

Family Manual

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

Second Edition

Promoting Incentives for Integrated and Self Employment Project

**The Arc of Illinois
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www.thearcofil.org

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 is mandated to begin at the age of 14 and is an important part of the Individual Education Plan. 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 Individual Education Plan 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 can be a thoughtful process for you and your child in the special education system. You and your child have rights. Throughout this manual we will be urging you to assert 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. Most 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 your advantage!

Your main goal right from age 14 should be full competitive community employment with benefits and career opportunities upon graduation from the special education system. Set your goals high. Have great expectations!

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 will have changed dramatically in the adult service system.

In the adult system, Medical Benefits (Medicaid) is the key to adult services. As you prepare for the adult system here in Illinois, you will still have to read the law, be skeptical of professional recommendations, become knowledgeable of Medical Benefits (Medicaid) rules, and developing a meaningful Individual Service Plan that meets the needs of your adult child. It will also be critical to know the important rules governing public benefits your adult child is eligible for. We have found by experience that not all professionals or staff understands the relationship between employment and public benefits such as Medicaid.

Throughout this Family Manual we have tried to give you important recommendations and information to make the transition from special education to adult services and full employment easier.

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.

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, I would love to hear from you with your suggestions. This is truly a work in progress!

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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 will be difficult to exercise them! There are many ways to learn about special education rights for families. We strongly recommend you become active in a parent support group. If there is not one in your area, start one. What you learn and the support derived from parent support groups cannot be underestimated. The Illinois Life Span Project keeps a listing of support groups on its website at www.IllinoisLifeSpan.org

Read the law. Oftentimes, educators and professionals profess to be knowledgeable in special education law, known as the Individuals with Disabilities Education Act. We have found that it is best for parents to read the law themselves and make their own interpretation of I.D.E.A. Another excellent resource on special education law is www.WrightsLaw.com

Youth with developmental disabilities also need to learn about the special education law and their rights. Starting at age 14, they must participate as equal partners in their own IEP meetings and be given the opportunities to share their opinions and 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 <http://www.stateart.com/productions/disabilities/myfuturemyplan/>.

The Minnesota Council on Developmental Disabilities has some very helpful consumer transition workbooks available for free download from their website: "It's Never too Early, It's Never too Late" and "It's My Choice" <http://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 three federally funded Parent Training and Information Centers. These Centers are funded to provide parents with free up-to-date training and information on special education issues and rights. The three Parent Training and Information Centers are:

1. Designs for Change

814 S. Western Avenue, Chicago, IL 60612

312-236-7252 voice / 312-236-7944 TTY/ 312-236-7927 FAX

E-mail: markse@designsforchange.org Website: www.designsforchange.org

2. Family Matters (ARC Community Support System) 2502 South Veterans Drive Effingham, IL 62401 217-347-5428 voice 217-347-5119 FAX 866-436-7842 Toll-Free E-mail: info@fmptic.org or deinhorn@arc-css.org Website: www.fmptic.org Serving: Statewide except Chicago.

3. 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: frcdptiil@ameritech.net Website: www.frcd.org

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 exits the special education system

The full text of the IDEA legislation is available at: <http://www.ed.gov/policy/speced/leg/idea/idea.pdf>

The IDEA legislation that pertains to transition planning in the IEP: Section 300.347 Content of the IEP and Section 300.348 Responsibilities for Transition Services can be found at http://www.cec.sped.org/law_res/doc/law/regulations/regs/SubpartC.php

Ideally the transition plan is driven by the student and his vision of future employment and career opportunities. Parents and guardians of youth with developmental disabilities need to help them become ready to participate in their own IEP meetings and to 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 <http://www.ncset.org/topics/sdmhs/resources.asp?topic=30>

The National Dissemination Center for Children with Disabilities has many free publications for families and youth, including “Transition Planning: A Team Effort” available on their website: <http://www.nichcy.org/pubs/transum/ts10txt.htm> , Helping Students with Cognitive Disabilities Find and Keep a Job, <http://www.nichcy.org/pubs/stuguide/ta3book.htm>, and A Student’s Guide to Jobs <http://www.nichcy.org/pubs/stuguide/st2script.htm>

We recommend that you plan backwards in the transition planning process.

First, think about what outcomes that the student and the family want when the student exits the special education system. Then, start the planning with this in mind. We also recommend that one of the important

outcomes for the transition plan is **full-time community employment** with benefits and the potential for a career.

Why do transition planning?

Some would say that transition planning should be a wake-up call for families of young adults with developmental disabilities. A wake-up call that indicates that special education does not last forever, and we must make the best possible use of the special education system and the services and supports it provides before the student reaches the age of 21 and exits the special education system.

Without a good transition plan, the following scenarios are quite possible:

- ✓ Your adult child could finish school and end up staying at home with nothing to do if you don't plan ahead.
- ✓ The student could be stuck in a "dead-end" job that offers no opportunity for advancement or career development.
- ✓ The student could end up in a segregated workshop model. Adult services are not an entitlement like special education, and providers are not required to provide a "continuum of options". Some community providers offer only segregated workshops and day programs for the adults whom they serve.
- ✓ Some students with developmental disabilities may exit the special education system and only get their name on a waiting list for adult community services. They could "wait" indefinitely - without receiving services.

The reasons for having a good transition plan are obvious, but the fact is that even with a good plan, the adult community service system is much different from the special education system.

Any 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 career interests and dreams.

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 should, whenever possible, begin at a very early age to plan for funding services and supports for the child with a developmental disability when they exit the special education system. The major difference for the family is that, unlike a college education, which typically lasts for a few years, services and supports for adults with developmental disabilities are needed throughout their 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.

Families need 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 more information and referrals to legal professionals. The Arc of Illinois also offers annual training seminars for families on this topic. Check The Arc's website (www.thearcofil.org) for dates and locations around the state.

The Arc of Illinois Board member, Brian Rubin, who is the parent of an adult with developmental disabilities, and attorney specializing in future planning for persons with special needs, has a comprehensive "Guide for Future Guardians and Trustees" on his website: <http://www.brianrubin.com/sys-tmpl/guideforinformationletter/>

Arc member and frequent presenter at Arc trainings, Theresa Varnet, who is a parent, attorney and social worker, has also written extensively on this topic, and has a number of helpful articles available on her website: http://www.spainpainvarnet.com/articles_and_publications.html

Families at all income levels need to be aware of financial planning and establishing special needs trusts. Otherwise, your child with developmental disabilities may not be eligible for services and supports funded by the government when he exits school and special education services. Friends and relatives need to be made aware of this also. Otherwise, for example, their well-intentioned gifts of money to your child could compromise eligibility for Medical Benefits (Medicaid) and SSI.

The brokerage house Merrill Lynch offers an interactive "Special Needs Calculator" on their website to assist in estimating your child's lifelong financial needs: <http://askmerrill.ml.com/snc/start.asp>

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?**

You may need government funded services if your adult child cannot stay home alone, cannot get and keep a job on their own, if they cannot travel on their own and you are not able to provide these supports yourself or pay some one else to do this.

Families do have a "choice":

1. If you have enough money to pay for services yourself, you may not need to get involved with government programs.
2. 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.

