

Family Manual

Transition to Employment and Adult Services for Youth with Developmental Disabilities in Illinois

The Arc of Illinois Family to Family Health Information and
Education Center and Family Voices of Illinois

The Arc of Illinois
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Introduction

The purpose of this manual is to assist families of young adults with developmental disabilities with the transition from the school system and services for children to the world of work and adult services.

Transition planning through the school system is mandated to begin at the age of 14 ½ and is an important part of the IEP. The sooner you begin to plan for the transition to employment and adult services, the better. Make sure your goals are clear and in writing because, as you know, the IEP drives the important services and supports your child needs. If it is not written into the plan, it is not likely to be implemented in the school program.

The Individuals with Disabilities Education Act (IDEA) is a powerful law, and transition planning is a process addressed by IDEA. You and your child have rights within the special education system. Throughout this manual we will be urging you to know and exercise your rights and utilize the special education mandate. Once the transition to adult services is complete, you will find that your child's rights are different and much less comprehensive. This is because special education is an entitlement. Special education students are entitled to special education services.

Adult services are based on eligibility and availability of funding. If you are eligible and if funding is available, services can be accessed. Many services and supports readily available in special education are not available in the arena of adult services. Good transition planning is critical to a successful transition to adult services. Use the special education mandate to help build a successful life for your young adult!

When your child exits the special education system, many of the same advocacy skills you learned in special education will be needed; but the rules and laws are dramatically different in the adult service system.

Set your goals high. Have great expectations! Be proactive in planning and know that you have a very important role in building a life that will be full and satisfying for your adult child with disabilities.

In the adult developmental disabilities system, Medicaid is the key to services. To be clear, Medicaid **pays** for adult services. As you prepare for the adult system here in Illinois, you will still have to read the law, consider carefully any professional recommendations, become knowledgeable of Medicaid rules, and develop a meaningful Individual Service Plan (also known as an ISP) that meets the needs of your adult child. It will also be critical to know the important rules governing the public benefits for which your adult child is eligible.

Manual Update

The original Family Manual for Transition focused on youth with developmental disabilities in Illinois and was written in 2005. Since the opening of The Arc of Illinois Family to Family Health Information and Education Center in May 2006, we have made updates to the Family Manual as predicated by program and policy changes in the areas of education, vocational rehabilitation, disability services and Medicaid in our state.

Over the past four years, our staff has spoken with hundreds of families and professionals with transition questions/concerns and presented at the annual Statewide Transition Conferences, numerous transition resource fairs, and family training seminars. Many of these youth, family members, and professionals have also shared their feedback and their transition experiences with us.

We have found that many youth and families have similar questions about the transition process, and frequently encounter similar barriers. Significant changes have been made at the state level pertaining to access to and availability of services and supports for youth and adults with developmental disabilities. Therefore, we decided that now is the time to present a new, completely revised edition of our Family Manual for Transition.

Disclaimer: The information contained in The Arc of Illinois Family Manual is general in nature and may not apply to all individuals. It is not designed to be a substitute for medical decisions, legal advice, future planning or financial guidance from qualified professionals serving individuals with disabilities and their families. Families, consumers and guardians are advised to seek guidance from appropriate professionals at all times regarding individual situations. We recognize that each individual has unique gifts and challenges and therefore, will need an individualized process for transition. Families, consumers and guardians are advised to seek guidance from appropriate professionals at all times regarding individual situations.

The Family Manual is divided into four sections:

- I. Special Education and Transition Planning
- II. The World of Adult Services/Supports
- III. Health Insurance and Employment
- IV. Services and Supports, Options and Trends

Key points to keep in mind as you read the Family Manual:

- Transition is a process, not an event.
- Think of transition as a tree, not a tunnel. There is no singular, correct path to follow. Each individual and family will have to choose the branch or path that works best for them.
- No government program can ever address all of a person's needs. Family involvement is crucial.
- Transition impacts the entire family.
- Most adults with developmental disabilities will need to rely upon state and federal government programs in order to obtain needed supports.
- Youth and adults with developmental disabilities can work. Maintain this expectation. Make employment/work skills a priority in each IEP and in your home.
- Youth and families must have back-up plans for transition. No one can assume that they will be "selected" from PUNS to receive funding for adult services.
- Families may need to do a "cost-benefit analysis" focused on family survival needs (maintaining employment and health insurance) versus what may be required when their young adult "ages out" of the school system as part of transition planning.

Today's youth have high expectations for their transition to the adult world! They want to work, live, and play in their communities alongside their school friends, neighbors, and family members. The bleak Illinois financial situation we are currently experiencing complicates the process of planning for transition. Needed services and supports are just not available for a large number of Illinois citizens.

Youth with developmental disabilities and their families need to be active and informed advocates, educating policymakers regularly about the needs their families' experience. At this critical time, we urge individuals with disabilities, families, and professionals alike to **join The Arc of Illinois and The Arc U.S.!** More than ever, we need to work together to keep our issues in the forefront and advocate collectively for policies, programs, and funding that will support our youth to live the lives they work so hard to build!

Please add your voice to one of the first national organizations supporting individuals with intellectual disabilities and the largest advocacy organization for individuals with developmental disabilities in Illinois! For more information, please call us at 815-464-1832 or [click here](#) to join online!

The Arc of Illinois hopes you will find this manual helpful and looks forward to collaborating with you on behalf of all people with developmental disabilities in our state. If you have recommendations to improve this manual, we would love to hear your suggestions. This is truly a work in progress!

We want to express our appreciation to our project partners and other contributors for their support in providing updated expert information for this manual, and/or for their role in reviewing the draft document and sharing helpful feedback with us.*

Special thanks to:

- ❖ Health and Disability Advocates
- ❖ Illinois Association of Microboards and Cooperatives
- ❖ Illinois Chapter, American Academy of Pediatrics
- ❖ Illinois Department of Human Services, Division of Rehabilitation Services
- ❖ Illinois Department of Insurance
- ❖ Illinois Life Span Project
- ❖ Project Reach
- ❖ UIC Division of Specialized Care for Children

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** Inclusion in this list does not imply approval of the contents of this document.*



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Section I - Special Education and Transition Planning

Knowing Your Rights in Special Education

Having a child with a disability in the family requires important communication, research and advocacy skills. In special education, children and their families have many rights; but if you do not know those rights, it is difficult to exercise them! There are many ways to learn about special education rights. We strongly recommend participation in a parent support group. If there are none in your area, start one. The support and knowledge derived from other parents and parent support groups cannot be underestimated. The Illinois Life Span Project website lists support groups by county and type at www.illinoislifespan.org.

Read the law.

Many educators and professionals have knowledge of the special education law, known as the Individuals with Disabilities Education Act (IDEA). We would suggest that parents read the law themselves and have personal familiarity with IDEA. You can read the law at <http://idea.ed.gov>.

The IDEA was recently reauthorized in 2004 with some significant changes. Find the summary of those changes here:

www.thearc.org/secure/reveal/admin/uploads/documents/CRSAnalysisofNewIDEAPL108-446.pdf

Another excellent resource on special education law is the Wrightslaw website:

www.wrightslaw.com.

The Illinois State Board of Education provides a comprehensive resource booklet on their website: [Educational Rights and Responsibilities: Understanding Special Education in Illinois](http://www.isbe.net). This booklet provides an overview of the special education process and parent rights information. You can download the booklet from their site at www.isbe.net. Go to the Special Education section and look in the right hand column for Resources. Click on the Parents section beneath it and you will find a wealth of essential information.

Youth with developmental disabilities also need to learn about special education law and their rights. Starting at age 14 ½, they must be invited to participate as equal partners in their own IEP meetings and be given the opportunity to share their opinions and develop plans for the future.

Learning about special education laws and rights, and transition planning can be incorporated into the goals on your child's IEP. Materials (including books, videos and workbooks) are available to help youth with developmental disabilities learn more about transition and self-advocacy. One helpful resource, a learning package including text, workbook and video entitled My Future, My Plan, is available for purchase at [State of The Art: www.stateart.com](http://www.stateart.com).

The Minnesota Council on Developmental Disabilities has some very helpful and free

consumer transition workbooks available for download from their website: It's Never Too Early, It's Never Too Late and It's My Choice. www.mncdd.org/extra/publications.htm.

The Institute on Community Integration at the University of Minnesota has a resource to help high school students with IEPs organize their transition documents and create a personal portfolio: P.R.O. Files (Products, Resources, Opportunities personal portfolio and filing system) available for free download at <http://ici.umn.edu/all/helptool.html#profiler>. Families and youth can review these materials at home to prepare for IEP and transition meetings and use the workbook format to write down information to share with other team members.

In Illinois, there are two federally funded Parent Training and Information Centers (PTICs). These Centers are funded to provide parents with free up-to-date training and information on special education issues and rights. Both provide training opportunities, information and assistance by phone, and website resources. Family Matters PTIC, located downstate, provides assistance to families outside of the Chicago and Chicago suburban area. Family Resource Center on Disabilities serves the Chicago and Chicago suburban area. The contact information for the Illinois Parent Training and Information Centers follows:

1. Family Matters Parent Training and Information Center

1901 S. 4th St., Ste. 209, Effingham, IL 62401
217-347-5428 voice
217-347-5119 FAX
866-436-7842 Toll-Free
E-mail: info@fmptic.org
Website: www.fmptic.org
Serving: Statewide except Chicago

2. Family Resource Center on Disabilities

20 E. Jackson Blvd., Room 300
Chicago, IL 60604
312-939-3513 voice
312-939-3519 TTY & TDY
312-939-7297 FAX
1-800-952-4199.
E-mail: frcdptil@ameritech.net
Website: www.frcd.org
Serving: Chicago and surrounding area

Getting Started - Transition Basics

Section 300.29 of the IDEA regulations defines transition service as a coordinated set of activities for a student with a disability that:

"Is designed within an outcome-oriented process, that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation

Is based on the individual student's needs, taking into account the student's preferences and interests

Includes instruction; related services; community experiences; the development of employment and other post-school adult living objectives; and, if appropriate, acquisition of daily living skills and functional vocational evaluation."

Transition planning is an important component of the Individualized Education Plan. Remember that anything that is not written into the Individualized Education Plan is not required. This is the law. Use your special education mandate to build the skills and experiences your child will need when he/she exits the special education system.

The full text of the IDEA legislation is available on the US Department of Education IDEA website (<http://idea.ed.gov>).

The IDEA legislation that pertains to transition planning in the IEP is noted below:

Section 300.347 Content of the IEP and

Section 300.348 Responsibilities for Transition Services

Ideally, the transition plan is driven by the student and his/her vision of future life goals as well as employment and career opportunities. Parents and guardians of youth with developmental disabilities can help their children prepare and participate in their own IEP meetings and partner with them in making plans for transition and adult life.

The National Center for Secondary Education and Transition has some helpful resources and links for parents available at www.ncset.org.

The National Dissemination Center for Children with Disabilities has many free publications related to transition for parents, students and professionals available on their website www.nichcy.org

Plan Backward

First, think about what your son/daughter wants life to look like when he/she exits the special education system. Start the planning with this in mind. Consider **full-time community employment** with benefits and the potential for a career as an important outcome for the transition plan.

Why Plan?

Some would say that transition planning should be a wake-up call for families of young adults with developmental disabilities. This wake-up call reminds us that special education does not last forever, and we must make the best possible use of the services provided through the special education system before the student ages out and exits. Illinois students in special education are eligible to receive services until the day before their 22nd birthday **if that need is agreed upon by the IEP team and reflected in the IEP**. This means also that your child may be done with school at any time during the final school year, not on the typical "last day of school".

The reasons for having a good transition plan are obvious. Without a road map, it's easy

to get lost. But the fact is that even with a good plan, the adult community service system is very different from special education.

A good transition plan will lay the groundwork for the student before he exits the special education system. The transition plan must be developed **with** the student and should center on his/her career interests and dreams. Vocational exploration and assessment are important elements of a quality transition plan.

The Financial Plan

It is common for families to save money for their children's future education, often referred to as a college fund. In some families, friends and relatives may also make monetary gifts to children. When a family has a child with a developmental disability, saving money for the child's future is just as important, but some extra steps need to be followed in order to protect the child's options to receive services as an adult. Financial planning is very important for families at all income levels.

Similar to saving for a college fund, the family can begin at a very early age to plan for funding adult services and supports for the child with a developmental disability. The major difference for the family of a child with a disability is that, unlike a college education, which typically lasts for a few years, services and supports for adults with developmental disabilities are sometimes needed throughout the lifespan. Few families are able to fund all needed services and supports independently. The majority of adults with developmental disabilities in the U.S. who receive adult services access these services through government-funded programs. There are state special needs trust laws and other legal protections available that may assist the family to fully or partially self-fund services after exiting the special education system.

It is very important for families to consult with lawyers and financial planners who specialize in future planning for adults with developmental disabilities. Contact The Arc of Illinois' Life Span Project (www.illinoislifepsan.org) for legal and/or financial planning professional resources. The Arc of Illinois also offers annual training seminars for families on this topic. Two frequent presenters are listed below. Check the [Events](#) section of The Arc's website (www.thearcofil.org) for dates and locations around the state.

Arc of Illinois Board member, Brian Rubin, is the parent of an adult with developmental disabilities and an attorney specializing in future planning for persons with special needs. Mr. Rubin has a comprehensive "Guide for Future Guardians and Trustees" that can be requested through his website: www.brianrubin.com.

Theresa Varnet, a parent, attorney and social worker, who has also served on The Arc Board, is a frequent presenter at Arc trainings. Ms. Varnet has also written extensively on this topic, and has a number of helpful articles available on her website: http://ssvlegal.com/founders_main.html

Families at all income levels need to be aware of financial planning and establishing special needs trusts. Otherwise, if there are assets in your child's name, he/she may not be eligible for government-funded services and supports when he exits school and special education services. Friends and relatives need to be made aware of this as well. Otherwise, for example, their well-intentioned gifts of money to your child could compromise eligibility for Medicaid and SSI.

Met Life provides financial planning information including a Special Needs Calculator for estimating lifelong financial needs for families that include a child with a disability on their site. Click on this link to the [Special Needs Calculator](#) or go to the MetLife website at www.metlife.com and search for MetDesk under Financial Planning.

Here are some questions for parents/guardians to answer as part of the transition process:

When my adult child with a developmental disability finishes school, how will we (parents/guardians):

- ✓ **Be able to maintain our own employment?**
- ✓ **Be able to afford health insurance for ourselves and our children?**
- ✓ **Be able to care for ourselves, our adult child with a disability and other family members?**
- ✓ **Be able to get help when we have a family emergency?**
- ✓ **Be able to meet the daily needs of all members of our family?**
- ✓ **Be able to plan for our own retirement years?**

If your adult child cannot stay home alone, cannot get and keep a job without support, cannot travel independently and you are not able to provide these supports yourself or pay someone else to provide them, you may need government funded supports.

Families do have a “choice”.

- If you have enough money to pay for services yourself, you may not need to get involved with government programs.
- If you cannot afford to pay for everything yourself, then you will need to work within the current “system” to access what may be available; whether or not it is ideal for your adult child.

It is clear that the transition plan should also be tied to a financial plan for supports after your adult child exits the special education system. A well-designed financial plan can provide important resources for job coaches, specialized equipment and other vital supports. Government-funded services and supports are not designed to meet all of the needs of adults with developmental disabilities.

Important Timelines in Transition Planning

Here are some critical areas to address at various times in your child’s special education experience.

When to Complete a PUNS Form

PUNS stands for Prioritization of Urgency of Need for Services. Currently, PUNS is the first step in accessing services outside of Early Intervention (for children birth to age 3) and the public school system (ages 3 – 21) for individuals who are determined to be disabled. The completion of a PUNS form provides valuable information to the DHS Division of Developmental Disabilities about current and anticipated service needs. It is also the pool from which names are drawn when funding becomes available for services.

So if your child or family has unmet needs or anticipates unmet needs (such as respite, day care, after school care, or other services) **at any age**, a PUNS interview should be completed. The PUNS form must be updated annually and sooner if there is a crisis or emergency situation.

Independent Service Coordination (ISC) agencies are in charge of collecting PUNS data and are located statewide. To find your ISC, you may call Illinois Life Span at 1-800-588-7002. You may also call DHS at 1-888-DD-PLANS. There is more information to follow about PUNS.

Early Intervention Years

Once your child has been diagnosed with a developmental disability and eligibility for early intervention has been established, it's time to consider developing a financial fund. This fund may be used to generate employment and educational opportunities and/or supports and services for him after exiting special education. It's important, however, to seek expert advice in financial planning when you have a child with a developmental disability.

Early Childhood Years – Ages 3 - 5

Find out about assistive technology and environmental modifications that may be available to help your child become as independent as possible. An assistive technology evaluation may be included in the IEP at no cost to your family if the team agrees that there is a need and it is reflected in the IEP. As parents, you may advocate for technology, programs, and services that will allow your child to reach his/her full potential.

Now is the time to start helping your child learn to become a self-advocate. This starts with giving your child opportunities to make developmentally appropriate choices and to express his or her opinion. Very young children should, for example, be given choices regarding food preferences (apple juice or orange juice?), clothing (denim or corduroy pants?) and activities (going for a walk to the park or listening to music?). Augmentative communication and assistive technology may be needed to help your child express preferences and opinions. This is the first step in self-advocacy, something that is very important in preparing for the future.

Self-advocacy and decision making skills need to be incorporated into your child's IEP, as well as "imbedded" into daily life at home. See our publication "Tools for School" for resources related to assistive technology, IEP accommodations and more:

www.thearcofil.org/familytofamily/documents/documentdetails.asp?did=1305

Elementary School Years – Ages 6 - 12

In the early years, it's important to develop a sense of value and work. Nearly everyone works in our society. Children should value their own contributions to their families and community. It's important for all children to know that work is rewarded by money and that work is valued in society. In the elementary school years, we want the child to:

1. Make sure they learn as many self-help and daily living skills as possible.
2. Be responsible for household chores.
3. Make more personal choices.
4. Earn an allowance and have opportunities to learn about and handle money.

5. Learn about the world of work and have “career exploration” included in the IEP each year.

As the parent, you may want to:

1. Work with your child to learn about his/her goals, dreams, and preferences.
2. Advocate that your child will be able to work in the future.
3. Begin to investigate work opportunities for adults with disabilities in your community.
4. If you are also an employer, you will want to make sure that you hire people with developmental disabilities.
5. Develop a network with families who have older children (including adult children) with developmental disabilities and find out what they are doing to help their children work.
6. Advocate with educators and professionals. Your child's future is in the community alongside his/her non-disabled peers. His/her goals include a meaningful career as an adult.
7. Once again investigate accessing assistive technology and environmental modifications to help your child become as independent as possible.

Age 12 – A Critical Time

If you haven't already, you will want to talk to an attorney who is knowledgeable about trusts, financial planning and estate laws specifically related to individuals with developmental disabilities. This is a specialized field, so do your homework. It's often recommended that a “Special Needs Discretionary Trust” is in place before the child's 13th birthday. It is very important to have in place at age 12 because this impacts your child's eligibility for government benefits (SSI and Medicaid) at age 18. The Illinois Department of Healthcare and Family Services, and their collaborating agency, the Illinois Department of Human Services, will look back at your child's finances for the five preceding years from the date of application, so planning to protect those benefits is critical to the adult years.

You may also want to work with a financial advisor who can inform you about the potential impact on your state and federal income tax situation as the parent of a young adult with a developmental disability. The IRS has publications on this topic:

Medical and Dental Expenses: www.irs.gov/pub/irs-pdf/p502.pdf,

Child and Dependent Care Expenses: www.irs.gov/pub/irs-pdf/p503.pdf.

Parents who receive or pay child support for a child with a developmental disability should contact their legal advisor in advance in order to plan ahead for changes that may occur when the child turns 18. Additional information on this can be found at www.hrtw.org/tools/divorce.html, the website of the Healthy and Ready to Work National Center.

Middle School Years - Ages 12-14

Illinois requires transition planning in the IEP during the year that a child turns 14 ½. Before the Transition Plan is written, it's important to gather as much information as possible about effective transition planning. The transition plan addresses the instruction and educational experiences that will help the student prepare for transition from school to

adult life. It includes activities with measurable outcomes that will lead to desired post-school outcomes.

Consider participating in a parent organization for your child's specific disability (for example, The Arc of Illinois, the National Association for Down Syndrome, the Autism Society). Contact The Arc of Illinois' Life Span Project (www.illinoislifespan.org) to find parent organizations and support groups in your area. Other families will likely have information to share about resources and supports available locally related to transition.

Remember that students and parents are full participating members of the IEP Team. Work with your child to prepare him to take an active role as an IEP Team member.

There are many useful tools and strategies available to help teens and young adults prepare for their future, such as person-centered planning and a process known as MAPS (Making Action Plans). For more information on MAPS and PATH planning strategies, go to www.inclusion.com. The PACER Center also has information about person-centered planning and how it contributes to effective transition plans at www.pacer.org/publications/parentbriefs/ParentBrief_Feb04.pdf.

It's important to build work experiences into the IEP, starting with in-school jobs, community volunteer work, and paid work in the community after age 16. Real work experience is very valuable, so be cautious of limiting your child to "*vocational readiness*" and "*pre-employment training*" that is offered only in a sheltered environment or simulated sheltered workshop within a school setting.

It is also important to pay social security taxes (F.I.C.A.) on any paid work. This will have major benefits for health coverage (under Medicare) in the adult years after school. There are additional financial benefits for paying into social security in terms of qualified earnings toward SSDI. Because of the complex nature of this information, we suggest consultation or training with a knowledgeable Benefits Specialist. There are three projects in Illinois – the Illinois Assistive Technology Program at 800 852 5110 (v/tty); Division of Mental Health at 866 390 6771 (v) and 866 390 6776 TTY; Mayor's Office for People with Disabilities in the City of Chicago at 312 746 5743 (v) 312 746 5713 (tty). All three projects are funded under the Social Security Administration. This free service can be also be accessed through the Illinois Worknet website at www.illinoisworknet.com/vos_portal/Disabilities/en/Home/FindLocation/.

Another tool to help plan for a successful transition is the "Day in the Life Worksheet" included in this manual. Remember that under IDEA, many aspects of transition must be addressed in the transition plan. This worksheet may be used to help with transition planning and developing appropriate IEPs during your student's transition years.

The Importance of the IEP for Transition Planning

An IEP transition plan that includes employment in the community, as well as a detailed strategy to address needed skills and the path to employment and independent living is critical.

The IDEA entitlement to appropriate services in the least restrictive environment covered by the federal special education law is a very powerful civil rights law for students with disabilities 21 and under. There is no law for adults with disabilities that is as powerful and

comprehensive. IDEA details the rights of students with disabilities, and includes mechanisms to protect these rights and advocate for their enforcement.

The annual IEP/transition plan meeting is the first step in the implementation of these rights. The student and the family have the right to express their opinions and have their plans and preferences **considered** by the IEP team. This includes preferences for access to work in the community and comprehensive, coordinated transition planning.

The legal mandate for services in the least restrictive environment applies equally to all services in the student's IEP, including employment and vocational training. This means, for example, that offering work only in a segregated setting such as a sheltered workshop is not appropriate if the student has goals for community employment or post-secondary education. Some school districts have transition coordinators and have formal "transition programs" and systems of support in place. Others do not. These transition programs should not be a barrier to self-determination or a substitute to making an individualized transition plan that may or may not include services and supports typically provided by a particular school district. You may have to work with the school district to get this in place in the IEP and in practice.

You have the right to have your plans for proposed services and supports considered by the IEP team.

Remember that you and your young adult student may need to develop your own proposed plan for action to present to the IEP team for consideration. It is not sufficient to merely oppose a plan that is being offered by the school for transition services and employment options. Be pro-active!

You will have a much better chance of success if you develop your own plan. This plan could include, for example, a proposal for starting a small business as the means to become self-employed; or a job in the community that you have obtained through your own contacts; or a vocational training course which you have researched thoroughly and are able to document all logistics and supports required.

Emphasizing self-determination in the transition process may be a new experience for some youth, families and school systems. Youth and families need to be ready to continue in their roles as strong self-advocates and trailblazers to make this happen.

In decades past, sheltered workshops and "day treatment programs" were generally the only options available for adults with developmental disabilities. These limited options are no longer acceptable or appropriate for many youth and young adults. Today, youth and adults with developmental disabilities often want to continue their education or join the workforce as they graduate or exit high school.

Although families and schools are, ideally, partners in the educational planning process, there are times when conflicts occur. Youth and families have the right to appeal decisions related to service and supports in the IEP. There are a number of important resources for families to access when questions about special education rights arise. Refer to the ISBE manual, Educational Rights and Responsibilities: Understanding Special Education in Illinois at www.isbe.state.il.us/spec-ed/html/parent_rights.htm (Available for free download in English and in Spanish). The information available there explains the conflict resolution options available but also begins with a section to help families and professionals process

the conflict.

