



RELATED TOPICS - TRANSITION

ADVOCACY

Advocacy is pertinent to all stages of life, but for people with disabilities it has additional significance. It is initially the responsibility of parents who have children with disabilities. Depending on the extent of the disability, it is best to equip the person to be a self-advocate as soon as that is possible. The principles of advocacy are the same; whether the speaker is making a case for someone else or for themselves.

Self-advocacy means standing up for your rights as a person. It means deciding what is best for you and speaking or acting on your own behalf. It often requires tremendous effort to make your voice heard by taking risks as you challenge rules or customs, acquire needed resources, and get service providers to respond to your needs.

The skill of self-advocacy can equip your youth to take control of their life. They can learn from their mistakes and successes, preparing for the day when you, the parents, or school personnel are no longer available to manage their life. Parents can encourage this skill in the following ways:

- Give youth opportunities to make decisions and experience the consequences.
- Teach youth about their disability and how it impacts their life.
- Practice role-playing situations in which a youth can learn to be a self-advocate.
- Allow and encourage a youth's independence.

You will be taking some risks as a young adult develops this skill. By expecting and accepting the consequences of choices, wrong as well as right, youth will learn from their experiences as you did from yours.

People with disabilities, their family members, and service providers can all be advocates who heighten disability awareness. Sharing information about issues like accessibility to buildings and services makes the Americans with Disability Act (ADA) a reality for those who do not recognize or understand the barriers. Ideas about accommodations and opportunities that can be created in transportation, housing, and employment will be valuable community input when it comes from people who truly understand the needs.

There are many ways to make your voice heard regarding these issues. You can do it individually by talking to neighbors, business owners, relatives, friends, and government officials to inform them of needed changes. You can serve on local or government committees, attend decision-making meetings, or support state and local legislation that provides more and better opportunities to include people with disabilities. You can also join a disability support group where you will be part of a collective voice. By informing the community about needs and reminding them about the value of people with disabilities, we increase the chance that they will be included in employment, residential, and recreational opportunities.

SUPPLEMENTAL SECURITY INCOME (SSI)

Your youth must have a disability or be blind to be eligible for SSI. Children may be eligible for benefits depending upon the family's income and assets, but when they turn 18, the family income is no longer considered. However, the benefit will be denied if the youth has more than \$2,000 in accountable resources.

If your child has special needs, so do you! We can help!

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This includes liquid assets like savings, stocks, bonds, etc., and real property beyond one vehicle the youth uses and the home in which the youth resides. If the youth is deemed eligible for SSI, they are automatically eligible for Medicaid.

Written applications for SSI are submitted at the local Social Security Administration (SSA) office. If you live in a metropolitan area, make an appointment to submit the application by calling their toll-free number. This can reduce or eliminate a lengthy wait. Begin this process six to eight weeks prior to the youth's birthday. They will also send the application so you can complete it before your appointment. Bring the following to the application interview:

- Social Security card number,
- An original document to prove age,
- Evidence of citizenship or immigration status,
- Records of earned and/or unearned income,
- Auto registration,
- Medical reports,
- IEPs for the last two years, and
- Any testing results which verify the disability.

You may also want to have written statements from others who will verify the youth's inability to do things that others their age can do for themselves. Benefits are paid back to the month of application so if you are missing some documentation, submit the application anyway. Provide SSA with the names and addresses of doctors, hospitals, or clinics where the youth has received treatment. For information or assistance call your local SSA offices or their toll-free number, 1-800-772-1213. They can explain how to appeal a decision which denies eligibility.

Whenever possible, SSI should be used as a stepping stone to economic self-sufficiency. SSA has developed programs that encourage people with disabilities to achieve a more independent and satisfying lifestyle when they take advantage of employment opportunities. Information is available from "The Red Book – A Guide to Work Incentives" (SSA Pub. No. 64-030). Benefit planning assistance is also available through Work Ability by calling (801) 887-9529 or visiting www.workabilityutah.org.

HEALTH CARE

Another part of your youth's independence is assuming some responsibility for their health care. Decisions must be made about their ability to realize when they need health care and whether or not they can communicate adequately with health professionals. It is also recommended that you address the issues of sexuality and reproduction. Helpful information on these topics is available at www.medicalhomeportal.org.

Financial resources to pay for the youth's health care must be identified. Medicaid may be available even if they do not receive SSI. More information can be requested by calling your local Family Support/Workforce Services Office, an agency of Utah government. Medicaid covers basic dental care after age 21, but prior approval is required for some services. Whenever using Medicaid and when using some insurance plans, parents should learn about their pre-request plan.

For students with medical needs it is important to give careful consideration to how medical care and services will change as they become adults. For more information, you may wish to contact Utah Family Voices, Family to Family Health Information Center by calling: (801) 272-1068 or (800) 468-1160. Information on medical transition issues is also available on the Utah Medical Home website at www.medhomeportal.org.

*This content is taken from the Utah Parent Center handbook:
From NO Where to KNOW Where: A Parent Handbook for the Transition to Adult Life.*