I hope you can see that the transition plan should also be tied to a special needs trust and a financial plan for supports after your adult child exits the special education system. A well-planned 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

What we hope to accomplish here is to give you some critical areas you should be working on at various times in your child's special education experience.

Early Intervention Years

Your child has been diagnosed with a developmental disability. Your child's eligibility for early intervention and special education services has been established. This is the time to begin a financial fund that will create possible employment opportunities and/or supports and services for him after exiting the special education system. This is much like the college fund, saving money for a college education for your children who do not have developmental disabilities.

Early Childhood Years (ages 3-5)

Find out about assistive technology and environmental modifications to help your child become as independent as possible. You can have an assistive technology evaluation done, as part of the IEP, for your child at no cost. If there are technologies available that can enhance your child's educational goals, you should make assistive technology part of the Individual Education Plan.

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.

New Children's Waiver. At the writing of this manual the State of Illinois is in the process of submitting a new Waiver for Children with Developmental Disabilities. It is expected that the new waiver will be submitted for approval by the Center for Medicare and Medicaid Services (CMS, the feds) by January, 2007. The Children's Waiver will have many options available for eligible children. Options in the waiver will be similar to early intervention services but with more choices. For more information on the Children's Waiver contact The Arc of Illinois or visit our website: www.TheArcofIL.org and look for the Children's Waiver Section on the left hand side of the homepage.

Elementary School Years (ages 6-12 years)

In the early years we want to develop a sense of value and work. Everyone works in our society. Children should value their own contributions to their families and community. They should know that work is rewarded by money. 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. Be making more choices about his personal life.
4. Be earning an allowance and opportunities to learn to handle money.
5. Be learning about the world of work and have "career exploration" included in their Individual Education Plan each year.

As the parent, you will want to:

1. Advocate that your child will be able to work in the future.
2. Begin to investigate about work opportunities for adults with disabilities in your community.
3. If you are also an employer, you will want to make sure that you hire people with developmental disabilities at work.
4. 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 get work.
5. Advocate with educators and professionals. Your child's future lies in the community along side his peers without disabilities. His goals include a meaningful career as an adult.
6. Once again investigate accessing assistive technology and environmental modifications to help your child become as independent as possible.

Age 12 – A Critical Time

This is when 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. What you want to do is set up a “Special Needs Discretionary Trust” for your child before his/her 13th birthday. It is very important to do at age 12 because this will relate to your child's eligibility for government benefits (SSI and Medicaid) at age 18. The Illinois Department of Healthcare and Family Services, formerly the Illinois Department of Public Aid, 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.

If you have not already done so, you may want to also 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: <http://www.irs.gov/pub/irs-pdf/p502.pdf>, Child and Dependent Care Expenses: <http://www.irs.gov/pub/irs-pdf/p503.pdf>. The Illinois Life Span Program can also direct you to financial planners who specialize in disability planning. www.IllinoisLifeSpan.org

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 <http://www.hrtw.org/tools/divorce.html>, the website of the Healthy and Ready to Work National Center.

Middle School Years (ages 12-14)

IDEA is the federal special education law requires that a Transition Plan be part of your child's Individual Education Plan, starting at age 14 years. Before the Transition Plan is written, we recommend that you read as much as you can about transition planning and different opportunities that a transition plan offers the student.

You should belong to a parent organization for your child's specific disability (for example, The Arc of Illinois, the National Association for Down Syndrome, the Autism Society of Illinois). Contact The Arc of Illinois' Life Span Project (www.illinoislifespanspan.org) to find parent organizations and support groups in your area. You will want to find out what resources and supports they have available related to transition.

You and the student should participate fully as a member of your child's Individual Education Plan Team. Work individually with your child to prepare him to take an active role as an Individual Education Plan Team

member.

Now is the time to learn about some of the tools being used to help teens and young adults prepare for their future, such as person-centered planning and MAPS (Making Action Plans):

<http://www.usd.edu/cd/systemschange/primer/maps.htm>

Make sure that work experiences are built into your child's IEP, starting with in-school jobs, community volunteer work, and paid work in the community after age 16.

It is critical that all paid work has social security taxes (F.I.C.A.) taken out of the paycheck. This will have major benefits for health coverage (under Medicare) in the adult years after school.

Transition Planning is all about real work experience, so say "no" to "*vocational readiness*" and "*pre-employment training*" that is offered only in a sheltered environment (or simulated sheltered workshop within a school setting). Say "no" to unpaid make work jobs such as emptying garbage cans in the school. Your transition plan should have the objective of a number of paid work experiences during the transition years.

Another tool in helping to plan for a successful transition is our "Day in the Life Worksheet". Remember that under IDEA, all aspects of transition must be included in the Transition Plan. Use this worksheet to help with transition planning and developing appropriate IEPs during your student's transition years.

The importance of the IEP for transition planning

Having an IEP transition plan that includes employment in the community, as well as a detailed plan to address all needed skills for employment and independent living, is of utmost importance.

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 under 21. There is not any law for adults with disabilities that is so powerful and comprehensive. IDEA states what student's rights are, 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 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 a student a job only in a segregated setting such as a sheltered workshop is not permissible. Some school districts have transition coordinators and have developed 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 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. You should be pro-active! Do not be afraid to say that, "John likes being around pets so I think we should try for a paid internship at the veterinary clinic in our town." You get the picture. Have your own ideas thought out well in advance of the transition planning

meeting.

Another option would be that you develop your own plan, which could include, for example, a proposal for starting a small business as the means to become self-employed; or a job in your community which 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.

This is no longer acceptable or appropriate.

Today, youth and adults with developmental disabilities need to be ready to join the workforce once they graduate from high school. Contact The Arc of Illinois’ Lifespan Project for information and technical assistance for your advocacy efforts. (www.illinoislifespan.org)

You have the right to appeal any decisions related to service and supports in your student’s IEP. The place to start in appealing any decision made by the IEP team is by a written request for another IEP meeting.

Refer to the ISBE special education rights manual for parents for additional information:

http://www.isbe.net/spec-ed/parents_rights.htm

(Available for free download in English and in Spanish).

If the issues are not resolved at the IEP meeting, you can then submit a request for mediation. Nowadays, schools districts and families strive to resolve their differences through the mediation process. Of course, if this is not successful, then filing a request for a due process hearing is the next advocacy step to pursue.

Information about appeals related to special education services, mediation and due process rights, along with the required forms, can be found on the Illinois State Board of Education (ISBE) website:

<http://www.isbe.net/spec-ed/> Refer to the sections on “Mediation,” “Due Process” and “Civil Rights Complaints” for instructions.

You should also contact the Parent Training and Information Centers in Illinois (listed earlier in this manual) for further information about special education and transition rights.

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 be doing 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?

This 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			
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

High School and Transition Years (ages 14-21)

One of the most important decisions you and your child will have to make is when he will exit the special education system. We strongly recommend that students remain in special education as long as the legal mandate allows and in Illinois it is until the age of 21. We recommend that students remain in the special education system until age 21. This should be a clearly stated goal in your child's Individual Education Plan.