The two Illinois Parent Training and Information Centers are also important resources when there are questions regarding rights within special education. [The Family Resource Center on Disabilities](#) serves the Chicago and Chicago suburban area and [Family Matters](#) serves the rest of the state. Families can access PTIC sponsored trainings on special education issues and will find many helpful resources on the websites of these agencies. Direct phone support is also available through both agencies.

Formal dispute resolution options include Mediation, a State Complaint, and Due Process. Mediation is a process designed to bring in a third, impartial party to help resolve conflicts between families and schools when they have reached an impasse. Mediation is a free and voluntary process. For more information about Mediation, please go to www.isbe.net/spec-ed/html/mediation.htm.

When families believe that the educational rights of their child have been violated and less formal attempts at resolution have not been successful, a State Complaint can be filed. Families must submit required information documenting the alleged violation and the ISBE will investigate and report their findings within a prescribed timeline. There is a form and more detailed information on the process available on the ISBE website at www.isbe.state.il.us/spec-ed/html/complaint_investigation.htm.

Many would consider Due Process the option of last resort. It is the most formal process available and can be both expensive and stressful for families and professionals alike. It is, however, a powerful tool that families need to know about when the stakes are high and they believe that legal action is warranted. Due process is a legal procedure. Schools generally use attorneys to represent them in due process. Although families are not required to have legal representation, they are often at a disadvantage without knowledgeable legal support. ISBE has forms and additional information about due process available in the [Educational Rights and Responsibilities guide](#) and on the ISBE website under [Due Process](#).

Illinois Attorney General Lisa Madigan has written [Guidelines for Choosing an Attorney for Special Education Representation](#), a two-page guide available on the ISBE website in the Special Education section under Due Process.

Individuals interested in learning more about dispute resolution in special education are encouraged to read the ISBE Rights Guide mentioned above, attend trainings available through your local Parent Training & Information Center, and also visit the following websites:

- [CADRE](#) – Center for Appropriate Dispute Resolution in Special Education
- [Wrightslaw](#)
- [NICHCY](#) – National Dissemination Center for Children with Disabilities

Consider this snapshot of “a day in the life” of your adult child with DD, following high school graduation.

Use this section to outline what an average weekday might be like for your adult child, assuming all other family members are going about their usual activities. What will your adult child do all day, every day, when attending school is no longer an option? If supports and supervision are needed, who will provide them and who will pay for this?

Even if your adult child receives government benefits, how will needs for transportation, employment, personal assistance, social activities, continuing education, housing and medical care be met? The following chart is designed for you to use as an IEP planning tool as you and your family get ready for transition.

Time of Day	Activity	Level of Independence	Help Needed	Family Resources
AM/wake up	Getting out of bed			
	Toileting			
	Bathing/grooming			
	Dressing			
	Eating			
Morning	Get ready for day			
	Transportation			
	Work/other activities			
Midday	Prepare/purchase/eat lunch			
	Errands/personal business			
Afternoon	Return home			
	Recreation/leisure			
Evening	Chores/responsibilities			
	Prepare/eat dinner			
	Clean up			
	Prepare for next day			
	Recreation/leisure			
Night	Bedtime routine			
	Hygiene			
	Sleeping			
"Down Time"	Vacations/holidays			
	Fitness/well being			
General or Any Time	Medications,treatments,care			
	Mobility, transportation			
	Socialization			
	Communication			
	Behavior, safety issues, supervision			
	Therapies			
	Counseling, mental health			
Emergencies	Guardianship/health surrogate			
	Evacuation plan, fire drill			
	Preregistration with paramedics/fire dept.			
	Portable medical summary			
	Communication plan			

Level of independence: 1= independent, no supervision, 2= independent with supervision, 3 = dependent, able to direct others, 4 = dependent, unable to direct others **Help needed:** staff, equipment, assistive technology, home modifications, financing, advocacy, other (specify) **Family resources:** people who can help, private pay ability, time, equipment, other

You may also find it helpful to use the “Week in the Life” chart in the Appendix of this document to develop a sample weekly schedule, useful for planning family logistics.

High School and Transition Years (ages 14-22)

Special education services can be accessed in Illinois until the day before the 22nd birthday. The planned exit date should be clearly stated in the child's IEP. Remember that the school exit date can occur at any time during the school year. As with all issues that are part of an IEP, services needed and timelines must be agreed upon by the IEP team.

A new Illinois law, referred to as “Brittany’s Law” allows students to walk across the stage with their peers during the graduation ceremony to receive a certificate of completion instead of a diploma. This allows the student in transition to continue with their special education transition program and still participate in this important right of passage with their classmates. See the full text of Brittany’s Law below for details. Contact the Parent Training & Information Center in your area for further details.

Full Text of Brittany's Law - Part of the Illinois School Code

Released: 12/2/2005

(105 ILCS 5/14-16)

Sec. 14-16. Participation in graduation ceremony.(a) This Section may be referred to as Brittany's Law. The General Assembly finds the following:

(1) Each year, school districts across this State celebrate their students' accomplishments through graduation ceremonies at which high school diplomas are bestowed upon students who have completed their high school requirements.

(2) There are children with disabilities in this State who have finished 4 years of high school, but whose individualized education programs prescribe the continuation of special education, transition planning, transition services, or related services beyond the completion of 4 years of high school.

(3) It is well-established that the awarding of a high school diploma to and the high school graduation of a child with a disability is tantamount to the termination of eligibility for special education and related services for the student under applicable federal law.

(4) Many children with disabilities who will continue their public education in accordance with their individualized education programs after finishing 4 years of high school wish to celebrate their accomplishments by participating in a graduation ceremony with their classmates.

(5) The opportunity for classmates with disabilities and those without disabilities to celebrate their accomplishments together only occurs once, and the opportunity to celebrate the receipt of a diploma several years after one's classmates have graduated diminishes the experience for students whose age peers have left high school several years earlier.

(b) Beginning March 1, 2005, each school district that operates a high school must have a policy and procedures that allow a child with a disability who will have completed 4 years of high school at the end of a school year to participate in the graduation ceremony of the student's high school graduating class and receive a certificate of completion if the student's

individualized education program prescribes special education, transition planning, transition services, or related services beyond the student's 4 years of high school. The policy and procedures must require timely and meaningful written notice to children with disabilities and their parents or guardians about the school district's policy and procedures adopted in accordance with this Section.

(c) The State Board of Education shall monitor and enforce compliance with the provisions of this Section and is authorized to adopt rules for that purpose.

(Source: P.A. 93-1079, eff. 1-21-05.)

Many students with developmental disabilities are now enrolling in and participating in post-secondary educational programs. All students interested in post-secondary education have to begin looking at entrance requirements and considering funding options early in their high school careers. Students with developmental disabilities interested in post-secondary education should begin exploring options at this time as well.

Summary of Performance

Upon exiting (aging out, graduation), Illinois students who have received services through the special education system should receive a Summary of Performance. The Summary of Performance is to be completed during the final school year and includes the student's desired post-secondary goals, a summary of the student's academic achievements and functional skill levels (with the assessment data to demonstrate this information), recommendations for post-secondary accommodations and modifications, as well as a post-secondary and interagency linkages record. For more information about the Summary of Performance, see the following links.

- Illinois State Board of Education Summary of Performance Form and Information
www.isbe.net/spec-ed/word/performance_summary.doc
- Questions and Answers on Secondary Transition from the U.S. Department of Education
<http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CQaCorner%2C10%2C>
- Summary of Performance Information from National Secondary Transition Technical Assistance Center (NSTTAC)
www.nsttac.org/indicator13/sop.aspx

What is post-secondary education?

Post-secondary education is any education or training in which youth with disabilities might consider enrolling after high school. Today, many more students with disabilities are considering post-secondary educational opportunities in their plans for transition.

Examples of post-secondary education include:

- a. Programs and courses (both for academic credit or noncredit) at colleges, universities, community colleges and vocational schools.
- b. Adult education classes offered by public or private organizations (for example, park districts, libraries, houses of worship, craft and hobby-related stores and more)
- c. Online classes and courses

How can students with developmental disabilities participate?

The manner in which students with developmental disabilities can participate in post-secondary education is as varied as the students themselves. There are significant differences in the availability of services and supports for students with disabilities among colleges. The way in which students go about securing that support is different from high school as well.

The young adult and family need to first think about:

- What kinds of supports, if any, are needed in order to participate? (Including texts in accessible formats, aides, interpreters, etc.)
- How much does the course cost and what resources are available to pay for this?
- How can I travel to/from the location of the class, and who can help with this?
- Is the course location accessible for my needs? (Consider a physically accessible entrance, accessible bathrooms, seating, etc.)
- What other accommodations and supports may be needed?

Supports are provided to students with special needs through the IEP in high school. Teams gather and decide at least yearly which supports and services are needed and the plan or IEP is put into action. After high school, there are no IEP meetings or plans to manage needed assistance. Helpful information can be provided in the Summary of Performance document that students will take with them upon exiting high school. However, the entitlement to special education services ends when a student graduates or otherwise completes public education. Students and their families must research their options, advocate for any needed supports available, and then arrange and manage the implementation of any needed assistance including transportation.

Some students are able to access the regular course offerings independently or with the supports offered through the disabilities services offices at the college. Supports offered vary among institutions.

How can youth and families explore needed accommodations and find resources to meet these needs?

The first step in understanding the types of assistance available is to contact the Disabilities Services office at the college/training center being considered. They will be able to explain the services available and how to access them. Community and other colleges will generally require verification of disability before services are offered. The information needed for verification may also vary.

Who pays for tuition and accommodations, and what resources are available to help?

With the passage of the Higher Education Opportunity Act Reauthorization in August of 2008, students with disabilities have greater post-secondary access than ever before. Students with developmental disabilities will qualify for financial aid in the form of Pell grants, Supplemental Educational Opportunity Grants, and College Work Study Programs as long as they meet the requirements and are admitted to qualifying programs and maintain satisfactory progress attending at least half-time. For details about qualification requirements, please see the **Policy Brief -The Higher Education Opportunity Act of 2008: An Overview** available on the Think College! Website at www.thinkcollege.net. Go

to Publications and find the above mentioned title.

Some may qualify for financial assistance for post-secondary programs through the Division of Rehabilitative Services (DHS-DRS). More discussion on this topic follows.

What's happening in Illinois?

There are a number of community and other colleges that have developed specific programs for students with developmental disabilities. For example, Lewis & Clark Community College in Godfrey, Illinois, developed the **College for Life** Program described on their website (www.lc.edu/campusLife/services/disbilty.aspx) as follows:

For those students with disabilities who have had few inclusive experiences in high school, the College for Life Program provides courses that continue the educational experience and also provides social growth opportunities on a college campus. College for Life courses are continuing education, non-credit courses which are not eligible for financial aid or support from the Division of Rehabilitation Services.

Elmhurst College, a private liberal arts college in Elmhurst, Illinois, developed the Elmhurst Life Skills Academy for students with developmental disabilities. It is described on their website (<http://public.elmhurst.edu/elsa>) as follows:

A four-year program, ELSA provides a full-time, post-secondary educational experience to young adults with developmental disabilities. The program emphasizes three key areas:

- *Academics*
- *Work Experience*
- *Social and Recreational Experience*

The following information describes a program offered through the College of Education at National-Louis University in Skokie, IL.

PACE is a two-year, post-secondary certificate program offered by the acclaimed National College of Education (NCE) at National-Louis University (NLU). The program, located at the new NLU campus in Skokie, Illinois, is designed to meet the transitional needs of students with multiple learning disabilities. The success of PACE is reflected in the success of its alumni; more than 80 percent of the graduates are employed.

Created in 1986, PACE is one of the leading on-campus programs in the country that integrates formal instruction in academics, career preparation, life skills and socialization into a curriculum to prepare students for independent living. Internationally recognized as a model for providing young men and women with the tools they need to transition successfully into the workplace and the community, PACE offers a positive environment as they prepare for their next stage in life.

A new class of approximately 25 students is admitted each fall.

More information about PACE is available at www.nl.edu/pace.

Can support from either the Adult DD waiver (Home-Based) or DHS/DRS Vocational Rehabilitation be used for post-secondary education?

Currently, funding from DHS-DRS Vocational Rehabilitation can, in some instances, be used to support post-secondary education leading to employment. DRS will first evaluate the likelihood of an individual's success in both degree and non-degree programs before allowing funding to be used in this manner. For more information, please go to the Administrative Rules section of the DRS website and look under Section 590 – Services.

DDD waiver funding cannot be used for post-secondary education at the current time.

Who can help youth with DD interested in post-secondary education?

If your child with a disability is interested in post-secondary education, be sure to include this goal in the transition plan included in the IEP. It will be helpful to work with high school staff members who are familiar with college requirements and may have a relationship with local community college staff. Students frequently include exploration of post-secondary opportunities, requirements and even incorporate classes at the community college in their transition plans.

What else do youth and families need to know about post-secondary education?

One of the most important facts to remember is that there is no entitlement to special education or support services and no IEP in college. Supports can be provided but colleges are not required to provide the level and extent of assistance many students receive in public education.

More and more colleges and universities are developing programs and supports to allow access to students with developmental disabilities all the time. You may need to work closely with the college disability services office staff. You may also need to be creative in designing a support system that will allow post-secondary participation.

A January 2010 court ruling allowed a student with a developmental disability in Michigan the right to live in the dormitory, even though he is not enrolled in a degree-granting program. This ruling may open additional opportunities for students with disabilities to have a more typical and integrated post-secondary experience. For more information, please go to: www.disabilitycoop.com/2010/01/04/dorm-lawsuit/6559/

For more information on post-secondary education options and transition, see the following resources:

ISBE Parent Guide - Educational Rights and Responsibilities: Understanding Special Education in Illinois. *See the section on Secondary Transition.* www.isbe.state.il.us/special/html/parent_rights.htm

Think College! College Options for People with Intellectual Disabilities
www.thinkcollege.net

Going to College – A Resource for Teens with Disabilities
www.going-to-college.org

Disability Friendly Colleges – A Guide for Students with Physical Disabilities

Illinois Department of Human Services, Division of Rehabilitation Services

It will be helpful to learn how the Division of Rehabilitation Services delivers services to high school students with disabilities in your area. In some high schools there are “in-house” Division of Rehabilitation Services counselors. In other areas, the local or regional Division of Rehabilitation Services office serves high school students and adults. You may contact your local Dept. of Human Services Division of Rehabilitation Services office to “open a case” for your child at age 16. (www.dhs.state.il.us/page.aspx?item=29736)

It may be helpful to get to know the Transition Coordinator at your child’s high school. Make sure that the Division of Rehabilitation Services counselor and the Transition Coordinator are invited to and participate in your child’s IEP/transition meetings. They likely have employment experience and expertise beyond the regular special education staff.

Investigate the vocational training options available at your child’s high school, as well as in your school district (for those that are different), for both “special education” and “regular education” students. Inclusive vocational experiences available to the “regular students” may be more appropriate and/or desirable. Examples include, but are not limited to, work-study options, career and technology training courses offered as part of the high school curriculum, in conjunction with community colleges, at regional vocational/career programs, and other specialized venues. These programs can be extremely beneficial to the student and offer opportunities beyond regular special education classes.

Take time to research the “one stop” career center in your area sponsored by the Illinois Department of Employment Security. You can find the One Stop Center and other resources in your area at www.careeronestop.org (enter your zip code in the service locator feature). These Career Centers can often offer links to community job-training and career services. This is, in essence, investigating all the possible resources in your community that could result in career development for your child.

Your child may qualify for other job training and work experience programs that are not specifically for young adults with disabilities. This could include experiences in your community, such as summer work programs for youth from low-income families, teen parent programs, programs sponsored by a labor union or professional group. These are often excellent opportunities for the student.

Work with your child’s IEP case manager, transition coordinator and DRS counselor to explore transition options for youth with developmental disabilities, beyond the traditional sheltered workshops and day training programs.

Paid community work experiences during the transition years are often cited as one of the best predictors of adult employment success. This experience also gives the student the opportunity to learn about his strengths and preferences in the workplace.

The possibility of **self-employment options** can be considered as well. Self-employment is a growing area for people with developmental disabilities and should not be ruled out

because it has not been done before!

PASS Plans and Ticket to Work

The following information was submitted by Marsie Frawley, Senior Policy Analyst for Health & Disability Advocates.

Ticket to Work – Practical Transition Advice for Youth with Developmental Disabilities

Gaining valuable work experience while in school is a goal to which all students can strive. There are many work incentives available for beneficiaries of Social Security disability cash benefits and applicable health care which all encourage working. Of particular interest to recipients of Supplemental Security Income, who are in any type of educational setting, under the age of 22 is the Student Earned Income Exclusion. This exclusion allows students to work and earn up to \$6,600 annually, with NO impact on their SSI monthly cash benefit. The monthly threshold in 2010 is \$1,640 in gross earnings and this amount changes as of January 1st each year.

*While it is important to remember that a SSI and Medicaid recipient may only have \$2,000 in assets in any month, there is another work incentive available that affords individuals the ability to set aside money in a special account to pay for expenses that will help to achieve a vocational goal and eventually reduce dependence upon disability cash benefits. This work incentive is called the Plan for Achieving Self Support. A valuable resource for information is the **2010 SSA Red Book on Employment Supports**. The PASS is explained on page 37 of this resource. www.ssa.gov/redbook/2010/2010%20Red%20Bookpdf.pdf*

Another valuable work incentive is the Social Security Administration's Ticket to Work. The Ticket is a paper voucher (kind of like a coupon) that students can use to receive free employment services and supports from an "Employment Network" or EN. An EN is an agency, organization, school or group of organizations that provide these services. The Illinois Division of Rehabilitation Services (DRS) is one Employment Network. For more information on the services and supports they provide, call 800/795-9973 [TTY: 800/524-9904]. To find additional Employment Networks in your area, call Maximus, the Ticket to Work program manager, at 866/968-7842, or go to their Web site at www.yourtickettowork.com.

As a voluntary work incentive, the beneficiary that receives the Ticket does not have to assign the Ticket immediately, but can wait until he/she leaves the school system at their 22nd birthday. Should a school decide to become an Employment Network, the Ticket can help to offset expenses utilized to provide transition services to beneficiaries receiving either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI). The assignment of the Ticket requires that the beneficiary be actively involved in the plan. This encourages best practices in transition planning, as the EN will have to meet these outcomes in order to qualify for the Outcome or milestone payments.

There are professionals in Illinois who can help to navigate these work incentives. The Work Incentives Planning & Assistance Projects (WIPA) across Illinois and can be located by calling 1-866-968-7842 or 1-866-833-2967 (TTY/TDD) for the hearing

*impaired. Or look in the service provider directory at:
www.socialsecurity.gov/work.*

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Consider Including Health and Health Care Coordination Goals in the IEP

Another important aspect of transition is the coordination of health care and health-related activities. Although each individual's goals will vary, consider the skills that your adult child will need to deal with health related issues. For some students, communicating and/or cooperating with a health care provider may be an appropriate goal. For others, goals related to making their own appointments and needed travel arrangements or managing medication will be suitable. Health, health care, and funding to access proper care are all appropriate areas for inclusion in the IEP. Work with your child's IEP team to address these issues appropriately.

We suggest that families start working with their children as early as possible to develop health-related transition skills. Examples of health related skill-building can include:

1. Learning the names of health providers (or recognizing their pictures) and reasons for seeing them.
2. Learning the names of medical equipment, medicines, and tests.
3. Learning to tell or otherwise indicate concern about symptoms to parent/caregiver.
4. Learning names of medicines and how they help.
5. Learning the name of one's diagnosis and/or disability.

There are resources available to assist youth and families interested in addressing health-related goals in the IEP. A Parent Brief titled [What Does Health Have to Do with Transition? Everything!](#) is available on the website for NCSET – The National Center on Secondary Education and Transition. (www.ncset.org/publications/viewdesc.asp?id=2967)

Information about including health-related goals in the IEP is also available in a Power Point Presentation titled [Health Conditions and the IEP Process](#) available on the website for Children and Youth with Special Health Care Needs at the Waisman Center, University of Wisconsin-Madison, Center for Excellence in Developmental Disabilities. (www.wsti.org/documents/Conference%20Handouts/Session%2024/health%20and%20IEP%20PP.ppt)

University of Illinois at Chicago, Division of Specialized Care for Children

Some children/youth with developmental disabilities, depending upon their medical diagnosis, may also be involved with the University of Illinois at Chicago, Division of Specialized Care for Children (DSCC). DSCC services are available to eligible children and youth up to age 21. Illinois does **not** have a program similar to DSCC that serves adults over age 21.

One of the responsibilities of the DSCC care coordinator is to assist with transition planning. Families whose young adult is enrolled in DSCC should make sure to ask their

DSCC care coordinator for assistance with transition. Be sure to invite the DSCC care coordinator to participate in IEP meetings and staffings related to transition. For youth with developmental disabilities who are also served by DSCC, it is very important to take full advantage of all the services and supports offered by DSCC prior to the 21st birthday. The DSCC staff can also assist families in applying for Medicaid.

DSCC also collaborates with Healthcare and Family Services to address the needs of medically fragile and technology dependent children and youth through a Medicaid Home and Community Based Services waiver. When youth in this program become 18 years old, the DSCC care coordinator helps the family connect with the Department of Human Services, Division of Rehabilitation Services (DRS) to plan a transition to the DRS' Home Services Program.

More transition information is available on the DSCC website:

<http://internet.dsccl.uic.edu/dscclroot/parents/transition.asp>,

<http://internet.dsccl.uic.edu/forms/0590.pdf>, and

<http://internet.dsccl.uic.edu/forms/0594.pdf>.

The Illinois Chapter, American Academy of Pediatrics, also has transition information for families on their website, covering both medical and practical concerns.

www.illinoisap.org/MedicalHome

The Seventeenth Year – A Critical Time for Planning

You may choose to make the application for Supplemental Security Income (SSI) and Medicaid eligibility determination part of your child's IEP. If you are applying for the first time, you may apply 30 days before your child's 18th birthday.

At age 18, a person with developmental disabilities can become eligible for both Medicaid (state program) and Social Security (federal program), based upon their own income and assets.

Both the state government and the federal government stop "counting" (called "deeming" in official language) the income and assets of the person's parent/guardian at age 18. This is extremely important information. **It means that your child is now considered an adult.** Since your child is now an adult (referred to as an "adult disabled child" in legal language), your (the parent/guardian's) income is no longer being considered for important public services.

Agencies and programs that accept government funding for their services are not allowed to bill your child (or you) for any additional amounts. The only income that can be considered is the income of your adult child. Organizations are not allowed to require participation in fundraising activities or impose other fees. (For more information see the DHS/DDD Program Manual:

www.dhs.state.il.us/serviceProviders/grantsContracts/pdfs/ProgManualAFY2005.PDF.

This only applies to Medicaid funding - and only for persons who are enrolled in Medicaid.

Be aware, however, that private agencies and providers are not required to accept government funding. If they choose not to accept government funding, they can bill you for services and supports. This is referred to as "private pay". When you contact potential service providers, always ask them if they accept government funding.

Many adults with developmental disabilities become eligible for SSI (Supplemental Security Income) for the first time when they turn 18. Many adults with developmental disabilities who get SSI will also be eligible for Medicaid health insurance for the first time at age 18.

Also note that some people with developmental disabilities receive SSI and/or Medicaid before they turn 18, based upon their parent/guardian's income or their "family status" (this means if they are a foster child or receive adoption assistance).

When children who have received SSI and/or Medicaid reach age 18, they are not automatically enrolled as a "disabled adult household of one". They need to reapply and be evaluated to see if they are still eligible for each program. This is called redetermination. Not everyone who got SSI as a child will still be eligible to get SSI as an adult.

If an adult with developmental disabilities is found not eligible for SSI, then he/she will likely not be able to get Medicaid. The only way to find out if you are eligible is to actually apply for each of these programs.

Good news from the Health Care Reform Act: Medicaid coverage will now be available for low-income adults who do not have children and are not determined to be "disabled" by the Social Security Administration starting in 2014:

Medicaid covers many people with disabilities now, and in the future it will provide insurance to even more Americans. Starting in 2014, most adults under age 65 with incomes up to about \$15,000 per year for single individual (higher income for couples/families with children) will qualify for Medicaid in every state. State Medicaid programs will also be able to offer additional services to help those who need long-term care at home and in the community.

www.healthcare.gov/foryou/disabilities/index.html

Please refer to the health insurance options section of this manual for more information regarding insurance coverage.

Action Needed:

Age 17 years, 11 months (30 days before the 18th birthday):

- Apply for SSI (if applying for the first time)
- Apply for SSI redetermination if you have received SSI as a child
- Apply for Medicaid health insurance (Be sure to attach a copy of your SSI application confirmation to your application for Medicaid insurance.)

Age 18 years 11 months:

- If you are already enrolled in All Kids/Medicaid, check with the caseworker at your local DHS office to make sure that your coverage is being transferred to the "adult" Medicaid program.

