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Transition Planning

“Transition planning is a way that young adults are supported or helped to move from school to adult lives in the community. Positive transition planning supports people in the following areas of their lives: recreation, education, self-determination, and community living.” (Mirfin-Veitch, 2003).

Mirfin-Veitch, B. (2003). *Education for adults with an intellectual disability (including transition to adulthood)*. National Advisory Committee on Health and Disability (National Health Committee). Available on NHC website: <http://www.nhc.covt.nz>

By Beth Cole, RN

As a parent of a son with complete agenesis of the corpus callosum (c-ACC), I would like to share some thoughts and information regarding transition planning. Typically, this should begin around the age of 14 years since transition goals are required by the Individuals with Disabilities Education Act (IDEA) by the age of 16. Unfortunately, I was totally unprepared to make the decisions that were necessary during that year of my son's education. As I dutifully attended yet another Individualized Education Program (IEP) meeting, I was asked to make a life-altering decision that would affect the remainder of his life. What will he do when he graduates from high school?

Based on my experience, I would advise you to begin transition planning as early as the sixth and seventh grades. Educate yourself regarding the anticipated timeline for transition planning. There are tools available to assist you with this. The one I used is available from the Full Life Ahead Foundation. For more information about this tool, you can go to their website or contact them using the information at the end of this article.

In preparation for these important decisions, I have some ideas for you to consider, found in the box on this page. Remember that no decision is written in stone. At any point in your child's life, the direction can be changed. After all, there is no limit to

what your child can do when provided with the supports needed.

These suggestions can be extremely beneficial to your child. However, I feel that by far the most important thing you can offer your child is an understanding of himself or herself, and your child's goals, dreams, and needs. Most importantly, they need an ability to advocate for themselves in relation to their disability. I learned that my need to protect my son from negative self-perceptions would not assist him to become an independent adult. Giving a young person with disabilities the knowledge they need to successfully advocate for themselves empowers them to become the individuals that they hope to become.

One additional tidbit of advice I offer is to look beyond your child's limitations and ignore those who tell you that your child will never be successful. These people may be doctors, teachers, and counselors who only see a small portion of your child's capabilities and generally focus on their disabilities. You are the main force behind your child's future success. We never know what our children may be capable of achieving. ☺

Beth Cole lives in Alabama, with her son Brandon (c-ACC) and daughter, Lauren. Brandon recently completed a year of volunteer service with Americorp and is applying to college programs for the fall 2007.

The Full Life Ahead Foundation

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Legal Issues to Consider During Transition

***Editor's note:** This article is intended as an introduction to some legal issues to consider as your child moves from childhood to adulthood. Please refer to the organizations and agencies listed in the resource list for more information. Also note that families living outside the United States will be governed by different laws, regulations, and services and should contact their local service providers for information.*

By Heather Richmond

For parents of children reaching that inevitable milestone, young adulthood, there is the usual mix of emotions ranging from a strong sense of pride, to happiness, sadness, and sometimes fear. Parents of children with disorders of the corpus callosum may have all these emotions. However, there are myriad concerns as that young adult prepares to leave home. We want our children to succeed in life, whether that is completing high school, going to a vocational school, college, or entering the workforce. But what can we do to ensure a smooth transition to adulthood? How can parents be assured their child has the tools needed to become a young adult who makes his or her own decisions?

The age of majority is a technical term that has huge implications for children with disabilities. In most states, with a few exceptions, the age of majority is 18 years old. This means that your child is no longer a minor and has the right and responsibility to

make certain legal choices made by adults. For example, the Individuals with Disabilities Education Act (IDEA) grants individual states the authority to elect to transfer education decision-making rights to your son or daughter when they reach this age. States are also authorized to determine the transfer of other rights such as the right to vote, marry, obtain a credit card, and consent to medical treatment (National Center on Secondary Education and Transition [NCSET] & Pacer Center, May, 2002). It is important to understand the laws within your state so that you and your child can best prepare for this transition well before their eighteenth birthday.

When your child is transitioning to the age of majority, it does not mean you cannot or should not be involved in their decision-making. In fact, family support can be extremely helpful in the transition to adult decision-making. This is an important time to consider your current roles as parent and child and recognize how these roles will change once your son or daughter reaches this age. Setting up systems to check in, address crises, or manage tasks like grocery shopping and cooking might alleviate some of the stress the family will feel during this time of change.

Fortunately, tools are available to help you and your child through this process, some of which have been validated through research. One in particular is known as "Person-Centered Planning" and focuses the transition around the needs of the young adult. (See the resource list for sources for Person-Centered Planning information and materials.) This tool provides guidance on how to formally and

informally identify, create, and utilize systems of support. These crucial supports may include vocational rehabilitation, day training programs, Social Security, Medicaid waivers, housing, and transportation support (NCSET & Pacer Center, February, 2004).

One difficult task may be deciding if your child has the ability to effectively make the transition to adult decision-making. In some cases guardianship or another form of representation by an advocate may be appropriate for a young adult with disabilities. (See below for definitions.) These court orders limit your child's legal rights to varying degrees, from a complete loss of adult legal rights to more limited forms of representation, so parents can consider more or less restrictive options based on the child's abilities and vulnerabilities (NCSET & Pacer Center, May, 2002). Some states have procedures that allow an advocate to make educational or medical decisions for your child without petitioning for guardianship or power of attorney. It is important to check your state laws to determine the best option for your family.