This is an individual choice for every student, but you will need to decide in advance if graduation will be at age 18 or age 21. This will involve whether or not your child will receive a "certificate of completion" or a regular high school diploma. This must be determined in advance of the 18th birthday, and it must be part of the IEP. Students who have IEP's can, under certain conditions, remain in high school until age 21 in order to access vocational and transition services even if they have earned all of the credits needed to graduate. Contact your Parent Training and Information Center (PTI) for more information.

Fortunately for youth 18-21 years old who have IEPs, a new Illinois law, referred to as "**Brittany's Law**" (<http://www.thearcofil.org/document.asp?did=96>) took effect in January 2005. This law permits students with IEPs who have completed their high school graduation requirements prior to age 21 to participate in their graduation ceremony with their class, "bank" their diploma, and continue to utilize their IEP until age 21 for the purpose of participation in vocational training and transition services. Contact the Arc of Illinois for additional information about Brittany's Law.

Contact your local Dept. of Human Services Division of Rehabilitation Services office to "open a case" for your child at the time of their 16th birthday.

You will want to investigate to find out 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 and the student will want to get to know the Transition Coordinator at your child's high school who is part of the school's staff.

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 should have employment expertise beyond the regular special education staff.

You will also want to find out about the vocational training options available at your child's high school, as well as in your school district, for both "special education" and "regular education" students. Inclusive vocational experiences for the "regular students" may be more desirable to the student. 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 beyond regular special education classes.

Spend 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 <http://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. You are really 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.

Your objective will be to 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.

You want paid real work experiences that give the student a variety of experiences so he can begin to determine the types of employment he is interested in pursuing for a career during these transition years.

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!

Illinois Division of Specialized Care for Children

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

One of the responsibilities of the DSCC consultants is to assist with transition planning. Families whose young adult is enrolled in DSCC should make sure to ask their DSCC consultant for assistance with transition. Be sure to invite the DSCC consultant to participate in IEP meetings and staffers 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.

More transition information for families whose child is participating in DSCC is available on the DSCC website: <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, including a brochure: http://www.illinoisAAP.org/IL-Teen_Trans.pdf

The Seventeenth Year – A Critical Time for Planning

We recommend that you make the application for Supplemental Security Income (SSI) and Medical Benefits (Medicaid) eligibility determination a part of your child's IEP. If you are applying for the first time, the time to apply is 30 days before your child's 18th birthday. This will insure that this gets done before your child exits the special education system.

At age 18, the person with developmental disabilities can become eligible for both Medical Benefits (Medicaid State Program) and Social Security (federal program), based upon their income and assets.

Age 18 is when the state government and the federal government stop "counting" (called "deeming" in official language) the income and assets of the person's parent/guardian. This is extremely important information. **It means that your child is now 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 looked upon for important public services.

Agencies and programs that accept government funding for their services cannot also bill your child or you, for any additional amounts. The only income that can be looked at is the income of your adult child. Organizations are not allowed to require you to participate in fundraising activities or other fees. (For more information see the DHS/DDD Program Manual, <http://www.dhs.state.il.us/serviceProviders/grantsContracts/pdfs/ProgManualAFY2005.PDF>)

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. Your Individual Service Coordinator or Case Manager will also have information about this.

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 can also be eligible for Medical Benefits (Medicaid) health insurance for the first time at age 18.

Also note that some people with developmental disabilities receive SSI and/or Medical Benefits (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 Medical Benefits (Medicaid) turns 18, they do not automatically get 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 still eligible is to actually apply for each of these programs. If you are found not to be eligible we **strongly recommend that you appeal this decision**. Often times these decisions can be turned around if they are appealed.

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

ACTIONS

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 Medical Benefits (Medicaid) health insurance, (Be sure to attach a copy of your SSI application confirmation to your application for Medical Benefits (Medicaid) insurance.)

A Different Kind of Transition Plan (ages 18 – 21).

If you and the student have made the choice to remain in special education until age 21, there are many opportunities available to you to enhance employment experiences and career development.

At this time the student and the IEP Team need to look at special education much differently. This is not the time to pursue only classes in the high school. It is the time to explore different careers and options available at your community colleges, work-study programs, academic electives and post-secondary education.

We recommend that the last three years of special education be devoted to at least three or four different paid work experiences each year based upon the student’s goals.

This is also a good time to contact friends, family, neighbors and community members regarding job options for your child. Research shows that these natural contacts often result in the most satisfying work experiences.

This is also the time to begin investigating the adult developmental disabilities community system in your local area. Between the ages of 18 and 21 we would recommend that you visit and research all options in the adult system.

The Individual Service Coordination (ISC) agency or PAS agency (Preadmission Screening) in your area can be very helpful and provide you with a great deal of information about services in your area. Think of the Individual 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 new form (implemented by DHS in 2004) called PUNS (**Illinois Prioritization of Urgency of Need for Services**) which is designed to track adults with developmental disabilities seeking services and supports.

All people applying for new services besides special education must be enrolled in the PUNS. This includes both children and adults.

More information about PUNS and a copy of the form can be found on the Arc of Illinois website: <http://www.thearcofil.org/document.asp?did=79>, as well as the PUNS Manual.

The Illinois Department of Human Services, Division of Developmental Disabilities, now has a website with information about PUNS. <http://www.dd.illinois.gov/>

You cannot, however, apply for PUNS online or over the telephone. You must contact the ISC agency in your area for an appointment. It's a good idea, however, to download both the application form and the PUNS manual from the Illinois Lifespan website and read them both carefully prior to your appointment with the ISC agency.

As your child gets closer to his last year of special education you will want to have a working relationship with an individual service coordinator and begin to invite him or her to your child's IEP meetings. This should be a goal in the IEP.

Another goal in the IEP should be having your adult child apply for Medical Benefits (Medicaid) eligibility for adult services. Remember that there are two steps in this process: first, apply for Medical Benefits (Medicaid) health insurance and second, apply for a Level 2 Medical Benefits (Medicaid) screening from the ISC agency. **Medical Benefits (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.) However if your child is found ineligible you should always appeal that determination!

It is in the best interest of your adult child to learn all you can about Medical Benefits (Medicaid) eligibility, the adult service system and the role of the Individual Service Organization in your area. The planning on these critical areas may make the transition to adult services much easier.

Two critical things you need to remember. You need to register for PUNS in order to get new children or adult services. You need to determine eligibility for Medicaid. Make these two issues part of the IEP.

Straight Talk on PUNS - Prioritization of Unmet Need for Services by Charlotte Cronin

A few years ago, advocates celebrated a historic victory when a bill was passed by the Illinois General Assembly creating a cross-disability database or waiting list for services for people with disabilities in Illinois.

Now, for the first time, disability advocates can anticipate having real and accurate information about the needs, met and unmet, of people with disabilities in Illinois. In 2004, the State began officially gathering that information for persons with developmental disabilities using a survey tool called the Prioritization of Urgency of Need for Service (PUNS).

The name is an unfortunate acronym because, for us, PUNS is no joke.

PUNS will allow us to have accurate information to use as advocates as we talk to our policymakers.

PUNS will be the tool the state uses as it decides who will receive services on an individual basis.

PUNS will be the tool the state uses as new programs and services are being developed.