Delegation of Rights for Educational Decisions

Recently, Illinois passed legislation that allows families to continue to take the lead in

educational decision-making for their young adults with disabilities in the educational system. The Delegation of Rights Form for Educational Decisions gives students with IEP's who have reached the age of majority (18) the chance to include the important adults in their lives in the ongoing process of IEP and transition planning. This form allows families who want to have input but aren't prepared to take full guardianship of their student to remain an integral part of the special education process. Most schools welcomed ongoing family/guardian support but there were districts that chose to restrict family participation after the student's 18th birthday. This Delegation of Rights Form remedies the problems created by that restriction. The form is available on the ISBE website at www.isbe.net within the IEP form or by clicking the following link: [Delegation of Rights Form](#).

A Different Kind of Transition Plan - Ages 18 – 21

If your child's IEP team has decided it's appropriate for him/her to receive special education services until the day before his/her 22nd birthday, there are many opportunities available to enhance employment experiences and career development. This is often time used to pursue options beyond the typical classes offered at the high school. Your student may take this opportunity to explore a variety of careers and options available at the local community college, in work-study programs, and through academic electives and post-secondary education.

Community employment and resume building experiences can be very valuable to pursue at this time. This is also a good time to contact friends, family, neighbors and community members regarding job options that may be a good fit for your child. Research shows that these natural contacts often result in the most satisfying work experiences.

This is also a good time to look into the local adult developmental disabilities community system. Between the ages of 18 and 21, you may want to visit and research all options in the adult system.

PUNS

The Independent Service Coordination (ISC) agency in your area can provide a great deal of information about local services and available providers. Think of the Independent Service Coordination agency as the "gatekeeper" to the adult system. When you contact the ISC agency in your area for help with the transition to adult services, the case manager will also work with you to complete a form (implemented by DHS in 2004) called **PUNS (Illinois Prioritization of Urgency of Need for Services)**, which is designed to track individuals with developmental disabilities seeking services and supports. More information about PUNS and a copy of the form can be found on The Arc of Illinois website at www.thearcofil.org and the website of the Family Support Network of Illinois at www.familysupportnetwork.org.

The Illinois Department of Human Services, Division of Developmental Disabilities, also has a website with information about PUNS. www.dd.illinois.gov.

Contact the ISC agency in your area for an appointment to complete the PUNS interview. It's a good idea to review the PUNS information available on the websites listed above prior to your appointment with the ISC agency.

Another important transition goal is the application for Medicaid or Medicaid eligibility for adult services. Remember that there are two steps in this process. First, apply for Medicaid health insurance and second, apply for a Level 2 Medicaid screening from the ISC agency. This happens now when a name is pulled from the PUNS list and not before. (This only applies to people who were not previously enrolled in Medicaid.) **Medicaid is the key to adult services in Illinois.** If your child does not apply for Medicaid, the chance to be eligible for adult services is greatly diminished. This applies to all adult services and programs that receive any government funding.

It is in the best interest of your adult child to learn all you can about Medicaid eligibility, the adult service system, and the role of the Independent Service Coordination agency in your area. Knowledge of and planning around these critical areas may make the transition to adult services much easier.

Refer to our booklet, [Illinois Medicaid Information for Children and Adults with Disabilities](#) for more information on this topic.

www.thearcofil.org/secure/reveal/admin/uploads/documents/MedicaidInfoBrochureFinal.pdf

Section II - The Adult Service System in Illinois

In July, 2007, the Illinois Department of Human Services, Division of Developmental Disabilities, implemented new options for services for children and adults with developmental disabilities. These options are funded by Medicaid Home and Community Based Services waivers.

The following information is from The Family Support Network Answers Frequently Asked Questions Regarding the Children's and Adult Home-Based Support Services Programs document available on the Family Support Network of Illinois website:
www.familysupportnetwork.org.

What is a Waiver? Why is it important to us?

The Children's and Adult Home-Based Support Services Programs (HBSS) for people with developmental disabilities are both part of "waiver" programs. They are funded with a mix of funding from the State of Illinois and the Federal Government. The State of Illinois pays the providers of supports and services. Then the Federal Government reimburses the State 50 cents for every dollar they have spent. In other words, they each pay half.

"Waiver Programs" are created when individual states design programs to support special populations. The states then apply to the United States Department of Health and Human Services to have rules for Medicaid Insurance "waived" so that they can receive reimbursement for part of the cost of the services.

The "waivers" allow states to create programs that provide much needed services in community settings.

This is done through Medicaid, the federal insurance program for people with low-income. Most adults with severe disabilities have low income, so they qualify. Illinois has also agreed to ignore income requirements for families of minor children in the Children's Home-Based Support Services program so all children who are enrolled in the program are eligible. When Medicaid was passed into law in the 1960's it only paid for people to be in hospitals and nursing homes. Eventually Congress realized that hospitals and nursing homes were very expensive and many people with developmental disabilities didn't want or need to live in them.

But, they were stuck using them, as there were no alternatives. Congress passed legislation allowing the Secretary of the U.S. Department of Health and Human Services to "waive" the rules in certain circumstances. States can design programs of services, make specific application, and get approval to waive the rules within those programs. States and participants have to live by the rules and guidelines the Feds require.

Of course, being able to "capture" these federal dollars is very important to the State of Illinois, especially as the State tries desperately to deal with a series of very bad budget years.

The Illinois Department of Human Services, through its Division of Developmental Disabilities, administers three "waiver" programs. They include a waiver for Adults

with Developmental Disabilities which provides funding for Community Integrated Living Arrangements (CILA services), the Adult Home-Based Support Services Program, and Developmental Training. The Children's Support Services Waiver provides funding for the Children's Home-Based Support Services Program. The Division of Developmental Disabilities also administers a third waiver which provides funding for children living away from home in residential settings.

What are all the programs funded by Illinois State DD Waivers?

The Illinois Department of Human Services (www.dhs.state.il.us/) administers three waiver programs specifically for people with developmental disabilities. Those three waivers provide funding for a total of six programs. They are:

- **CILA (or Residential CILA)** – Community Integrated Living Arrangements are the supports and services adults with disabilities receive from provider agencies when living in residential settings such as group homes.
- **In-Home CILA or Family CILA** – These terms are used interchangeably for the same supports and services as above. However, a provider agency usually delivers the supports and services in the family home. The amount of funding is typically much less than residential CILA.
- **Adult Home-Based Support Services Program** – In this flexible program, adults with disabilities develop an array of services and supports that can be delivered in a variety of ways.
- **Adult Developmental Training (DT)** – Through this program, people with disabilities receive services during the day. DHS awards this to people with disabilities as a separate service. People can receive this service only, or it can be part of their CILA services, or they may select it as part of their Adult Home-Based Support Services Program. Sometimes people refer to this as “Day Training” or “Sheltered Workshop”.
- **Children's Home-Based Support Services Program** – This is a new program which started July 1, 2007. Families who were receiving services through DHS program code “72D” were transitioned into this program.
- **Children's Residential Waiver** – This is also a new program which started July 1, 2007. Children who were already living in residential settings, with DHS program code “17D”, were transitioned into this program. The Division of Developmental Disabilities strives to keep children OUT of this program by using the Children's Home-Based Support Services Program.

Some children are now enrolled in the new Children's Support Waiver. If your child participates in the Children's Support Waiver, you will need to work with your Service Facilitator on transition planning.

If your young adult participates in the Home-Based option of the Adults with Developmental Disabilities waiver, you also need to work with your Service Facilitator on transition and employment options.

You can look up Service Facilitator agencies and contact information by county on The Family Support Network website:

www.familysupportnetwork.org/Service%20Facilitators%20by%20County.htm.

For more information about the Home-Based waiver options, please see the document referenced above on Family Support Network of Illinois website at

www.familysupportnetwork.org.

Some children and youth, including those with developmental disabilities who are medically fragile and technology dependent, may be enrolled in a different Medicaid waiver, the Home Care Program. This waiver program is administered by the Division of Specialized Care for Children (DSCC) and allows recipients to receive home nursing services. See the information available on the DSCC Home Care Program web page at http://internet.dsccl.uic.edu/dscclroot/home_care.asp for more information.

Services under this specific waiver end on the 21st birthday, and Illinois does not have a comparable waiver for adults. If you participate in the Home Care waiver, it's very important to work closely with your DSCC Care Coordinator during the transition process.

By age 22, your adult child will exit the special education system. If he is not employed and/or needs additional services, you may need to access the adult service system. Many of the timelines and resources discussed in the special education transition section of this manual still apply. If you addressed issues as they were mentioned earlier, some of this section may be repetitive.

The key to the adult service system in Illinois is Medicaid eligibility.

If your child did not make Medicaid eligibility a part of the transition plan, he/she now must establish Medicaid eligibility to qualify for services. If your adult child has a cognitive impairment or a related developmental disability and has been found eligible for SSI, Medicaid eligibility should be relatively simple. The application for Medicaid can be obtained from the DHS website (it is a single application form for Medicaid, Federal Supplemental Nutrition Assistance Program (SNAP) and cash assistance). You can now apply online. Here is a link to the application form:

www.dhs.state.il.us/page.aspx?item=33698

Here is the form to use if you prefer to apply in person or by mail:

www.dhs.state.il.us/OneNetLibrary/27897/documents/Forms/IL444-2378B.pdf

To apply for medical assistance, visit the nearest [Illinois Department of Human Services](#) (DHS) office. Staff will help with submitting an application. You may bring a downloaded application with you to the appointment.

Some hospitals, medical centers, clinics and health departments have staff members designated to help their patients apply for Medicaid insurance. It's a good idea to check with your medical care provider or facility to see if there is a staff person who can help you apply for Medicaid.

Here are links to information about Medicaid for adults (over 18) with disabilities:

- www.dhs.state.il.us/page.aspx?item=44574
- www.ilga.gov/commission/jcar/admincode/089/08900113sections.html
Joint Committee on Administrative Rules
Administrative Code
TITLE 89: SOCIAL SERVICES
CHAPTER IV: DEPARTMENT OF HUMAN SERVICES

SUBCHAPTER b: ASSISTANCE PROGRAMS

PART 113 AID TO THE AGED, BLIND OR DISABLED

If you are unable to travel to a DHS office for health reasons, you may call and ask that an application be mailed to you. After you complete and return the application, the DHS staff will arrange an interview by telephone. You can find the office in your area on the DHS website at www.dhs.state.il.us/page.aspx?module=12 or you may call DHS at 1-800-843-6154, TTY 1-800-447-6404.

Here is the link to the HFS website information about applying for Medicaid: www.hfs.illinois.gov/medical/apply.html Please note that HFS has a contract with DHS to handle applications for Medicaid for people 18 years of age and older. You must contact a DHS office for an appointment or to get an application.

Persons applying for Medicaid for the first time after July 1, 2006, or having their first Medicaid re-determination after this date, must also provide proof of their U.S. citizenship as part of the application process. Here is a link to the latest information on this topic from the Centers for Medicare and Medicaid Services:

www.cms.hhs.gov/smdl/downloads/SMD06012.pdf

The Illinois Coalition for Immigrant and Refugee Rights has contracted with the Illinois Department of Human Services to assist people who do not speak English to apply for Medicaid by contacting one of their member agencies. A list of the member agencies and the languages represented can be found at:

www.icirr.org/outreach_files/resources/outreachcontact.doc

To review, there are 7 major steps in accessing adult services and supports:

1. Make sure that a PUNS form has been completed for your child with the Independent Service Coordination Agency in your area and update it annually.
2. Develop a strong Transition Plan in your child's IEP, starting at age 14 ½.
3. Complete financial planning and set up a Special Needs Trust by age 12 if possible.
4. Apply for SSI.
5. Apply for Medicaid health insurance (via DHS).
6. Apply for Vocational Rehabilitation services from DHS/DRS.
7. Check out all health insurance options that may be possible (including continuing on private insurance in addition to Medicaid, as well as Medicare).

Good News - Health Care Reform

Expanded Medicaid eligibility for low-income adults will start in 2014. Under provisions of the Patient Protection and Affordable Care Act of 2010, new options for Medicaid eligibility will begin in 2014. These new options will be important for some adults with disabilities:

- Eligibility will be based on income (earning under (\$15,000 per year), NOT on being found eligible for SSI and/or having a child.
- Youth who had IEPs when they were in school, but do not qualify for SSI may be eligible when this law goes into effect.

More information is available from Health and Disability Advocates publication:

“Medicaid Categories for People with Disabilities—Before and After PPACA”

<http://hdadvocates.org/files/Health%20Care%20Reform/MedicaidCategoriesBeforeAndAfterPPACAMay2010.pdf>

What are Independent Service Coordination Agencies (ISC) and what is their role in helping adults with DD get jobs and other services?

In Illinois, the system point of entry for services through the Illinois DHS Division of Developmental Disabilities for adults with developmental disabilities is the Independent Service Coordination or ISC agency. The state (DHS/DDD) contracts with private, not-for-profit ISC agencies to fulfill this task. There are 18 ISC agencies across the state; each assigned to serve a specific geographic catchment area of the state. Each agency is independent with a community volunteer board of directors. There is not a central coordinating entity for the ISC's. Some of the agencies also serve other populations and may receive funding from multiple public and private sources.

It is sometimes possible to change ISC agencies if you would like. Those requests must be directed to the DHS/DDD Network Facilitator for your region. Contact information for the network facilitators is located at www.dhs.state.il.us/page.aspx?item=48541

When an adult with a developmental disability is seeking services from the state-funded system, he/she is required to start with the ISC for that region. PUNS is the first step in accessing services. Once a name is drawn from the PUNS list, eligibility determination begins. Eligibility determination is a critical part of the intake process. Proof of a developmental disability must be furnished, along with proof of eligibility for SSI and Medicaid.

Next, the applicant (adult with a developmental disability) will be “screened” to see if they meet the requirement for needing an institutional level of care. This screening is done using a standardized screening instrument called the ICAP or the Inventory for Client and Agency Planning, a 16-page booklet.

For more information on the ICAP, see the ICAP home page of the publisher, Riverside Publishing: www.riversidepublishing.com/products/icap/index.html.

Only persons with developmental disabilities whose ICAP scores indicate that they require an “institutional level of care” (typically in an ICF/DD - intermediate care facility for developmental disabilities) can be considered for institutional placement or a Medicaid waiver for home and community based services. Typically, an individual with cognitive impairment or related developmental disability will meet this requirement.

As a part of Medicaid regulations, the case manager at the ISC agency will then offer the individual a “choice” of institutional placement or the option to receive home and community-based services funded via a Medicaid Home and Community Based Service waiver.

Unfortunately, at the present time, services are not always available, or may only be available in certain areas of the state. In addition, DHS/DDD will first address “emergency cases”. The definition for emergency criteria can be found on the DHS website within the DD Resource Library for Providers www.dhs.state.il.us/page.aspx?item=50038.

This situation may be subject to change. Contact the [Illinois Life Span Project](#) or the [Family Support Network](#) for additional information.

At the present time (August 2010) there are over 20,100 children and adults who have completed a PUNS interview, waiting to receive services.
www.dhs.state.il.us/page.aspx?item=31193

Case managers will refer clients to **existing options**: center-based community programs such as employment services, supported employment, day training (DT= a form of day care for adults with severe developmental disabilities), sheltered workshops and residential services.

Each client is assigned to a case manager, and in some agencies, certain case managers may specialize in particular disabling conditions. Case managers do not have state certification or credentials (unlike, for example, teachers or early intervention professionals). The case manager is required to have a minimum of a bachelor’s degree in a human service field, to have completed at least one year of direct service work experience, and to complete yearly continuing education requirements set by the state.

Once a person with a developmental disability starts to receive adult services, the case manager is required to meet with the person and make site and/or home visits on a quarterly basis. The number of hours per year that a case manager can work on a client’s “case” is pre-determined by DHS; however, this can be appealed, and the annual allotment of hours can sometimes be increased.

Case managers are required to develop Individual Service and Support Plans (ISSA plans) for people with developmental disabilities who have Medicaid waivers. For more information on ISSA plans, see www.legis.state.il.us/commission/jcar/admincode/059/059001200D01600R.html.

Case managers act like brokers, informing clients and their guardians of **available options** and providing them with contact information to apply for services. Case managers at the ISC agencies can only advocate for clients receiving services funded by DHS/DDD. They cannot get involved with services funded by DRS (Division of Rehabilitation Services). Independent Service Coordination is not available for persons who receive services solely from DRS.

Division of Developmental Disabilities Services

The Illinois Department of Human Services Division of Developmental Disabilities states their commitment to home and community-based services for people with developmental disabilities, as posted on their website:

“Services and supports for individuals with developmental disabilities are provided to help individuals with developmental disabilities achieve as much independence as possible and to live in their home communities with family and friends. Emphasis

is placed on enabling individuals to stay in their own homes, in family homes, or in small-group settings. DHS funds over 640 community-based agencies that serve individuals with developmental disabilities and administers 11 state-operated developmental centers and programs. Services funded by the State of Illinois are delivered in the least restrictive setting appropriate for the individual.”

www.dhs.state.il.us/mhdd/dd/

At the present time, the State of Illinois Department of Human Services is changing the way that direct services to adults with developmental disabilities are funded. This includes changes in billing Medicaid for services received by individuals with developmental disabilities. This is the reason that all adults who are seeking developmental disability services are now required to apply for Medicaid, if they have not already done so.

Remember that you can have both private and Medicaid health insurance in Illinois. This change should help adults with developmental disabilities have more choices of service providers and options in the kinds of supports they want in order to be able to live and work in their own communities. For more information, contact The Arc of Illinois:

www.thearcofil.org Refer to our Medicaid Information brochure for details regarding who is eligible for Medicaid and how to apply:

www.thearcofil.org/familytofamily/documents/documentdetails.asp?did=2035

Families of adults with developmental disabilities who are interested in community-based employment, supported by consumer-directed funding, should discuss this in detail with their ISC case manager. More information about consumer-directed funding is available from the Center for Self-Determination: www.self-determination.com/index.html

The Illinois Department of Human Services, Division of Rehabilitation Services

The other major player in Illinois in providing services to people with developmental disabilities is another division of the Department of Human Services, the Division of Rehabilitation Services. The Division sometimes is also referred to as “voc rehab” or “VR”.

What is Vocational Rehabilitation?

Vocational rehabilitation was first established by the federal government in 1913, with creation of the National Vocational Guidance Association. In 1916, Congress passed the National Defense Act, providing vocational training and education for members of the armed services. In 1918, the Smith-Sears Veterans Rehabilitation Act provided vocational training for veterans with service-related disabilities, and in 1920, passage of the Smith-Fess Act established limited vocational training, job placement, and counseling services for the general population of persons with physical disabilities. By 1935, every state had some form of vocational rehabilitation program (VR), although there was no mandate to serve persons with developmental disabilities. Vocational rehabilitation programs in the states are funded by the Rehabilitation Services Administration (RSA), part of the United States Department of Education, Office of Special Education and Rehabilitation Services (OSERS) (www.ed.gov/osers/rsa).

In 1973, the Rehabilitation Act (Rehab Act) was passed which provided increased federal funding to states for vocational rehab services, coordinated federal and state efforts to promote and expand employment for persons with disabilities, and prohibited discrimination against persons with disabilities in employment and job promotion. **Further, this federal law requires that first preference for VR services must be given to those**

persons with the most severe disabling conditions (Turnbull, Turnbull, Bronicki, Summers and Roeder-Gordon, 1989). The Rehab Act also requires that the person with a disability must manifest “employability”.

The Rehabilitation Act was amended in 2001 to revise the scope of employment outcomes under the VR program. Effective since October 2001, **“employment outcomes” of VR programs refers to outcomes in which the person with a disability works in an integrated setting. This can include full-time or part-time competitive employment, labor market, supported employment, or “other vocational outcomes.”** Sheltered employment is no longer considered a positive VR outcome. This has set the stage for some vocational counselors to avoid serving individuals with severe disabilities. This is extremely problematic because of the federal mandate to serve people with severe disabilities. This can also result in limitation of the client’s right to “informed choice” regarding participation in “extended employment” (non-integrated, supportive or sheltered employment) versus integrated employment. In other words, “extended employment” cannot be the only option offered to a client

<http://www2.ed.gov/legislation/FedRegister/finrule/2001-1/012201a.html>.

The federal Office of Special Education and Rehabilitation Services (OSERS) funds the vocational rehabilitation services offered by DRS. DRS has 51 local offices around the state, designated to serve people residing in specific geographic areas. These offices are separate (and in different locations) from the DHS offices that handle Medicaid and Food Stamp applications.

Your local office can be found using the DHS Office Locator:

www.dhs.state.il.us/OfficeLocator/

DRS now has an option on their website to submit a request for Vocational Rehabilitation Services electronically: <https://drs.dhs.state.il.us/owr/setReferral.do>. If you choose to use this new option, be sure to save the request form on your computer as well as printing out a hard copy for your records.

The following information on Illinois DHS/DRS Vocational Rehabilitation was submitted by Randy Staton - Policy Advisor, DHS/DRS, Bureau of Field Services.

Vocational rehabilitation (VR) is the provision of services to enable individuals with disabilities to pursue meaningful careers and employment commensurate with their abilities and capabilities.

Vocational Rehabilitation can provide a variety of services as long as those services assist an eligible individual with disabilities to obtain, regain, or maintain employment consistent with their unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice. In order to be determined an individual eligible for services the individual must meet a two pronged test, general eligibility and an order of selection. General eligibility is determined by a Certified VR Counselor employed by the Division of Rehabilitation Services. The determination is based on all three of the following: 1) is the individual a person with a disability; and 2) does the individual require VR services; and 3) can the individual benefit from those VR services. If the individual is determined eligible they must then meet an order of selection. The order of selection process has been approved by the Federal Government and implemented due to budgetary

constraints. The determination is a priority of services based functional limitations for those individuals with most significant disabilities being served first.

Once an individual has been determined eligible and meeting the order of selection, an Individualized Plan for Employment (IPE) will be developed and implemented with agreement of the individual and the VR Counselor. This IPE can be amended as situations change and must be agreed to by the individual and the VR Counselor. It is important to understand VR services provided in an IPE are not intended to extend for the life of the individual but are time-limited dependent upon the employment support needs of the individual.

If you require more information, want to make a web referral, or find an Illinois VR office go to:

www.dhs.state.il.us

What is the “Order of Selection” for vocational rehabilitation services and what does it mean for adults with developmental disabilities who want to work?

In December, 2004, the DHS Division of Rehabilitation Services made a major change in the way they deliver services, implementing “Order of Selection”, as stipulated in the Rehabilitation Act. The policy governing the “order of selection”- meaning the order in which adults with disabilities are deemed eligible and are provided funding for vocational rehabilitation - can be found in the federal legislation, the Rehabilitation Act. When the order of selection is implemented, it means that applicants for VR services will be ranked in order of the “significance of their disability” and selected for funding according to this significance. Other applicants (including many individuals with “less significant” disabilities who have been traditionally served by DHS/DRS) may be put on a waiting list.

It is important to remember that vocational rehabilitation and other services and supports for adults with developmental disabilities are not an **entitlement** - unlike special education services. This means that the vocational rehabilitation system is not required to serve everyone who is potentially eligible. The VR system is required to serve eligible persons who can be accommodated within the limitations of agency funding at a given point in time.

It is also important to remember that DHS/DRS serves persons with all types of disabling conditions. The terms “most significant”, “very significant” and “significant” disabilities are not specific to developmental disabilities, but apply equally to all disabling conditions.

Of course, people with the “most significant” and “very significant” developmental disabilities must be considered eligible to receive VR services on the same basis with applicants who have other types of “most significant” and “very significant” disabilities (for example, physical disabilities, mental disabilities and health impairments).

Since DHS/DRS receives federal funds to provide VR services in IL (80% of the DHS/DRS budget is from federal sources, The Arc of Illinois, 12/02/04), Section 504 of the Rehabilitation Act, which prohibits discrimination on the basis of disability, applies to all DHS/DRS programs and functions. This is the URL for Section 504:

http://assembler.law.cornell.edu/uscode/html/uscode29/usc_sec_29_00000794----000-.htm

As discussed earlier in The Arc Family Manual, people with developmental disabilities are often informed that they must “choose” between Division of Developmental Disability (DDD) and Division of Rehabilitation Services (DRS) services. This is not correct. Services from both of these divisions of the Illinois Department of Human Services may be needed in order for adults with developmental disabilities to succeed in the workplace and in living as independently as possible. There is confusion because **only one waiver program** may be accessed at any given time. Not all DRS services are waiver services.

How should youth with DD proceed in accessing vocational rehabilitation services?

A. Prior to high school graduation

1. Make sure that “opening a case” with DHS/DRS is part of the IEP transition plan.
2. Invite the DHS/DRS counselor – in writing - to all IEP and transition team meetings.
3. Be sure to apply for SSI prior to your 18th birthday - this is the “proof” that is needed to establish the degree of “significant disability.”
4. Decide whether or not to pursue adult service options from DHS/DDD in addition to VR services from DHS/DRS.
5. Explore post-secondary education and career training opportunities and request support from DHS/DRS in writing.

