration that provides income for individuals with disabilities who meet low-income and asset requirements. Benefits received from SSI are usually less than SSDI. In the year 2000, the amount was $512 per month.

An individual can work and still receive SSI income up until the amount they earn is greater than the amount of SSI. The amount received from SSI is reduced as the amount of earnings increase except for the first $65 of earned income that is not counted. An individual can receive both SSI and SSDI.

To be eligible for SSI, income and assets must be below $2000 as of 2000. Income includes earnings from employment, pension, alimony, interest, and food, clothing and shelter given on a regular basis. Any amount of money that is given as a gift or through inheritance is counted as income, hence the importance of a special needs trust. An individual is allowed to own their own home if they are living in it, own household goods and personal effects up to $2,000, and to own one car with guidelines of use. If a life insurance policy is owned, the face value cannot exceed $1,500. Social Security does not count the first $65 per month of earned income and the first $20 per month of unearned income. Food stamps, energy assistance,
federally funded student assistance, and federally subsidized housing are not counted as income.

**What is SSDI (Social Security Disability Insurance)?**

SSDI differs from SSI in that it is not based on financial need. There are no limits on assets, but it is based on money paid into Social Security. An individual with a disability can receive benefits without paying into Social Security him or herself, instead receiving benefits through money their parents paid into Social Security. A child with a disability of an individual who is retired, disabled, or deceased can collect monthly benefits based on the parent’s earnings. The child must have been disabled prior to age 22, unmarried, and dependent on the parent who is retired, disabled, or deceased for support.

**What is Medicaid?**

Medicaid is a health insurance program for individuals with low income. Since it is also a “needs-based” program, most individuals who qualify for SSI will qualify for Medicaid. However, unlike the majority of other states, applying for it is not an automatic process in Illinois. A separate application through the Department of Public Aid is required for Medicaid.

Keeping an individual eligible for Medicaid is critical to accessing health care and many other services. Medicaid, in addition to providing health care, is the funding source for the majority of other services offered in the developmental disabilities service system. For example, the Medicaid Home and Community Based Waiver funds such services as supported living, supported employment and family support. Medicaid funds almost all residential services.

**What is Medicare?**

Medicare is a health insurance program for individuals who are aged 65 or older and individuals who are “disabled” according to the Social Security Administration definition. For “disabled” individuals under age 65 the qualifications for Medicare are based on SSDI. An individual who received SSDI benefits for two years is entitled to Medicare coverage. Medicare is not comprehensive, but it can cover things or services from medical providers that Medicaid does not cover. Generally, Medicare Part A (hospital insurance) covers such things as inpatient hospital care, skilled nursing, hospice and home health aids. Medicare Part B (medical insurance) covers doctor’s appointments and outpatient services. An individual can receive both Medicaid and Medicare.
Individuals with income or assets in excess of the Department of Public Aid standards must “spend down” their excess amount and document that they have met the spenddown obligation. Qualified Medicare Beneficiary (QMB) only allows public Aid to pay a persons Medicare premiums and certain deductibles and copayments to meet the spenddown obligation. QMB dual recipients receive Medicaid as well as Medicare; eligibility is based on income.

**How Do I Apply for Social Security Benefits?**

You apply for Social Security through your local Social Security Administration office. To locate your local office, you can call toll free (800) 772-1213.

When you apply for disability benefits (SSDI), you will be asked to prove disability. You will be asked for names of doctors, hospitals, and other medical providers who have provided treatment in order for Social Security to obtain medical records. Social Security will make a determination of whether the person is “disabled.”

Social Security’s definition of “disability” generally requires the following:
- Not performing “substantial gainful employment” (around $700 a month)
- Having a “severe impairment” that limits ability to work
- Having a medically documented impairment that is on their “listing of impairments”

When applying for SSI, you may need the following original (not copied) documents:
- Social Security Card
- Proof of Age
  1. Birth certificate prior to age 5
  2. Religious birth record prior to age 5
  3. Other document showing age or date of birth
- Citizenship of Alien Status Records
  - Birth Certificate (born in U.S.)
  - Religious birth records
  - U.S. Passport
  - Certificate of Citizenship
  - Naturalization Certificate
- Proof of Income
  - Earned income - payroll stubs or tax return
  - Unearned income - records including award letters, bank statements, court orders, receipts
• Proof of Records
  ◦ Bank statements
  ◦ Deed or tax appraisal for property owned besides the house you live in
  ◦ Insurance policies
  ◦ Certificates of deposit, stocks or bonds

• Proof of Living Arrangements
  ◦ Deed or property tax bill
  ◦ Lease or rent receipt
  ◦ Medical assistance cards for all household members
  ◦ Information on household costs, food, utilities, etc.

• Medical Sources
  ◦ Medical reports if available
  ◦ Names, addresses and telephone numbers of doctors and medical providers

Benefits Planning, Assistance and Outreach (BPA&O)

The Benefits Planning, Assistance and Outreach Project is a federally-funded initiative to educate and assist individuals with disabilities receiving SSI/SSDI, and those who support them to anticipate and plan for changes that may occur in their state and federal benefits as a result of employment. These benefits include SSI/SSDI, Medicaid, Medicare, Temporary Aid to Needy Families (TANF), Food Stamps, subsidized housing, worker’s compensation, and unemployment benefits.

Protection and Advocacy for Beneficiaries of Social Security (PABSS)

Protection and Advocacy for Beneficiaries of Social Security is a federally-funded initiative to assist beneficiaries of Social Security who are trying to return to or begin working. This project is staffed by a licensed attorney and advocate who are able to provide legal and advocacy assistance with return to work issues.

How Can These Projects Help Me?

These projects are for people with disabilities who receive either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) or both. The Social Security Administration has many “Work Incentives” that may make it worthwhile for you to go back to work.

How Do I Contact a PABSS Advocate?

If you need advocacy or legal services concerning work issues, contact your statewide PABSS project at:

Equip for Equality, Inc.
How Do I Contact a BPA&O Planner?

The BPA&O Project has divided the state geographically. To contact your local Benefits Counselor:

Mayor’s Office for People with Disabilities (City of Chicago)
1-312-746-5743
Toll Free: (800) 807-6962
e-mail: benplan@dhs.state.il.us

The SSI coalition for Responsible Safety Net also offers information to assist SSI beneficiaries; their number is (312) 233-9600.

A Plan for Achieving Self Sufficiency (PASS) program can be written to enable a person with a disability to purchase needed items on supports to enter or return to the workforce without reducing their SSI benefit. For more information on PASS, contact Ms. Jackson at (312) 575-5970 or toll free at 1-866-575-4889.

Health Benefits for Workers with Disabilities (HBWD) came into effect early in 2002. The HBWD program enables persons with a disability, under the age of 65, whom are working and whom meet certain income and asset requirements to maintain their medicaid coverage without incurring a spend down, by paying a monthly premium. For information on this program call 1-800-226-0768.

Assistive Technology

What types of Assistive Technology are there?

Assistive Technology is the use of equipment to help a person increase their independence. There are many activities of daily living and other areas where creative assistive technology can be used.

- Food Preparation
  Food preparation goes from the handling of ingredients and moving around in the kitchen, to eating and finally cleaning up. The simplest thing to get is a “reacher”. A “reacher” can help someone get things that are placed on high shelves or if you can’t bend down to reach the floor, it could be used to pick
things up from the floor. Handling of foods can be made easier if a person uses sandwich holders, a cutting board that holds food while being cut, as well as right-angled knives.

- Eating
  Simple technology can assist people with eating. Some things that can be used are contoured utensils, long straws, and plate guards. Plate guards keep food from spilling out of the plate, contoured utensils can assist persons to grip utensils, long straws can enable persons with limited body movement to drink safely without assistance.

- Bathing
  Taking baths and showers are also important parts of daily living. These activities can be made easier with the use of long-handled brushes. These may be hair brushes, tooth brushes or brushes used for bathing. There are also bath mitts for individuals who have difficulty holding soaps. Shower mats can prevent slipping in the tub or shower.

- Dressing
  Dressing is an area with many low-tech, and inexpensive devices. These are things such as button hooks for pulling buttons through holes, zipper pulls to help pull up zippers, sock cones to help pull socks onto feet, and long-handled shoe horns to decrease bending.

- House Chores
  Inexpensive devices can also be useful in cleaning the home. Carts or trays can simplify taking dishes to the sink to wash. Using long-handed dustpans and dusters, lightweight sweepers can help cleaning. Power-driven vacuums can be easier to push and pull.