The PUNS Survey is the result of a year and a half of planning and design by Celia Feinstein of Temple University in Pennsylvania and the Illinois Department of Human Services. Ms. Feinstein was brought to Illinois by the Illinois Council on Developmental Disabilities after developing a similar survey in Pennsylvania. Based on that survey, Pennsylvania increased funding for disability services by \$835 million!

History tells us that this is an important effort!

THE PUNS SURVEY IS A FAMILY SUPPORT ISSUE.

As with any new project, there has been plenty of confusion. Many people perceive the PUNS survey as being ONLY for people anticipating the need for residential services. Others perceive the survey as being only for adults.

The survey is for **ANYONE** or the family of anyone anticipating the need for services in the next five years. The person with a disability must have a developmental disability as defined by the Division of Developmental Disabilities.

For families of minor children the need may mean respite or after school care. It may mean access to therapies or equipment or home modifications. Do not think about available services or specific programs; think about what your need is.

Think about what you haven't been able to get, either because it doesn't exist or because it is not available to you.

If you do not anticipate having a need in the next five years, the PAS agent is not supposed to complete the survey! So be thoughtful about your needs! This is your chance!

Families that include members with disabilities have a hard time acknowledging their needs. Our need to be self-sufficient and competent is vital. Our need to present ourselves to the world as "normal" is powerful. All we want to do is lead a typical life. We bury our struggles.

THIS IS NOT THE TIME TO BE PROUD. NOW IS THE TIME FOR YOU TO STEP UP AND BE COUNTED.

This is the time to think critically about what our loved one with a disability needs to be successful, either in your home or his home in the community.

Your willingness to complete the survey will allow us to advocate for family support programs!

At the writing of this manual, just over 10,500 individuals have completed the survey.

THIS IS HOW TO DO IT.

Call your local Pre-Admission Screening (PAS) Agency (ISC Agency). They must fill out the survey for you with your input. You can identify your PAS agency on the web at <http://www.dhs.state.il.us/OfficeLocator/> or through Illinois Life Span on the web, www.illinoislifespan.org, or by phone, 800-588-7002.

Your PAS agency representative will make an appointment to meet with you, probably in your home, or possibly in their office.

The process of filling out the form involves a face-to-face conversation between the PAS agent and the person with a disability, a family member or a guardian, and any other person the individual with a disability wishes to include. The survey represents the combined perception of all these parties.

The PUNS survey must be updated on an annual basis.

At twelve months, a notice will be issued to all parties of the need to update the form. If not updated, an additional warning will be submitted of the intent to close the PUNS record.

Some people report being told that they don't qualify or that they're not eligible. Others report being told that if they don't have a need within five years that they don't need to complete the PUNS. Everybody with a developmental disability who anticipates a need within the next five years should complete the PUNS form.

Think critically about your needs. Even if it is "just" respite or "just" after school supports, or "just" transportation.

If you are not satisfied with the survey, feel it has been filled out inadequately or if you feel you have been inaccurately turned down in your request to fill out the survey, you should contact your DHS Network Facilitator at 217-524-2521 or 312-814-2735.

Please also contact Mike Kaminsky at the Illinois Life Span Project at 800-588-7002. We are trying to understand how well things are going and Mike is tracking questions and concerns.

Also, please remember that inclusion in the database does not assume eligibility for services or guarantee the receipt of services.

WHAT DOES THE FORM LOOK LIKE?

The PUNS form first categorizes need by three levels of urgency.

Emergency: the individual or caregiver needs support immediately;

Critical: the individual or caregiver needs support within one year;

Planning: the individual or caregiver needs support within 1-5 years or their caregiver is aged 60+.

Then it asks you to identify supports and services you or your loved one with a disability need or will need in the future. Even if you are doing well now, you need to think about what you need to continue doing well! Our families should not have to become dysfunctional to access help!

Think carefully about the choices being presented. Most will be obvious.

The PUNS Survey is a new and exciting opportunity for Illinois advocates. But it is frustrating. As with any new project we are learning. Some question if the PUNS survey is asking the questions we want to answer. Do we really have the opportunity to share our needs? Others wonder if we shouldn't be asking for

information for more than five years out. Maybe. Probably. As this process goes forward we will have opportunities to ask for changes to the survey.

But, we must step up and use it to understand it! Please take this opportunity to contact your PAS/ISC Agency and ask for an appointment today!

The World of Adult Services and Supports

The Adult Service System in Illinois

At age 21, your adult child will exit from the special education system. If he is not employed and needs further community services, you will need to access the adult system in Illinois. Many of the timelines and resources we recommended in the special education transition part of this report can make this transition much easier. If you have followed our recommendations, some of this section may be repetitive.

The key to the adult service system in Illinois is Medical Benefits (Medicaid) eligibility. If your child has not made Medical Benefits (Medicaid) eligibility a part of the transition plan, you will now have to establish Medical Benefits (Medicaid) eligibility. If your adult child has mental retardation or a related developmental disability and has been found eligible for SSI, Medical Benefits (Medicaid) eligibility should be somewhat easy. The application for Medical Benefits (Medicaid) can be obtained from the DHS website (it is a single application form for Medicaid, Food Stamps and cash assistance). You cannot apply online. Here is a link to the application form:

<http://www.dhs.state.il.us/serviceProviders/Forms/IL444-2378B.pdf>

To apply for medical assistance, visit the nearest Illinois Department of Human Services (DHS) office. Staff will help you submit an application... You can bring the application which you have downloaded with you to the appointment.

Some hospitals, medical centers, clinics and health departments have staff members designated to help their patients apply for Medical Benefits (Medicaid) insurance. It's a good idea to check at the place where you get medical care to see if there is a staff person who can help you apply for Medicaid.

Here is a link to information about Medical Benefits (Medicaid) for adults (over 18) with disabilities:

<http://www.dhs.state.il.us/ts/fss/aabd.asp>

If you are unable to go to a DHS office because of 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. Human Services offices in your area 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:

<http://www.hfs.illinois.gov/medical/apply.html>

Please note that HFS has a contract with DHS to handle applications for Medical Benefits (Medicaid) for people 18 years of age and older. You must contact a DHS office for an appointment or to get an application. You can find the DHS office for your area by visiting the Illinois Lifespan Project website: www.illinoislifespan.org.

The Illinois Department of Public Aid has a new name: it is now called the Illinois Department of Healthcare and Family Services

The website is www.hfs.illinois.gov

To apply for Medical Benefits (Medicaid) eligibility you will have to connect with both the Illinois Department of Human Services (they handle all Medical Benefits (Medicaid) applications) as well as with the local Individual Service Coordination agency that serves your area. (Please note that the ISC case manager does not process the Medical Benefits (Medicaid) application; this is done by the Department of Human Services.) The ISC case manager completes the application for “adult services” (extra services for adults with developmental disabilities) under Medical Benefits (Medicaid) (called the waiver application) after your “adult child” has completed the regular Medical Benefits (Medicaid) application.

When adults with developmental disabilities who get SSI qualify for Medicaid, this means that they have both Medical Benefits (Medicaid) health insurance (called the Medical Benefits (Medicaid) State Plan) as well as Medical Benefits (Medicaid) Waiver services (this pays for services and supports obtained from providers contracted with DHS).