B. Following high school graduation

1. Maintain contact with your DHS/DRS counselor in writing (also maintain a log of all telephone calls).
2. Connect with friends and community members for help in finding work, inform your DHS/DRS counselor when you find a job, and ask for needed supports.
3. Be sure to maintain a paper trail for all of your communications with DHS/DRS.
4. Request that your DHS/DRS counselor provide you with all information regarding policies and procedures in writing (or other format that is accessible to you).
5. Know who to ask for help if you need advocacy assistance with DHS/DRS (see advocacy resources in the appendix of this Manual).
6. Contact the Illinois Life Span Project (www.illinoislifepsan.org) of The Arc of Illinois for information resources and technical assistance for your advocacy needs.

Consumers and families must be clear right from the start that they are definitely interested in community-based employment and want to have their “case opened” by DRS. They may need to ask lots of questions about “employment programs” to find out if they actually support adults with developmental disabilities to have paid jobs in the community.

Many students with developmental disabilities can benefit from VR services and supports to help them get jobs. DRS can sometimes pay tuition costs for students with disabilities who are enrolled in colleges and other post-secondary education that is focused on training to get and keep a job. Be sure to ask your DRS counselor about this.

More Information About Vocational Rehabilitation “Qualifiers”

Vocational rehabilitation programs do not typically offer specialized services and supports for persons with developmental disabilities. In many states, including Illinois, specialized vocational rehabilitation services are available for persons with vision and/or hearing impairments. Some persons with developmental disabilities may qualify for these services and supports if they also have a vision and/or hearing impairment.

Vocational rehabilitation programs state that they serve persons with all types of disabilities, as long as they meet the eligibility criterion and are considered “**employable**”. In Illinois, people with disabilities, including those with developmental disabilities, can access vocational rehabilitation services from DRS.

Once again, families and consumers hear that “you can’t be served by two waivers, so you have to pick one.” This statement refers to the Medicaid waivers that are available for adults in Illinois. One waiver, known as “DRS Home Services,” is a waiver for people with disabilities (including developmental disabilities) to receive personal care services at home. Another waiver is the Division of Developmental Disabilities waiver for adults with developmental disabilities to receive community services or residential placement in the community. For more information about the Medicaid waivers in Illinois see www.hfs.illinois.gov/hcbswaivers. **Consumers can only benefit from one of these waivers so would have to make a choice if both were available.**

Vocational rehabilitation services, however, are not a waiver service. They are funded by the federal Rehabilitation Services Administration, part of the Office of Special Education and Rehabilitation Services of the U.S. Department of Education. www.ed.gov/about/offices/list/osers/rsa/about.html

Adults with developmental disabilities can utilize both Vocational Rehabilitation Services and Home and Community Based Medicaid Waiver services at the same time. They do not have to choose between them.

To receive supports from DRS, an individual must be considered “able to benefit from VR services” unless proven otherwise in a “trial work experience” arranged by DRS: www.ilga.gov/commission/jcar/admincode/089/089005530000200R.html

Without a good transition plan, the adult system can be a real “tiger by the tail” for individuals seeking employment services. This is why researching the ins and outs of Medicaid eligibility, services of the Division of Developmental Disabilities and services of the Division of Rehabilitation Services before exiting the special education system is wise.

Also important to remember is the fact that persons with developmental disabilities who receive SSI or SSDI do not have to pay to receive services from DHS/DRS. For more information on DRS financial participation, see www.legis.state.il.us/commission/jcar/admincode/089/089005620000300R.html This means that if you do NOT receive SSI or SSDI payments, you may have to pay to receive services from DHS/DRS.

If issues and concerns arise regarding DRS services, you can contact the Client Assistance Program (CAP): Client Assistance Program 100 N. 1st St., 1st Floor West, and Springfield, IL 62702 Phone: 1 800 641-3929 (Voice/TTY) Email: dhscap@dhs.state.il.us.

You can also contact The Arc of Illinois' Life Span Project (www.illinoislifespan.org), as well as your state senator and state representative for assistance with advocacy related to DHS and other state agencies.

A useful consumer and family guide produced by the Institute for Community Inclusion for individuals seeking vocational rehabilitation services, Getting the Most from the Public Vocational Rehabilitation System, is available at www.communityinclusion.org/article.php?article_id=129

DRS Home Services Program

The following information was provided by Canda Scott, Acting Bureau Chief for the Illinois Department of Human Services, Division of Rehabilitation Services.

The Home Services Program of the Division of Rehabilitation Services (HSP) works one-on-one with individuals who have disabilities and their families to empower them to reach their independent living goals. HSP provides services to individuals with the most significant disabilities so they can remain in their homes and live as independently as possible. Our customers are empowered to live self-directed lives, be actively involved in their communities, and retain control over the services they receive. We provide the following types of assistance in an individual's home: Personal Assistant, Homemaker Services, Maintenance Home Health, Electronic Home Response, Home Delivered Meals, Adaptive Equipment, Home Modification, Respite and Adult Day Care. An individual can be eligible for any combination of the above services.

In order to be eligible for HSP, a customer must:

- *Be under the age of 60 at time of application with no age criteria for the AIDS or BI waiver*
- *Be a resident of the State of Illinois*
- *Be a citizen of the United States or a legally admitted alien*
- *Have a severe disability that will last a year or longer*
- *Have a DON score of 29 points or more – this is an assessment completed by HSP staff*
- *Have less than \$17,500 in assets or \$35,000 family assets for a child under the age of 18*
- *Have needs that can be met at a cost less than or equal to the cost of nursing services in an institutional setting*
- *Have a Physician's Certification that certifies you are at risk of institutionalization and that services can be provided safely in the home – HSP staff will submit this form to your doctor if you meet the other criteria of eligibility*
- *Fully co-operate with the Medicaid application process*

To refer yourself for services on the internet: <https://drs.dhs.state.il.us/owr/>

To locate the office nearest you: www.dhs.state.il.us/page.aspx?module=12

To visit the DHS web-site: www.dhs.state.il.us

For questions about any Illinois Department of Human Services (IDHS) program you may call the automated helpline 24 hours a day at: 1-800-843-6154 or 1-800-447-6404 (TTY)

What if I need an ongoing job coach in order to maintain my job?

- Adults participating in the Home-Based waiver option can assign their personal support worker to assume job coaching duties, within their allotment of hours.
- Adults participating in DRS Home Services **cannot** use their Personal Assistant (PA) as a job coach.
- Adults participating in a center-based program (whether via private pay, paying for the program with waiver dollars, or as part of their package of CILA funding) may ask the provider to provide this service as part of their Individual Service Plan. However, provider agencies are not required to provide job coaching services for their clients.
- Adults working in the community in competitive employment may be able to utilize Social Security initiatives to cover the cost of the job coach and/or deduct this from their income on tax returns.

Microboards and Cooperatives

Additional options for families seeking alternate paths to transition success are microboards and cooperatives. Microboards and cooperatives are small non-profit organizations managed and operated by people with disabilities, their family members and friends. A microboard (a Board of Directors) serves one person. A cooperative can serve three or more, and is managed by a board of directors consisting of 80% members served or their representatives. Each type of organization is based on self-determination, and living a quality life in the community. A microboard or cooperative can apply to the State of Illinois to serve as an official service provider, and manage the funding intended for the support of the individual(s). For more information, contact *Illinois Association of Microboards and Cooperatives* at 217-778-5388, email illinoisamc@gmail.com, or visit www.managingtheartofliving.org.

Illinois Association of Microboards and Cooperatives (formerly known as Managing the Art of Living) is a project of the Illinois Council on Developmental Disabilities. The project is aimed at helping people live the lives they *want* to live, with the support of family, friends, community and public resources.

The project offers self-advocates, families and friends the opportunity to create [Microboards](#) and [Human Service Cooperatives](#), consumer-governed structures that bring resources, authority and responsibility directly into the hands of the people whose lives are most affected by the way support services are organized.

[Community-Building and PATH training](#) provide the underlying planning, community development and management skills that lie at the center of these emerging service forms.

Here's what people are saying about these new options.

Justin's Party Face, Inc. (Microboard)

"I just wanted to let you know what this process has meant to me and my family. We set out three months ago to create Justin's path. Justin is in residential placement and has been for almost two years. We aren't happy with the current provider. I had lost sight of the dreams I had for my son. I had let go of the possibilities and through this process we have been able to rekindle the passion, support and creativity of everyone surrounding Justin."

I think mapping out his life path is brilliant. This way we were able to breakdown where we are today, where we want to be in two years and how we need to get there. Now these goals seem to be more manageable and we have an army of volunteers to help him succeed. The visual path serves as a reminder of what we need to work on at school, at home and in the community. Everyone is on the same page and I am not the only one responsible for his education and well being.I am glad that we have had the opportunity to go through this process because our family and friends have come together with the express goal of managing the art of living for Justin. He has gone to Six Flags; he has been to the soup kitchen to assist those less fortunate. Justin has started attending a non-segregated high-school where he has joined the Pep squad. He is on his way to living in his apartment with a roommate, working at the theatre, and having a healthy relationship with the opposite sex."

Heroes of the Game (Microboard)

Despite appalling challenges with the school district, Quinn's home and community life remains rich with relationships and possibilities. Quinn's microboard is playing a vital role in supporting Quinn to accomplish positive and possible outcomes. Quinn works out 5 days a week at the local Y, attends sporting events, movies, and is hosting a volleyball match at his house next month. He volunteers with friends at a local soup kitchen. Quinn will be speaking at a statewide conference on typing to communicate in May. He is also an invited speaker at a college in Iowa. Quinn types to communicate and he frequently asks about getting together with friends. We are so grateful he has been supported to have the simple freedoms he deserves.

Community Choices Cooperative, Inc.

So far, 10 families have joined together to create the first official human service cooperative in Champaign-Urbana, Illinois. Initially, individuals receiving home and community-based waiver funding will be served through service facilitation. CCC, Inc. has also created a volunteer component which allows families to share supports by providing opportunities for individuals in social, recreation, education or transportation. Looking toward the future, we will eventually provide opportunities and support for customized employment or micro-enterprise, as well as supports for people to live in their own homes in the community, based on their individual needs.

Section III - Health Insurance and Employment- Plan Ahead for Transition Success

The Health Care Reform Act and Impact on Transition - A Work in Progress

In previous sections of this manual, we have discussed the importance of Medicaid as a means to access services and supports for adults with disabilities. Medicaid is also a very important source of health insurance for people with disabilities in the U.S.

Under the Health Care Reform Act, major changes are now underway that will help many people get and keep health insurance. Here is a link to a detailed Health Care Reform Timeline: www.kff.org/healthreform/8060.cfm

What are some of the major changes that will impact youth and adults with disabilities?

1. Starting in September 2010, young adults up to age 26 will be able to stay on their parent's health insurance. This expands upon the existing Illinois law. www.kff.org/healthreform/8065.cfm
2. Starting in 2014, adults with disabilities who have low incomes but have been found ineligible for SSI will be able to access Medicaid health insurance. Here is a letter from CMS (the Center for Medicare and Medicaid Services) to State Medicaid Directors regarding this new eligibility category. www.cms.gov/smdl/downloads/SMD10005.pdf

CMS has a Health Care Reform page on their website, where you can check for new information and updates: www.cms.gov/Center/healthreform.asp.

3. Starting in August 2010, some uninsured persons with chronic conditions will be able to receive a premium subsidy to participate in the **Illinois Pre-Existing Condition Insurance Plan (IPXP)**: www.insurance.illinois.gov/ipxp/.

What is the Illinois Pre-Existing Condition Insurance Plan?

In Illinois, the federally-funded temporary high risk pool is known as the Illinois Pre-Existing Condition Insurance Plan (IPXP). The IPXP will be a transitional insurance program for uninsured Illinois residents. The IPXP is not a public aid or entitlement program. Enrollees will be required to pay a premium and out

Many, but not all, adults with disabilities are able to get Medicaid health insurance. However, some people may find that Medicaid health insurance does not provide them with the same access to providers (doctors and hospitals) and services (like certain prescription drugs) that they had under previous private health insurance coverage. Illinois Medicaid regulations do permit individuals to have both private and Medicaid health insurance. The private insurance is considered the primary payor, and the Medicaid insurance is the secondary payor. See our "Medicaid Hints and Tips" page in the appendix for more information about coordination of benefits for persons who have both Medicaid and private health insurance.

Successful transition for young adults with special health care needs also requires extra attention to be dedicated to health insurance coverage as plans are being made to seek employment and career training.

The U.S. Department of Labor has an excellent website with extensive resources related to employment-based health insurance. Features with special significance for youth in transition and their families are:

- “Life Changes Require Health Choices - Know Your Benefit Options” - www.dol.gov/ebsa/publications/life_changes.html
- “Personal Assistance Services in the Workplace” - www.dol.gov/odep/pubs/ek97/personal.htm
- “Work Changes Require Health Choices - Protect Your Rights” - www.dol.gov/ebsa/publications/work_changes.html
- “eLaws Health Benefits Advisor” - www.dol.gov/elaws/ebsa/health/5.asp

Since Medicaid eligibility is the key to accessing services and supports for adults with developmental disabilities in Illinois, the following summary of the process involved in applying for Medicaid health insurance may be useful.

In Illinois, Medicaid eligibility is a two-part process. The information in this section pertains to persons over age 18 not previously enrolled in Medicaid or SSI. Both state and federal government regulations require that from the individual's 18th birthday forward, only his/her income and assets are “counted” to determine eligibility. Prior to the 18th birthday, the parents/guardians income and assets are counted. (Information for youth who participated in All Kids insurance is in a separate section.)

First, the young adult must apply for SSI (Supplemental Security Income). This includes determination as to whether or not the person is “disabled” according to the Social Security Administration. More information and an application form can be found at www.ssa.gov/notices/supplemental-security-income/

Next, you must obtain an application for Medicaid from the Illinois Department of Human Services: www.dhs.state.il.us/OneNetLibrary/27897/documents/Forms/IL444-2378B.pdf

Submit it following the instructions on the website:
www.dhs.state.il.us/page.aspx?item=33698.

It is now possible to apply online, by mail or fax, or in-person at your local DHS office.

It is sometimes possible for adults with disabilities who do not receive SSI to qualify for Medicaid as a “disabled adult” (for example, if they are “over assets” for SSI). However, the Illinois Department of Healthcare and Family Services Client Assistance Unit (CAU) uses the criterion (called SSI standards) when they review an applicant's medical records to determine if you are “disabled”.

The Illinois Department of Human Services, Division of Rehabilitation Services, has a Benefits Planning Assistance and Outreach program to provide benefits advice and counseling. This program can be reached at: 1-800/807-6962 (Voice)

1-866/444-8013 (TTY). This project has no web site.

Special Information for Youth Who Have Had Medicaid Health Insurance (All Kids) Prior to Age 18

Thanks to Michele Piel, Special Assistant, Division of Medical Programs, Illinois Department of Healthcare and Family Services for information in this section.

Transitioning Children from All Kids to Adult Health Benefits (Medicaid)

All Kids health insurance is for children and youth under age 19. Families must “redetermine” their child’s eligibility each year. The Department of Healthcare and Family Services sends out a letter to families about the redetermination process. Families need to fill out and submit the form. This determines which All Kids program their children will participate in for the coming year (meaning whether or not they will need to pay monthly premiums and co-pays).

Remember that under the new All Kids system, redetermination now means finding out the All Kids Level for which you qualify. This level assignment means that some families will pay premiums and co-pays and at varying levels. In the past, redetermination meant finding out if you were still eligible, based upon income. Families could lose coverage if their incomes were too high. This redetermination process has now ended and all families at all income levels can buy in to the Health Benefits Plan. Costs will vary by family income.

This change took place on July 1, 2006.

For more information, see the manual “Medical Assistance Programs in Illinois”, available for free download from [Health and Disability Advocates](http://www.hdadvocates.org). (www.hdadvocates.org)

Families receive an annual renewal notice for All Kids. A child’s eligibility for the next 12 months is determined in the renewal process.

For All Kids Assist, the monthly income limit is at or below 133% of the Federal Poverty Level (FPL). If the child remains eligible, no notice is sent. If the child is not eligible, All Kids sends a Notice of Change that explains the reason for cancellation and the date coverage ends.

FPL stands for “Federal Poverty Level”, an income level that has been determined by the federal government and updated each year. A chart with the income levels and additional information for consumers can be found at the Work World Employment Support Project: www.workworld.org/wwwwebhelp/poverty_guidelines_federal.htm. You can also determine your personal FPL level by using the FPL Calculator online tool: www.coalitionclinics.org/fpl.html

The “cancellation” means that the child can no longer get All Kids Assist (Medicaid) but will need to transfer to All Kids Premium in order to keep the health insurance coverage. This means that the family will be required to pay monthly premiums and co-pays, based upon their income level, in order to keep the All Kids insurance in effect.

For All Kids Share and All Kids Premium Levels 1-8, the monthly income limit is over

133% of the FPL. If the child remains eligible, All Kids sends a notice that states the All Kids program for which the child is eligible and explains the co-pays and premium requirements. If the child is not eligible, All Kids sends a Notice of Change that explains the reason for the cancellation and the date coverage ends.

Once a child reaches age 18, the parents' income is no longer counted for the child's eligibility. All Kids only counts an 18 year old's own unearned income to determine income eligibility for these programs. Many 18 year olds qualify for All Kids Assist. **The 18-year olds' earned income is not counted.** This means that in the new All Kids system, parents may not have to pay premiums for their young adults from age 18 until their 19th birthday.

Before children reach their 19th birthday, a special redetermination notice (Form 3766 or 3766A) is sent to the family. The following link to the DHS website has information available to explain this procedure: www.dhs.state.il.us/page.aspx?item=17150)

If the child receives SSI, is pregnant, or has a child, the caseworker will review eligibility for Medicaid under AABD, Moms & Babies, or FamilyCare. If eligible, the child does not have to complete a new application. Coverage is closed under All Kids and opened under the new program.

If the child has a disability but does not receive SSI, a referral is made to the Client Assessment Unit (CAU) which will determine the child's disability status based on a review of the child's medical records. The child's medical coverage will continue until CAU makes a decision regarding the child's disability. CAU uses the same rules as the Social Security Administration in making its decision. This procedure will change in 2014 when the new Medicaid eligibility guidelines of the Patient Protection and Affordability Act go into effect.

If a child with a disability has a job and would have a spenddown, the child may qualify for Health Benefits for Workers with Disabilities (HBWD). The DHS caseworkers do not set up HBWD cases. The child needs to file a new HBWD application with HFS' central HBWD unit. Visit the HBWD web site at www.hbwdillinois.com to download an application or call the Health Benefits hotline at 1-800-226-0678.

It is also possible for people to participate in HBWD if insurance is offered by their employer. Workers can pick HBWD if it is cheaper than their employment-based insurance coverage, or they can choose to have both HBWD and employment-based health insurance. In this case, the employment-based insurance will be primary and the HBWD Medicaid coverage will be secondary. This may be a good option if your employment-based insurance does not cover needed items (for example, nutritional supplements, incontinent supplies or durable medical equipment).

How much time does one have to change to a different Medicaid program?

If the 19 year old qualifies for another program, the caseworker will set up the new coverage. There is no gap in coverage from All Kids to the new program. If the 19 year old does not qualify for another program, the 19 year old may make an application at any time in the future if there is a change in the 19 year old's circumstances. If eligible, then they may qualify for up to a 3 month backdate.

How is continuity of care handled for someone who may be taking medications, receiving treatment, or is hospitalized during the transition period?

If the 19 year old is determined eligible, medical care can continue without interruption. The 19 year old's Recipient Identification Number remains the same between programs. The 19 year old may have a small co-pay for medical services under the new program.

Medical providers who are authorized to accept the All Kids coverage are authorized to accept HFS' other programs. However, HFS has no authority to pay for medical care for anyone who no longer qualifies for one of the HFS programs. This means that young adults who have All Kids coverage before their 19th birthday need to pay careful attention to their Medicaid status.

Be sure to let your medical providers (doctors, hospitals, clinics, pharmacies, vendors, etc.) know when you will be turning 19 years old and that you may have a change in health coverage status. Ask them to work with you on your transition plans for health care coverage.

Read over the following section about options for youth who do not have health insurance coverage, so you will be prepared to deal with possible changes and options.

The following is an overview of possible options for health insurance coverage for youth who are unable to access health insurance either through employment, or from Medicaid health insurance.

Remain on Parent/Guardian's Health Insurance

In some cases, youth with special needs may be able to remain on their parent/guardian's health insurance. As part of the Affordable Care Act, young adults up to age 26 are permitted to stay on their parent's private health insurance starting on September 23, 2010 (regardless of their disability, marital or employment status). Here is link to a fact sheet on this new law:

www.whitehouse.gov/sites/default/files/rss_viewer/fact_sheet_young_adults_may10.pdf.

This new Federal law supercedes the 2008 Illinois law.

In September, 2008, a new law was passed in Illinois allowing unmarried young adults to stay on their parent's health insurance until their 26th birthday. This is for all eligible young adults - whether or not they have a disability. Military veteran dependents are eligible up until age 30. This law took effect in September 2009. Here is a link to more information about this Illinois-specific law:

Here is the Illinois Department of Insurance's June 2010 revised fact sheet on the Illinois and Federal legislation: http://insurance.illinois.gov/HealthInsurance/ya_dependent.asp

In addition, another Illinois law, passed in 1969, permits some youth and adults with severe disabilities to remain on their parent's existing insurance. This is what the Illinois Insurance Code says about allowing youth with special health care needs to remain on their parent/guardian's health insurance:

215 ILCS 5/356b) (from Ch. 73, par. 968b)

Sec. 356b. (a) This Section applies to the hospital and medical expense

provisions of an accident or health insurance policy.

(b) If a policy provides that coverage of a dependent person terminates upon attainment of the limiting age for dependent persons specified in the policy, the attainment of such limiting age does not operate to terminate the hospital and medical coverage of a person who, because of a handicapped condition that occurred before attainment of the limiting age, is incapable of self-sustaining employment and is dependent on his or her parents or other care providers for lifetime care and supervision.

(c) For purposes of subsection (b), "dependent on other care providers" is defined as requiring a Community Integrated Living Arrangement, group home, supervised apartment, or other residential services licensed or certified by the Department of Human Services (as successor to the Department of Mental Health and Developmental Disabilities), the Department of Public Health, or the Department of Public Aid.

(d) The insurer may inquire of the policyholder 2 months prior to attainment by a dependent of the limiting age set forth in the policy, or at any reasonable time thereafter, whether such dependent is in fact a disabled and dependent person and, in the absence of proof submitted within 60 days of such inquiry that such dependent is a disabled and dependent person may terminate coverage of such person at or after attainment of the limiting age. In the absence of such inquiry, coverage of any disabled and dependent person shall continue through the term of such policy or any extension or renewal thereof.

(e) This amendatory Act of 1969 is applicable to policies issued or renewed more than 60 days after the effective date of this amendatory Act of 1969.

(Source: P.A. 88-309; 89-507, eff. 7-1-97.)

www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=021500050HArt%2E+XX&ActID=1249&ChapAct=215%26nbsp%3BILCS%26nbsp%3B5%2F&ChapterID=22&ChapterName=INSURANCE&SectionID=52237&SeqStart=107000&SeqEnd=116500&ActName=Illinois+Insurance+Code%2E

It is important to pay close attention to the legal requirements for a “disabled adult child” to remain on his/her parent’s health insurance, while supporting your child’s plans for seeking and maintaining employment. This is another factor to consider during the transition process.

Illinois Health Benefits for Workers with Disabilities Program

This is a State of Illinois program which allows workers with disabilities, ages 16 through 64, to “buy into” Medicaid health insurance if they do not receive insurance through their jobs. Here is a link to the website and application form. www.hbwdillinois.com

Illinois is part of the national movement to help people with disabilities return to work. The program called Health Benefits for Workers with Disabilities (HBWD) started providing medical benefits in January 2002.

Disability advocates have long noted that returning to work is difficult for people with disabilities. Many fear that working means losing Medicaid healthcare coverage. Often private insurance is difficult or impossible to obtain.

The goal of this program is to help people with disabilities work with full Medicaid [healthcare benefits](http://www.hbwdillinois.com). HBWD not only encourages enrollees to work, but to increase

the number of hours they are currently working. Just as the name says, the program provides health benefits for workers with disabilities.

If you are an individual with a disability, between the ages of 16 and 64 and working, you may qualify for HBWD. Workers with countable income of up to \$3,159 per month for a single person and \$4,250 per month for a couple may [qualify for the program](#). Unlike other Medicaid programs, HBWD allows enrollees to have up to \$25,000 in assets. Depending on their income, enrollees pay a [monthly premium](#) based on their income range to receive comprehensive healthcare coverage.

You may [download an application](#) or [request an application](#) to be E-mailed. For more information please call our hotline at 1-800-226-0768 or TTY 1-866-675-8440

The Illinois Comprehensive Health Insurance Program (ICHIP)

ICHIP is Illinois' "high risk pool" which offers health insurance to persons who are unable to otherwise access health insurance due to their pre-existing conditions and do not have employment-based insurance available. People who have health insurance coverage of any type are not eligible for ICHIP.