- Augmentative Communication
  Communication is an extremely important part of life, in telling others what you are thinking, and feeling. Augmentative communication is the use of different ways of communicating or using equipment to express your needs.

  When considering communication devices, it is important to know the communication needs of each individual. It is also important to know how much technology a person can use and how difficult it will be to learn to use the equipment or device.

  Examples of low-tech equipment are communication boards or books with letters,
words or pictures. A person may use high-tech electronic devices to help in ways such as typing, using a pointer or using a switch.

- **Computer Access/Equipment**
  Computer access has become a common tool for school, work and recreation. Assistive Technology can also help with gaining access to the computer. Equipment for the computer is divided into two categories: hardware and software. The hardware is made up of the actual computer parts, such as the keyboard, the monitor, disk drives and so on. Software are programs that let you use the computer.

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One way to adjust the computer for access is to reposition the computer. Rearranging hardware until it is comfortable for the person to use is one example of repositioning. Some other changes may be to use larger or smaller keyboards or keyboards with different layouts. Another option is a touch window for the monitor. There are now voice output software packets, where one is able to talk to the computer and “read” e-mail.

- **Environmental Control**
  Environmental control refers to the person’s living environment. The home is filled with appliances and switches that need to be turned on and off on a daily basis, such as lights, fans, televisions, radios, etc. Environmental control units to assist persons completing these tasks are helpful when it is difficult for a person to move around the home.

- **Wheelchair Seating**
  Proper seating can improve a person’s productivity at a job, and/or their ability to concentrate in school, and can limit the chances of other physical problems such as pressure sores. A seating system may include a seat cushion, back cushion, side support, headrest, pelvic positioning belt, etc. Types of seating include:
  1. Linear - seating systems that are made up of cushion and pads that are flat and compress when the person sits on them
  2. Modular-Contoured - seating system that has curves in it to provide support and comfort
  3. Custom-Contoured - seating system that has seat and back cushions, which are shaped to the person using them

- **Worksite Modification**
  Assistive technology used at the workplace are most often low-tech and individualized equipment. Modifications at the workplace are identified through a detailed look at work activities. An accurate job description helps
pinpoint specific things that are/will be difficult for the worker. There are also non equipment related modifications that can be done, such as a more flexible work schedule or shared work responsibilities.

What questions should I ask during an evaluation for Assistive Technology?

Activities of Daily Living
• What activities will I be able to do by myself with this equipment?
• Are there any safety concerns regarding this equipment?

Augmentative Communication
• Will the device recommended be able to handle all of my future communication needs?
• Will the device hold up in the environments I live, work, and play in?

Computer Access
• What is the best way for me to be able to use the computer?
• What type of computer system do I need to use in my home, school or Worksite?

Environmental Control
• How many devices can I control with this device?
• How far away do the appliances have to be?

Seating
• How can I tell if the seating system is not doing its job?

Worksite Modification
• Can I take the equipment home, or does it have to stay at work?
• Will I be able to perform all of my work tasks with the recommended equipment?

How can I fund Assistive Technology and Service?

• Medicare
Medical equipment which is durable (equipment that can withstand repetitive use), is primarily used for medical purposes, and generally used only during injury or illness is covered under Part B of Medicare, Title XVIII of the Social Security Act.

• Medicaid and private medical insurance
Medicaid, Title XIX of the Social Security Act, is a combined federal-state program. It provides healthcare to people who are below a specified income level as well as people who are medically indigent, with each individual state determining the meaning of what is considered “medically indigent”. Also, for funding, each state has their own guidelines for funding services and technology. Private insurance coverage differs across as well as within plans but often follows Medicaid and Medicare guidelines.
• **Vocational Rehabilitation Services**
  For Vocational Rehabilitation services to pay for assistive technology, a person must qualify for needing rehabilitation services to obtain employment. Assistive technology must be essential for the individual to becoming employable after training. It must be written into the Individualized Transition Plan (ITP), done as early as age 14, and/or the Individualized Plan for Employment (IPE) for individuals no longer in school.

• **Individuals with Disabilities Education Act (IDEA)**
  Public schools receiving federal assistance must provide any child with a disability a free and appropriate public education in the least restrictive environment with an Individualized Educational Program (IEP). The school team must screen for and provide, if indicated, the technology needs of any child receiving related services.

**How do I get more information on Assistive Technology?**

One place where you can get help is through Illinois Tech Connect Information and Assistance Service. It provides information about technology, alternatives, where to locate services, how much services cost, funding resources and more. This Project also offers a demonstration and loan program for individuals to try out different equipment.

Tech Connect/IATP  
1 West Old State Capitol Plaza  
Suite 100  
Springfield, IL 62701  

(800) 852-5110 v/tty (IL only)  
(217) 522-7985 (voice)  
(217) 522-9966 (tty)  
http://www.iltech.org

**Home and Community Residential Supports**

What community support options are there available through the Illinois Department of Human Services?

• **HBSSP (Home Based Support Services Program) and SLS (Supported Living Services) Program**
  The goal of the HBSSP and the SLS

• “I am very happy because I can provide my son with adventures such as rode trips and museum visits. These exposures give him stimulation to question things.”

• “It has made it possible for me to work outside the home.”

• “HBSSP gave us the chance to keep our daughter at home with respite. It also helped greatly with services, but we got to choose.”

• “This gave me a chance to take a vacation alone after 43 years of caregiving.”

Families participating in the HBSSP
Program is to support individuals with developmental disabilities at home and in the community. The HBSSP is funded solely by Illinois, while the SLS Program is funded by the Medicaid Home and Community Based Waiver program and Illinois. The programs are primarily used to provide family support to families with individuals with disabilities living within the family home. However, they also can be used to support individuals with developmental disabilities in their own apartments or homes. The HBSSP allocation per month is $1,635.00; $1,335.00 if the client attends a Day Program and $1,090.00 for students up to age 21 that attend school and are in special education. With the help of a facilitator, families and individuals purchase a wide variety of services and supports to meet their individual needs. Because the programs allow families and individuals more control in designing supports, they are sometimes referred to as “consumer-directed.” There are guidelines, but the programs allow a lot of flexibility and creativity.

Some examples of how families have used the HBSSP and the SLS Program include:
- Accessible Home Modifications
- Transportation Services (even making payments on wheelchair accessible vans)
- Social or Recreational Activities and Supports
- Uncovered Medical, Therapy, or Related Expenses
- Uncovered Assistive Technology Equipment
- Employment Services (for example, hiring a job coach)
- Respite and Personal Assistance Services
  (allowing individuals and families to hire and manage their own workers - it is possible to hire family members who do not live in the immediate home or other individuals who are known and trusted to provide services)

Currently there are over 2600 individuals enrolled in the HBSSP (and a similar program called the Family Assistance Program for children under the age of 18). Unfortunately, there is a waiting list for this program, but DHS has significantly expanded the program since it began in 1990. Individuals are randomly selected once a year, usually in the summer when new money is allocated. Families sometimes call this selection “the lottery” in that you have to get in the pool to have a chance. There is a short application in the appendix of this book that you can fill out and mail directly to DHS to get in the pool. It is also very important to return a postcard that DHS sends to you each year to see if you still want to remain in the pool. Best of luck!
• **CILA (Community Integrated Living Arrangement)**
  CILAs are another residential option for individuals with developmental disabilities. They are also funded by the Federal Medicaid Program and the State, through the Medicaid Home and Community Based Waiver Program. Typically CILA are smaller facilities than ICFs/DD (Nursing Facility), but they also range in size from a few individuals up to 8 individuals living together in an apartment or group home type setting. Ideally, emphasis in placed on community integration, with individuals supported by staff to reach goals developed through an individual plan.

• **SLA (Supported Living Arrangement) and CSLA (Community Supported Living Arrangements)**
  SLAs and CSLAs are other residential options for individuals with developmental disabilities. The primary difference between the two is their funding source. CSLAs are funded by the Medicaid Home and Community Based Waiver Program and the state, while SLAs are funded primarily by the state. These programs support individuals in an apartment or home. Typically, individuals select a roommate or two to live with. Support is provided by staff, based on the needs and desires of the individual with emphasis on community integration and participation.