The Illinois Life Span Project can provide you with the location of the nearest ISC for you. As well as the DHS office to apply for Medicaid. The Illinois Life Span Project can be reached at 800-588-7002 or 708-206-3993, or www.illinoislifespan.org

In addition, persons applying for Medical Benefits (Medicaid) for the first time after July 1, 2006, or having their first Medical Benefits (Medicaid) re-determination after this date, must also provide proof of their U.S. citizenship as part of the application process unless you are on SSI. Here is a link to the latest information on this topic from the Centers for Medicare and Medicaid Services:

<http://www.cms.hhs.gov/smdl/downloads/SMD06012.pdf>

The Sargent Shriver Center on Poverty Law, headquartered in Chicago, has filed a lawsuit regarding the citizenship requirement for Medical Benefits (Medicaid) applicants, including children, youth and adults with disabilities. This case has not been settled. For more information on this topic, please see <http://www.povertylaw.org/news-and-events/misc/medicaid-lawsuit/default> or call the Sargent Shriver Center at 312-263-3830.

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 Medical Benefits (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. Develop a strong Transition Plan in your child’s IEP, starting at age 14
2. Complete financial planning and set up a Special Needs Trust by age 12
3. Apply for SSI
4. Apply for Medical Benefits (Medicaid) health insurance (via DHS)
5. Apply for Medical Benefits (Medicaid) waiver services for adults with developmental disabilities at your ISC agency
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)

The Gatekeepers. What are Individual Service Coordination Agencies (ISC) or Preadmission Screening Agencies (PAS) and what is their role in helping adults with DD get jobs and other services?

In Illinois the system point of entry for adults with developmental disabilities to get information about and access to adult services is the Individual Service Coordination agencies.

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 of 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 too. Those requests must be directed to the DHS/DDD Network Facilitator for your region.

A detailed description of the ISC program can be found in the DHS, Division of Developmental Disabilities Program Manual:

<http://www.dhs.state.il.us/mhdd/dd/pdf/DDfy03-intro.pdf>

Contact information for the network facilitators is located at <http://www.dhs.state.il.us/mhdd/dd/networks.asp>

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.

Eligibility determination is the first component and most 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 by 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 User's Group Home Page, <http://www.cpinternet.com/~bhill/icap/>, or the ICAP home page of the publisher, Riverside Press: <http://www.riverpub.com/products/clinical/icap/home.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 Medical Benefits (Medicaid) waiver for home and community based services. Typically, an individual with mental retardation or related developmental disability will meet this requirement.

As a part of Medical Benefits (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 Medical Benefits (Medicaid) Home and Community Based Service waiver.

Unfortunately, at the present time, services are not always available, or may only be available in certain area of the state. In addition, DHS/DDD has determined certain groups to have priority for receiving services and will first address "emergency cases". Information on the current "priority groups" can be found on the DHS/DDD website: <http://www.dhs.state.il.us/mhdd/dd/priorityPopulations.asp>

This situation may be subject to change. Contact the Illinois Lifespan Project www.illinoislifespan.org for additional information.

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. There are generally 24 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 Advocacy Plans (ISSA plans) for people with developmental disabilities who have Medical Benefits (Medicaid) waivers. For more information on ISSA plans, see <http://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 9 state-operated developmental centers and programs. Services funded by the State of Illinois are delivered in the least restrictive setting appropriate for the individual.” <http://www.dhs.state.il.us/mhdd/dd/>

At the present time, changes in the DHS/DDD system could mean, for example, that instead of “picking” one provider in your region in order to access available services, the adult with developmental disabilities who has a Medical Benefits (Medicaid) waiver would be able to access services and supports from an individualized menu of options, which could include but would not be limited to traditional provider agencies. (This would be similar to how the Early Intervention system currently operates in Illinois.)

The Illinois DHS/DDD Home-Based Support Services Program is moving toward a system of provider choice and portability of services based on this model. Eligible applicants who are selected for this program are able to select services and supports needed to enable them to continue to live at home and to work in the community. For more information about options available from the Home-Based Support Program, contact your ISC agency case manager or the Family Support Network. An application for this program is available for free download on the Family Support Network website:

<http://www.familysupportnetwork.org/dhsbrochure.htm>

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 Medical Benefits (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 Medical Benefits (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: <http://www.thearcofil.org/>

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: <http://www.self-determination.com/index.html>

A New Adult Waiver for Individuals with Developmental Disabilities is being at the issuance of the revised manual. Changes in the adult waiver are very exciting because services and supports being discussed are very flexible and offer many options to people. This is a dramatic change from the traditional services that have been available here in Illinois. A very exciting option being offered on a pilot basis is the new Individual Support Option. We believe this will be the model for services/supports in the future. At this time the proposal is only a draft but it should be submitted to the Centers for Medicaid and Medicare (the feds) in January, 2007. Contact The Arc of Illinois for more information or check their website look for Adult Waiver: www.TheArcofil.org

The Division of Rehabilitation Services in Illinois

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”.

In December, 2004, the DHS Division of Rehabilitation Services made a major change in the way they deliver services, a change that can have positive implications for adults with developmental disabilities. This change means that Illinois will now implement the “Order of Selection”, as stipulated in the Rehabilitation Act, as outlined below:

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

Background

The policy governing the “order of selection”- meaning which adults with disabilities are deemed eligible for vocational rehabilitation - can be found in the federal legislation, the Rehabilitation Act. The following is a link to the full text of the federal legislation pertaining to the “Order of Selection” which DHS/DRS is now implementing in Illinois:

http://a257.g.akamaitech.net/7/257/2422/14mar20010800/edocket.access.gpo.gov/cfr_2002/julqtr/34cfr361.36.htm

A news alert from The Arc of Illinois regarding the current DHS/DRS budget shortfall and the move underway to implement the “order of selection” for VR services in Illinois (<http://www.thearcofil.org/document.asp?did=80>) provides the following background:

Vocational Rehabilitation Shortfall
Released: 12/2/2004

Today, Rob Kilbury, Director of the Division of Rehabilitation Services, called together stakeholders from around the state to discuss a \$4 million shortfall in the state's Vocational Rehabilitation Services budget.

The Director's current thinking is that the Division will make the top priority for vocational rehabilitation individuals with the "most significant" disability. To do this, the Division will amend its current "Order of Selection" for services to the Fed's. The resulting changes may affect your current contracts with the Division of Rehabilitation Services. Therefore, the top priority for vocational rehabilitation services will be individuals with severe disabilities.

PROPOSED CHANGE IN ELIGIBILITY OR "ORDER OF SELECTION"

The Division is recommending that a new category for priority services be added which would be a change in the definition of "most severely" disabled. This is my understanding of the new definitions in order of priority.

Top Priority. "Most" significant disability is an individual with three or more functional limitations requiring two or more substantial services.

"Very" significant disability is an individual with two or more functional limitations requiring one substantial service.

"Significant" disability is an individual with one functional limitation.

Resources and services will be allocated based upon the person's disability in accordance with the federal guideline requiring service to individuals with the most severe disabilities. If resources are not available, individuals will be placed on waiting lists.

The local counselors will be responsible for evaluating eligibility for vocational rehabilitation services and the documentation of serious limitations. (The Arc of Illinois, 2004)

Analysis

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.