ICHIP insurance is generally more expensive than other types of insurance, and you must be able to pay the premium in full each month in order to remain covered. Here is a link to ICHIP, including an application form:

www.chip.state.il.us/

Another new feature of the Affordable Care Act is the availability of temporary subsidies for State High Risk Pool enrollment, which began in August, 2010. Here is a link to a fact sheet on this new, temporary option from the Illinois Department of Insurance and an excerpt from that document: www.chip.state.il.us/ICHIP-THRP-Questions.pdf

Illinois' Federally-Funded Temporary High Risk Pool

With the passage of the Patient Protection and Affordable Care Act ("national health reform" or "the Affordable Care Act") on March 23, 2010, Illinois families and employers can anticipate a health insurance marketplace that will provide more meaningful benefits, be more accountable to consumers, and be more transparent. Most health insurance reforms are scheduled to be implemented and effective by January 1, 2014.

The establishment of a federally-funded temporary high risk pool is among the components of the Affordable Care Act scheduled for implementation in the near future. By design, the federally-funded high risk pool will provide transitional coverage to 2014 for the currently uninsured with preexisting conditions. Of course, effective January 1, 2014, the Affordable Care Act prohibits health insurers from basing coverage or pricing decisions on health status. We know that day will not arrive soon enough for many families and employers, especially in Illinois which does not require that health insurer rate increases be actuarially justified.

The following Illinois Department of Insurance fact sheet has additional information:

Illinois Pre-Existing Condition Insurance Plan (IPXP): <http://insurance.illinois.gov/ipxp/>

Other information resources for health insurance for young adults with special needs:

- *National Overview of Transition and Health Insurance: From Healthy and Ready to Work* National Center: www.hrtw.org/tools/documents/Insurance_issues_tools.doc
- *Getting and Keeping Health Insurance in Illinois - A Detailed Consumer Guide:* <http://healthinsuranceinfo.net/getinsured/illinois> (updated June 2009)
- *Illinois Insurance Facts - Overview of Legal Mandates* (This pertains to people who have health insurance coverage, and explains which medical services the State of Illinois mandates (requires) private insurance plans to cover): http://insurance.illinois.gov/healthinsurance/Mandated_benefits.asp

What are my options if I cannot get either private or public health insurance?

As part of the Affordable Care Act, there is a new website, www.healthcare.gov that includes a state-by-state search feature to enable consumers to find health care and insurance options. Here is the link to the Illinois page: <http://finder.healthcare.gov/?state=IL&x=17&y=11>

Possible options include accessing health care at local, county or regional health departments. The following is a link to Illinois county health department offices alphabetical listing: www.idph.state.il.us/local/alpha.htm

Federally qualified health centers (FQHCs) are not-for-profit organizations with contracts to operate health clinics which meet federal government standards. People without health insurance are able to access medical care on a sliding fee scale at FQHCs.

Cook County, which includes Chicago and part of the metropolitan area north, west and south of Chicago, operates public health clinics and hospitals for its residents, including people without health insurance. More information about these options is available from the Cook County Bureau of Health Services: www.ccbhs.org

People who live in suburban Cook County (outside of Chicago) and the northwest part of Chicago (who do not have health insurance and are not eligible for Medicaid or Medicare) may be able to access medical care by joining Access to Care, sponsored by the Suburban Primary Health Care Council. An application form and more information are available from: [www.accesstocare.org/main/Access to Care](http://www.accesstocare.org/main/Access_to_Care). Access to Care® is a model primary health care program serving low-income uninsured individuals in suburban Cook County, Illinois and in northwest Chicago (west of Pulaski Road AND north of North Avenue).

The Access to Care program is a unique public/private partnership making primary health care and the ancillary pharmacy, laboratory and radiology services available to those individuals caught in the gap between eligibility for public health insurance programs ([All Kids](#), [Family Care](#), [Medicaid](#), [Medicare](#)) and having private insurance. The program provides affordable diagnosis and treatment to individuals and families for a small co-payment per visit, procedure or prescription medication.

Eligibility screening is determined by the following criteria: family incomes below 200% of the federal poverty level, with no health insurance (or a deductible of \$500 or more per person); ineligible for [All Kids](#) (or have income necessary to pay premiums), [Family Care](#), [Medicaid](#), or [Medicare](#) and residence in suburban Cook County or northwest Chicago.

If you live outside of Cook County, you can contact the Campaign for Better Health Care, Uninsured Helpline at 888-544-8272 for referrals to free or low-cost clinics in your area: www.cbhconline.org/helpline-2/

Here is a link from the U.S. Health Resources and Services Administration (HRSA), Bureau of Primary Care, which can link you to a free or low-cost health center in Illinois: http://findahealthcenter.hrsa.gov/Search_HCC_byAddr.aspx

It's important to remember that if you are faced with a loss of health insurance coverage, it's wise to let your doctor and other medical providers know right away. You may be able to set up a monthly payment plan or other payment arrangements based on your circumstances and medical needs. Your doctor may also be able to refer you to philanthropic programs which provide assistance in obtaining prescription medications.

Many hospitals and medical centers work with patients who do not have insurance to set up payment plans. Generally, you are required to provide proof that you have applied for Medicaid and Medicare but are not eligible. You may be asked to provide copies of your latest income tax return and pay stubs from your job. You can find out more about this option from the business office (sometimes called 'patient financial services') at the hospital or medical center where you receive care.

The Health Insurance Info project at George Washington University Health Policy Institute has a helpful publication, "*A Consumer's Guide to Getting and Keeping Health Insurance in Illinois*", available for free download at <http://healthinsuranceinfo.net/il.pdf>. This guide provides detailed information for consumers regarding Illinois insurance laws, options such as COBRA conversion when group coverage ends (paying for "converting" your group coverage to an individual policy for specified length of time), possibilities for purchasing individual coverage, and more.

To summarize, obtaining health insurance for youth with special health care needs who are not eligible for Medicaid and do not get health insurance from their employment can be complicated. Planning ahead for ongoing health insurance coverage is a very important part of the transition process.

Fortunately, the Affordable Care Act of 2010, which will be fully implemented by 2014, will make health insurance coverage available to more people. This law is being implemented in stages, with some components already in effect. The Illinois Department of Insurance is our state's lead agency for Health Care Reform. You can refer to their *Health Insurance Reform Information Center* for more information and updates: <http://insurance.illinois.gov/hiric/>

The Health Insurance Reform Information Center is a forum for information on the recent national health insurance reform and its effects on Illinois. The Department will post fact sheets, legislation, and other useful material as it becomes available. Please check back routinely for updates. For further information, [contact the Department](#) toll-free at (877) 527-9431 .

You can contact the Arc of Illinois Family to Family Health Information and Education Center for more information about health insurance for young adults up to age 21 with special needs at 866-931-1110/708-560-6703 or by email at familytofamily@thearcofil.org

Reminder for parents of youth covered by All Kids who have had health insurance from the Illinois Department of Healthcare and Family Services Family Care program:

Unfortunately, Family Care health insurance for parents ends on your (youngest) child's 18th birthday. Your child's All Kids coverage can continue until their 19th birthday. You will need to check with HFS to find out if you may qualify for another Health Benefits (Medicaid) program. You can also use the information in this section about health coverage options to try and find health benefits for yourself. More options will be available as implementation of the Affordable Care Act rolls out. Check possible options now available at www.healthcare.gov.

If you have any questions or concerns, please contact Health and Disability Advocates: www.hdadvocates.org, 312-223-9600 for assistance.

Special information for families of youth who were not born in the U.S.

Starting in July, 2006, the Federal government has new guidelines for people applying for Medicaid and other public programs related to their citizenship and immigration status.

People applying for the first time, or undergoing their first redetermination, will need to provide proof of their citizenship/immigration status and identity (see section in manual about "documents needed").

People who are already enrolled in SSI and/or Medicare are exempt from this requirement.

Remember, that in Illinois, children can participate in All Kids health insurance until their 19th birthday, regardless of their immigration status. According to federal law, children residing in the US have a legal right to attend public schools, which includes children who have IEPs and continue in public school until age 21.

However, for some youth with special needs exiting the school system, this new requirement may cause some concerns. Some youth who have had All Kids insurance may lose coverage after their 19th birthday if they do not get a job with insurance benefits, marry someone who has private insurance with dependent benefits, or have the ability to find and pay for private health insurance themselves. Their immigration status may prevent them from accessing Medicaid insurance and adult services which require Medicaid enrollment.

If you have any questions about Medicaid eligibility for your young adult with special needs who was not born in the US, please contact **Health and Disability Advocates**, www.hdadvocates.org or call them at 312-223-9600.

If you live in or are able to travel to the metropolitan Chicago area, the **Illinois Coalition on Immigrant and Refugee Rights** (ICIRR) and their member agencies, have a contract with the Illinois Department of Human Services to help people who do not speak English apply for Medicaid, SSI, and other public benefits. This means that instead of having to go to the local DHS office, you can go instead to a community agency which has staff members who speak your language. Here is a link to a list of these agencies: <http://icirr.org/outreachresources.htm>. You can also call ICIRR at 312-332-7360x32. The agency list is also included in the appendix of this document.

Thanks to Stephanie Altman, J.D., of Health and Disability Advocates, Chicago, IL, www.hdadvocates.org for reviewing this section.

What about Medicare?

Youth with special health care needs can sometimes qualify for a different public health insurance program, Medicare, if they meet the eligibility guidelines. The following information is from the Healthy and Ready to Work National Center regarding Medicare coverage for youth:

What is Medicare?

Medicare is a form of national health insurance which is part of the federal government, the Health Services and Resources Administration, Center for Medicare and Medicaid Services (CMS), www.cms.gov.

Medicare covers people over age 65, certain people with disabilities of any age, some children and youth with special needs who are the children of parents who are retired, disabled, or deceased, and a few other specific diagnostic groups. People qualify if they or their spouse has 40 or more quarters (10 years) of Medicare-covered employment.

Part A: Hospital Insurance: One half of the Original Medicare Plan is known as hospital insurance. Under certain conditions, it also covers home health agency (HHA) care, hospice care, inpatient psychiatric care, blood transfusion and limited stays in nursing homes (known as skilled nursing facilities, or SNF).

Part B: Medical Insurance: Medicare Part B helps cover doctors' services and outpatient hospital care. It also helps cover some other medical services that Part A does not cover, such as some of the services provided by physical and occupational therapists and some home health care. Part B helps pay for these services and supplies when they are medically necessary. Most people pay a monthly premium for Medicare Part B.

Part D (prescription drug benefits): Prescription drugs are now covered by Medicare. Participants must choose a prescription benefit plan in order to access this coverage. The coverage is somewhat complicated for people who have both Medicaid and Medicare health benefits. Medicare is now the "primary" coverage, and Medicaid is "secondary".

The Arc of the United States has an online information guide, *A Guide to Medicare Part D Prescription Drug Coverage for People with Developmental Disabilities* available at: <http://thedesk.info/PartD/>.

Medicare rules can be complicated. Each individual's situation is different. You will need to get specific instructions that apply to you.

Make Medicare Work, a collaborative project of Age Options, Health & Disability Advocates, and Progress Center for Independent Living, has a guide list of agencies throughout the state of Illinois that can assist people with questions about Medicare and prescription drug programs available. Their website is www.makemedicarework.org.

South Carolina's **Access: Aging and Disability Information** has a helpful document on their website to explain Medicare and Disabled Adult Child Benefits in greater detail. We have updated some facts and figures in this excerpt.

Q & A from South Carolina Access: Aging and Disability Information:

<http://scaccess.agis.com/AGModules/LearnAbout/ArticleView.aspx?mid=3018&tabid=0&articleid=3447&categoryrelationarticleid=20343>

Disabled Adult Child Benefits

Who is eligible for Disabled Adult Child Benefits?

An adult, who became disabled before age 22, may be eligible for child's benefits if his/her parent is deceased or receiving retirement or disability benefits. Social Security Administration (SSA) considers this a "child's" benefit because it is paid on a parent's Social Security earnings record. SSA makes the disability decision using the disability rules for adults.

Who is considered an "adult child"?

The "adult child"—including an adopted child, or, in some cases, a stepchild, grandchild, or step grandchild—must be unmarried, age 18 or older, and have a disability that started before age 22.

What if the adult child never worked?

It is not necessary that the adult child ever worked because benefits are paid on the parent's earnings record.

What if the adult child is currently working?

The adult child must not have been engaging in substantial gainful activity. This means, in 2008 working and earning more than \$940 a month. (This earnings amount increases each year. Certain impairment-related work expenses may be excluded from these earnings as may an unearned employer subsidy.

What if the adult child is already receiving SSI benefits?

An adult child already receiving SSI benefits should still check to see if benefits may be payable on a parent's earnings record. Higher benefits might be payable and entitlement to Medicare may be possible.

What if the adult child is already receiving disability benefits on his or her own record?

An adult child already receiving disability benefits should still check to see if benefits may be payable on a parent's earnings record. It is possible for an individual disabled since childhood to attain insured status on his or her own record and be entitled to higher benefits on a parent's record.

What if the parent never worked?

No benefits would be payable on the record of a parent who never worked.

Can an application be completed online for disabled adult child's benefits?

At this time you cannot apply for child's benefits online. If you wish to file for benefits, contact Social Security immediately at 1-800-772-1213, so that you do not

lose any potential benefit.

How does SSA decide if an adult “child” is disabled for SSDI benefits?

If a child is age 18 or older, SSA will evaluate his or her disability the same way it would evaluate the disability for any adult. SSA sends the application to the Disability Determination Services.

How do you apply for these benefits?

You must make application to the Social Security Administration to receive these disabled adult child benefits. Once found eligible for these benefits, you will be notified by the Social Security Administration that you may continue to be eligible for Medicaid coverage under this group.

If you are already Medicaid eligible, can you keep your Medicaid eligibility and receive these disabled adult child benefits?

SSI disabled adult children who start receiving or receive an increase in benefits are allowed to keep their Medicaid coverage if they meet the following:

- Age 18 or older;
- Have lost eligibility for SSI and Medicaid because they started receiving or received an increase in disabled adult child benefits on or after July 1, 1987;
- Have become disabled or blind before reaching age 22;
- Would continue to be eligible for SSI if the disabled child benefits they started receiving or the increase and later increases they received on or after July 1, 1987 were not counted; and
- Meet financial and non-financial requirements of SSI.

Are you also eligible for Medicare coverage?

You may be eligible for Medicare after receiving these disabled adult child benefits for 24 months. These Social Security benefits can begin no earlier than age 18; therefore, Medicare benefits do not begin before the month you turn age 20.

What happens if you are found Medicare and Medicaid eligible?

Those disabled adult children who receive both Medicaid and Medicare benefits are referred to as “dual eligibles.” Medicaid pays the Medicare Part B premiums, co-insurance amounts and deductibles for individuals who are aged (65+), blind or totally and permanently disabled who are:

- Entitled to Medicare Part A
- Have countable income below 100% of the FPL (For 2010- \$903 for an individual)
- Have countable resources below \$6,600 for an individual.

Several sources of income are not counted. Your child's SSI, for example, is not counted. Also, the first \$65 a month of your child's earned income, plus one-half of all remaining net earned income is not counted. In addition, \$20 in unearned or earned income is excluded.

If your adult child meets these requirements, Medicaid can pay the following costs:

1. The monthly premium for Medicare Part B. In 2010, this premium is \$96.40 a month for those who have been on Medicare and \$110.50 for those

new to Medicare in 2010. (Medicare Part B helps pay for doctors' bills and other medical services. A person is enrolled in Part B when he or she enrolls in Part A, unless they state they don't want it.)

2. The monthly premium for Premium Hospital Insurance under Medicare Part A. (Medicare Part A is hospital insurance.)

3. Medicare Part A and B deductibles and coinsurance. (A deductible is an initial dollar amount which Medicare does not pay. Coinsurance is your share of expenses for covered services above the deductible.)

4. Prescription coverage through Medicare Part D. Dual eligibles in institutions (nursing facilities and intermediate care facilities for persons with mental retardation (ICF/MRs) are exempt from prescription co-pays, premiums, and deductibles. Dual eligibles, living in the community, pay limited prescription co-pays of \$1 for generic drugs and \$3.10 for brand name drugs if their income is below 100% of the Federal Poverty Level (FPL) and \$2.25 for generic drugs and \$6.30 for brand name drugs if their income is above 100% of the FPL up to the out-of-pocket limit each year. They have no cost sharing above the annual catastrophic limit. Dual eligibles can also switch prescription drug plans at any time throughout the year.

Impact for YOUTH

Under Social Security Disability Insurance (SSDI), there is a benefit to adult children with disabilities existing before age 22. When such a person's parent becomes disabled, retires, or dies, a payment based on the parent's earnings becomes payable to the adult child.

Adult children are required to apply for this benefit within 30 days of the parent's disability, retirement, or death. SSDI then becomes the new primary income maintenance program for adult children who have previously participated in SSI. The SSDI payment is based on the deceased parent's income. If the SSDI payment is low, an adult child may continue receiving a reduced SSI payment as well.

Because SSI is intended to be a program of last resort, individuals must have first applied for all other public assistance to which they may be entitled, and must apply in the future for any to which they become entitled.

A person no longer covered by SSI when their primary cash benefit source is switched to SSDI cannot lose Medicaid coverage.

LAW: The Employment for Disabled Americans Act of 1986 (Public Law 99-643) requires states to continue Medicaid coverage when an individual who became disabled before age 22 and received SSI becomes eligible for SSDI or has an increase in SSDI benefits. Such disabled adult children continue to be considered SSI recipients for Medicaid purposes. Disabled adult children c. 175 § 108 2(a) (3) c. 176A §8(d); c. 176B § 6(c)

You can contact Health and Disability Advocates at www.hdadvocates.org for more information about Medicare, Medicaid and SSI.

More information and application forms for Medicare are available at:
www.medicare.gov

Here are some additional Medicare resources.

Medicare's Personal Plan Finder helps you narrow down your Medicare health plan choices and choose the plan that's best for you. The tool will ask you a few questions that will help the Medicare Personal Plan Finder give you a personalized report of the health plans available in your area. www.medicare.gov/find-a-plan/questions/home.aspx

Center for Medicare Advocacy - A Citizen's Guide to Medicare
www.medicareadvocacy.org

This comprehensive packet helps health insurance counselors assist patients who have been denied Medicare coverage. The guide includes 4 sections: hospital care, home health care, skilled nursing facility care, and Medicare. To order call: 1-800-262-4414 or 860-456-7790.

Social Security Administration: www.ssa.gov

Benefits Planning Query Handbook: www.ssa.gov/chicago/awic.htm

Area Work Incentives Coordinators

The Area Work Incentives Coordinator (AWIC) is a position established by the Commissioner to improve service to Social Security disability beneficiaries and Supplemental Security Income disability recipients who wish to work.

The AWICs manage and coordinate work incentives, public outreach, and service programs. Additional information about the AWICs and Regional AWIC contact information can be found at: www.socialsecurity.gov/work/awiccontacts.html. The 6 states in the Chicago Region are organized into 9 areas.

The Red Book serves as a general reference source about the employment-related provisions of Social Security Disability Insurance and the Supplemental Security Income Programs for educators, advocates, rehabilitation professionals, and counselors who serve people with disabilities. You can find the Red Book on Work Incentives at: www.socialsecurity.gov/redbook/. SSA Publication No. 64-030, (2010 Red Book), January 2010, ICN 436900 (Español).

The Medicare Rights Center (MRC) – www.medicarerights.org

MRC was established in 1989 to provide free counseling services to people with Medicare questions or problems. Since its founding, MRC has helped more than one million people with Medicare-related issues. MRC has conducted training programs and presentations for organizations as diverse as the U.S. HHS, the Administration on Aging, Ceridian Performance Partners, American Public Health Association, AARP, the Practising Law Institute, Families USA, AFSCME and Visiting Nurse Service.

Your Health Care Coach, a project of the National Health Law Center, has extensive consumer-friendly information about Medicare at:
www.healthcarecoach.com/resources/index.php?view=detail&id=92&node=

The Kaiser Family Foundation has extensive consumer resources regarding Medicare, Medicaid and health insurance options for people with disabilities who are working or seeking work:

- Medicare: People with Disabilities: www.kff.org/medicare/disabilities.cfm
- Keeping Medicare and Medicaid When You Work: www.kff.org/medicare/7241/ssdi.cfm

The summary table of health insurance coverage and options for young adults in Illinois at the present time follows:

The Arc of Illinois Family to Family Health Information & Education Center Health Insurance for Young Adults in Illinois – August 2010

Who?	All Kids	Medicaid options	Private insurance options	Medicare	Other options	Affordable Care Act Changes
Up to age 18	-if uninsured -OR maxed out of lifetime coverage -sliding fee scale buy-in	-based on parent's income OR -based on Medicaid Waiver enrollment (parent's income waived)	- dependent coverage IF parent's employer offers insurance -Qualified Medical Child Support Order (ends at 18)	-if parent is disabled, retired or deceased	-ICHP if enrollment is open, child is eligible and parent can afford it -DSCC up to 21, if medically eligible, income eligible,(no coverage for primary care) -FQHC/public health dept -School-based Health Services (if available) -sliding scale/charity care	Check into temporary ICHP subsidies -after 2014, new options to purchase affordable insurance
All young adults age 18+	Ends on 19 th birthday	FamilyCare if pregnant/parenting and low-income -Emergency Medicaid -Spenddown	-Stay on parent's insurance until age 26 -get job with insurance -marry spouse with insurance -purchase individual policy	NA	-enroll in school insurance @ college/university if eligible -purchase short-term individual policy -FQHC/public health dept. -Sliding scale/charity care -Access to Care(Cook County) -HFS partial coverage (IL Healthy Women,IL Care Rx) -local programs (e.g.: Access to Care) -School-Based Health Services, if available and still in school.	-After 2014, Medicaid eligibility will expand -After 2014, having insurance will be required and options to purchase will expand
Disabled per SSA- www.ssa.gov	Ends on 19 th birthday	-AABD if SSI recipient -HBDW if employed especially if prior SSI recipient	-Stay on parent's insurance until 26/ or indefinitely depending on severity of disability	-if eligible -not before age 20	-DSCC until age 21 (if eligible),parental income counted until 21 -Medicaid stops counting parental income on 18 th birthday -School-based health services up to age 22,per IEP (if available: http://www.hfs.illinois.gov/mch/sbc.html)	
Special health care needs/not "disabled per SSA"	Ends on 19 th birthday	-Spenddown -Emergency Medicaid - HBWD if employed and prior SSI recipient	-Stay on parent's insurance until 26 -ICHP if eligible and affordable	-if eligible	-DSCC until 21, if eligible -School-based health services if available (up to age 22, per IEP) -FQHC/public health clinic -sliding scale/charity care -possible local options	-After 2014, Medicaid eligibility will expand- no longer based solely on disability and/or parenthood. -Temporary ICHP subsidy -New options under Affordable Care

Medicaid Hints and Tips

When young adults enroll in Medicaid for the first time, or transfer from the Medicaid program for children (All Kids), questions may arise regarding how to navigate the adult Medicaid system.

Unlike people enrolled in many private health insurance plans, adult Medicaid enrollees do not receive a detailed member handbook.

Many basic questions can be answered by reviewing The Arc of Illinois Family to Family Health Information and Education Center's [2009 Medicaid Brochure](#).

Here is an overview of some frequently-sought information:

1. How do I find a provider or vendor? A pharmacy?

There are a number of ways to find a health care provider and/or vendor for equipment or supplies.

- Ask your current provider for a referral to a new provider in your area who accepts Medicaid (if the current provider does not accept Medicaid).
- Ask staff members from program in which you are involved (for example, case managers at your Independent Service Coordination (ISC) agency; service facilitators for Adult Home-Based Waiver participants; social workers and nurses at schools and provider agencies; physician referral offices and discharge planners at your local medical center).
- Ask other families and consumers in your area about their providers.
- Contact **Illinois Health Connect** (IHC) by phone or email.
- [Illinois Health Connect](#) is a company contracted by the Illinois Department of Healthcare and Family Services to help persons enrolled in Medicaid to find providers.
- Or Call the Illinois Client Enrollment Broker (ICEB) toll-free
Hay informacion en español. Servicio de intérprete gratis!
Hours: Monday - Friday 8 a.m. to 7 p.m.
Saturday 9 a.m. to 4 p.m.
1-877-912-8880
(TTY: 1-866-565-8576)
- Contact the Illinois Department of Healthcare and Family Services, Medical Programs for help in finding a provider:
Medical Programs 217-782-2570
[Medical Programs Bureau Directory](#)

Division of Medical Programs
Department of Healthcare and Family Services
201 South Grand Avenue East
Springfield, Illinois 62763-0001
Telephone number: 217-782-2570
Fax number: 217-782-5672
E-mail: [Medical Programs](#)

2. How can I keep track of my providers and vendors?

- Care coordination record-keeping forms are available for free download from the National Center for Medical Home Initiatives for Children with Special Needs “[Build Your Own Care Notebook](#)” page.
- Please note that these record-keeping forms are useful for children and adults of all ages. Keeping complete and up-to-date records of medical providers and vendors is an important part of the transition process. These records should be updated at least once a year (and more often, if needed). Copies should be given to all medical and human service providers, as well as to any caregivers or support staff who may work with your adult child.