• **ICF/DD (Intermediate Care Facility for Individuals with Developmental Disabilities)**
  ICFs/DD is a residential option for individuals with developmental disabilities. They are jointly funded by the Federal Medicaid program and the state. These facilities range in size from smaller group home environments, with approximately 8-16 residents, to larger institutional environments, with upwards of 100 residents. It is mandated by Medicaid that individuals living in ICFs/DD receive “Active Treatment.” This is determined by a treatment team through an Individual Plan (IP) with input from the individual with a disability and their family or advocates.
What resources are there for individuals with disabilities to own their own home?

- The Illinois Housing Development Authority (IHDA) and the Illinois Department of Human Services (DHS) are entering a partnership to provide funding and technical assistance to adults with developmental disabilities to finance their own homes. The IHDA would provide funding for a down payment and the Illinois DHS would fund the necessary support staff. The Independent Service Coordination Agencies would administer the program locally. The program details, including funding and start date, have not been determined at this time.

For more information contact your DHS Network Facilitator at the number listed previously.

- **Fannie Mae Foundation**
  The Fannie Mae Foundation is private shareholder-owned company that invests in the mortgages lenders create to make sure there is a consistent source of mortgage money available across the United States. Fannie Mae does not provide loans directly to home buyers.

  Fannie Mae has developed several mortgage products to extend home ownership to underserved populations, such as people with developmental disabilities.

  These programs contain features to expand the availability of affordable housing, including lower or no down payment requirements, acceptable lower qualifying incomes, assisting with closing costs, acceptance of nontraditional credit histories, and technical assistance with the purchasing process.

  - The **Home Choice** program underwrites mortgages for people with developmental disabilities and their families to purchase owner-occupied principle residences.

  - The **Community Living** program provides financing for small residential group homes that provide permanent housing in the community service agencies, and parent groups.

  - The **Section 502 Guarantee Rural Housing Loan** program targets moderate and low-income individuals in rural areas.
Reverse Equity Mortgages
The Reverse Equity Mortgage converts the cash value or equity of the family residence into cash that can be used for any purpose the homeowner decides. Families of adults with developmental disabilities could use these funds to purchase a home for their relative or to retrofit their home and provide much needed support services to bolster families’ caregiving.

The loan advances from reverse equity mortgages are not taxable and do not affect Social Security or Medicare benefits. All owners of the home must be at least 62 years old to be eligible. No payments on the Reverse Equity Mortgage are due while the owner continues to reside in the home. The mortgage becomes due when the owner dies, permanently moves out of the residence, or sells the home.

For more information contact the Fannie Mae Foundation at 1-800-471-5554 or your local or state chapter of the American Association of Retired persons (AARP), which has developed guide books.

U.S. Department of Housing and Urban Development (HUD)
HUD operates several housing subsidy programs that adults with developmental disabilities can utilize.

- **Section 8 Housing** provides rent subsidies for low-income individuals and families so they pay no more than 30% of their monthly income for rent. HUD pays landlords the difference between the amount the tenant can afford and the market value rent. This subsidy can go to the landlord directly or be given to the tenant in form of a voucher so they select their own apartment.

- **Section 811** Housing targets this subsidy to people with disabilities.

- **Section 202 Housing** provides funds to develop housing for the elderly and people with disabilities. Tenants pay 30% of their income for rent.

- **Community Development Block Grants** provides rehabilitation grants and loans for homes and rental housing for low-income people. It funds new construction if the developer is a nonprofit organization.

- **Section 8 Moderate Rehabilitation Program** provides rent subsidies to the owners of buildings that have been rehabilitated explicitly for low and moderate income tenants.

For more information contact:
What other resources are there to support individuals and families in the home and community?

- **Illinois Department on Aging**
  The Illinois Department on Aging can provide support for both older individuals with developmental disabilities and older caregivers. Many older families with whom we had contact have told us that the Department of Aging has been understanding and responsive to their needs. There are a number of programs that can be utilized by individuals and families.

  - The **Community Care Program** assists individuals, who might otherwise need nursing home care, to remain in their own homes. This program is funded by the Medicaid Home and Community Based Waiver and the State. Eligibility for the Community Care Program services is limited to adults age 60 and over, who have nonexempt assets of $10,000 or less. This program provides:

    - **Case Management** - Case Managers arrange for services, make appropriate referrals, monitor needs, and develop a care plan
    - **Homemaker Services** - Homemakers provide assistance with household tasks, which include cleaning, planning and preparing meals, doing laundry, shopping and running errands. Homemakers also assist individuals with personal care tasks, such as dressing, bathing, grooming, and following special diets.
    - **Adult Day Services** - These services, which also offer respite for family members, are designed for older individuals who cannot be alone during the day due to their impairments. Adult Day Service facilities may provide health monitoring, medication supervision, personal care, recreational and therapeutic activities.
    - **Senior Companion** - These services are available on a limited basis in six areas of the state. They offer assistance, support, and companionship,
provided by low-income volunteers, who are also age 60 and older.

- **Ethnic Providers** - Community Rate Program clients can locate an ethnic provider by contacting the Coalition of Limited-English Speaking Elderly (CLESE), a consortium of ethnic organizations representing 18 different languages and serving older persons not fluent in English. Call (312) 461-0812.

- **Choices for Care** - Illinois Law requires that anyone seeking admission to a long term Care Facility over the age of 60 be informed of all care options prior to admission. Case Managers, who also follow-up with seniors who chose to be admitted to facilities are to determine if they can eventually return home.

There are many other programs that the Illinois Department of Aging provides, or assists with referrals to other resources. Some of these resources include:

- Home Health Care Services
- Home-Delivered Meals
- Emergency Response Systems
- Low Income Prescription Medication Assistance
- Assistive Technology
- Residential Repair and Renovation
- Senior Housing Options
- Transportation and Escort Services
- Senior Centers and Focal Points
- Respite Services
- Long Term Care ombudsman
- Assistance Understanding Medicare
- Long Term Care Insurance
- Support Groups
- Legal Assistance

The Illinois Department on Aging can also provide complimentary copies of the Living Will and Power of Attorney for Property forms by calling the Senior Help Line at 1-800-252-8966.

- Department of Human Services, Office of Rehabilitation Services (ORS) The OPTIONS Through Home Services program also provides services through the Medicaid Home and Community Bases Services Waiver. This program provides services to individuals with disabilities under 60 years of age, who otherwise might be at risk for institutionalization in a nursing home or facility.

Individuals who enter the program before the age of 60 can choose to remain in the program. Primarily this program serves individuals with physical disabilities; however, individuals with developmental disabilities and individuals with
multiple disabilities have received services. Therefore, it is another option. Families and individuals with disabilities have used the program to provide the following services:

- Personal Assistance Services
- Homemaker Services
- Adult Day Care
- Home Health maintenance (including PT, OT, Speech)
- Assistive Technology
- Home Modifications
- Respite

The process of applying for this program involves a home services counselor visiting your home to discuss eligibility and available services. In order to apply or find out more information contact:

DHS Help Line
1-800-843-6154
1-800-447-6404 (voice/tty)

Dentistry

Some resources have been identified to assist in securing dental services for persons with disabilities. These include:

- Illinois Foundation of Dentistry for the Handicapped (IFDH); on affiliate for the National Foundation for Dentistry for the Handicapped offers An individual can work and still receive SSI income up until the amount they earn is greater than the amount of SSI. The amount received from SSI is reduced as the amount of earnings increase (except for the first $65 of earned income that is not counted). An individual can receive both SSI and SSDI.:

- Donated dental services (call 1-800-893-1685 for the Chicago Metropolitan area; other Illinois residents call (309) 689-6785 for information

- Illinois Masonic Medical Center Dentistry for the Handicapped at 811 W. Wellington, Chicago, IL 60657; phone (773) 871-1461

- Metropolitan Chicago Easter Seal, (Dental Screening). Call Dr. Cantor at (708) 349-1818; ask for Diane to schedule screening.

Employment Supports
Community employment supports in Illinois are most often funded by the Illinois Department of Human Services / Office of Rehabilitation Services or through the Office of Developmental Disabilities.

The following points below have been identified by James Emmett from the Illinois Institute of Technology to assist families and persons with disabilities in planning for employment. The following five points can provide guidelines for writing transition plans.