When the order of selection is implemented, this means that applicants for VR services will be ranked in order of the "significance of their disability" and selected 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 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)

This change in DHS/DRS policy has the potential to have a positive impact for youth and adults with developmental disabilities who want to work.

As discussed earlier in The Arc Family Manual, often people with developmental disabilities are informed that they must “choose” between DD and VR 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.

The new change in DHS/DRS to implement the “order of selection” for access to vocational rehabilitation services should be regarded as a window of opportunity for transition-age youth and adults with developmental disabilities.

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 Arc Family Manual).
6. Contact The Arc of Illinois’ Illinois Lifespan Project (www.illinoislifepsan.org) for information resources and technical assistance for your advocacy needs.

Tools to help you with applying for adult services, including services from DHS/DRS, and keeping your own transition records can be found in the Appendix of this manual.

A new tool recently released by the Institute for Community Inclusion is a helpful consumer and family guide for people seeking vocational rehabilitation services: **Getting the Most from the Public Vocational Rehabilitation System**, available at <http://www.communityinclusion.org/publications/pub.php?page=to19>

There are a number of ways that people with developmental disabilities can participate in DHS/DRS services:

1. People with developmental disabilities, including people who also have a physical disability, can receive personal assistant (PA) services at home from a separate Medical Benefits (Medicaid) waiver, the DRS Home Services Program. Medical Benefits (Medicaid) eligibility is required, as well as an assets test. DRS Home Services is available to eligible persons from age birth-59 years who have disabilities.
2. People with developmental disabilities who do not meet the eligibility for HCBS Medical Benefits (Medicaid) Waiver services for adults and/or are not found eligible for SSI. This can include, for example, persons with mild mental retardation (EMH), persons who have “only” epilepsy or “only” cerebral palsy that is not “severe”. Under the current “order of selection,” these individuals will not get first priority for DRS services and may be put on a waiting list for vocational rehabilitation supports. It is, however, still important to apply for DRS services and maintain all documentation.
3. People with developmental disabilities, eligible for HCBS waiver services, can choose community-based employment rather than participation in day training or sheltered workshop programs.
4. People with developmental disabilities who do not qualify for Medical Benefits (Medicaid) and SSI because they are “over assets” (not over-income). DHS/DORS has a higher assets limit (currently \$10,000) than DHS/DD and Medical Benefits (Medicaid) (currently \$2,000). Remember, however, that people who are not enrolled in Medical Benefits (Medicaid) and/or SSI may be asked to pay for DHS/DRS services.

In Illinois, people with significant development disabilities have sometimes traditionally been told that they must “choose” between Division of Developmental Disabilities and Division of Rehabilitation Services (DORS). Coordination between these two Divisions of the Department of Human Services has sometimes been complicated. This practice should be ameliorated by implementation of the “order of selection.”

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.

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 Medical Benefits (Medicaid) and Food Stamp applications.

Your local office can be found using the DHS Office Locator: <http://www.dhs.state.il.us/OfficeLocator/>

While your child is still in high school, you should connect with DRS, get a “case opened,” and invite the DRS counselor to join the transition team. Some high schools have on-site DRS counselors, while others collaborate with the local DRS offices. Check with the transition coordinator in your high school for more information. Be sure that collaboration with DRS is written into your child’s IEP/transition plan by their 16th birthday.

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 try this new option, be sure that you save the request form on your computer as well as printing out a hard copy for your records.

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.

Consumers and families 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.

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 <http://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.illinoislifespanspan.org), as well as your state senator and state representative for assistance with advocacy related to DHS and other state agencies.

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 mean 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 then set the stage for vocational counselors avoiding to serve individuals with severe disabilities. This is extremely problematic because of the federal mandate to serve people with severe disabilities. Other outcomes include the VR client’s ability to make an “informed choice” regarding participation in “extended employment” (non-integrated or sheltered employment) provided that the VR program also makes available options to participate in integrated employment. In other words, “extended employment” cannot be the only option

offered to a client, www.ed.gov/legislation/FedRegister/finrule/2000-1/

Vocational rehabilitation programs do not typically offer specialized services and supports for persons with developmental disabilities. In many states, including Illinois, specialized voc rehab 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 DORS.

Sometimes families and consumers hear that “you can’t be served by two waivers, so you have to pick one.” What this refers to is the Medical Benefits (Medicaid) waivers that are available for adults in Illinois. One waiver, known as “DORS 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 Medical Benefits (Medicaid) waivers in Illinois see <http://www.dpailinois.com/hcbswaivers/>)

Vocational rehabilitation services 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, <http://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 Medical Benefits (Medicaid) Waiver services at the same time; they do not have to choose between one and the other.

Accessing the DHS Division of Rehabilitation Services (DORS) <http://www.dhs.state.il.us/ors/>

Regulations governing the Illinois Department of Human Services, Division of Vocational Rehabilitation can be found at: <http://www.ilcode.net/ILCODE/ILCODE.dll/slist?stitle=89&spart=553>

Persons with a developmental disability are able to request services and the Institute for Community Inclusion has recently released a helpful consumer and family guide for people seeking vocational rehabilitation services: **Getting the Most from the Public Vocational Rehabilitation System**, available at <http://www.communityinclusion.org/publications/pub.php?page=to19>

Supports from DRS must be considered “able to benefit from VR services” unless proven otherwise in a “trial work experience” arranged by DRS: <http://www.ilcode.net/CodeText.asp?citeid=660250>

When you add to this the lack of a good transition plan, the adult system can be a real “tiger by the tail” for individuals seeking employment services. This is exactly why you should do your research on Medical Benefits (Medicaid) eligibility, services of the Division of Developmental Disabilities and services of the Division of Rehabilitation Services before exiting from the special education system.

For additional information and advocacy assistance regarding vocational rehabilitation for people with developmental disabilities, please contact the Illinois Life Span Project, www.illinoislifespan.org

Health Insurance and Employment- Plan ahead for transition success (new)

section)

In previous sections of this manual, we have discussed the importance of Medical Benefits (Medicaid) as a means to access services and supports for adults with disabilities.

However, Medical Benefits (Medicaid) is also a very important source of health insurance for people with disabilities in the U, S.

Many- but not all- adults with disabilities are able to get Medical Benefits (Medicaid) health insurance. However, some people may find that Medical Benefits (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 Medical Benefits (Medicaid) regulations do permit individuals to have both private and Medical Benefits (Medicaid) health insurance. The private insurance is considered the primary payor, and the Medical Benefits (Medicaid) insurance is the secondary payor.

Successful transitions 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”

http://www.dol.gov/ebsa/publications/life_changes.html and

“Personal Assistance Services in the Workplace”

<http://www.dol.gov/odep/pubs/ek97/personal.htm>

“Work Changes Require Health Choices Protect Your Rights”

http://www.dol.gov/ebsa/publications/work_changes.html

“ELaws Health Benefits Advisor”

<http://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, here is a summary of the process involved in applying for Medical Benefits (Medicaid) health insurance:

In Illinois, this is a 2-part process. The information in this section pertains to persons over age 18 that were not previously enrolled in Medical Benefits (Medicaid) or SSI (both state and federal government regulations require that from the individual’s 18th birthday on, 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
<http://www.ssa.gov/notices/supplemental-security-income/>

Next, you must obtain an application for Medical Benefits (Medicaid) from the Illinois Department of Human Services:

<http://www.dhs.state.il.us/serviceProviders/Forms/IL444-2378B.pdf>

And submit it, following the instruction on the website (note that you cannot apply online)

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 Medical Benefits (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 up to their 19th birthday. 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 or not).