3. What should I do if my doctor (or vendor) stops accepting Medicaid?

- It’s also important to remember that providers and vendors may change over time. Sometimes, providers inform their patients that they will no longer accept Medicaid insurance. If this happens to you, you will need to find a new provider.
- Medical providers and vendors in Illinois are not required to accept Medicaid insurance. However, any provider or vendor who is willing to enroll can become a Medicaid provider.
- If your doctor or provider is not currently enrolled with Medicaid, they can file an application to become approved. More information is available from: the Illinois [Department of Healthcare and Family Services Provider Enrollment Unit](#).

4. Is Illinois Medicaid accepted outside of Illinois?

- The Illinois Department of Healthcare and Family Services has a reciprocal agreement with the 5 states that border Illinois (Wisconsin, Indiana, Kentucky, Missouri and Iowa), so these states will accept Illinois Medicaid. You must have a valid reason to seek services from an out-of-state provider (for example, if a doctor or hospital in a bordering state is closer to your home than a comparable provider in Illinois), or if your doctor has prescribed care that is only available in another state but not in Illinois.
- If you travel outside of the 5 states that border Illinois to attend school, go on vacation or to visit friends and family, for example, your Illinois Medicaid coverage will not be accepted.

- Medicaid in another state may only cover emergency care for persons who are not residents of that state. If you require medical care or prescriptions while you are outside of the “coverage area” you may need to either return to Illinois for this, or pay for the service yourself.
- Only people who are residents of a state and meet that state’s eligibility criteria are eligible to apply for Medicaid there; so you will not be able to “transfer” your Medicaid coverage from one state to another. Medicaid waivers are **not** “transferrable” from state to state either.
- For more information, see the article: **“A Warning for Medicaid Beneficiaries Traveling Out of State”**, written by attorney Shari Abrams:

However, many Medicaid recipients don’t realize that their health insurance coverage may not provide a full set of benefits should they require care while out of state. For example in some states Medicaid only covers out-of-state emergency room visits to stabilize emergency conditions. Should a beneficiary need to be admitted to a hospital in another state or if he must receive essential, regular psychiatric care or medications from an out-of-state provider, some states will not pay for the services through Medicaid. In these situations, a caregiver or other family member is often required to sign an agreement to pay for the services before the person with special needs can receive care.

Since Medicaid is administered as a joint program between the state and federal governments, each individual state has its own rules regarding out-of-state Medicaid coverage. If a loved one with special needs is planning to take an out-of-state trip, or if you live near your state border and travel between states for work or recreation, it makes sense to find out your states out-of-state Medicaid rules. By investing the time now you could save thousands of dollars in medical bills down the road.

5. How do I coordinate benefits if I have both Medicaid and private insurance?

- Some people are covered by both private insurance and Medicaid. This includes some children and adults who are enrolled in Medicaid Home and Community Based Waivers, and a few other groups. If you have both Medicaid and private insurance, you must follow certain rules in order for your claims to be covered.
- Remember that your private insurance is always the primary payor, and Medicaid is the payor of last resort.
- What are the rules?
 - If you want both your private insurance and Medicaid to cover a claim, you can only get services from providers/vendors who accept both types of insurance.
 - You must show your provider/vendor both your private insurance card and your Medicaid card before you receive services.
 - If you are seeking coverage for something that your private insurance does not cover, you must still submit the claim to your private insurance and get a written rejection before Medicaid will consider paying the claim.

- If you are seeking coverage for something that neither your private insurance nor Medicaid covers, you have the option of paying for it yourself (called “out-of-pocket” or “OOP”). If you are also enrolled in a Medicaid waiver, you can ask your service facilitator if the service/item could possibly be covered by your waiver.

6. What is the difference between Medicaid coverage for young adults age 18- and those who are over age 21?

In Illinois, children enrolled in Medicaid are in the All Kids plan until their 19th birthday. <http://allkids.com> After the 19th birthday (regardless of disability status), Medicaid enrollees participate in one of the Medicaid options for adults, as outlined above.

It's important to remember, however, that under the Federal Medicaid regulations, all enrollees ages birth-21 years are protected by the EPSDT regulations (EPSDT stands for Early Periodic Screening, Diagnosis and Treatment).

www.cms.gov/MedicaidEarlyPeriodicScrn/02_Benefits.asp. This means that Medicaid must cover what the child's doctor prescribes for treatment of a diagnosed condition, whether or not it is included in the Medicaid State Plan for adults age 21 and older. www.hrsa.gov/epsdt/overview.htm

One example of the differences in coverage before and after age 21 in Illinois is dental care. Before age 21, children enrolled in Medicaid have full dental coverage. After age 21, dental benefits are very limited.

7. Can I pay for a medical service out of pocket and then ask Medicaid to reimburse me?

Medicaid regulations do not permit enrollees to be reimbursed under any circumstances. If you paid for a medical service out of pocket, you may be able to deduct it from your income taxes. Please refer to the F2F publication, [Income Tax Facts](#), for more information.

8. How can I get more information about Medicaid coverage in Illinois?

- The Illinois Department of Healthcare and Family Services has extensive information on their [Medical Programs website](#).
- Medical Provider Handbooks are available at: www.hfs.illinois.gov/handbooks/. The Healthy Kids handbooks cover the All Kids program, including the federal EPSDT (Early Periodic Screening Diagnosis and Treatment) regulations. These handbooks cover the following information, according to the HFS website:
 - *Handbooks have been prepared for the information and guidance of providers who participate in the Illinois Medical Assistance Program and other health care programs funded or administered by the Illinois Department of Healthcare and Family Services. Handbooks state Department of Healthcare and Family Services policy with sufficient instructions and guidelines to enable providers to:*
 - *know which services provided to eligible participants are covered;*
 - *submit proper billings for services rendered; and*

- *Make inquiries to the proper source when it is necessary to obtain clarification and interpretation of department policy and coverage.*
 - *Providers will be held responsible for compliance with all policy and procedures contained herein.*
- The Illinois Department of Human Services website includes the [Administrative Rules](#) which govern Medicaid eligibility, the Medicaid application process and Medicaid waivers. The Worker's Action Guide (WAG) contains detailed information on these topics: www.dhs.state.il.us/page.aspx?item=13474
 - [Health and Disability Advocates](#), a not-for-profit organization headquartered in Chicago, has an extensive online resource library which includes many documents and fact sheets pertaining to Medicaid, for both children and adults.
 - The federal Department of Health and Human Services (HHS), [Centers for Medicare and Medicaid Services \(CMS\) website](#) has program information and links to state Medicaid websites.
 - In addition, the following national organizations have extensive, up-to-date Medicaid information::
 - Kaiser Family Foundation: <http://kff.org/medicaid/index.cfm>
 - Families USA: <http://familiesusa.org/issues/medicaid/>
 - National Health Law Project: www.healthlaw.org/index.php
 - National Association of State Medicaid Directors: www.nasmd.org/Home/home_news.asp

Section IV - Services and Supports, Systems and Trends

Through effective transition planning, we expect the trend in special education in future years will be much greater emphasis on the student exiting the special education system with a full-time job with benefits. We also believe that in special education there will be much more emphasis placed on developing employment opportunities for individuals with the label of severe disabilities, which is already an important part of the Rehabilitation Act.

Currently, Illinois is moving its adult service system to a Medicaid funded system. This allows the state to then receive a 50% match from the federal government for community services that qualify for a Medicaid match. One of the benefits to people and families in a Medicaid funded system is that they are given “choice” of providers and their service funds are “portable” or described as a situation where the “money follows the person.” Another important trend is consumer directed funding where the individual chooses the services and supports that he needs to live and work in the community.

Here are some examples of the use of consumer-directed funding to help people with developmental disabilities. They include but are not limited to:

- Paying for transportation to and from work (for example, via a car service or taxi).
- Paying for a personal assistant to help in getting ready for work, as well as for helping with personal needs during the work day.
- Paying for an ongoing job coach.
- Paying for specialized supplies and equipment needed but not provided by an employer (for example, a small refrigerator to store nutritional supplements at the workplace).
- Paying for costs related to setting up a self-employment business.

These are just a few examples of how “money could follow the person,” a person with a developmental disability who wants to work.

Since having “money follows the person” may be a new and different idea for some providers and service coordinators, families and consumers need to do their homework and be very specific about the supports and services that are needed, ways to access them and the actual costs involved.

For youth who are still in school, IEP transition plans need to clearly state that going to work and utilizing consumer-directed funding upon graduation are what is planned. The State of Washington has a helpful booklet entitled **Preparing for the Transition from School to Supported Employment**. This booklet is specific to programs and services in Washington State but offers some helpful guidelines and questions to ask adult service providers. The booklet is available at

<https://depts.washington.edu/dbpeds/TransitionToEmployment.htm>

You can use this guide to for help in preparing your own questions during the transition process.

The U.S. Department of Labor has a fact sheet on Supported Employment for People with the Most Significant Disabilities available at www.dol.gov/odep/archives/ek01/support.htm

PASS Plans - Another way for adults with developmental disabilities to achieve their employment goals.

PASS, which stands for “Plan for Achieving Self Support,” is an often-overlooked transition option for people who receive SSI and/or SSDI benefits. PASS plans essentially allow eligible applicants to “set aside” some of their money (from government benefits, wages, or other sources) to purchase goods, services and training needed to meet a specific career goal in a specified amount of time. The money that is set aside is not “counted” as income and the applicant continues to be eligible for Medicaid and SSI benefits until their goal is reached.

PASS plans can be incorporated into IEP transition plans, as well as in Individual Rehabilitation Plans (IRE) developed by DHS/DRS.

Additional information about PASS plans and Ticket to Work incentives from Marsie Frawley of Health & Disability Advocates was cited earlier in this manual in Section I.

Technical assistance and information related to developing and implementing PASS plans and other issue is available from the Ticket to Work Program at Equip for Equality: www.equipforequality.org/programs/tickettowork/index.php and from Health & Disability Advocates Workforce Development Project: www.hdadvocates.org/workforce/IllinoisSpec/illindex.htm.

Several websites have detailed information about PASS plans, including case studies, samples of currently approved PASS plans, application forms and more:

- www.passplan.org
- www.ssa.gov/work/ResourcesToolkit/generalinfo.html (official site of the Social Security Administration)
- www.workworld.org/wwwwebhelp/pass.htm
- www.t-tap.org/training/online/seminars/nblself/slide3.html

PASS plans can be a very important tool for people with developmental disabilities to achieve their career and self-determination goals. If your transition or vocational rehabilitation counselors do not offer information about PASS plans, be sure to speak up and ask them yourself.

The more tools and resources you are aware of, the greater the likelihood that your transition plans for employment will be achieved.

People with disabilities, in general, have very high rates of unemployment. The unemployment rates of adults with developmental disabilities are frequently even higher. The National Organization on Disability/Harris Survey, in their 2004 study of Americans with disabilities, found that:

“Only 35 percent of people with disabilities reported being employed full or part time, compared to 78 percent of those who do not have disabilities. ... The severity of disability makes a significant difference in all of the gap areas, and people with severe disabilities have much greater disadvantages.”

www.nod.org/content.cfm?id=1537

Currently, a significant number of adults with developmental disabilities in Illinois work in settings such as sheltered workshops or other center-based programs. However, things are changing. The young adults with developmental disabilities of today are typically finishing high school with work experience gained during their transition years. Driven by their IEP transition plans, young adults today can access real job experiences and training

designed to help them participate in the adult workforce while they are still in school.

High schools across the state are using a variety of models to provide work experience and transition training to their students with developmental disabilities. These include, but are not limited to: "in-house" transition coordinators and/or DRS counselors; collaborating with DRS counselors in the community; including students with developmental disabilities in the school's "regular" work-study program; implementing off-site transition programs with volunteer and paid work experiences; and employing students at in-house jobs.

Families of young adults with developmental disabilities can advocate for opportunities for their child to access employment experiences and transition training during the final years of their schooling. For additional information regarding special education rights, IEP's and transition plans, contact one of the Parent Training and Information Centers (PTIs) listed earlier in this manual.

The Illinois State Board of Education supports a transition training initiative, under the auspices of the Illinois Interagency Coordinating Council. The Illinois Interagency Coordinating Council (ICC) was established in 1990 by the Interagency Coordinating Council Act, 20 ILCS 3970 to facilitate collaboration among state agencies and improve outcomes for youth with disabilities. The ICC is charged with: gathering and coordinating data on services for transition-age youth with disabilities; providing information, consultation, and technical assistance to state and local stakeholders; assisting state and local stakeholders in establishing interagency transition agreements; conducting an annual statewide evaluation of student transition outcomes and needs; and providing in-service training to consumers in developing and improving awareness of transition services. You can contact the ICC for additional information and transition-related training opportunities at www.isbe.net/iicc/default.htm.

As with all other special education and related services, appropriate transition plans, which include real work experiences, are driven by your son or daughter's IEP. It is important to make sure that preparing for work and getting work experiences in the community before your young adult with a developmental disability graduates (or completes) high school is included in the IEP, starting at age 14 ½ .

In addition, introducing your child to work, chores and family responsibilities is very important. Using your own networks and community linkages can play an important role in finding job opportunities for your young adult with developmental disabilities. Many adults with developmental disabilities who are working report that they found their jobs through friends and family members - just like many adults without disabilities.

Microboards and cooperatives were discussed in some detail in Section II. Individuals with disabilities and their families can be creative and entrepreneurial in their efforts to build the work and living situation that works best through microboards or human service cooperatives. The [Illinois Association of Microboards and Cooperatives](http://www.illinoisassociationofmicroboardsandcooperatives.org) can provide needed support and information for individuals and families interested in researching these individualized options.

To summarize, families need to be aware of trends and new developments related to employment and transition options for youth with developmental disabilities and be proactive in transition planning.

Making the Transition to Work and Adult Services a Reality for My Young Adult

Child with Developmental Disabilities

Sometimes, people who are seeking work, whether or not they have a disability, experience periods of unemployment. It is well known that the unemployment rate for adults with any disability is much higher than that of the general population. So, what can be done when the job search takes longer than expected?

Here are some suggestions:

- ✓ Do volunteer work in your chosen field or in any type of work that can give you experience and references.
- ✓ Contact people you know and ask if you can do an unpaid internship in their place of employment in order to get more experience.
- ✓ Ask friends and family members to hire you for temporary work assignments.
- ✓ Start your own business.
- ✓ If you participate in a day program for adults with developmental disabilities, ask the program staff to help you set up an in-house job, paid or volunteer. Be sure that this is written into your Individual Participation Plan and discussed at your staffings.
- ✓ Look for classes and training opportunities to help you develop new skills. Ask your DRS counselor for support in enrolling and paying your tuition.
- ✓ Contact employment programs designed for the general public (such as the One Stop shops), and ask them to help you find work. People with disabilities have the right to access any community employment and job-training programs for which they are eligible and participate with needed accommodations.

The most important point to remember is that you need to be involved in some type of work, paid or volunteer, on an ongoing basis. If this isn't possible, then look into ways to set up your own business, however small, or get more training.

If you are finished with school, and don't have a job, don't give up! It takes many people time to get a job. In the meantime, keep developing your skills and connections in the community. Many adults find their jobs through personal contacts, not from employment programs.

Steps to take:

1. Develop a pro-active transition team.
2. Be prepared to apply for Medicaid and SSI.
3. Ask for help along the way. Contact Illinois Life Span for resources if you're not sure who to contact. (www.illinoislifespan.org).
4. Focus on your child's and your family's vision for the future.
5. Get involved in developmental disability advocacy. Join The Arc of Illinois.
6. Make joining the workforce top priority for your adult child.
7. Ask questions - look at the big picture.
8. Be patient but determined.
9. Don't settle for less.
10. Be ready with Plan B . . . don't wait for someone else to arrange things.

Parents of Young Adults with Developmental Disabilities - Know Your Rights!

- You have the right to apply for any government-funded program for your adult child.
- You have the right to get an application form, fill it out and submit it.

- You have the right to have your adult child's application considered. He/she cannot be rejected from a program solely on the basis of a telephone conversation.
- You have the right to get a written denial letter from any program to which you apply.
- You have the right to appeal any rejection or denial of services.
- You have the right to communication access if your primary language is not English (this applies to both spoken language and print communication).

What are Rights and Legal Protections for Adults with Developmental Disabilities over Age 21?

Legal authority is not as clear cut as it is for persons under age 22 (under IDEA), since multiple federal, state and local agencies and programs may be involved. Detailed information about laws governing services for adults with developmental disabilities can be found on the following websites:

The United States Department of Justice website includes a comprehensive guide to disability rights laws: www.usdoj.gov/crt/ada/cguide.htm

Chicago Kent College of Law's site, www.illinoislegalaid.org includes *The Guidebook of Laws and Programs for People with Disabilities*, available for free download at www.illinoislegalaid.org/index.cfm?fuseaction=home.dsp_content&contentID=784.

This guidebook includes detailed information about laws governing all types of programs and services for people with disabilities of all ages, how to protect your rights and how to access advocacy assistance when needed.

Every state in the United States is required to offer legal assistance to people with developmental disabilities through a Protection and Advocacy agency (referred to as "P&A"). These private, not-for-profit legal assistance agencies are funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services (for more information, visit the website of the National Association of Protection and Advocacy services: www.napas.org)

Equip for Equality is the Protection and Advocacy agency for Illinois with three offices around the state www.equipforequality.org. You can contact them for help with difficulties related to accessing services and supports of people with developmental disabilities, including access to integrated employment and vocational rehabilitation.

Adults with developmental disabilities who have limited incomes may also be eligible to receive legal services free of charge from Legal Assistance programs around the state (eligibility is determined solely by income, not disability) or from legal clinics at law schools. A directory of legal aid and legal advocacy programs in Illinois can be found at: www.illinoislegalaid.org/index.cfm?fuseaction=organizationDirectory.dspOrganizations

It is important for you to become familiar with the laws governing services and supports for adults with developmental disabilities before contacting any agencies for additional help.

Here are some examples of state and federal laws that govern services for adults with developmental disabilities.

- Programs receiving any federal funding must comply with Section 504 of the Rehabilitation Act.

- Entities serving the public must comply with the Americans with Disabilities Act, to the extent that this is applicable.

More detailed information about the Americans with Disabilities Act and Section 504 of the Rehabilitation Act can be found on the website of the United States Department of Health and Human Services:

www.hhs.gov/ocr/civilrights/understanding/disability/laws/disabilitylawsregandguidancemp.html

Programs and services receiving any funding from Medicaid are governed by the regulations of the Center for Medicare and Medicaid Services and sections of the Social Security Act. More information can be found on the Social Security Administration's website, under Compilation of Social Security Laws, Title XIX, Grants to States for Medical Assistance Programs: www.ssa.gov/OP_Home/ssact/title19/1900.htm

Illinois Medicaid regulations, including regulations governing Medicaid Home and Community Based waivers, can be found in the Illinois Administrative Code, Laws and Rules Governing Medical Assistance programs: www.hfs.illinois.gov/lawsrules/

The Illinois Administrative Code, Title 89: Social Services:

www.ilga.gov/commission/jcar/admincode/089/089parts.html

Title 59: Mental Health Services (this includes developmental disabilities)

TITLE 59: MENTAL HEALTH

CHAPTER I: DEPARTMENT OF HUMAN SERVICES

PART 120 MEDICAID HOME AND COMMUNITY-BASED SERVICES WAIVER

PROGRAM FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

www.ilga.gov/commission/jcar/admincode/059/05900120sections.html

More information regarding advocating for continuation of home nursing care, including a current class action suit being filed by attorney Robert Farley and the U.S. Department of Justice can be found on The Arc of Illinois website at:

www.thearcofil.org/document.asp?did=2379.

The website of Neighborhood Legal Services, based in Buffalo, New York, includes a summary of successful litigation in Illinois involving young adults who aged out of the Home Care waiver. See ***Challenging Medicaid Home Service Benefit Reductions Using the ADA*** at www.nls.org/conf09/olmstead.pdf.

The importance of keeping a paper trail (copies of all documents and communications) related to your efforts in transition planning and integrated employment cannot be emphasized enough. Use the forms in the Appendix section of this manual to help you keep track of your paperwork.

If you contact an agency or program seeking assistance and do not hear back from them, send them a letter confirming your conversation. End your letter as follows: "I assume that the information contained in this letter is correct, unless I hear back from you in writing within a week." For more letter writing hints, see the National Dissemination Center for Children Disabilities Parent Guide: *Communicating with your Child's School through Letter Writing* at www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/pa9.pdf.

The Partners in Policy Making Program of the Minnesota Council on Developmental Disabilities has a free, on-line self advocacy course for people with developmental disabilities, their families and friends: Partners in Making Your Case. It includes training in written and electronic communication. www.partnersinpolycymaking.com/makingyourcase/,

Paying for Adult Services and Supports: What Are the Options?

The following chart provides an overview of some commonly-used services and supports.

Paying for Adult Services and Supports - What Are My Options? Examples of Common Supports and Payment Sources

Service/ Support Type	DD Waiver (Home-Based)	DRS Home Services Waiver	Other/ Local Options	Private Pay	Comments
Transportation	Can be included in PSW job duties (if self-directed, can have PSW use own vehicle to transport). Ask if agency vehicle available.	No	1. Check for local transportation options. 2. Enroll in paratransit, if available - pay discounted fee. 3. Enroll as private provider under Medicaid (for medical appts). 4. For medical appointments only, use First Transit, the company contracted to provide pre-arranged transportation to Medicaid recipients.	Yes	If mass transit available in your locale, apply to Circuit Breaker for free public transit pass: (for fixed route buses and trains) http://www.state.il.us/aging/1rx/cbrx/ridefree.htm
Job Coaching	Yes-can be included under PSW assigned duties, per Service Plan.	No-need to access DRS VR services for this.	Include in IEP while still in school.	Yes	
Recreation Support	Yes-can be included in PSW assigned duties (activity fees not covered).	In-home activities only (you supply the equipment/materials).	Local park district, special recreation district.	Yes	
Help with ADLs	Yes-according to Service Plan.	Yes-according to Service Plan.	Check for local-level programs, volunteers.	Yes	Family must provide supplies (including disposable gloves, paper towels). Make sure Universal Precautions followed.
Home Modifications	Yes-within program limits and with prior approval.	Yes-within program limits and with prior approval.	Check for local-level programs.	Yes	Check with area social services, community groups.

Dealing with Out-of-Pocket Expenses

Incurring out-of-pocket expenses (services/supports/equipment etc.) is a fact of life for families of persons who have special needs of all ages. It is simply not possible for all of any individual's needs to be covered by third party payors and/or government programs. Unfortunately, many families of children, youth and adults with special health care needs are confronted with large out-of-pocket costs on an ongoing basis.

However, resources are sometimes available to assist with these costs. Among the most common resources are:

1. Income Tax deductions for medical and disability-related expenses. Extensive information is available from the Internal Revenue Service (IRS):

- *Publication 502 : Medical and Dental Expenses*: www.irs.gov/publications/p502/index.html
- *Medical Savings Accounts*: www.irs.gov/formspubs/article/0,,id=213743,00.html
- *Tax Highlights for Persons with Disabilities*: www.irs.gov/publications/p907/index.html

2. Child and Dependent Care Deductions (to enable parents to work):

www.irs.gov/individuals/article/0,,id=121435,00.html

If you paid someone to care for a child or a dependent so you could work, you may be able to reduce your federal income tax by claiming the Credit for Child and Dependent Care expenses on your tax return. This Credit is available to people who, in order to work or to look for work, have to pay for child care services for dependents under age 13. The Credit is also available if you paid for the care of a spouse or a dependent of any age who is physically or mentally incapable of self-care.

- [Child and Dependent Care Credit](#) - Tax Tip 2006-46
- [Publication 501](#), Exemptions, Standard Deduction, and Filing Information
- [Publication 503](#), Child and Dependent Care Expenses
- [Form 2441](#), Child and Dependent Care Expenses
- [2441 Instructions](#)
- [Form W-10](#), Dependent Care Provider's Identification and Certification

3. Earned Income Tax Credit (EITC): www.irs.gov/individuals/article/0,,id=96406,00.html

Remember that there is no upper age limit for a child who is "permanently and totally disabled"; eligibility is based upon parental income.

From the EITC Home Page: ***It's easier than ever to find out if you qualify for EITC***

The Earned Income Tax Credit or the EITC is a refundable federal income tax credit for low to moderate income working individuals and families. Congress originally approved the tax credit legislation in 1975 in part to offset the burden of social security taxes and to provide an incentive to work. When the EITC exceeds the amount of taxes owed, it results in a tax refund to those who claim and qualify for the credit.

To qualify, taxpayers must meet certain requirements and file a tax return, even if they did not earn enough money to have a filing requirement.

The EITC has no effect on certain welfare benefits. In most cases, EITC payments will not be used to determine eligibility for Medicaid, Supplemental Security Income (SSI), food stamps, low-income housing or most Temporary Assistance for Needy Families (TANF) payments.


