

# TRANSITION FOR YOUNG ADULTS WITH INTELLECTUAL DISABILITY



**Children's**  
HOSPITAL • ST. LOUIS  
BJC HealthCare

 **Washington**  
University in St. Louis  
Physicians



# TRANSITION FOR YOUNG ADULTS WITH INTELLECTUAL DISABILITY

Transition is a process where young adults with challenges prepare for the future beyond the K-12 school system. Choices on the road to increased independence may include further education, specialized training or employment.

Basic transition concepts:

- Think about goals for your child’s life after high school and develop a plan to get there. Consider their talents, interests and abilities and set goals to obtain the greatest degree of independence possible.
- Work with your child’s high school to ensure that they gain the skills and competencies needed to achieve their desired post-school goals.
- Begin to identify and link to any needed post-school services, supports or programs before they exit the school system.
- Remember: Successful transition is complex. It takes the cooperation and involvement of parents, students, teaching professionals and community organizations to smoothly shift from school to adult life.

## EDUCATION AND BEYOND (E.G. EMPLOYMENT)

It is very important to start transition planning early (at age 13 or 14). If you and your child feel that he or she may attend a post-secondary education program (college or a trade school), this is a good time to gather information about choices and to begin appropriate preparation for specific programs. Choosing college may lead to one type of high school program while getting ready for a job may mean another set of courses are more appropriate. You will also want to begin looking for activities that focus on developing skills related to independence — either through school programs or programs offered by organizations concerned about young people with disabilities.

Agencies throughout the country offer job-readiness programs, job training and placement. Enlist the services of your school district and local groups such as ARC (an organization for those with intellectual and developmental disabilities), the Learning Disabilities Association and other groups that work with individuals with disabilities. Your state’s Developmental Disabilities Council can also be a source of information about opportunities to help your child get ready for the working world.



There is a wide range of abilities among people with intellectual and developmental disabilities. For some, college programming is not appropriate, while for others, it can be quite rewarding. More and more, young adults with challenges are attending college sponsored programs, primarily at local community colleges, but also at larger universities across the country that provide support for learning disabled students. The level of support available for students varies from very little (other than special testing methods and accommodations in work load) to quite pronounced. There are also an increasing number of post-secondary programs whose primary focus is independent living skills; practical academics (such as check balancing and money management); social development; and vocational preparation. Adults who complete this training may work at a variety of paid jobs such as, restaurant workers, office clerks, day care assistants, and “greeters” at major chain stores. Others work as volunteers in nursing homes, hospitals and day care programs, as well as many other alternatives. Agencies such as Vocational Rehabilitation and Centers for Independent Living, among others, can be helpful in this process and can be found on line by searching for the organization’s name and the state of residence.

These organizations may also be helpful in providing initial information regarding how social security benefits may be affected by various employment options. They aim to ensure youth and families receive the most accurate information possible. Helpful on-line tools and resources include:

**Work Incentives Planning and Assistance Project Fact Sheet**

[socialsecurity.gov/work/wipafactsheet.html](http://socialsecurity.gov/work/wipafactsheet.html)

**Social Security Work Incentives**

[dps.missouri.edu/resources/ssawork/default.html](http://dps.missouri.edu/resources/ssawork/default.html); <http://www.socialsecurity.gov/disabilityresearch/workincentives.htm>;

**Going to Work: A Guide to Social Security Benefits and Employment for Young People with Disabilities**

[communityinclusion.org/pdf/GTW2011\\_F.pdf](http://communityinclusion.org/pdf/GTW2011_F.pdf)



## MEDICAL TRANSITIONS

As individuals age out of the school, they also typically age out of their pediatric medical care. Each doctor's office and hospital is different, but many pediatric hospitals and specialists will only care for individuals until age 18 or age 21. Consequently, families should discuss the transition to adult doctors starting around 15 or 16. Many times the pediatric specialist or pediatrician can help identify an internist (adult doctor) and the appropriate adult specialists.

## LIVING ARRANGEMENTS AND ETC.

Just as there are many options for work, there are many different living arrangements that can be suitable for adults with intellectual or developmental disabilities. Some of these adults are able to live completely on their own, with or without a roommate. Others live semi-independently (usually with a roommate) in a supervised apartment complex where they receive minimal to moderate amounts of support. Still others live in group homes with other adults with a variety of disabilities, and some prefer to stay at home with their parents. The choice for an appropriate living environment is often influenced by the availability of public transportation and proximity to the adult's workplace. Local ARC groups, State Developmental Disabilities Councils and other disability-related groups can help locate local agencies that can help to prepare your son or daughter for independent living and work with him or her on a living arrangement that works best.





For adults who do not work or volunteer outside the home, continued socialization is particularly important. Many communities offer social and travel opportunities geared toward individuals with special needs. In some areas, parent volunteers may help initiate and coordinate adult social events. Groups usually meet informally every month or so to share time together. There are also groups that offer chaperoned trips for young adults, and link parents who have volunteered to host travelers with young people who want to travel. If your child has a specific medical diagnosis (Down syndrome, Williams syndrome, etc), resources may be available through local chapters of the family associations. Social activities are also available locally through your ARC and community recreation programs, etc.

### **ADDITIONAL RESOURCES FOR FAMILIES: MPACT**

MPACT's mission is to empower families of children with special needs to advocate for themselves — through support, training and education. They offer many resources related to transitions. In addition, their website includes numerous fact sheets, and sample letters (e.g. to request forms or services) and links to useful community resources. They are based in Missouri so many of their resources are Missouri specific, but the topics covered may be useful to any family. MPACT can be reached at 1-800-743-7634 or online at [ptimpact.org](http://ptimpact.org).

#### *Contributors:*

*Karla Jacquin MSW, LCSW, social worker*

#### *References/Quoted materials:*

*Social Security Administration Website [www.ssa.gov](http://www.ssa.gov)*

*Williams Syndrome Association Materials on Transition [williams-syndrome.org](http://williams-syndrome.org)*

*MPACT Website: [ptimpact.org](http://ptimpact.org)*

#### *State of Missouri Resources Toolkit:*

*"A toolkit for Independent Living Specialists, Vocational Rehabilitation Counselors and Teachers/Educators:" [dese.mo.gov/sites/default/files/transitiontoolkit.pdf](http://dese.mo.gov/sites/default/files/transitiontoolkit.pdf)*



## ST. LOUIS CHILDREN'S HOSPITAL

One Children's Place  
St. Louis, Missouri 63110  
StLouisChildrens.org

314.454.KIDS (5437) or 800.678.KIDS (5437)

Supported in part by a grant from HRSA H46MC24089



**children's**  
HOSPITAL • ST. LOUIS  
BJC HealthCare

 Washington<sup>®</sup>  
University in St. Louis  
Physicians