Remember that under the new All Kids system (which includes Medical Benefits (Medicaid)(called All Kids Assist), and All Kids Premium (which includes both the former Kid Care insurance-(Medical Benefits (Medicaid)buy-in) which was based on the parent’s income, along with the new All Kids , which allows families at any income level to “buy in” to the Health Benefits Plan redetermination now means “finding out which All Kids level you are eligible for “ (whether you will have to pay premiums or not, and how much you will have to pay)

In the past, redetermination meant finding out if you were still eligible, based upon your (parental) income. If parental income was “too high”, children could lose their coverage. This old type of redetermination has now ended. 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 (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: http://www.workworld.org/wwwwebhelp/poverty_guidelines_federal.htm

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 a youth covered by All Kids insurance turns 19 years old, the family is sent a special redetermination form, as outlined below by HFS:(email correspondence,9/06)

Before children reach their 19th birthday, a special redetermination notice (Form 3766 or 3766A) is sent to the family. If the child receives SSI, is pregnant, or has a child, the caseworker will review eligibility for medical benefits 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.

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 cheaper than their employment-based insurance coverage, or they can chose to have both HBWD and employment-based health insurance. (In this case, the employment-based insurance will be primary and the HBDW 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 do they have to change to a different Medical Benefits (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 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 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 Health Benefits status.

Be sure to let your medical providers (doctors, hospitals, clinics, pharmacies, and vendors) 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 section in this manual about options for youth who do not have health insurance coverage, so you will be prepared to deal with possible changes and options.

Here is an overview of other possible options for health insurance coverage, for youth who are unable to access health insurance either through employment, or from Medical Benefits (Medicaid) health insurance:

1. Remaining 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. However; this may not be possible for youth who have full-time jobs (regardless of whether or not the job provides insurance benefits)

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.)

<http://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&S>

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.

2. 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” Medical Benefits (Medicaid) health insurance if they do not receive insurance through their jobs.

Here is a link to the website and application form.

<http://www.hbwdillinois.com/>

3. 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:

<http://www.chip.state.il.us/>

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

a. National overview of transition and health insurance: From Healthy and Ready to Work National Center: www.hrtw.org

www.hrtw.org/tools/documents/Insurance_issues_tools.doc

b. Information on “getting and keeping health insurance in Illinois”

<http://healthinsuranceinfo.net/il.pdf> (Detailed consumer guide)

c. Information about all insurance coverage mandates in Illinois:

(Illinois Insurance Facts- overview of legal mandates:

http://www.idfpr.com/DOI/HealthInsurance/Mandated_benefits.asp)-

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.

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

Possible options include accessing health care at local, county or regional health departments (link to list of health departments: in Illinois: <http://www.idph.state.il.us/local/map.htm>)

Federally qualified health centers (FQHCS) (not-for-profit organizations who have contracts to operate health clinics which meet federal government standards) here is a link to a list of all of the federally-qualified health centers in Illinois: <http://ask.hrsa.gov/pc/searchresults.cfm?state=IL&zip=>

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: <http://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 Medical Benefits (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 is available from: <http://acesstocare.org/>

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:

<http://www.cbhconline.org/Helpline/index.htm#Uninsured>

Here is a link from the U.S. Health Resources and Services Administration (HRSA), Bureau of Primary Care, which lists all of the free clinics in Illinois: <http://ask.hrsa.gov/pc/searchresults.cfm?state=IL&zip=>

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 Medical Benefits (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 Medical Benefits (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. 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.

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 Medical Benefits (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 Medical Benefits (Medicaid) insurance and adult services which require Medical Benefits (Medicaid) enrollment.

If you have any questions about Medical Benefits (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.

Here is some comprehensive information 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 on a new website: <http://thedesk.info/PartD/>

The Original Medicare Plan is a fee-for-service plan that is available nationwide. With the Original Medicare Plan, you may go to any doctor, specialist, hospital, or other health care provider that accepts Medicare. Generally, a fee each time is charged each for a service from a provider (set amount out-of-pocket co-pays to reach deductible.) Once the deductible is satisfied, Medicare pays its share, and you pay your share (coinsurance or co-payment).

People under age 65 who have worked and receive SSDI (Social Security Disability Income) for 24 months, become eligible for Medicare after the 24th month.

What it covers: Plan pays for Hospitalization charges with charges individual with some co-pays.

May cover the cost of some services—such as home healthcare and doctors' visits—provided in such a facility.

Durable Medical Equipment (DME)

Medicare Part B - Durable medical equipment (such as wheelchairs, hospital beds, oxygen, and walkers)

The beneficiary pays nothing for the Medicare-approved services and 20% of the Medicare-approved amount for durable medical equipment.

What it costs:

Website: <http://thedesk.info/PartD/>

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 this 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 Medical Benefits (Medicaid) coverage.

LAW: The Employment for Disabled Americans Act of 1986 (Public Law 99-643) requires states to continue Medical Benefits (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 Medical Benefits (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: www.hdadvocates.org for more information about Medicare, Medical Benefits (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.

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- <http://www.ssa.gov/chicago/BPQYHandbookSep04.pdf>

Red Book on Work Incentives

A Summary Guide to Social Security and Supplemental Security Income

Work Incentives for People with Disabilities

Medicare Qualifying Period --SSDI ONLY

The first 24 months of disability benefit entitlement is the waiting period for Medicare coverage. During this qualifying period for Medicare, an SSDI beneficiary may be eligible for health insurance through a former employer. The beneficiary should contact the employer for information about health insurance coverage.

Continuation of Medicare Coverage

rsvp.icdi.wvu.edu/Training/APmanua/Module3/RED6M3.HTM#SEC3

SSDI beneficiaries can receive at least 39 months of hospital and medical insurance after the trial work period. This provision allows health insurance to continue when a person goes to work and is engaging in SGA.

Medicare for People with Disabilities Who Work

<http://www.rcep7.org/~ssawork/glossary/medicareDisabilities.html>

Certain people who have returned to work may purchase continued Medicare coverage, after premium-free Medicare coverage ends, due to work as long as he/she remains medically disabled. If the person becomes medically disabled again within 5 years (7 years for widow(ers) and disabled adult children) after the prior period of disability ends, he/she does not have to serve another 5-month waiting period to get benefits or Medicare.

