

TRANSITIONING TO ADULTHOOD WITH SPINA BIFIDA:

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Why Support Can be Necessary

- The typical neuropsychological profile of children with spina bifida includes problems with executive functioning skills as well as difficulties problem solving.
- In addition, children with spina bifida have increased medical and adaptive needs, transitioning into adulthood can be complex and difficult.

Objectives

- We will discuss transition issues for young adults, including:
 - guardianship/conservatorship,
 - independent living,
 - higher education,
 - development of self care skills.
- In addition, we will also cover skill building and planning to support more independent functioning in the long term.

Getting prepared for adulthood: what needs to be done in middle school or early high school

Evaluations

- It can be very important to have a complete and thorough evaluation of skill profiles:
 - For individuals whose functioning is in the mentally retarded range (IQ < 70), careful documentation of adaptive skills before the age of 18 is necessary.
 - It can be helpful to medical teams and parents to understand functioning levels in decision making and how to support the transition to adult medical facilities and functional independence.

Discussions with Your Child

- Begin involving your child in decision making processes, including participation in medical visits and IEP meetings
- It is also essential to begin to discuss with your child what their intentions and desires are- and to carefully evaluate whether these are reasonable given their skill sets (e.g., moving out, becoming a doctor, etc.) For example,
 - Are they considering more education after high school?
 - Do they have the financial skills necessary to be independent?

Legally becoming an adult: the transitions at 18 years of age

Support for Young Adults

- If your child has an IQ less than 70, it will be important to explore the idea of full guardianship
- Otherwise, you can examine each of the three areas independently
 - ▣ Financial decisions
 - ▣ Medical decisions
 - ▣ Social decisions

Guardianship

- Designed to provide support with medical, financial, and social decisions.
- Is a legal process that involves the probate courts.
- Because it is the most restrictive level of support, the courts try to restrict who qualifies and families are encouraged to use other means if possible.

<http://www.jud.ct.gov/probate/Guardian-MR.pdf>

Conservatorship

- This is a legal process that involves support through the probate courts.
- Designed to provide support to individuals who are not able to manage their finances independently.
- Allows for families to co-manage accounts, pay bills, and assist in decision making for larger purchases.

<http://www.jud.ct.gov/probate/GuidelinesConservators.pdf>

Health Care Representative

- Authorizes the health care representative to make any and all health care decisions for the individual, including decisions to accept or refuse any treatment, service or procedure used to diagnose or treat physical or mental conditions.
- The young adult would sign this document with two witnesses; however, they have to be competent to make this decision.

How to create plans for after high school?

Transitioning to Adult Services

- If in special education, your child should receive a referral at 16 years of age to Vocational Rehab or DDS
- These services are designed to take over once special education services end
- Each have eligibility requirements
- Both can provide support around living assistance, vocational training programs, and life skill supports

Vocational Rehab Agency

- VR helps persons with cognitive, sensory, physical, or emotional disabilities to find employment and achieve increased independence.
- VR services usually last for a limited period of time and are based on an individual's rehabilitation plan. If necessary, additional services can be requested, and a new rehabilitation plan will be developed.

Vocational Rehab Agency

- VR provides:
 - employment services (e.g., vocational guidance and counseling, assessments to determine vocational potential, job development/ placement, rehabilitation/ technological service)
 - independent living and adult services (e.g., housing or transportation for work, mobility and orientation services)
 - educational services (more later)

Dept of Developmental Services

- The person's IQ score must be 69 or less; this must be documented before age 18.
- At the same time, the person must have deficits in adaptive functioning (including communication, social activities, relationships, and daily living skills such as handling money, cooking, dressing, and grooming.)
- Phone number: 1-866-433-8192

College?

- Many students are now attending colleges
- There is significant variability in college programs, ranging from vocational/life skills programs to ivy league schools
- Many more programs now (than 20 years ago) that provide more substantial support for learning disabled students

Transition to College

- You can receive most accommodations at most colleges/universities; they can not change the manner of teaching (no modifications)
- Office of Disability Services on most campuses, require recent comprehensive assessments
- Most schools have learning support centers (writing labs, math center, tutoring center)
- Choose a school with these needs in mind, many of the big college books will list learning support services of each campus

College: Services

- Pre-registration for classes
- Extended time
- Central storage facility
- Assistance with mobility- clearing sidewalks, elevators, access to bathrooms
- Support through tutoring centers

College: VR Resources

- VR can also provide postsecondary education services such as:
 - apprenticeship programs (With Dept of Labor)
 - vocational training
 - college training towards a vocational goal as part of an eligible student's financial aid package

College: Medical

- Essential to make sure that emergency medical services are provided
- Essential to speak to the school staff about latex allergies, particularly if the student will be living and eating on campus or taking science classes
- Think about changing delivery of medical supplies (caths, medications, etc.)
- Should also locate the counseling center on campus before school begins

What about medical transitions?

Meeting New Doctors

- Need to rehearse before this process begins, often can increase anxiety, which can further affect organization skills
- There is a lot of medical history, so the more than can be written out before hand, in sequential order, the easier the transition will be
- Will need to make sure that they get explicit, written directions from doctors
- Rehearse asking questions before you go

Medical: Organizational Needs

- Will need to think about how coordination of services will occur; consider the binder available through the national SBA
- Remember that sequencing information and organizing information can be hard
- As they tend to process detail by detail, you often need to review information or receive it in written format
- Ask for clear, brief instructions

How can we support independent living?

Self Care

- Motor skills, limited planning, and poor organization skills can all affect self care
- Will be important to start teaching these skills early
- Remember that learning new information can be hard without rehearsal of routines
- Use of checklists can be very helpful

Community Navigation

- Visual spatial skills are needed for accurate navigation and map reading- use verbal cues as much as possible
- Rehearsal of familiar trips and routines is important
- Discussing and trying public transportation with your children is important
- You can call 211 in Connecticut or check <http://www.211ct.org/>

Home Living

- Learning requires more repetition and explicit steps to support executive skill deficits
- Laundry, vacuuming, cooking, etc. all require multiple steps in order- so create a checklist to help
- Work on teaching these skills through repetition and checklists early, so they are solid when the children leave home

Victimization

- As children are social, easily comfortable with adults, and have trouble reading social cues, they are at high risk
- Need to talk about touching, visiting/going with strangers, and loaning money
- Make the distinction between “being helpful” and “being safe”