1. **PREPARE**
   - Status of support services for adults with disabilities is improving, but is not close to a high point
   - Transition goals that require certain support services that are not readily available should be re-examined
   - Figure out probable area of residence and begin to look at services in that area
   - Do not accept traditional services (non-individualized)
   - Use DHS-ORS counselors, high school Vocational Coordinators, and other professionals as resources
   - Transition plans should always be included in the IEP (earlier the better)

2. **PEDESTRIAN (POUND THE PAVEMENT)**
   - It is recommended to visit as many adult service programs as possible
   - Begin exploring programs at least 2 years prior to graduation (earlier if also interested in residential services)
   - Place your name on a variety of waiting lists
   - Always visit in person - priority is often given to people who have met administrators in person
   - Top ten questions to ask adult service providers:
     1. What is your agency philosophy?
2. What types of occupations are past clients working in (not only cleaning, fast food, retail)?
3. What percentage of clients you placed receive benefits?
4. Do you train the person and then place them on a job or place them on a job and then train them?
5. How many people have you placed in the last year?
6. Do you write goals in concrete, frequency based terms?
7. What is the average salary of past clients?
8. Tell me about your employment support strategies (general versus individualized)?
9. Tell me about how your program develops natural supports.
10. What other supports are offered?

- Top ten questions to ask training programs and colleges:

  1. What is your school’s philosophy?
  2. Is diversity important at your school?
  3. What services are available on campus for people with disabilities? Do you have a disability resource center?
  4. What is the estimated percentage of people with disabilities on campus?
  5. What is the future of the person’s major? Are skills marketable?
  6. Does your school have job placement assistance?
  7. What is the placement rate overall and for a given major?
  8. What are major social activities?
  9. Are your buildings accessible?
  10. What types of tutoring services are available?

3. PRECISE

- When writing transition goals, insist on three long term options that are as precise as possible
- Every meeting, take lead and update
- Always document responsible parties for follow up

4. POLITICAL

- Use all resources at disposal
- Don’t accept substandard services
- Contact state agency, administration and government reps if needed
- Use advocacy services if needed
5. **POSITIVE**

- Things are getting better
- Reward professional who works hard to provide services
- However, do not always accept poor services with a smile - advocate for proactive services

**WHAT’S HOT AND WHAT’S NOT**

**HOT (currently “in”)**

1. Vouchers
2. Privatization
3. One Stops (going to one entity for all services)
4. Labor Market - Business Partnerships
5. Empowerment

**NOT (currently “out”)**

1. Sheltered Workshops
2. Traditional Services
3. Supported Employment (traditional job coaching)
4. Isolation

5. Institutionalization

**The Ticket to Work and Self Sufficiency Program**

President Clinton signed the Ticket to Work and Work Incentives Improvement Act of 1999 on December 17, 1999. This new law:
- increases beneficiary choice in obtaining employment services, vocational rehabilitation services and other support services;
- removes barriers that require people with disabilities to choose between health
care coverage and work; and
• assures that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits.

One major provision of the law establishes the Ticket to Work and Self-Sufficiency Program, or Ticket Program. The Ticket Program provides that eligible Social Security and Supplemental Security Income (SSI) beneficiaries with disabilities will receive a Ticket they can use to obtain employment services, vocational rehabilitation services or other support services from an approved provider of their choice. Illinois is one of 13 states to begin the Ticket Program. Most Social Security and SSI beneficiaries with disabilities will receive a ticket.

**How Will Beneficiaries Receive the Ticket?**

Eligible beneficiaries automatically will receive a Ticket in the mail. The ticket is a personal document that has the beneficiary’s name and social security number on it. Along with the ticket, each beneficiary will receive a notice explaining the important points about the program.

**Do Beneficiaries Have to Participate In the Ticket Program?**

No. The Ticket Program is voluntary. Beneficiaries do not have to participate. If beneficiaries choose not to participate in the program, this decision will have no effect on their benefits.

**Who Provides the Services to the Beneficiaries?**

Beneficiaries participating in the Ticket Program will receive employment services, vocational rehabilitation services or other support services from organizations called Employment Networks. Employment Networks can be
• any qualified State, local or private organization, including the State vocational rehabilitation services agency
• One-Stop delivery systems
• Public or Private schools that provide vocational rehabilitation or employment services
• Employers

Beneficiaries will “assign” their ticket to an Employment Network when they agree to work together. These employment networks are under contract to Social Security, which will pay them for helping beneficiaries work. Employment Networks cannot charge beneficiaries for the services they provide.

**How Can You Find Out About Employment Networks**

For information about Employment Networks, call Maximus, Inc. at 1866-968-7842 (1-866 your ticket) or tty # at 1-866-833-2967 (1-866-TDD 2 work).
Maximus is a private organization that will help Social Security manage the program.

**Program Definitions / Descriptions**

- **Supported Employment**

  Supported Employment Programs (SEP) provide necessary supports and services to assist individuals with developmental disabilities to obtain paid employment in a variety of community integrated work environments in which persons without disabilities are also employed. It is community based employment with services and supports from a Job Coach. Supported employment provides supports related to a person’s disability that are separate from and beyond those provided by a supervisor or employer. Supervision, advocacy, ongoing assessment, training, counseling, coaching, and follow up services are provided in SEP to maintain individuals in an integrated work site. Over time, natural supports should be facilitated on the work site to decrease the person’s need for job coaching.

- **Vocational Development**

  Vocational Development is time-limited service, including, but not limited to, work adjustment training, vocational evaluation, skills training and placement. It often is in segregated settings, although in best practice, training and evaluation are done at a job site in the community.

- **Regular Work / Organization Employment / Sheltered Employment**

  Regular Work / Organizational Employment is a set of services specifically designed to provide paid work. Work is compensated in accordance with the Fair Labor Act of 1938 and Department of Labor rules. Sub-minimum wages are typically provided. Persons in regular work / organizational employment / sheltered employment receive services in locations owned, leased, rented or managed by the service provider.

- **Developmental Training**

  Developmental training is a program of day habilitation for adults with developmental disabilities providing activities of daily living skills, such as motor development, safety problem solving, toileting, eating, communication and independent living. Development Training programs are often segregated and they may work exclusively with person with disabilities. Programs typically run a minimum of five hours per day, Monday through Friday. A minimum level of
skill is not required to enter a developmental training program. Paid work opportunities are available through some service providers, as well as opportunities for volunteering. Transportation services may be available through some service providers.

Participants must be age 18 or over. Some organizations offer services for older adults through Developmental Training, with special emphasis on age appropriate, retirement related activities.

Recreation and Leisure

Individuals with disabilities should have opportunities to participate in the same social and recreational activities as people without disabilities. Often, it is a matter of being creative, exploring different activities and building upon individual interests. For people with developmental disabilities, some of the major barriers include attitudes of the general public, inadequate personal assistance, and lack of transportation to participate.

There are also recreational programs specifically for people with disabilities. Sometimes these are chosen for the more readily obtained accommodations and the opportunity to meet others within the disability community. Some of these programs are discussed in this section, but keep in mind that they’re only a small sample of what is possible. Recreational opportunities vary from community to community. Individual provider agencies are also likely to provide some type of organized social and recreational activities for the individuals they serve - so ask within agencies. The focus of this section is primarily on greater Chicago metropolitan area, but it may suggest resources to pursue in different areas of the state.

Park Districts

Under the Americans with Disabilities Act, park districts are required to make their services accessible to people with disabilities. However, sometimes individuals with disabilities must advocate strongly to enforce this requirement. Most park districts offer some type of therapeutic recreational programs specifically for people with disabilities.

The Illinois Association of Park Districts may help you locate contact information for the park district in your area and find out their full range of services. Their website also has links to many of the park districts.

Illinois Association of Park Districts
211 E. Monroe Street
The Chicago Park District provides many recreation opportunities for everyone. A park can be found almost anywhere in the city. Within those parks there are many different things to do. Many parks have tennis courts, basketball courts as well as field houses for indoor sports. The park district also hosts concerts and festivals. Some interesting activities specifically for people with disabilities are listed below:

- **Judd Goldman Adaptive Sailing Program**  
  (summer address)  
  Rainbow Fleet Boat House  
  1362 Linn White Drive  
  Chicago, IL 60605  
  (312) 747-7684 (voice)  
  (winter address)  
  Chicago Park District  
  Sailing Program Coordinator  
  425 East McFetridge Drive  
  Chicago, IL 60605  
  (312) 747-0737 (voice)

- **Programs are offered by the Chicago Park District at Welles Park related to music, fitness sports training and powerlifting, contact:**  
  Welles Park  
  2333 W. Sunnyside Avenue  
  Chicago, IL 60625  
  (312) 742-7511

**Special Olympics**

Did you know Special Olympics began in Illinois? In 1968 Eunice Kennedy Shriver organized the First International Special Olympics Games at Soldier Field in Chicago. Since 1968, millions of children and adults with developmental disabilities have participated in Special Olympics and it continues to grow worldwide.

