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## BRIDGING THE GAP BETWEEN PEDIATRIC AND ADULT SERVICES

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Most parents of children with special health care needs, at some point come face to face with the need to look at their child as a young adult. They usually must come to think about adult services, because of the age of their child. This is partly due to the advances in caring for children with chronic illnesses and disabilities, prolonging and improving life for many. The diseases, that, in the past, were thought to be only conditions of childhood, such as cerebral palsy, cystic fibrosis, congenital heart disease others, must now be planned for in a meaningful adult life. It is never too early to start considering how to cope with adult services for your child. (Although he/she reaches maturity, all parents tend to continue to think of their adult children as “my/our child.”) We hope you find the following information helpful.

### Adult Medical Services

By the time your child reaches young adulthood, usually considered to be during the ages of about 16-21, your pediatric specialist may start talking with you about transitioning your young adult to an adult doctor. If your doctor does not do this, **you should bring up the subject**. You need to know if a different doctor that cares for adults is needed, the pediatric specialist may suggest a doctor to see. If he/she doesn't know of another doctor, your DSCC care coordinator can help with this.

When you have a name, you should call the new doctor's office to make sure they will accept your young adult's insurance. It is also useful to call and make an appointment to establish care. The adult doctor will need the medical records of the young adult sent to him/her.

Here are some questions for you to think about and discuss: Does your young adult make his/her own appointments and keep them? Does he/she take his/her own medicine? Can he/she describe his/her medical condition? Does he/she know when to call the doctor?

### Guardianship and Alternatives to Guardianship – Issues

When your child reaches the age of 18, he/she is considered to be an adult and his/her own guardian by law. If you or someone else needs to be able to make decisions for the child/adult, you must look into **guardianship issues**. That means legally getting guardianship of the young adult. Getting guardianship of the youth should be considered for his/her lifetime. This may mean you will need a lawyer to handle the legalities and going to court, as well as identifying whom the guardian(s) will be. If you do not have the money for a lawyer, contact the local bar association and ask where you can get help. You can also ask your DSCC care coordinator about resources for this. It is also possible to ask the court to not charge you the usual court fee involved.

Guardianship is not the only way to safeguard your young adult's interests. Less intrusive ways are: a **joint bank account**, created to prevent rash spending; a **representative payee** can be named to manage the funds of a disabled person who gets benefits checks. A **Durable Power of Attorney for Property (POA)** may be useful for persons who are mildly or moderately disabled and capable of choosing another person to handle their money; a **Durable Power of Attorney for Health Care** may be helpful for persons who might need help in making health care decisions. Call **ARC of Illinois** at 1-815-464-1832 for information on these and other alternatives.

## **Medicaid and SSI**

**If your child has All Kids, he/she is eligible until his/her 19<sup>th</sup> birthday.** During his/her 18<sup>th</sup> year, he/she should apply for his/her own Medicaid card or coverage through Health Benefits for Workers with Disabilities. The ARC of Illinois Family to Family Health Information and Education Center may be able to answer your questions about health care coverage. Call toll free 1-866-931-1110. **If your child gets SSI payments, at age 18, he/she must reapply as an adult. If either Medicaid or SSI is denied and you believe the young adult is eligible, immediately file an appeal.** These applications should be done through your local Department of Human Services and Social Security offices. You may need to get letters from the physician(s) and send records with the paperwork. Your DSCC care coordinator may be able to help with the needed records. When a person has SSI, he/she may also be eligible for a Medicaid card. This should be explored with the SSI person you talk with. The young adult with a disability may also consider applying for Medicare if that is appropriate.

## **Adult Work Services**

If the child is eligible for Special Education Services, the school system is, by law, required to begin to transition the child into adult services at age 14. The child should be included in the Individualized Education Plan (IEP) meetings at age 14. This is so he/she can give input on what he/she wants. The Illinois Division of Rehabilitation Services (now DRS, formerly ORS) should be involved during the transition planning. The IEP should include what kind of work interests the child has and what he/she is able to do. The IEP should also include what training/services the school is going to provide and additional resources needed to accomplish these goals. These services must be provided at no cost to the parents. Your signature on the IEP only shows you were at the IEP. If you would like an advocate to go with you and help you at the IEP, see the list of resources included in this book. Give them as much time to put you on their schedule as you can.

You should have a copy of a booklet from the Illinois State Board of Education called [Educational Rights and Responsibilities: Understanding Special Education in Illinois](#) (*Revised 2009*). Please be sure to read page 48 and 49, Participation in Meetings. Call toll free number 1-866-262-6663 or the direct number 1-217-782-4321 (Springfield) with any questions about this booklet or to get your own copy. Also, the school should be able to provide the booklet or your DSCC care coordinator may be able to give you one.

If you have access to the internet, the ISBE Special Education homepage has many resources and is located at <http://www.isbe.net/spec-ed/default.htm>.