Will you qualify for EITC this year?

Find out if you are eligible for the Earned Income Tax Credit by answering questions and providing basic income information using the EITC Assistant. The Assistant also calculates the amount of EITC you may receive. The EITC Assistant is available in [English](#) and [Spanish](#).

The Arc of Illinois Family to Family Health Information and Education Center has some additional resources on this topic

1. Income Tax Facts (including record-keeping forms):
www.thearcofil.org/familytofamily/documents/documentdetails.asp?did=722
2. When Insurance Won't Pay:
www.thearcofil.org/familytofamily/documents/documentdetails.asp?did=1250

The Catalyst Center, part of the Health and Disability Working Group at Boston University School of Public Health has some additional resources for families and policy makers on this topic. The Catalyst Center is a project of the Health and Disability Working Group at the Boston University School of Public Health and is funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services, under co-operative agreement #U41MC13618.

Breaking The Link Between Children's Special Health Care Needs and Financial Hardship  [Printable version \(PDF, 44 pages\)](#) www.hdwg.org/catalyst/breaking-the-link

Improving Financing of Care for Children and Youth with Special Health Care Needs - retrieved (03/02/10) from www.catalystctr.org.

The Federal Government website, www.healthcarereform.gov, provides the following resource:

Out-of-Pocket Expenses: Americans Shoulder the Burden of Growing Health Care Costs: www.healthreform.gov/reports/out_of_pocket/index.html

As we have discussed previously in this manual, families and youth often need to include financial planning in the overall picture of making plans for transition and beyond.

Each transition option may carry different cost-benefit ratios for each individual and family. Each consumer and family may need to gather information about all options, using the resources in the Family Manual for Transition, and proceed carefully to weigh the pros and cons of each one before deciding what may work best for them. The resources we have compiled here for your reference can be a starting point for exploring viable transition

options.

The Private Pay Option

You may have heard about the “private pay option” for transition services. What is the “private pay option” and how can you find out more about it?

The ability to pay privately for services and supports for children and adults with disabilities typically only applies to a small number of families, including those with adequate financial resources and some individuals who have won settlements as the result of lawsuits.

Avenues for Independence, a provider agency located in north suburban Cook County, has information on their website which provides a helpful example of typical costs associated with the private pay option: www.avenuestoindependence.org/reality.html

Obtaining Residential, Day or Employment Support Services

Avenues and other organizations provide a variety of day, employment and residential support [services for individuals](#) with autism, cerebral palsy, Down's syndrome and other intellectual and developmental disabilities.

Services can be provided as part of a [transition program](#) from school to adult-based services, or as part of a general need for services for anyone with a developmental disability who is over the age of 21.

Programs will vary depending upon the needs of the individual and the type of services (day training, employment support or residential) required.

Depending upon the level of behavioral, social, medical, daily living and other support services required, some individual support costs in a 24 hour, 7 day per week residential program can easily exceed \$40,000 per year. Depending upon transportation and other individual requirements, day training begins around \$9,500 per year. Employment placement and support averages \$3,000 for the first 120 days and will require additional funding if continued supported employment is needed.

If you do not require state support to pay for services, you can [contact Avenues](#) or another agency directly to begin the enrollment process.

However, the average individual or his/her family generally has a limited ability to pay for the cost of these support services. This is where government funding has been a benefit to those families in need. Through these subsidies, individuals have been able to access high quality services at an affordable cost. Unfortunately, access to this funding is extremely limited due to the state's on-going budget problems.

Despite the funding limitations, the State of Illinois has established a process for

individuals/families to obtain these needed services. You can click on the link below to obtain information and to begin the state application procedure.

Families who are interested in pursuing private pay options may want to consider contacting the Center for Independent Futures, an agency in Evanston (north suburban Cook County) which specializes in supporting youth and families within this paradigm (private pay only). www.independentfutures.com

Center for Independent Futures
743 Main Street • Evanston, IL 60202
P: 847.328.2044 • F: 847.328.2665
center@independentfutures.com

Who Can Help with Advocacy for Adults with Developmental Disabilities?

For problems related to services, programs and State of Illinois agencies:

Illinois Life Span Project at the Arc of Illinois
www.illinoislifespan.org
800-588-7002 voice

For problems related to SSI, Medicaid, Medicare and Health Benefits for Workers with Disabilities

Health and Disability Advocates
www.hdadvocates.org
312-223-9600 voice
800-427-0766 TTY

For problems related to youth transition and health (including access and coverage)

The Arc of Illinois Family to Family Health Information and Education Center
www.thearcofil.org/familytofamily
866-931-1110/708-560-6703 (voice)
711 Illinois Relay

For legal problems, including problems with services for people with disabilities from state agencies:

Equip for Equality
www.equipforequality.org
800.537.2632(voice)
800 -610-2779(TTY)

For problems related to continuation of home-based nursing care after age 21, including problems with services from state agencies:

US Department of Justice Joins Farley Lawsuit
www.thearcofil.org/pastissues/document.asp?did=2379

Released: 7/19/2010

The Arc of Illinois

July 15, 2010

Leaders in The Arc:

The Justice Department is participating in Bob Farley's lawsuit against the State of Illinois on the behalf of medically fragile disabled persons (Katie Beckett Waiver). Here is Bob's press release.

The Justice Dept. joined the lawsuit on Friday.

Tony Paulauski

The Arc of Illinois

815-464-1832

PRESS RELEASE

Contact: Robert H. Farley, Jr.

Attorney for William Hampe and others

630-248-4880 (cell)

The United States Department of Justice has joined with Attorney Robert H. Farley, Jr., of Naperville, Illinois in challenging the [State of Illinois] systematic failure to modify its current policies and practices of providing insufficient home-based medical care for Medicaid-eligible adults to prevent institutionalization. The Justice Department stated, The United States supports the Plaintiffs Motion for Class Certification because it advances the important public interest in community integration. The Justice Department stated, due to the State of Illinois refusal to modify [its] policy and practice despite the fact that individual plaintiffs have successfully challenged this very policy in five separate lawsuits underscores the need to address this problem on a systemic, class-wide basis.

The Justice Department further stated the medical fragile / technology dependent Medicaid waiver program sets the maximum capacity at 700 persons while the persons with disabilities waiver program has a capacity of 27,870 persons. Together, these programs constitute a sizeable amount of the states community-based services. Plaintiffs claims will require system-wide change in policies to ensure that defendants Medicaid programs allows individuals to live in the most integrated setting appropriate to their needs.

Attorney Robert H. Farley, Jr. and his clients welcome the assistance of the United States Department of Justice in this litigation against the State of Illinois. If any disabled person has been denied sufficient or adequate funding due to their disability, then please contact Attorney Robert H. Farley, Jr. at 630-369-0103.

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Fax: 630-369-0195

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For information about past litigation related to continuation of in-home nursing care for youth who are medically fragile:

See the document "*Challenging Medicaid Home Services Benefit Reductions Using the ADA*" prepared by Neighborhood Legal Services of Buffalo, NY in 2009, which cites 6 cases from Illinois: www.nls.org/conf09/olmstead.pdf. Included in this document are guidelines for preparing aging-out lawsuits.

Looking Toward the Future - Adults with Developmental Disabilities in The Workforce

The service delivery system for adults with developmental disabilities in Illinois continues to change. Consumers and families need to be involved and aware of these changes and their impact on opportunities for integrated employment and community living. Join The Arc of Illinois to receive the latest news and information related to people with developmental disabilities (www.thearcofil.org).

On the national level, supported by Federal initiatives, more and more youth and adults with developmental disabilities are joining the regular workforce, living in their own communities and making their own choices about services and supports.” Options” such as sheltered workshops and day training programs are becoming obsolete. Consumer-directed funding, PASS plans and self-determination are enabling increasing numbers of adults with developmental disabilities to work and live where they choose.

A vital part of transition planning involves creative thinking, knowing and advocating for your rights, and focusing on the dreams of your adult child with disabilities.

The Arc of Illinois and the Illinois Life Span Project are here to help you. Parents and guardians of youth with developmental disabilities can hold high expectations for successful transition. Expect that your young adult will have opportunities to continue learning, to hold a “real” job in the community, to live in the home and community of his choosing, and do everything in your power to make it happen.

Appendix

Arc of Illinois Family Manual for Transition to Work and Adult Services

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Links to Regulations and Other Legal Guidance

Many references are made to legal protections in this manual. The following list provides links to additional information and resources.

A Guide to Disability Rights Laws – from the U.S. Department of Justice, Civil Rights Division, Disability Rights Section
<http://www.ada.gov/cguide.htm>

ADA – Americans with Disabilities Act
<http://www.ada.gov/>

Disability Law Resources – Cornell University Law School – Legal Information Institute
http://topics.law.cornell.edu/wex/disability_law

Disability Laws, Regulation, and Guidance – U.S. Department of Health & Human Services
<http://www.hhs.gov/ocr/civilrights/understanding/disability/laws/disabilitylawsregandguidancemp.html>

Fact Sheet – Your Rights Under Section 604 of the Rehabilitation Act – from U.S. Department of Health & Human Services Office for Civil Rights
<http://www.hhs.gov/ocr/civilrights/resources/factsheets/504.pdf>

IDEA – Individuals with Disabilities Education Act
<http://idea.ed.gov/explore/view/p/%2Croot%2Cstatute%2C>

Illinois School Code – Article 14. Children with Disabilities
<http://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=010500050HArt%2E+14&ActID=1005&ChapterID=17&SeqStart=102800000&SeqEnd=108200000>

Illinois State Board of Education – Illinois Administrative Code - Part 226 Rules
<http://www.isbe.state.il.us/rules/archive/pdfs/226ark.pdf>

The Guidebook of Laws and Programs for People with Disabilities – from Illinois Legal Aid
http://www.illinoislegalaids.org/index.cfm?fuseaction=home.dsp_content&contentID=784

Family Transition Toolbox – Items Needed

1. Record keeping supplies (office supplies).
2. In-home filing system.
3. Fax machine (for sending and receiving faxes, applications, release of information forms, prescriptions and more, as well as for making copies of documents).
4. Calendar.
5. Notebook for recording telephone calls and contact information.
6. “Extra” blank copies of all relevant application forms (hint: make copies on your fax machine BEFORE filling out an application, as well as before mailing/faxing in the completed form).
7. System for saving receipts and recording potential medical expense deductions from your federal income taxes*.
8. Copies of all needed documents - NEVER submit originals, unless you apply in person and can get the originals back immediately.
9. Secure place to store originals and copies of all documents (such as safe deposit box).

Links to Helpful Articles and Websites

“Aging Out of Early and Periodic Screening, Diagnostic and Treatment (EPSDT): Issues for Young Adults with Disabilities” – Kaiser Commission on Medicaid and the Uninsured
<http://www.kff.org/medicaid/7491.cfm>

Administrative Rules for Medicaid
http://www.dhs.state.il.us/page.aspx?Item=22450#a_toc13

Department of Health and Human Services (HHS), Centers for Medicare and Medicaid Services (CMS) website
<http://www.cms.hhs.gov/home/medicaid.asp>

“eLaws Health Benefits Advisor”
<http://www.dol.gov/elaws/ebsa/health/5.asp>

Health & Disability Advocates Resource Library
<http://hdadvocates.org/library/index.asp>

Home Records Forms – DSCC
<http://internet.dsccl.uic.edu/forms/ccr/CCR.pdf>

Illinois HFS Medical Programs Website
www.hfs.illinois.gov/medical/

Medicaid Provider Enrollment Information

- <http://www.hfs.illinois.gov/enrollment/>
- <https://illinoisceb.com/enroll/ceblogin.aspx>
- <http://sheriabrams.com/blog/?p=29>
- <http://www.thearcofil.org/familytofamily/documents/documentdetails.asp?did=722>

Service Facilitation Review Packet for Children’s Support and Adults with Developmental Disabilities (Home-Based Services) Waiver – Information and Forms
<http://www.dhs.state.il.us/page.aspx?item=50967>

<http://www.dhs.state.il.us/OneNetLibrary/4/documents/QualityReview/SFReviewPacket071910.pdf>

“Work Changes Require Health Choices . . . Protect Your Rights”
http://www.dol.gov/ebsa/publications/work_changes.html

Agency Website and Application Overview

Agency Name	Website	Available Application Forms
Social Security Administration	www.ssa.gov	SSI Starter kit- application forms http://www.ssa.gov/disability/disability_starter_kits_adult_eng.htm
Illinois Department of Healthcare and Family Services	http://www.hfs.illinois.gov/	Health benefits for Workers with Disabilities http://www.hbwdillinois.com/application.html
Illinois Department of Human Services	http://www.dhs.state.il.us/	Combined application for Medicaid/Nutrition assistance (SNAP)/Cash Assistance http://www.dhs.state.il.us/ts/fss/pdf/IL444-2378b.pdf
Illinois Family Support Network	www.familysupportnetwork.org	DHS/DDD Home-Based Assistance application http://www.familysupportnetwork.org/dhsbrochure.htm
Illinois Department of Human Services, Division of Vocational Rehabilitation	http://www.dhs.state.il.us/ors/	On-line application for vocational rehabilitation services https://drs.dhs.state.il.us/owr/
The Arc of Illinois	www.thearcofil.org	PUNS (DHS Prioritization of Need for services) application form http://www.thearcofil.org/document.asp?did=79
The Illinois Life Span Project	www.illinoislifespan.org	Online registration and request for assistance form http://www.illinoislifespan.org/registration/index.asp
Family to Family Health Information Center	www.thearcofil.org/familytofamily	Information about transition and special health care needs

What's Out There for Adults with Developmental Disabilities? Employment, Benefits and Support Options

Who is eligible?	Income support	Health insurance	Help in getting and keeping a job	Residential options/support	Other services
People with severe developmental disabilities who qualify for Medicaid waivers	SSI Nutrition assistance (SNAP) SSDI survivor benefits (if eligible)	Medicaid for SSI recipients (AABD) Continue on parent's insurance Medicare if work history or parent/guardian retired/disabled/deceased	DRS Employment options from providers funded by DDD	DRS Home Services In-home CILA CILA homes/placements funded by DDD	Home-based assistance Paratransit (where available)
Adults with developmental disabilities who are working	Depends upon income	Medicaid buy-in: Health Benefits for Workers with Disabilities Employment-based insurance, if available	DRS vocational rehabilitation services Community-based employment options	DRS Home services Private pay options	Paratransit (where available)
Adults with DD not on SSI or waiver-eligible	Nutrition assistance (SNAP) (depends on income) TANF- if dependent children General Assistance- if available from township	FamilyCare if parent of children under 18 on Medicaid/All Kids Medicaid buy-in Medicare - if eligible Continue on parent's insurance ICHIP, if affordable	DRS vocational services Community-based employment programs and training	Private pay options	Paratransit (where available)

**The Government and You: Transition and Beyond –
Overview for Families of Adults with Developmental Disabilities**

For Everyone: Based on Residence	Based on Your Adult Child's Income	Based on Your Adult Child's Disability	Based on Your Adult Child's Income Plus Disability	Based on Special Circumstances
<ul style="list-style-type: none"> ▪ Streets and roads ▪ Garbage/waste collection ▪ Water ▪ public schools (including public colleges and universities), ▪ Police and Fire Departments ▪ Public Health Services ▪ Libraries ▪ Local, county, state and federal government ▪ Public transportation 	<ul style="list-style-type: none"> ▪ Nutrition Assistance (SNAP) ▪ Public Housing ▪ Energy Assistance ▪ General Assistance ▪ TANF (if your adult child has children) ▪ Legal Assistance 	<ul style="list-style-type: none"> ▪ Vocational Rehabilitation Services ▪ Developmental Disability Services ▪ Mental Health Services ▪ Paratransit ▪ Special Recreation ▪ "Special User Fees"- discounts for some services 	<ul style="list-style-type: none"> ▪ SSI ▪ AABD-MANG (Medicaid for people on SSI) 	<ul style="list-style-type: none"> ▪ SSDI - if you have worked and become disabled, or parent/guardian becomes disabled, retires or dies. ▪ Medicaid - if you are pregnant and/or have children (in addition to income eligibility). ▪ Earned Income Tax Credit - based on adult child's disability and parental income.
<i>Some counties/townships/municipalities have additional services.</i>	<i>Other local programs.</i>	<i>These are not entitlements - only "what's available" - often waiting lists.</i>	<i>Sometimes charitable resources available.</i>	<i>Immigration status may affect eligibility.</i>

Getting Ready to Apply for Government Benefits – Documents Needed

Type of Document	How Old Does Child Need to Be to Apply?	Where to Apply?
Proof of Identity 1. Birth certificate 2. Social security card 3. State ID card 4. Passport	1. at birth 2. at birth 3. at any age- (required for airplane travel) 4. at any age- required to travel outside of US	1. birthing hospital or local/county health department (list of health departments: http://www.idph.state.il.us/local/alpha.htm) 2. local Social Security office (must get birth certificate first) www.ssa.gov Local Office Search by zip code: https://s044a90.ssa.gov/apps6z/FOLO/fo001.jsp 3. Secretary of State/Driver's license facilities application for free Illinois Disabled Person Identification Card: http://www.cyberdriveillinois.com/publications/pdf_publications/dsd_x1641.pdf Or "Under 65 Identification Card" (\$20 fee applies)" http://www.cyberdriveillinois.com/publications/pdf_publications/dsd_x1641.pdf 4. US Post Office or Passport Office (list of Passport Acceptance Facilities: http://iafdb.travel.state.gov/)
Proof of Disability 1. IFSP 2. IEP 3. Medical reports 4. SSI Disability Determination	1. IFSP if child is under 3 years only 2. IEP if child is ages 3-21 years 3. Medical reports- at any age 4. SSI Disability Determination papers- at any age	1. IFSPs handled by Child and Family Connections (http://www.cfc-lic.org/forms/list.pdf) 2. IEPs developed by school district (Illinois High School Association- list of high schools/web page links: http://www.ihsa.org/school/memlinks.htm) List of IL school districts by county: http://www.ihsa.org/school/memlinks.htm 3. Medical records from medical providers ("Your Medical Record Rights in Illinois": http://medicalrecordrights.georgetown.edu/stateguides/il/ilguide.html) 4. SSI from Social Security Administration (www.ssa.gov)
Proof of Legal Status 1. Guardianship order 2. Birth certificate 3. Foster care agreement	1. Birth certificate 2. Adoption or foster care status	1. Probate court in your county (Guide to Adult Guardianship in Illinois: http://gac.state.il.us/pdfs/GTAGII/GuideAdultGuardianship2006.pdf) 2. Local/county health department 3. Department of Children and Family Services or contracting agency (http://www.state.il.us/dcf/index.shtml)
Proof of Citizenship	At any age: 1. Your child's Birth certificate or passport 2. Your child's naturalization papers 3. Other immigration documents	U.S. Citizenship and Immigration Services office for your region http://uscis.gov/graphics/index.htm

Applying for Government Benefits Summary

Program	Application/ Phone Info	Application - Form Online (forms only- cannot apply online)	Agency Website
Medicaid Health Insurance	<p>All Kids 866-468-7543 (voice) 877-204-1012 (TTY)</p> <p>Medicaid 800-468-75343 (voice) 877-204-1012 (TTY)</p> <p>Health Benefits (Medicaid) for Workers with Disabilities 800-226-0768 (voice) 866-675-8440 (TTY)</p>	<p>Medicaid www.dhs.state.il.us/ts/fss/dhs_foodStamps_fsai.asp (the same application is used for Medical Assistance, Nutrition Assistance (SNAP) and cash benefits)</p> <p>Medicaid for disabled working persons www.hbdwillinois.com/application.html</p>	<p>http://www.allkidscovered.com/</p> <p>http://health.illinois.gov/parentorchild.html</p> <p>www.hbwdillinois.com</p>
Nutrition Assistance (SNAP)	800-252-8635 (voice) 800-447-6404 (TTY)	www.dhs.state.il.us/ts/fss/dhs_foodStamps_fsai.asp	www.dhs.state.il.us
SSI	800-772-1213 (voice) 800-325-0778 (TTY)	Disability Starter Kit - forms needed for your initial SSI application interview available for free download. Starter kit includes link to on-line application form.	www.ssa.gov
Developmental Disability Services	800-843-6154 (voice) 800-447-6404 (TTY)	Available only from Independent Service Coordination (ISC) agencies. Find ISC at www.illinoislifespan.org	www.dhs.state.il.us/mhd/dd/
Vocational Rehabilitation Services	800-843-6154 (voice) 800-447-6404 (TTY)	Available only from Vocational Rehabilitation (VR) counselors at DRS offices. Find VR office at www.illinoislifespan.org	www.dhs.state.il.us/ors

Applying for Government Benefits - Document Checklist

Type of document	Documents (and copies) Ready/Date
Proof of identity <ul style="list-style-type: none"> • Birth certificate • State ID card • Passport 	
Proof of disability <ul style="list-style-type: none"> • SSI determination letter • IEP • Medical reports 	
Proof of legal status <ul style="list-style-type: none"> • Guardianship order • Foster care agreement • Adoption order 	
Proof of citizenship/immigration status <ul style="list-style-type: none"> • Passport • Naturalization certificate • Other immigration documents 	

Rent Record

Name:
RIN
DOB
SSN
Address:
Telephone number:
Landlord name:
Year:

Date	Check number	Amount
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		
Total		

Program/Benefit Application Record

Program/Benefit Applied For	Application Date	How Submitted	Copy on File	Outcome	Follow up
SSI					
Medicaid (Health Benefits)					
Nutrition Assistance (SNAP)					
VR Services					
DD Services					
Case Management Services					
Residential Services					
Paratransit					
Medicare					
Circuit Breaker					
Guardianship					
State ID Card					
Parking Permit/License Plates/Reserved Parking Space					
Other					
Other					

A Day in the Life Worksheet

Time of Day	Activity	Level of Independence	Help Needed	Family Resources
AM/Wake Up	Getting out of bed			
	Toileting			
	Bathing/grooming			
	Dressing			
	Eating			
Morning	Get ready for day			
	Transportation			
	Work/other activities			
Midday	Prepare/purchase/eat lunch			
	Errands/personal business			
Afternoon	Return home			
	Recreation/leisure			
Evening	Chores/responsibilities			
	Prepare/eat dinner			
	Clean up			
	Prepare for next day			
	Recreation/leisure			
Night	Bedtime routine			
	Hygiene			
	Sleeping			
“Down Time”	Vacations/holidays			
	Fitness/well being			
Any Time	Medications,treatments,care			
	Mobility, transportation			
	Socialization			
	Communication			
	Behavior, safety issues, supervision			
	Therapies			
	Counseling, mental health			
Emergencies	Guardianship/health surrogate			
	Evacuation plan, fire drill			
	Preregistration with paramedics/fire dept.			
	Portable medical summary			
	Communication plan			

Level of independence: 1= independent, no supervision, 2= independent with supervision, 3 = dependent, able to direct others, 4 = dependent, unable to direct others

Help needed: staff, equipment, assistive technology, home modifications, financing, advocacy, other (specify)

Family resources: people who can help, private pay ability, time, equipment, other

A Week in the Life: Another Way to Look at Life After High School

	What? Job Activities Chores Recreation Etc.	Where? Home Community	When? Time Frame Schedules	Who? Family Friends Staff	How? Transportation Accommoda- tions	How much? Costs Resources	Why? How does this fit into transition “game plan”
Sunday							
Monday							
Tuesday							
Wednesday							
Thursday							
Friday							
Saturday							
Holidays							
Vacations							
Emergencies							

Making Sense of Portable Medical Record Options/Devices/Services – A Sample of Available Options

From The Arc of Illinois
Family to Family Health Information & Education Center

Name of Service/Device Contact Info.	Description	Cost	Resources/ Comments
Illinois Premise Alert Program (PAP) – Register with First Responders <i>First Responders: When a call is made to 911, first responders are those who are specially trained and dispatched to deal with a medical or other emergency.</i>	<p>On August 28, 2009 the Illinois Premise Alert Program (PAP) Act became effective in Illinois. PAP is a public safety program that supports individuals living with disabilities as well as Police Officers responding to calls at a specific address. PAP is a database of individuals with special needs kept in a computer aided dispatch (CAD) database and is to be maintained by public safety agencies at the request of families, caregivers, or individuals with disabilities or special needs. The PAP allows families to voluntarily notify the police and first responders about their special circumstances free of any charge. The PAP will assist police departments to identify individuals who have special needs, which will enable the responding officer to have additional information at his/her disposal. Excerpt from the Woodridge, IL website http://www.vil.woodridge.il.us/uploadedFiles/Departments/Public_Safety/Premise%20Alert%20Program.pdf</p>	Free	<p>The Illinois Premise Alert Program (PAP) Act states the following: (430 ILCS 132/5) Sec. 5. <i>Purpose. It is the policy of the State of Illinois to ensure that consistently high levels of public safety services are available to all members of the State, including people who may require special consideration in order to access services. This program shall seek to afford people with disabilities or special needs or both the same access to public safety services provided to all citizens. It is the intent of this program to offer guidance and direction to public safety workers in responding to and assisting those people with special needs or disabilities or</i></p>

			<p><i>both with whom they will have contact in the performance of their duties and responsibilities. The ability to effectively deal with special needs individuals is enhanced with knowledge or information. The ability to identify special needs individuals, their places of employment, educational facilities, and residences are valuable resources in instances when or if an emergency response by law enforcement or fire protection personnel or both are needed.</i></p>
Illinois Secretary of State's Emergency Contact Database www.cyberdriveillinois.com/departments/drivers/ecd/home.html	Participation in this database is free and voluntary. It allows IL driver's permit, driver's license and ID card holders to enter emergency contact information for use by law enforcement in emergency situations.	Free	
Knox Box Knox Company 1601 W. Deer Valley Road Phoenix, AZ 85027 800-552-5669 www.knoxbox.com	<i>Knox Box is a rapid entry system that allows a local Fire Department to enter a home or business in case of emergency. When the Knox Box system is used in a community, residents can register with the Fire Department and have a box mounted on the home that is keyed to single master, held by the department. A house key, floor plans and other important information can be stored in the box in case of emergency, reducing response time and</i>	Starting Price is \$159.00 and up	

	potential damage to home or property. From www.knoxbox.com		
Medic Alert 2323 Colorado Avenue Turlock, CA. 95382 888-633-4298 www.medicalert.org	How it works: <ol style="list-style-type: none"> 1. In an emergency, first responders look for a MEDICALERT ID and read the engraved information. 2. First responders can call the MedicAlert 24/7 emergency response center for critical medical information. 3. The MedicAlert emergency response center calls a designated contact so the individual is not alone in an emergency. MedicAlert is a medical identification bracelet, necklace, shoe tag, watch or wallet card that will have a code to which medical information is linked when first responders call the service. From www.medicalert.org	<ul style="list-style-type: none"> • Medic alert Advantage (adults 18 & over) \$30.00 per. year \$9.95 start up fee • Medic Alert Kid Smart (children 17 & under)\$15.00 per. year \$14.95 set up fee 	
Medical ID Tags American Medical ID 949 Wakefield, Suite 100 Houston, Texas 77018 800-363-5985 www.americanmedical-id.com	A medical ID is jewelry that can save a life. Medical conditions, drug and food allergies, prescribed medicines and emergency contacts can be engraved onto the surface of a medical ID bracelet or necklace. The individual is responsible for updating as needed, and this tag is not connected to any centralized support system.	<ul style="list-style-type: none"> • No membership fees and free engraving. • Personalized Medical ID Jewelry starting price is \$29.95 	Many generic forms of medical ID tags sharing information about allergies and medical conditions can be found at local drug stores or pharmacies.
Forms and Paper Record-Keeping Tools			
American Academy of Pediatrics - EMS Record Form www.medicalhomeinfo.org/tools/emer_med.html	This emergency medical information form is available without charge on the American Academy of Pediatrics website.	Free online.	

