

Providing care for children and youth with developmental disabilities does not have to be much different than caring for youth with other special health needs. The opportunities for youth with developmental disabilities are great. Many youth live and work in the community, living full and typical lives.

1. **TALK TO THE PERSON** - Speak directly to the child or youth. Many youth with developmental disabilities have speech challenges and it may be very difficult to understand them. However, it is essential to speak directly to the youth. If the youth does not have an augmentative communication device, encourage the family to actively work with school personnel to identify communication aides or a device that will provide assistance in communication. As a physician you will be called upon to provide information about the youth when the family is applying for a device.
2. **YOUTH PARTICIPATION** - Assist the youth in learning about his health care. Identify with the youth and family health care tasks that are needed and ways that the youth can participate. Even if the youth cannot do the entire health care task, such as take his or her medication, he or she can assist in setting up the medications and being responsible for reminding the caregiver when to take them.
3. **INCREASE ADLs** - Assess the skills of the youth to care for him or herself and identify opportunities for participation and the supports that are needed to provide success in being as independent as possible in personal care. Identifying the steps of a certain task and then agreeing on the steps that the youth can perform and the steps that need support is an easy way to develop a plan of care and provide opportunity for the youth to assume responsibility for parts of his or her care.
4. **STAYING WELL** - Encourage the youth and family to learn about general health care such as hygiene, nutrition, etc. Many youth with developmental disabilities can learn to cook and plan healthy meals and care for their hygiene. If there are tasks the youth needs assistance with, assist the family in identifying support in completing these tasks in preparation for the youth moving to his or her own residence.
5. **AGE APPROPRIATE** - Provide age appropriate health care. Despite the fact that the youth may have cognitive delays, he or she is often age appropriate in their physical development and will require the same assessment and care that any youth needs, such as information on sexuality, alcohol and drugs. Families may require assistance and support in discussing these subjects with their youth and in identifying supports to assure safety.
6. **SUPPORTING ASPIRATIONS** - Ask the youth what his or her future plans are. What does he or she want to do after graduation is over? Discuss possible options and services such as county social services and vocational services. Persons with developmental disabilities often receive specialized services and funding to realize their dreams of working and living in the community.
7. **MAINTAINING HEALTH CARE INSURANCE** - Discuss health insurance options. Many states provide an opportunity for families of children and youth with developmental disabilities living at home as adults to continue on the family insurance indefinitely. This information can be obtained from each state's insurance commissioner.
8. **SUPPORT SERVICES** - Assist in identifying resources to support the youth with developmental disabilities to live and work in the community. If the youth does not have an association with developmental disabilities resources such as county social services, Supplemental Security Income (SSI) and vocational rehabilitation services, assist the family in contacting these resources. Oftentimes, the school is responsible for assisting families with contacting the latter

resources, however, the health care provider is often required to provide important documentation about the youth's disabilities so he or she is eligible for services. Be sure to work closely with the family to provide the appropriate documentation. There are strict guidelines for wording and if documentation is not clear and concise the youth may risk not receiving needed support services.

9. **DECISION MAKING: WITH SUPPORT** - This is a lifetime process on learning how to speak for yourself. Start early as possible by including the child in small decision at home by giving choices in all domains (school, community, home and self-care). Areas to consider-the child/youth participate in their IEP, learn how to be an informed decision maker through practice - assent to consent for health care treatment, As the youth turns 18, the usual age of majority, health care decisions will become the responsibility of the youth. HIPAA requires the signature of the person for treatment and confidentiality issues regarding medical records.

**YOUTH NEEDS SUPPORT** - If the youth cannot make informed decisions about his or her own health care, it is important that the family becomes legal guardians or conservators. If the family decides on guardianship, the family will be responsible for all the youth's decisions, not only in health care, but financially, where to live, who to marry, etc. If the family decides on conservatorship, the family can decide on what decisions they wish to be responsible for such as health care or financial management, while the youth will retain rights to vote, and decide other important decisions in his or her life. This is an important difference families and youth must understand.

Assist the family in identifying a health surrogate. A health surrogate can be a legal designation or an informal one. Oftentimes families have a friend or family member who is designated to be the "health" expert or surrogate and this person will be up to date on the youth's health needs and monitor the care, so there is continued continuity and appropriate health care decisions.

#### **SELF-ADVOCACY MOVEMENT**

<http://www.thearc.org/faqs/samove.html>

#### **SELF-ADVOCACY MOVEMENT Directory**

<http://www.thearc.org/misc/WebSAdir.html>

#### **SELF-DETERMINATION** – The ARC Position Paper

<http://www.thearc.org/posits/selfdetpos.htm>

#### **NATIONAL GUARDIANSHIP ASSOCIATION (NGA)**

[www.guardianship.org](http://www.guardianship.org)

The mission of NGA is to establish and promote a nationally recognized standard of excellence in guardianship. Guardianship is designed to protect and promote the well being of those whose functional limitations prevent them from making their own decisions.

10. **TRANSITION TO ADULTHOOD** – Develop an Individualized Health Transition Plan at age 14. Discuss with the family and youth a plan of care for transition to an adult provider, how to locate quality services in the community. If the youth moves out of the family home to a community residence, how will medical records and treatment updates be shared with the medical team and family? Planning ahead is the key so there are minimal problems as the youth transitions to adulthood and into life in the community.

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**HRTW Phase II Projects** are currently active in Arizona, Iowa, Maine, Mississippi, and Wisconsin.

*The opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of the funding agency or working partnerships.*