Special Olympics provides sports training and competition year-round in different
Olympic-type sports for children (over 8 years of age) and adults with developmental disabilities. Sports include: alpine skiing, aquatics, athletics, badminton, basketball, bocce, bowling, cross country skiing, cycling, equestrian, figure skating, floor hockey, soccer, golf, gymnastics, powerlifting, rollerskating, sailing, softball, speed skating, table tennis, handball, tennis, volleyball.

In Illinois, local park districts often are involved with coordinating Special Olympics. You can also locate your local Special Olympics office by contacting the Illinois Special Olympics Office:

Mr. Gerald Cole, Board Chairman
Mr. Doug Snyder, Executive Director
Special Olympics Illinois
605 East Willow Street
Normal, IL 61761
(309) 888-2551

In Chicago, the Chicago Park District Office of Special Olympics phone number is:
(312) 747-0827

The website and address for Special Olympics headquarters is:
Special Olympics, Inc.
1325 G Street, NW / Suite 500
Washington, DC 20005
www.specialolympics.org

Chicago Mayor’s Office for People with Disabilities

The Chicago Mayor’s Office for People with Disabilities (MOPD) offers many opportunities for individuals with disabilities to take part in recreational activities. Programs that MOPD sponsors are:

- Recreational program
- Gardening program
- Swiggy’s Juice Bar

If you would like to receive more information on the programs offered, contact:
The Mayor’s Office for People with Disabilities
(312) 744-6673 (Voice)
(312) 744-7833 (TTY)

Public Libraries
If you are one who enjoys books, magazines, videos, then libraries are the place to go. Check your phone book for the public library in your area. In Chicago, contact:

Main Chicago Public Library Branch
Harold Washington Library
400 South State Street
Chicago, IL 60605
Monday - Thursday: 9:00 - 7:00 pm
Friday and Saturday: 9:00 - 5:00 pm
Sunday: 1:00 pm - 5:00 pm

The Library also has a talking book center. The talking book center provides free loans of recorded and Braille books and magazines, music scores in Braille and large print, and specially designed playback equipment to Chicago residents who have difficulty reading print materials.

There is an application process to go through in order to receive these services. This is the application process as set by the library:

- Obtain an application for the services from The Talking Book Center. Request either the “Application for Free Library Services: Individuals” or the “Application for Free Library Services: Institutions”
- Indicate the nature of the disability
- The disability must be certified by someone in the professions listed on the application, such as a physician, optometrist, nurse, public librarian or social service professional
- Persons certified as having a reading disability resulting from an organic dysfunction and of sufficient severity to prevent their reading printed material in a normal manner must be certified by a doctor of medicine or a doctor of osteopath
- Mail the completed form to the Talking Book Center (TBC)

The Talking Book Center is located at the main Chicago Public Library

Fifth Floor North
400 South State Street
Chicago, IL 60605
(312) 747-4001
(800) 757-4664

Senior Multi-purpose Centers through the Department of Aging

Senior Centers offer many activities to older adults (those age 60 and above). Each center offers different activities and services, but below are some examples. To find the nearest Senior Center near you and to find out what services are available, contact
your local Area Agency on Aging (contact information is on pages 14 & 15 of resource guide).

Activities offered include:

- Fitness activities
- Educational activities
- Holiday parties
- Trips and tours
- Dancing lessons
- Arts and crafts
- Hot lunches

Chicago has 5 Senior Multi-Purpose Centers:

- Central/West Senior Center
  2102 W. Ogden
  Chicago, IL 60612
  (312) 746-5300 (voice)
  (312) 744-0319 (tty)

- Northwest Levy Senior Center
  2019 W. Lawrence Avenue
  Chicago, IL 60625
  (312) 747-0784 (voice)
  (312) 744-0320 (tty)

- Northwest Copernicus Regional Center
  3160 North Milwaukee Avenue
  Chicago, IL 60618
  (312) 744-6681 (voice)
  (312) 744-0321 (tty)

  Southwest Atlas Regional Center
  1767 East 79th Street
  Chicago, IL 60649
  (312) 747-0189 (voice)
  (312) 744-0322 (tty)

- Southwest Regional Center
  6117 South Kedzie Avenue
  Chicago, IL 60629
North American Riding for the Handicapped Association (NARHA)

NARHA is a non-profit organization whose purpose is to promote the rehabilitation of individuals with physical, emotional, and learning disabilities through the equine-facilitated activities. They do this through a world wide network of member therapeutic riding centers; there are many facilities in Illinois. For individuals with disabilities, therapeutic riding has been shown to improve muscle tone, balance, posture, coordination, and motor development. And it’s fun!

NARHA
P.O. BOX 33150
Denver, CO 80233
1-800-369-RIDE

NARHA Facilities in Illinois

<table>
<thead>
<tr>
<th>Area</th>
<th>Name (Websites)</th>
<th>Address</th>
<th>Phone</th>
</tr>
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<tbody>
<tr>
<td>Burr Ridge</td>
<td>Ray Graham Association</td>
<td>15 W 431 59 Street</td>
<td>(630) 325-5330</td>
</tr>
<tr>
<td>Decatur</td>
<td>Big Creek Stables</td>
<td>2044 Walnut Grove Avenue Decatur, IL 62525</td>
<td>(217) 428-9255</td>
</tr>
<tr>
<td>Decatur</td>
<td>STARR</td>
<td>3180 S. Mt. Zion Road Decatur, IL 62521</td>
<td>(217) 864-2463</td>
</tr>
<tr>
<td>East Dubuque</td>
<td>TROT (Therapeutic Riding of the Tri States)</td>
<td>5475 Dunn Road East Dubuque, IL 60118</td>
<td>(847) 844-9070</td>
</tr>
<tr>
<td>East Dundee</td>
<td>Cowboy Dreams of Illinois <a href="http://www.cowboydream.com">www.cowboydream.com</a></td>
<td>31 W. 952 Penny Road East Dundee, IL 60118</td>
<td>(847) 844-9070</td>
</tr>
<tr>
<td>East Peoria</td>
<td>Central Illinois Riding Center</td>
<td>305 Neumann Drive East Peoria, IL 61611</td>
<td>(309) 699-3710</td>
</tr>
<tr>
<td>Farmington</td>
<td>Horses are Recreational Therapy (HART)</td>
<td>32249 N. Il Hwy. 78 Farmington, IL 61531</td>
<td>(309) 245-2264</td>
</tr>
<tr>
<td>Location</td>
<td>Program Name</td>
<td>Address</td>
<td>Phone</td>
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<tr>
<td>Godfrey</td>
<td>Beverly Farm Equestrian Program</td>
<td>6301 Humbert Road Godfrey, IL  62035</td>
<td>(618) 466-0367</td>
</tr>
<tr>
<td>Harrisburg</td>
<td>Rafter M Therapeutic Riding Center</td>
<td>50 Stever Road Harrisburg, IL 62946</td>
<td>(618) 252-3494</td>
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<tr>
<td>Joliet</td>
<td>Strides Therapeutic Riding Program</td>
<td>100 N. Gougar Road Joliet, IL 60432</td>
<td>(815) 838-1694</td>
</tr>
<tr>
<td>Mattoon</td>
<td>Paradise Equestrian Therapy Center</td>
<td>1120 Lakeland Blvd. #2 Mattoon, IL 61938</td>
<td>(217) 235-4890</td>
</tr>
<tr>
<td>Morton Grove</td>
<td>Equi Therapy</td>
<td>9501 N. Austin Avenue Morton Grove, IL 60053</td>
<td>(847) 967-9800</td>
</tr>
<tr>
<td>Morrison</td>
<td>White Oaks Therapeutic Riding Stable</td>
<td>14116 Damen Road Morrison, IL 61270</td>
<td>(815) 772-2669</td>
</tr>
<tr>
<td>Newark</td>
<td>Equine Dreams</td>
<td>Newark, IL 60541</td>
<td>(815) 786-1844</td>
</tr>
<tr>
<td>Oregon</td>
<td>Pegasus Special Riders</td>
<td>P.O. Box 293 Oregon, IL 61061</td>
<td>(815) 732-3189</td>
</tr>
<tr>
<td>Pearl</td>
<td>Mounted Angels Therapeutic Horsemanship</td>
<td>Four Forty Farm RR 1 Pearl, IL 62361-9716</td>
<td>(217) 829-4547</td>
</tr>
<tr>
<td>Plainfield</td>
<td>Ready, Set, Ride Therapeutic Recreation Facility</td>
<td>13056 S. 224 Ave. Plainfield, IL 60544</td>
<td>(815) 439-3639</td>
</tr>
<tr>
<td>Richmond</td>
<td>Main Stay Therapeutic Riding Center</td>
<td>6919 Keystone Rd. Richmond, IL 61108</td>
<td>(815) 653-9374</td>
</tr>
<tr>
<td>Rockford</td>
<td>BVRH Therapeutic Riding Program</td>
<td>907 23rd Street Rockford, IL 61108</td>
<td>(815) 397-9755</td>
</tr>
<tr>
<td>Rockford</td>
<td>Hands-N-Hooves Riding Center</td>
<td>8595 Spring Creek Road Rockford, IL 61114</td>
<td>(815) 654-3650</td>
</tr>
<tr>
<td>Springfield</td>
<td>Brave Heart</td>
<td>2340 S. 7th Street Springfield, IL 62703</td>
<td>(217) 544-4537</td>
</tr>
<tr>
<td>Union</td>
<td>The Light Center</td>
<td>17421 Marengo Road Union, IL 60180</td>
<td>(815) 925-4321</td>
</tr>
<tr>
<td>Winfield</td>
<td>Friends for Therapeutic Equine Activities</td>
<td>28W051 Liberty Winfield, IL 60190</td>
<td>(630) 588-8543</td>
</tr>
</tbody>
</table>