Some parents may have learned about Supplemental Security Income (SSI) when their infant was born, and others may have learned about SSI later in life when the child needed support. Yet, some parents are unaware that the young adult child may be eligible for this benefit. SSI is a government program that can provide income support to individuals with disabilities who meet specific disability and financial criteria. (Both income and financial resources are considered.) If your adult child is eligible, SSI can help them pay basic expenses when making the transition from school to work, during training or postsecondary school, or while working at a low-paying or part-time job. Also, SSI allows an individual to apply for Medicaid, a nationwide program to assist qualified persons with disabilities with health care coverage (NCSET & Pacer Center, March, 2003).

Becoming well informed of the legal issues is a constant task for a parent of a child

with a callosal condition or other disability, but that information is critical to making informed decisions during transition. Families should become familiar with options for ongoing support provided to young adults by the federal and state governments. The resource list includes several organizations that provide up-to-date information and suggestions to guide families through this process.

Whether your young adult child is off to college, off to work, or making other plans for the future, there are a number of resources available to help him or her. I encourage you to consider Person-Centered Planning tools to determine the best options for identifying financial, medical, and educational support. Even if your young adult child does not qualify for government-funded services, taking the time to plan for their future may be the best start to the rest of their lives. ♡
Heather Richmond, her husband, Brian, and daughters, Emmy (2 years) and Sabine (c-ACC, 8 months old), live in Ohio.

References

National Center on Secondary Education and Transition & Pacer Center. (2002, May). *Parent brief: Age of majority*. Minneapolis, MN: University of Minnesota.

National Center on Secondary Education and Transition & Pacer Center. (2003, March). *Parent brief: Supplemental security income: A bridge to work*. Minneapolis, MN: University of Minnesota.

National Center on Secondary Education and Transition & Pacer Center. (2004, February). *Parent brief: Person-centered planning: A tool for transition*. Minneapolis, MN: University of Minnesota.

Parent Briefs may be requested from NCSET by using the contact information below or downloading from their website (<http://www.ncset.org/>).

Guardianship: A court order that appoints a parent or other designated person to make decisions for a person of legal age in areas such as education, housing, medical care, contracts, public assistance, etc. This order defines the individual under guardianship as legally incompetent.

Conservatorship: A form of limited guardianship. This court order assigns a parent or designated person to manage specific responsibilities for another adult based on their individual limitations. This allows the retention of some legal rights.

Power of Attorney: A legal relationship that addresses the well-being of another individual without removing their civil rights. This relationship allows a designated person to pay bills and make financial and/or medical decisions on the behalf of another.

Legal definitions may vary from state to state, so parents are encouraged to seek guidance from local professionals in determining the best options for their family.

Transition Planning Resources

The Arc

<http://www.thearc.org/support.html>
The Arc of the United States
1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
Phone: (301) 565-3842
Fax #1: (301) 565-3843
Fax #2: (301) 565-5342

Beach Center on Families and Disability

<http://www.beachcenter.org>
Beach Center on Disability
University of Kansas
Haworth Hall
1200 Sunnyside Ave., Room 3136
Lawrence, KS 66045-7534
Phone: (785) 864-7600
TTY: (785) 864-3434
Fax: (785) 864-7605
e-mail: beachcenter@ku.edu

IMPACT: Transition to Empowered Lifestyles Project Person-Centered Planning

<http://www.ptimpact.com>
8301 State Line Rd.
Suite 204
Kansas City, MO 64114
Local: 531-7070
Toll Free: (800) 743-7634

Individuals with Disabilities

Education Improvement Act

<http://www.ed.gov/policy/speced/guid/idea/idea2004.html>
U.S. Department of Education
400 Maryland Ave., SW
Washington, DC 20202
Phone: (800) 872-5327
Spanish speakers available
(se habla español)
TTY: (800) 437-0833
Fax: (202) 401-0689

Medicaid and People with Disabilities

<http://www.kff.org/medicaid/4017.cfm>
Headquarters:
Kaiser Family Foundation
2400 Sand Hill Rd.
Menlo Park, CA 94025
Phone: (650) 854-9400
Fax: (650) 854-4800

**National Center on Secondary
Education and Transition**

<http://www.ncset.org/>
National Center on Secondary
Education and Transition
Institute on Community Integration
University of Minnesota
6 Pattee Hall
150 Pillsbury Dr. SE
Minneapolis MN 55455
Phone: (612) 624-2097
Fax: (612) 624-9344
e-mail: ncset@umn.edu

**National Dissemination Center for Children
with Disabilities**

<http://www.nichy.org>
P.O. Box 1492
Washington, DC 20013
(800) 695-0285 (v/tty)
(202) 884-8441 (fax)
e-mail: nichy@aed.org

PACER Center

<http://www.pacer.org>
8161 Normandale Blvd.
Minneapolis, MN 55437
Voice : (952) 838-9000
TTY : (952) 838-0910
Fax : (952) 838-0199

Supplemental Security Income

<http://www.ssa.gov/work>
Office of Public Inquiries
Windsor Park Building
6401 Security Blvd.
Baltimore, MD 21235
Toll Free: (800) 772-1213
Toll Free TTY: (800) 325-0778

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