Care Notebook Forms American Academy of Pediatrics www.medicalhomeinfo.org/Tools/care_notebook.html	<i>The Care Notebook has multiple uses. A major role of this notebook is to help parents/caregivers maintain an ongoing record of their child's care, services, providers, and notes. This notebook is a great tool in empowering families to become the experts on their child's care. It is also a way to maintain the lines of communication between the many providers and services that help care for a child and their family. Health professionals recommend that parents/caregivers bring this notebook to all medical appointments, therapies, care conferences, on vacations, etc. . . .</i> From http://www.medicalhomeinfo.org/Tools/care_notebook.html	Forms available online without charge.	
Electronic Locating Devices			
BrickHouse Security Child Locator www.brickhousesecurity.com/child-locator.html	<i>The instant your loved one wanders too far, the hand-held Locator will instantly notify you with loud beeping, vibration and directional guidance all at once. As featured in the newest Duracell "Power To Protect," commercial, The BrickHouse Child Locator gives parents peace of mind in a way that simply has not been possible before. Perfect for special-needs children & everything else you care about, we help take the worrying off your shoulders by alerting you the second they wander. Not a moment too late. From</i> www.brickhousesecurity.com	Price: \$129.95 + additional materials available	PLEASE NOTE: There are additional vendors for these services available online. These are provided as examples only.
EmFinders 6170 Research Road Suite 200 Frisco, TX. 75034 866-426-3386 www.emfinders.com info@emfinders.com	<i>The Emfinders EmSeeQ is a small, watch-like, wireless device without buttons or a screen and is under the secure and remote control of the EmFinders operation center. The device can only be activated by the caregiver. Once activated, the device</i>	EmSeeQ device ranges from \$185.00-\$225.00 per unit. Service is \$25.00 per month	

	<p>places a call and provides its location to a 911 operator via the cellular network, just as standard cell phone would. The EmFinders system does not use GPS. Instead it uses triangulation through the cellular network to accurately determine a person's location, including in building or environments that would typically interfere with GPS locators.</p> <p>From www.emfinders.com</p>		
<p>I-DENTI-FIED, Inc. 5213 W 121st Avenue, Crown Point, IN 46307 p 866-99IDNOW or 866-994-3669 f 866.496.9123</p> <p>www.i-denti-fied.com/index.php</p>	<p><i>I-DENTI-FIED was originally conceived by Kevin M. Brunski, D.D.S., as a way to help missing or abducted children be returned safely to their families. His vision was to find a way to place an RFID Transponder ("Transponder") securely and safely in a dental structure for use in human identification. Through his dental practice, Dr. Brunski has developed a patent pending technique which provides a method of implanting the Transponder in a tooth, denture, or dental prosthesis. Once implanted, the Transponder provides a secure, noninvasive, and confidential method for the storage and retrieval of both identification and critical medical information. Currently the I-DENTI-FIED System™ is approved for use in Denture, Partial Dentures and Dental Prosthetics.</i></p> <p>From www.i-denti-fied.com</p>	<p>Charges for placement of the I-DENTI-FIED System™ are paid directly to the dentist. A two-year subscription agreement for the I-DENTI-FIED PHR™ is required.</p>	<p>This system requires dentists trained to insert the devices and specialized equipment to retrieve the information by participating medical providers. There are none currently listed in Illinois on the I-DENTI-FIED website.</p>
<p>Project Lifesaver Project Lifesaver International 815 Battlefield Blvd South Chesapeake, VA 23322 877-580-LIFE (5433) Ph: 757-546-5502 Fax: 757-546-5503</p> <p>www.projectlifesaver.org</p>	<p><i>Citizens enrolled in Project Lifesaver wear a small personal transmitter around the wrist or ankle that emits an individualized tracking signal. If an enrolled client goes missing, the caregiver notifies their local Project Lifesaver agency, and a trained emergency team responds to the wanderer's area. Most who wander are</i></p>	<p>Costs vary.</p>	<p>Not available in all areas. Check the Where Are We section of the Project Lifesaver website for current provider locations.</p>

	found within a few miles from home, and search times have been reduced from hours and days to minutes. From www.projectlivesaver.org		
Fingerprinting			
IL CHIP Grand Lodge of Illinois, A.F. & A. M. Att: Office of the Grand Secretary 2866 Via Verde Springfield, IL 62703 www.illinoisfreemason.org/ilchip.html 217-529-8900	<i>The IL CHIP program -- sponsored by the Grand Lodge of Ancient Free & Accepted Masons of the State of Illinois -- is held by experts as the "premier child identification program" currently offered in the State of Illinois. The Freemasons of Illinois hold and fund the entire cost of identification workshops for families all around the State of Illinois. These are called ILCHIP events. They're sponsored by local Masonic Lodges and held at neighborhood functions or community schools. We put together everything parents need to help the authorities find their lost child. It's the most comprehensive program of its kind ...and it is FREE OF CHARGE TO PARENTS. Best of all, it only takes 10-minutes and supplies parents with a complete child identification package that can be taken home or carried with the family on vacation. The information -- most of which is contained on a CD -- is compact and totally private. The IL CHIP program keeps only the parental permission form!</i> From www.illinoisfreemason.org/ilchip.html	Free	
Medical Records Application for iPhone and iPod Touch			
My Life Record iPhone App www.myliferecord.com	<i>Everything from medical imaging, charts, medications and even lab results can now be accessed and shared all via your iPhone. Never before has your official medical record been so easy to organize and track. The days of waiting for your medical charts to arrive at</i>	The My Life Record application is available on the iPhone and iPod touch through the Apple App Store. My Life Record comes in two editions,	<i>Will My Life Record Work On My iPod touch?</i> <i>Yes, the My Life Record software will function on both the iPhone and the iPod touch. The</i>

your doctor's office are over. The days of waiting to get results from one doctor to another are a thing of the past. My Life Record puts instant access to your entire medical chart within reach, or should we say within a touch of your screen.

From
www.myliferecord.com

the My Life Record Personal Edition and the My Life Record Family Edition. Both are identical in functionality; however the family edition allows up to 6 family members per device whereas the Personal Edition allows one family member per device. Price: \$49.99

same technologies are used in both devices, and My Life Record utilizes those technologies. The iPhone always has an available network connection via the cell phone carrier, however the iPod touch does not. In order to use My Life Record with an iPod touch, you will need to have an available Wifi connection.

How Do I Get My Health Records Into My Life Record?

My Life Record has an easy to use function that allows you to get your medical records from your physician and into your My Life Record profile with ease. You simply touch an icon on your iPhone and your iPhone will provide you with a fax number and a code. Simply provide this fax number and code to your doctor. All your doctor has to do is print or write that code on the front of the fax and fax your chart. My

			<p><i>Life Record will take your chart and tie it to your My Life Record profile, creating an exact copy of your medical chart in your My Life Record profile. Your doctor does nothing more than fax your chart, just as he or she would do if he or she were giving your record to another physician for treatment.</i></p> <p>From www.myliferecord.com</p>
Personal Flash Drive Devices			
<p>MED Flash www.med-flash.com 1-888-696-3346</p>	<p><i>MedFlashtm is a simple-to-use web-based electronic personal health manager with a USB storage device for your health, lifestyle and medical information. MedFlashtm comes with a user friendly web based software that will allow you to quickly enter your information and access it anywhere you have an Internet connection. A "key-chain" version of MedFlashtm can be worn on a necklace or placed on your keychain.</i></p> <p>From www.med-flash.com</p>	<p>The price is \$34.95 with no monthly fees</p>	<p>PLEASE NOTE: There are other companies that provide this service and you can find them through an internet search. These are shared as examples only.</p>
<p>MedInfo911,LLC P.O. Box 911 Somis, CA. 93066 www.medinfo911.com email: support@medinfo911.com</p>	<p><i>How It Works: Just plug the unit into the USB port on any Windows compatible computer. , , , MedInfo911 EMR proprietary software is preloaded on your MedXKey. No additional software is needed. Medical and Emergency information is easily entered by you. Information can be updated by you as needed. The</i></p>	<p>\$39.95 no monthly service fee</p>	

	<p><i>MedXKey will work with all Windows compatible computers worldwide. Step by step instructions are provided with each unit.</i></p> <p>From www.medinfo911.com</p>	
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TRANSITION PLANNING COMMITTEE FACT SHEET

From The Arc of Illinois
Family to Family Health Information & Education Center

From the Illinois Transition Planning website: <http://illinoistransition.org>

A Transition Planning Committee (TPC) is a consortium of local members of schools, agencies, and not-for-profit organizations, parents of children with disabilities and people with disabilities that band together to improve the transition life-cycle from high school to a successful adult life.

As part of the Education to Careers (ETC) school to work initiative, the Illinois general assembly enacted legislation that the Department of Rehabilitation Services (DHS-DRS) coordinate the creation of local Transition Planning Committees.

Vision: *Helping secondary students with disabilities transition into their local communities.*

What is a TPC or Transition Planning Committee?

A TPC is a local group of people with an interest in transition. They include school and agency staff, service providers, parents, youth with disabilities and others. They work together to improve the transition process for their local youth with disabilities.

How do TPC's help youth and families with Transition?

Joining in the work of the local TPC gives families the opportunity to get to know the people and providers in their area. Parents may want to be involved to share their concerns and questions and help improve the process. TPC's often hold information and resource fairs that can be very helpful to families.

How can I find the TPC that serves my area and how do I get involved?

- Ask the transition coordinator or case manager at your local high school who to contact.
- Check the Illinois Transition Planning website (<http://illinoistransition.org>). This website includes contact information for the 42 Illinois TPC's.
- If you are unable to find your TPC on the Illinois Transition Planning website, contact:

Marva Campbell Pruitt	Chicago, IL 60601
State Administrator	312.814.5081 - Voice or 773.768.8436
Dept of Human Services, Div of	312.814.5849 - Fax
Rehabilitation Services	888.440.8995 – NexTalk
100 West Randolph St. Suite 5300	
- TPC meetings are open to anyone who is interested in attending. You will be welcome!



Summary of Provisions for Young Adults in Health Care Reform

Background

The Patient Protection and Affordable Care Act was signed into law on March 23, 2010. Many pieces of the bill affect young adults specifically, as one of the largest populations to lack health insurance.

Why Young Adults Lack Coverage:

- Young adults are more likely to work for small businesses that do not offer health care coverage.
- Young adults change jobs more often than older adults.
- Many young adults are unemployed for a period after graduating from college and no longer remain eligible for their parent's coverage.
- Young adults are more likely to be low-income and purchasing insurance on the private market may be too costly.
- Young women are charged higher premiums than men as a result of gender rating.

The Benefits of National Health Care Reform for Young Adults:

- Health insurance reform will allow young adults to remain on their families' health insurance policies as dependents until the age of 26, with very few limitations. In Illinois, state law allows for veterans to remain on some policies as dependents until age 30.
- Health insurance exchanges will offer a range of affordable plans for young adults, including catastrophic coverage for individuals under 30.
- Free prevention services will be available to all insured people, so young adults will begin lifelong habits of good health care early in life.
- Small businesses, the predominant employer of young adults, will receive tax credits to provide health insurance coverage to their employees.
- Affordability credits and federal subsidies will help young adults afford coverage on the private market, as well as assist with out-of-pocket expenses, co-pays and deductibles.

Things to Remember about the Extension of Dependent Coverage

With the change in insurance regulations this means that insurance companies will not be able to limit coverage of dependents based on anything besides age. Some of the limitations that are currently in place include the requirement that the dependent be in enrolled in school full-time, is financially dependent or be unmarried. These limitations will not be allowed for health plan years that begin after September 23, 2010. However, some private insurance companies have already changed their policies to allow for this expansion to take place earlier.

*Information compiled from the Georgetown Center for Children and Families and
www.Healthreform.gov (last updated 5-12-10)*

*Information compiled from the Georgetown Center for Children and Families and www.Healthreform.gov
(last updated 5-12-10)*

Illinois Maternal & Child Health Coalition * 256 West Chicago Ave. * Chicago, IL 60642
V: (312) 491.8161 * F: (312) 491.8171 * www.ilmaternal.org

Addressing Vision and Hearing Needs in Transition

Michelle Clyne, Philip Rock Center

Persons with significant care needs in adulthood might also be visually impaired/blind, hard-of-hearing/deaf, or dual-sensory impaired/deaf-blind. These sensory challenges can add to a person's needs, and might mask abilities and opportunities for growth. If your son or daughter has a known visual impairment, hearing impairment, or deaf-blindness, please consider some of the following questions and suggestions to help facilitate a better transition to work, day program, or living situations.

VISION

Give a copy of the most recent eye doctor report to the program staff. If the most recent report is not the most DETAILED report, also give the most detailed report to the program staff. Not every doctor's visit report is as informative as others, so please share those that YOU found most helpful.

Consult with the eye doctor to determine how often future visits are needed. Some eye conditions (for example, glaucoma) may require very frequent visits. Some eye conditions are stable or require no treatment. Let your child's program staff know about the medically-required schedule for eye doctor visits. Discuss with staff who will bring your son/daughter to appointments, make follow up appointments, and how the information from appointments will be shared among family and staff.

Does your son/daughter wear contacts or glasses? If so, be sure that staff has a current copy of the prescription. If your son/daughter needs physical assistance to put on the glasses or contacts, demonstrate to staff how you do it so that your son/daughter will be more comfortable when assisted by staff. If there are times when your son/daughter should NOT wear glasses or contacts (for example, if you son/daughter might break the glasses when not sitting next to staff during a car ride) also let staff know that so they can act to protect the glasses/contacts as needed. Also let staff know if they will need to help your son/daughter clean glasses and contacts, and the best way to do that.

Most importantly, give descriptions of what you think you son/daughter can and cannot see. Include things that make it hard to use vision (for example, outside when the sun is too bright) as well as things that improve vision (for example,

using a hat with a brim outside). If you feel your son/daughter does not use vision at all, let staff know that AND let staff know what you do to give vision information in another way (for example, you might say “I always tell Bob where we are going as we walk from place to place” or “I tap Bob’s mouth before I give him a spoon of food.”

HEARING

Give a copy of the most recent ENT or hearing report to the program staff. If the most recent report is not the most DETAILED report, also give the most detailed report to the program staff. Not every doctor’s visit report is as informative as others, so please share those that YOU found most helpful.

Consult with the ENT or audiologist to determine how often future visits are needed. Some ear conditions (for example, difficulty with PE tubes) may require very frequent visits for a while, while some hearing issues are stable or require no treatment. Let your child’s program staff know about the medically-required schedule for visits. Discuss with staff who will bring your son/daughter to appointments, make follow up appointments, and how the information from appointments will be shared.

Does your son/daughter wear hearing aids or cochlear implants? If so, be sure that the staff gets a copy of the instruction manual for the device. If you cannot find yours, sometimes they can be found online at the web site for the manufacturer of the device. If your son/daughter needs physical assistance to put on the device, demonstrate to staff how you do it so that your son/daughter will be more comfortable when assisted by staff. If there are times when your son/daughter should NOT wear the device (for example, if you son/daughter might put the device in the toilet) also let staff know that so they can act to protect the device as needed. Also let staff know if they will need to help your son/daughter clean any hearing aids, and the best way to do that.

Most importantly, give descriptions of what you think you son/daughter can and cannot hear. Include things that make it hard to hear (for example, if the radio is on in the background or if congested during an illness) as well as things that improve hearing (for example, turning off the radio or facing your son/daughter while talking). If you feel your son/daughter does not use hearing at all, let staff know that AND let staff know what you do to give vision information in another way (for example, you might say “If I sign “eat” Bob moves to the table for dinner” or “I tap Bob, get his attention, and then point to his shoes so he knows to put them on.”

DEAF-BLINDNESS

The hearing and vision suggestions above might be pertinent to your son/daughter. Please look those over to see if they are.

Even if there is remaining vision and hearing, a deaf-blind person might need more tactile cues to do things. Can your son/daughter look at pictures and get information? Can they look at objects and get information? Can they only get information by touching the object? Let staff know if any of pictures, looking at objects, or touching objects is better for your son/daughter. Persons who are deaf-blind require more time to take in information and reply. Ask that staff give your son/daughter one piece of information at a time, and wait for a response, before changing topics.

Simple adjustments in the way people who are deaf-blind are approached can lead to much more successful social, activity, and quality of life outcomes. The Helen Keller National Center has a list of suggestions at www.hknc.org/Guidelines.htm and at www.hknc.org/images/Guidelines%20brochure2006.pdf

More helpful information can be found at www.nationaldb.org.

Advocacy Tips for Transition

From Mike Kaminsky, Director
Illinois Life Span Project of The Arc of Illinois

1. What do you see as the most common barrier to successful transition?

The most common barrier I encounter is a lack of awareness of the issues concerning transition and an understanding of the specific tasks to be completed, depending on the individual's needs. Many people are not aware that a family should apply to be placed on the PUNS list as soon as possible because the waiting list is so long (20,000 + as of this writing in August, 2010). Also there are few if any resources that people may take advantage of directly, once a person leaves the special education system. Special education is an entitlement which does not exist in the adult world of service for people with developmental disabilities. Knowing your local Independent Service Coordination agency is helpful. Also, developing a relationship with your legislator and sharing your specific family concerns is an important advocacy task.

Another barrier is that people do not have high expectations for individuals with developmental disabilities in terms of vocational possibilities. Teachers, parents, professionals and students themselves, need to have higher expectations and career goals. The interest of the potential worker needs to be explored before vocational goals are developed. Currently, people with disabilities are not afforded the variety of employment options typically afforded to their peers. It is important to begin with the interests of the individual rather than merely what is available.

2. What are some of the most effective self-advocacy strategies that youth and families can use?

The most effective self-advocacy strategy is to know what you want and what your purpose is for your future. You will need to be able to share your transition goals with the transition team as well as your legislators. Legislators need to hear from youth and families about what they need to be successful in the community. Only you can motivate your legislators to help you by simply sharing your story.

3. How can youth and families learn more about self-advocacy?

There are many self-advocacy groups throughout our state. Join a self-advocacy group and learn from other self-advocates. Join The Arc of Illinois and stay informed about the issues that impact people with developmental disabilities statewide. Attend trainings and other informational events that will help you to understand the issues that have an impact on you and your loved ones. Get involved. Let your legislators know what you need to lead a full and productive life in your community.

4. How can people decide if they need to seek help from advocacy organizations?

It's important to get involved and stay informed. Don't wait until you have a problem to learn about the organizations that address issues important to you. Be active and vocal. Be diligent about being informed of issues concerning services and legislation that will impact you or your child.

5. What's the difference between an advocacy (legal assistance) agency and private advocacy resources? What are advocacy services?

When people speak of advocacy, they may mean many different things. Webster defines advocacy as: *the act or process of advocating or supporting a cause or proposal*. The word advocacy in this definition acts as a noun. People with disabilities and their families need to learn about advocacy and how they can effectively lobby for the supports and services they need. Policy-makers need to know the stories of individuals to make good decisions.

Individuals and groups can advocate. It simply means to support a cause. When people speak of self-advocates, they refer to people with disabilities who speak on behalf of their own causes, wants and needs. This is important because people with disabilities have not historically had the opportunity to have their voices heard.

Sometimes, people need direct advocacy services – or the assistance of a knowledgeable third party - to advocate for them. Advocacy can be very difficult and emotionally charged when it is situation specific. For example, families who experience difficulties in the education system occasionally look for an experienced advocate or knowledgeable third party to accompany and support them in an IEP meeting. It can be helpful to have assistance from someone who is not emotionally involved who also has expertise in the law.

Advocacy can also mean support in the form of information. Many organizations exist that provide information to help individuals with disabilities and their families learn about the issues important to them. These organizations are also referred to as advocacy organizations.

6. "Advocate" in private practice vs. lawyer r- what do families and youth need to know?

If a family needs assistance in advocating for educational needs, there are a number of resources available. If you need information on the rights of children and families within special education, a great resource is the Parent Training and Information Center (PTIC) for your area. There are two PTIC's in Illinois. The Family Resource Center on Disabilities (www.frcd.org) serves the Chicago and Chicago suburban area. Family Matters Parent Training and Information Center (www.fmptic.org) out of Effingham serves the rest of the state.

Attorneys and lay advocates (advocates who are not attorneys) that specialize in educational issues are listed on the Illinois Life Span website. You may also want to contact local parent groups for their suggestions. Local Centers for Independent Living are also available in some areas to assist families with educational concerns.

There is a very helpful resource for families who are considering using a paid advocate on the Illinois State Board of Education website from Lisa Madigan, the Illinois Attorney General. The

document is titled “Guidelines for Choosing a Lay Advocate in Special Education” and provides families with the information they need to choose wisely. www.isbe.state.il.us/SPEC-ED/pdfs/lay_advocate_guideline.pdf

7. Is help available in paying for advocacy costs?

There are also free advocacy services available for families. Equip for Equality is an organization that provides legal and other advocacy specifically to people with disabilities in Illinois. Their mission is described as follows on their [website](#): ***The mission of Equip for Equality is to advance the human and civil rights of children and adults with physical and mental disabilities in Illinois.*** It is the only statewide, cross-disability, comprehensive advocacy organization providing self-advocacy assistance, legal services, and disability rights education while also engaging in public policy and legislative advocacy and conducting abuse investigations and other oversight activities.

Local Centers for Independent living sometimes provide advocacy services as well. For more information, contact your local CIL. You can find out which CIL serves you at the [Illinois Network of Centers for Independent Living website](#).

Other possible resources for free advocacy services include general legal advocacy agencies available in your geographic area.

8. What else do youth and families need to know about advocacy?

Advocacy skills are important to every individual and family. It’s often said that knowledge is power – and that is certainly accurate when it comes to the world of disability supports and services. It is important for youth with disabilities to have a voice and learn to advocate for what they want and need. Incorporate self-advocacy skills into IEP’s and the goals you have for your children at home from an early age. Self-direction and the highest level of independence possible is a worthy goal for all children. Self-advocacy is an important element of that.

Parents must also learn as much as they can about education and the world of services and supports to advocate effectively for their children. Connect with other families and with organizations that advocate for and support people with disabilities to learn all you can and beyond that, who to connect with when it’s beyond your level of expertise. No one can know everything – so it’s important to know who you can call when you need help.