The Medicare Rights Center (MRC)

www.medicarerights.org/aboutmrcframeset.html

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:

<http://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

<http://www.kff.org/medicare/disabilities.cfm>

Keeping Medicare and Medicaid When You Work:

<http://www.kff.org/medicare/7241/ssdi.cfm>

Services, Supports, Systems and Trends

At the writing of this revised manual many new developments in the provision of supports and services to children and adults with developmental disabilities are taking place. When the new federal waivers are approved one for children and another for adults we will see a new system of choices, options and services available to Illinois citizens. For up-to-date information on these new options contact The Arc of Illinois at 708.206.1930 or visit our website: www.TheArcofIL.org

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 Medical Benefits (Medicaid) funded system. This allows the state to then receive a 50% match from the federal government for community services that qualify for a Medical Benefits (Medicaid) match. One of the benefits to people and families in a Medical Benefits (Medicaid)funded system is that they are given “choice” of providers and their service funds are “portable” or 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 <http://depts.washington.edu/~transctr/ETP.html>

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 Supported Employment for People with the Most Significant Disabilities available at <http://www.dol.gov/odep/archives/ek01/support.htm>

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

PASS stands for “Plan for Achieving Self Support,” 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 met 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 Medical Benefits (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.

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:

<http://www.equiforequality.org/programs/tickettowork/index.php> and from Health Disability Advocates Workforce Development Project: <http://www.hdadvocates.org/workforce/llinoisSpec/illindex.htm>.

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

<http://www.passplan.org/>

<http://www.ssa.gov/work/ResourcesToolkit/generalinfo.html> (official site of the Social Security

Administration)

<http://www.workworld.org/wwwwebhelp/pass.htm>

<http://www.t-tap.org/training/onlineseminars/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 you 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 American 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.***

<http://www.nod.org/content.cfm?id=1537>

Currently, most adults with developmental disabilities in Illinois who are working may often 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 DORS 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 for in-house jobs.

Families of young adults with developmental disabilities need to make sure that their child is able to access employment experiences and transition training during the final years of their schooling. (For additional information regarding special education rights, IEPs and transition plans, contact one of the three Parent Training and Information Centers (PTIs) in our state listed 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 them for additional information and transition-related training opportunities at

<http://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 your responsibility 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.

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).

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 pro-active in transition planning.

For more information about employment options for adults with developmental disabilities, see The Arc of Illinois' 2004 report: Promoting Incentives for Integrated Employment and Self Employment in Illinois: <http://www.thearcofil.org/document.asp?did=54>

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 Medical Benefits (Medicaid) and SSI.
3. Ask for help along the way-contact Illinois Life Span (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. Keep asking 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 you apply to.
- 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 so clear cut as it is for persons under age 21 (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: <http://www.usdoj.gov/crt/ada/cguide.htm>

Chicago Kent College of Law's site, www.illinoislegalaid.org (or www.illinoislawhelp.org) includes The Guidebook of Laws and Programs for People with Disabilities, available for free download at http://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: www.equipforequality.org, with three offices around the state. 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:

<http://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:

<http://www.hhs.gov/ocr/504ada.html>

Programs and services receiving any funding from Medical Benefits (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, Compilation of Social Security laws, Title XIX, Grants to States for Medical Assistance Programs:

http://www.ssa.gov/OP_Home/ssact/title19/1900.htm

Illinois Medical Benefits (Medicaid) regulations, including regulations governing Medical Benefits (Medicaid) Home and Community Based waivers, can be found in the Illinois Administrative Code, Laws and Rules Governing Medical Assistance programs: <http://www.dpaillinois.com/lawsrules/index.html>, The Illinois Administrative Code, Title 89: Social Services:

<http://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 MEDICAL BENEFITS (MEDICAID) HOME AND COMMUNITY-BASED SERVICES WAIVER
PROGRAM FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

<http://www.ilga.gov/commission/jcar/admincode/059/05900120sections.h>

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" <http://www.nichcy.org/pubs/parent/pa9txt.htm>).

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.

<http://www.partnersinpolicymaking.com/makingyourcase/>,

Who Can Help with Advocacy for Children & 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 TTY

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

The service delivery system for adults with developmental disabilities in Illinois continues to change. In the past year, major changes have taken place in the two divisions of the Illinois Department of Human Services often involved with services for adults who have developmental disabilities: the Division of Vocational Rehabilitation and the Division of Developmental Disabilities.

Consumers and families need to get involved and become 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)

Be aware that 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 being willing to take chances, being a trailblazer, advocating for your rights, and focusing on your dreams.

The Arc of Illinois and the Illinois Life Span Project are here to help you

Parents and guardians of youth with developmental disabilities should have high expectations for successful transitions - expect that your young adult will hold a "real" job in the community and do everything in your power to make this happen.

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

Information resources and references

Agency overview

What's out there for adults with DD?

The government and you

Illinois law on continuing on parent's health insurance

Advocacy resources

Applying for benefits summary

Record-keeping forms for families

1. Program/benefit application record

2. Getting ready to apply

3. Documents checklist

4 A day in the life

5. Family transition toolbox

A. Information Resources

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.hbwfillinois.com/application.html
Illinois Department of Human Services	http://www.dhs.state.il.us/	Combined application for Medicaid/Food Stamps/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	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 Medical Benefits (Medicaid)waivers	SSI Food Stamps SSDI survivor benefits (if eligible)	Medical Benefits (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	Medical Benefits (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	Food stamps (depends on income) TANF- if dependent children General Assistance- if available from township	FamilyCare if parent of children under 18 on Medicaid/All Kids Medical Benefits (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 Special Circumstances
<p>Streets and roads, garbage 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</p>	<p>Food stamps Public housing Energy assistance General assistance TANF (if your adult child has children) Legal Assistance</p>	<p>Vocational Rehabilitation Services Developmental disability services Mental health services Paratransit Special recreation "special user fees" (discounts for some services)</p>	<p>SSI AABD-MANG (Medical Benefits (Medicaid)for people on SSI)</p>	<p>SSDI (if you have worked and become disabled, or parent/guardian becomes disabled, retires or dies) Medical Benefits (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</p>
<p>Some counties/ townships/municipalities have additional services</p>	<p>Other local programs</p>	<p>These are not entitlements- only "what's available", often waiting lists</p>	<p>Sometimes charitable resources available</p>	<p>Immigration status may affect eligibility</p>

Toolbox for Families: Instructions and Forms

1.

Getting Ready to Apply for Government Benefits – What Documents are 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	1. Birth certificate 2. Adoption or foster care	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. Foster care agreement	status	3. Department of Children and Family Services or contracting agency (http://www.state.il.us/dcfs/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	http://uscis.gov/graphics/index.htm U.S. Citizenship and Immigration Services office for your region

Applying for Government Benefits Summary

Program	Application Phone Info	Application - Form Online (forms only- you cannot apply online)	Agency Web site
Medical Benefits (Medicaid)Health Insurance	All Kids 866-468-7543(voice) 877-204-1012(TTY) Medicaid 800-468-75343(voice) 877-204-1012 (TTY) Health Benefits (Medicaid)for Workers with Disabilities 800-226-0768(voice) 866-675-8440(TTY)	Medical Benefits (Medicaid) www.dhs.state.il.us/ts/fss/dhs_foodStamps_fsai.asp (the same application is used for Medical Assistance, Food Stamps and cash benefits) Medical Benefits (Medicaid)for disabled working persons www.hbdwillinois.com/application.html	www.hbwdillinois.com
Food Stamps	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/mhdd/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

3.

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	

4.

Program/Benefit Application record

Program/benefit applied for	Application date	How submitted	Copy on file	Outcome	Follow up
SSI					
Medicaid					
Food Stamps					
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					

5. 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

Family Transition Toolbox

- 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)**