**Search Beyond Adventures, Inc.**

Since 1979, Search Beyond Adventures has provided all inclusive escorted vacations for adults with disabilities, mostly adults with developmental disabilities. Although not all tours are wheelchair accessible, they do offer many tours that can accommodate wheelchairs. Tours operate with one staff escort for every two to five
participants. Staff is provided to assist with participant’s needs. Prices are very reasonable considering they include all activities, accommodations, meals, transportation, tour staff, and tips.

Vacations are arranged nationally and internationally. Group sizes range from 3 to 30 participants and tours vary in length from 3 to 12 days. Most tours are to popular urban or entertainment vacation destinations, but vacations can also include cruises, dude ranches, national sport team games, wilderness camping trips and national park destinations. So where do you want to go? Disney World, Las Vegas, Yellowstone, Niagara Falls, Nashville, Hollywood, Ireland, Africa? Get a catalogue of their destinations and prices by contacting:

Search Beyond Adventures, Inc.
4603 Bloomington Avenue
Minneapolis, MN 55407-3662
1-800-800-9979

Other organizations offer similar types of vacations.

**National Center on Physical Activity and Disability**

The National Center on Physical Activity (NCPAD) is operated by the Department of Disability and Human Development at the University of Illinois at Chicago and works in partnership with the Rehabilitation Institute of Chicago (RIC) and the National Center on Accessibility. Their goal is to encourage and support people with disabilities who wish to increase their overall level of activity and participate in some form of regular physical activity. They offer a variety of resources to help people with disabilities become more active. They also offer resources for fitness and exercise professionals, health professionals, and researchers.

One excellent resource offered by NCPAD is a database that contains information on accessible programs and facilities across the nation. Simply typing in “Illinois” produces a list of over 250 different programs and facilities from camps to accessible fishing to accessible golfing to dancing. Try out the database on their website or contact the NCPAD for more information.

NCPAD (MC 626)
1640 W. Roosevelt Road
Suite 711
Chicago, IL 60608-6904
1-800-900-8086

on line: [http://www.ncpad.org](http://www.ncpad.org)
e-mail: ncpad@uic.edu
Transportation

Public transportation services vary from community to community. In this section we concentrate on the transportation systems in the Chicago metropolitan area. Transportation is a major barrier for people with disabilities. The Americans with Disabilities Act requires public transportation systems be accessible to riders with disabilities. Even with the ADA, people with disabilities may need to advocate for their mandated services from the Chicago Transit Authority (CTA). In areas of Illinois, public transportation does not exist, or is very limited, or transportation is very difficult to find. Keep in mind that in addition to public transportation, other programs may provide transportation or resources to purchase transportation: the Home Based Support Services Program, the Supported Living Services Program, services from the Department on Aging for older individuals, services from the Department of Rehabilitation Services for employment, hospitals or clinics and churches.

What transportation options are there in the Chicago Metropolitan area for people with disabilities?

- Regularly scheduled public transportation, such as the bus at the corner and the “L” (elevated). Not all elevated stations are accessible. Metra trains each have one accessible car.
- If regularly scheduled public transportation is not possible for you or your family member, the CTA provides paratransit service. Pace Suburban Bus provides a similar service.
- Taxi Cabs are available. There are wheelchair accessible cabs for people to use.
- Medicare service which picks you up at your home and drive you to the office of a healthcare provider, then takes you back home.

How do I apply for paratransit services?

In order to be eligible for paratransit service from both CTA and Pace (suburban), the rider must go through an application process. This involves:

1. First, request the application from the Regional Transit Authority (RTA) Paratransit Certification Program. Phone (312) 917-4357.
2. When the application arrives, fill out as much as possible. Do not mail the
application back to RTA.
3. Call the RTA and arrange for an in-person interview, which is part of the process. Take the RTA paratransit application form along with a valid photo ID to the interview. The RTA, if necessary, provides transportation to and from the interview.
4. During the interview, the application is completed and some questions may be asked of you. When answering a question, especially if it is a yes or no question, answer only yes or no. Do not add more information. With long answers, you may open the door to more questions.
5. After the interview, there may be a simulated bus trip. This will take about 30-45 minutes.
6. It will take 21 days to receive the RTA’s decision to approve or deny your application. If the decision takes more than 21 days, you will be provided with temporary transportation until a decision is reached.
7. If it is decided that you are not eligible and you disagree with the decision, there is an appeal process. Information on how to appeal is provided when your letter of denial is mailed to you.

There are three different types of eligibility for ADA Paratransit Service.

- **Conditional Eligibility**
  You are able to use fixed route buses or “L” trains for some of your trips, and qualify for ADA Paratransit Services for other trips.

- **Unconditional Eligibility**
  Your disability or health condition always prevents you from using the fixed route buses or “L” trains and you qualify for ADA Paratransit Services for all of your trips.

- **Temporary Eligibility**
  You have a health condition or disability that temporarily prevents you from using the fixed route buses or “L” trains.

For more information or to apply for paratransit services contact:

Regional Transit Authority (RTA)
181 West Madison Street
Suite 1900
Chicago, IL 60602
(312) 917-0700 (voice)
Services: Travel Information Center, Transit Check Reduced Fare,
How do I arrange a paratransit ride?
Once you are notified of your eligibility to use paratransit, there is a process to reserve a ride.

1. When arranging for a pickup, have your ID number.
2. Be ready to give the exact address of where you’re going and the time to be picked up.
3. Rides must be arranged 24 hours in advance.
4. Call the service provider of your choice and arrange a ride.

The process sounds simple, but it can be frustrating.

- Calls are arranged between six and eight in the morning. Since many people are trying to reserve their ride, you may get a busy signal when calling. Do not give up calling until you are told that the provider is all booked. A redial button on your phone is a good idea.
- Once you get through, just provide the requested information. When you are done, your ride for the following day is set. You must do this every time you need a ride. Contact:

Chicago Transit Authority (CTA)
Paratransit Operations
(312) 432-7925 (voice)
(312) 432-7140 (tty)

Monday through Friday
7:00 am until 6:00 pm
www.transitchicago.com

Paratransit Service Providers
- CDT
  (312) 226-0310; (312) 226-7300 (voice)
  (312) 633-2713 (tty)
- SCR
  (773) 768-7000 (voice)
Pace paratransit

Paratransit services in suburban areas, outside of the City of Chicago, are provided by Pace. Pace serves nine areas:

- South and Southwest Cook
- West Cook
- North Cook
- Will
- Dupage
- Kane
- Southeast Lake
- North Lake
- Mc Henry

It is important to note, however, that paratransit fares for Pace can be up to twice the regular fare.

In order to learn more about the Pace system call:

Pace Passenger Services
(847) 364-7223 (voice)
(847) 364-5093 (tty)
Monday through Friday
8:00 am until 5:00 pm

What other transportation services are there?

- The Taxi Access Program (TAP) is a voucher program providing reduced taxicab fares for qualified passengers with disabilities (qualifying under RTA). The TAP is a program designed where the rider may purchase a voucher worth ten dollars for just $1.50 per voucher. The ride can be arranged in advance or even when a taxi is hailed on the street. The rider pays for the ride with the voucher. If the ride is over ten dollars, the rider pays the difference.

TAP vouchers can be purchased from the CTA at its Merchandise Mart headquarters or at the Chicago Department on Aging’s five regional offices.

- Central/West Regional Center, 2102 W. Ogden Avenue
- Northwest Regional Center, 2019 W. Lawrence Avenue
• Northwest Regional Center, 3160 N. Milwaukee Avenue
• Southeast Regional Center, 1767 E. 79th Street
• Southwest Regional Center, 6117 S. Kedzie Avenue

Additional Tap information is available from:

The Chicago Transit Authority (CTA)
(312) 521-1154 (voice)
(312) 521-1153 (tty)

The Department of Consumer Services
(312) 744-9400 (voice)
(312) 744-9385 (tty)

The Mayor’s Office for People With Disabilities
(312) 744-6673 (voice)
(312) 744-7833 (tty)

Participating cabs are marked by blue and white decals on the rear passenger windows. Participating Tap Taxi Companies:

• American United Cab Company
  (773) 248-07600; (773) 248-7601 (voice)
• Blue Ribbon Taxi
  (773) 878-5400 (voice)
• Cade Cab Company
  (312) 401-3748 (voice)
• Checker Taxi Association
  (312) 243-2587 (voice)
• DART Cab Company
  (773) 866-9200 (voice)
• Jimmy Morgan Taxi
  (773) 684-1111 (voice)
• Yellow Taxi
  (312) 829-4222 (voice)

Another form of transportation used when traveling from the home to a healthcare facility is Medicar. Both private and public companies offer Medicar service. The service can be somewhat expensive. A round trip is about 60 dollars. If you are on Public Aid or Medicare, however, the cost can be billed to them. Before reserving Medicar transportation, contact your Public Aid or Medicare office to discuss using these services. Ask about the maximum number of trips allowed for reimbursement

• Metra Passenger Services offers the following:
Advocacy

Why is strong advocacy needed in Illinois?

Many people are unaware of how Illinois compares with other states in regard to services for individuals with developmental disabilities. Illinois ranks low in many measures of the community services provided by the state.

- Illinois ranks 48th out of 50 states and the District of Columbia in the percentage of individuals living in community settings of 6 or fewer individuals. While the national average is 57%, and some states are as high as 94%, Illinois serves only 37% of individuals with developmental disabilities in community residences.
- Illinois serves 49% of all individuals with developmental disabilities in residential services in institutional settings of 16 or more individuals. Only 5 states serve a higher percentage of individuals in institutions.
- Illinois spends $500 million a year on institutional settings (16 or more individuals). Illinois spends only about $50 million on individual and family support - only $12.4 million of this amount on supported living services and $11 million on supported employment.
- Illinois ranks 44th in the usage of the Medicaid Home and Community Based Services (HCBS) Waiver, which allows states to utilize federal monies to expand community services.
- Illinois also ranks well below the national average of total fiscal effort toward individuals with developmental disabilities. Total fiscal effort is the proportion of money for services over total statewide personal income. It can be used to compare state’s efforts to support service for individuals with developmental disabilities. While Illinois is one of the “richest” states, it is one of the poorest when it comes to disability services.

Source:
What advocacy organizations are there for families and individuals with disabilities?

- **The ARC of Illinois**
  The Arc is the largest advocacy organization for individuals with developmental disabilities, parents, educators, direct staff, and professionals. The Arc works with policy makers to protect rights and improve services. They are involved in advocacy at the national, state and local levels. They keep individuals with disabilities and advocates updated on policy issues and ways they can become involved in issues affecting the lives of people with disabilities. There is a national Arc, state Arcs in every state, and hundreds of local chapters. The Arc of the United States and Arc of Illinois websites are wonderful resources for families. There is a $25 membership fee to join the Arc of Illinois and this helps keep families more informed through a newsletter.
  The Arc of the United States  
  1010 Wayne Avenue, Suite 650  
  Silver Spring, MD 30910  
  (301) 565-3842  
  http://www.thearc.org

  Arc of Illinois  
  1820 Ridge Road, Suite 300  
  Homewood, IL 60430  
  (708) 206-1930  
  Http://www.thearcofil.org

**Illinois Life Span Project**

Illinois Life Span Project is a free service for people with developmental disabilities, funded as an investment project by the Illinois Council on Developmental Disabilities. Illinois Life Span is:

I. A statewide information and advocacy coordination system for people with developmental disabilities. You will be linked to a local advocacy service if you wish. Life Span staff will check to be sure you received the advocacy assistance you requested to help you advocate for yourself.
II. A means by which gaps in advocacy services will be identified for future advocacy.

III. An opportunity for people with developmental disabilities to get advocacy services to help them plan their future.

For Information contact:
Illinois Life Span Project
% The Arc of Illinois
1820 Ridge Road #300
Homewood, IL 60430
1-800-588-7002
or
708-206-3993
Fax: 708-205-1171
E-mail: IllinoisLifeSpan@aol.com

ARC Link

The ArcLink is a powerful internet-based data system that allows individuals to search not only Illinois but nationwide for service providers and advocacy supports.

• SRCA An Advocacy Organization

SRCA is a grassroots advocacy organization that has been fighting for quality programs for individuals with developmental disabilities since 1949. Among its services is professional representation at staffings and problem-solving meetings to support the individual and/or the family in the pursuit of appropriate, quality services.

SRCA
6223 W. Ogden Avenue
Berwyn, IL 60402
(708) 788-5777
www.UKNOL@JUNO.com

• TASH (The Association for Social Justice and Human Rights) Illinois

TASH is committed to building communities in which no one is segregated and everyone belongs. TASH believes that no one with a disability should be forced to live, work or learn in a segregated setting and that all individuals and families deserve the right to direct their own lives. TASH’s mission is to
eliminate physical and social obstacles that prevent equity, diversity, and quality of life. TASH is a national organization made up of over 30 chapters, one of which is the Illinois chapter. They produce a journal call JASH and a newsletter called TASH Connections that keep individuals informed. Their national website and the Illinois Chapter website are also excellent resources. Membership fees vary, starting at $20.

TASH
29 W. Susquehanna Avenue, Suite 219
Baltimore, MD 21204
(410) 828-8274
(800) 482-8274
http://www.illinois-tash.org

Illinois TASH
712 Westfield Drive
St. Charles, IL 60175-3845
(630) 584-0970
http://www.illinois-tash.org

• Illinois Network of Centers for Independent Living (INCIL)

The INCIL is a made up of 24 Centers for Independent Living (CIL) in Illinois. CILs work to increase the involvement of people with disabilities in every aspect of life. CILs provide assistance for people with disabilities in their transitions to independent living. Each CIL offers unique services based on the specific needs of the community. The most frequently provided services are community education and other public information services, equipment repair, recreational activities and home modifications.

To contact a Center for Independent Living in your area call:
(800) 587-1227
http://www.incil.org

<table>
<thead>
<tr>
<th>Agency</th>
<th>Address</th>
<th>Phone</th>
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<tbody>
<tr>
<td>Regional Access &amp; Mobility Project (RAMP)</td>
<td>202 Market Street</td>
<td>(815) 968-7467 (v/tty)</td>
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<tr>
<td></td>
<td>Rockford, IL 61007</td>
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<tr>
<td>Fox River Valley Center for Independent Living (FRVCIL)</td>
<td>730B W. Chicago Street</td>
<td>(847) 695-5818 (v/tty)</td>
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<td></td>
<td>Elgin, IL 60123</td>
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<tr>
<td>Center Name</td>
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<tr>
<td>Illinois-Iowa Independent Living Center (IIILC)</td>
<td>3708 11th Street Rock Island, IL 61201</td>
<td>(309) 793-0090 (v/tty)</td>
</tr>
<tr>
<td>Northwestern Illinois Center for Independent Living (NICIL)</td>
<td>229 1st Avenue, Suite 2 Rock Falls, IL 61071</td>
<td>(815) 625-7680 (voice) (815) 625-7863 (tty)</td>
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<tr>
<td>Stone Hayes Center for Independent Living</td>
<td>39 N. Prairie Street Galesburg, IL 61401</td>
<td>(309) 344-1306 (voice) (309) 344-1269 (tty)</td>
</tr>
<tr>
<td>Illinois Valley Center for Independent Living</td>
<td>12 Gunia Drive LaSalle, IL 61301</td>
<td>(815) 224-3126 (v/tty)</td>
</tr>
<tr>
<td>Independent Network Center (INC)</td>
<td>Durst Building 406 N. 24th Street Quincy, IL 62301</td>
<td>(217) 223-0400 (voice) (217) 223-0475 (tty)</td>
</tr>
<tr>
<td>Jacksonville Area Center for Independent Living (JACIL)</td>
<td>60 E. Central Park Plaza Jacksonville, IL 62650</td>
<td>(217) 523-2587 (v/tty)</td>
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<tr>
<td>Springfield Center for Independent Living (SCIL)</td>
<td>426 W. Jefferson Street Springfield, IL 62702</td>
<td>(217) 523-2587 (v/tty)</td>
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<tr>
<td>IMPACT Center for Independent Living</td>
<td>2735 E. Broadway Alton, IL 62002</td>
<td>(618) 462-1411 (voice) (618) 474-5308 (tty)</td>
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<tr>
<td>Living Independently Now Center for Independent Living (LINC)</td>
<td>120 E. A Street Belleville, IL 62220</td>
<td>(618) 235-9988 (voice) (618) 235-0451 (tty)</td>
</tr>
<tr>
<td>Opportunities for Access Center for Independent Living (OFACIL)</td>
<td>3300 Broadway Suite #5 Mt. Vernon, IL 62864</td>
<td>(618) 244-9212 (voice) (618) 244-9575 (tty)</td>
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<tr>
<td>Southern Illinois Center for Independent Living (SICIL)</td>
<td>100 N. Glenview P.O. Box 627 Carbondale, IL 62903</td>
<td>(618) 457-3318 (v/tty)</td>
</tr>
<tr>
<td>Lake County Center for Independent Living</td>
<td>377 N. Seymore Avenue Mundelein, IL 60060</td>
<td>(847) 949-4440 (v/tty)</td>
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<tr>
<td>Access Living of Metropolitan Chicago (AL)</td>
<td>614 W. Roosevelt Road Chicago, IL 60607</td>
<td>(312) 253-7000 (voice) (312) 253-7002 (tty)</td>
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<tr>
<td>Progress Center for Independent Living (PCIL)</td>
<td>7521 Madison Street Forest Park, IL 60130</td>
<td>(708) 209-1500 (voice) (708) 209-1826-1828 (tty)</td>
</tr>
<tr>
<td>DuPage Center for Independent Living</td>
<td>739 Roosevelt Road Building 8, Suite 109 Glen Ellyn, IL 60137</td>
<td>(630) 469-2300 (v/tty)</td>
</tr>
<tr>
<td>Will-Grundy Center for Independent Living (WGCIL)</td>
<td>2415A W. Jefferson Street Joliet, IL 60435</td>
<td>(815) 729-0162 (voice) (815) 729-2085 (tty)</td>
</tr>
<tr>
<td>Options CIL</td>
<td>61 Meadowview Center Kankakee, IL 60901</td>
<td>(815) 636-0100 (voice) (815) 939-0132 (tty)</td>
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Family Support Network
The Family Support Network unifies individuals with disabilities and their families to advocate for funding, services and community resources, especially the Family Assistance Program and the Home Based Support Services program. The network advocates for services that strengthen and support the individual and the family directly by responding to their individual needs and empowering them to live in their own homes. The Network further seeks to ensure the continuation of all individual supports throughout the life span of the individuals. The Family Support Network produces a wonderful newsletter that keeps families informed about important policy issues.

Family Support Network
5739 West Martindale Lane
Peoria, IL 61615
(309) 693-8981
http://www.familysupportnetwork.org

- Mothers from Hell 2 (MFH2)
MFH2 is a grass-roots parent advocacy group, fighting for appropriate education, community acceptance, needed services, rights of and entitlements for individuals with disabilities. They primarily focus on the rights of children with disabilities to appropriate education. They educate, entertain and empower families in many ways, including newsletters, presentations, exhibits, products, a website, assisting in forming support groups and attendance in service plan meetings.

Advocacy for the Rights of Individuals
With Disabilities Organization
People First of Illinois
People First is an advocacy organization for and run by people with disabilities. People First is committed to empowering people with disabilities to make their own decisions and choices and speak for themselves. They work to ensure that people with disabilities are treated equally and are active members in their communities. People First is unique in that it is run entirely by people with disabilities for people with disabilities. Only people with disabilities can serve as officers on the state board or in local chapters. There are currently 27 chapters in the state of Illinois. You can contact People First to find the chapter nearest to you.

What agencies assist with legal rights of people with disabilities?

Equip for Equality
Equip for Equality is a statewide advocacy and protection organization for people with disabilities. They provide services such as self advocacy assistance, legal assistance, training on disability rights, and public policy advocacy. Equip for Equality focuses on enforcement of the ADA, self-determination, for services provided in the least restrictive setting, personal safety and community integration.

http://www.equipforequality.org

Northwestern Region
11 East Adams, Suite 1200
Chicago, IL 60603
(312) 341-0022 Se Habla Espanol
(800) 537-2632 (voice)
(800) 610-2779 (tty)

Northwestern Region
• **Great Lakes ADA and Accessible Information Technology Center**
The Center provides technical assistance and training to businesses and people with disabilities regarding the Americans with Disabilities Act (ADA). The training sessions include lecture, discussion and hands-on participation. Staff are very knowledgeable about the ADA and rights of people with disabilities. For information, contact:

  Department of Disability and Human Development (MC 626)  
  College of Health and Human Development  
  Great Lakes ADA and Accessible Information Technology Center  
  1640 West Roosevelt Road, Room 405  
  Chicago, IL 60608  
  (800) 949-4232 (voice, tty)

**Participating on Advisory Boards**

Did you know there is legislation in Illinois that requires agencies that provide services specifically to people with disabilities to have individuals with disabilities represented on their boards of directors? There are many different boards that seek persons with disabilities to join their boards or committees. Examples are: service providers, agencies, park districts, transportation systems.

Each Regional Network of the DHS Office of Developmental Disabilities also has a Network Advisory Council. They generally meet quarterly, and participation of families and individuals with disabilities is vital in order to advise, advocate and provide feedback to DHS. Contact your Network to find out when meetings are scheduled and request to be added to their mailing list.
Contacting Elected Officials

Individuals and their families need to be politically active. Elected officials who approve budgets and pass legislation that impact individuals with disabilities and their families need to constantly be educated and reminded to do the right thing. They need to be told when they do something that may be harmful to people with disabilities and thanked and praised when do something that benefits people with disabilities. Furthermore, they need to hear the personal stories of families and how the service system does or does not respond to their needs.

It may sound intimidating if you have never contacted an elected representative, but remember that it is their job to listen to you and respond to the needs of you and others that are their constituents. Positive changes can happen if you get them to listen.

Through the internet, it is now easier than ever to locate elected officials, find out about their backgrounds, look at their voting records on disability issues and contact them. One of the best resources to do so is through the Arc of the United States website. You simply enter your zip code and the program will provide you with a list of your state and congressional representatives. By clicking on the name of an elected official, you can check their voting record on key disability legislation. You can also click on the legislation for a brief description of it. The website provides sample letters and guidelines on contacting officials: addresses, phone numbers and e-mail addresses for all elected officials are listed.

Arc of the United States - Action Alert
http://capwiz.com/thearc/home/
Attend community meetings. Speak up. Get to know your senators and state representatives. I wrote my Governor, State Representative, and State Senator. I didn’t receive a letter back from my senator. I got a letter back from my governor. My state representative sent me a letter with her sympathies for our situation stating that she was well aware of my son’s situation but there were budget constraints and so on. This went on for 3 to 4 years until an aide to my state representative called DHS on behalf of my son. I wasn’t aware that the aide did this until she contacted me after the fact. The state representative aide sent information about my son to the PAS agent in my region. Shortly after, the PAS agency Community Alternatives Unlimited asked us to get together an application for residential placement. At that time Clearbrook was developing a new Community Integrated Living Arrangement (CILA) but the funding and placement in the CILA was only available for people in states of emergency. I often reminded the president at Clearbrook of our family’s needs. Something happened. For whatever reason, our son was placed at the new CILA. We weren’t in a state of emergency, but somehow our family was at the right place at the right time. It is important to explain your family member’s needs to whomever will listen.

Family Member from Future Planning Project