



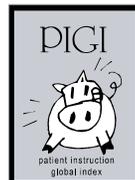
# Moving On

## Transition Tips for Parents of Young Adults with Disabilities

Moving On for Parents 02/07

Shriners Hospitals for Children  
Intermountain  
Fairfax Road at Virginia Street  
Salt Lake City, Utah 84103  
801 – 536 – 3500

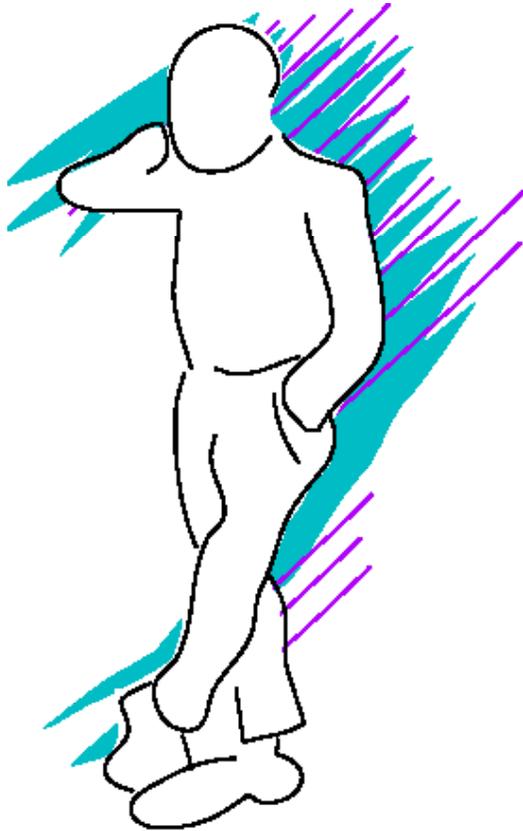
[http://www.shrinershq.org/Hospitals/Salt\\_Lake\\_City/](http://www.shrinershq.org/Hospitals/Salt_Lake_City/)



## Letting Go

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- Letting go means encouraging your young adult to become as independent as she is able.
- Look at letting go as a process rather than an event. Continue to give your young adult choices, responsibilities and permission to make mistakes.
- Letting go is difficult for most parents and may be especially so for parents of young adults with disabilities.
- It is natural to have mixed feelings about your young adult growing up and moving on. Find a healthy way to deal with your anxieties and fears. Talk with a close friend, another parent of a young adult with a disability, a support group or a counselor
- If your young adult will continue to live in your home as an adult, recognize that you may have mixed emotions. You may feel a sense of relief about being able to protect your adult child while at the same time feeling resentment about ongoing care giving responsibilities.



- **University of Wisconsin Family Village:** Information, resources, and communication opportunities for people with disabilities, their families, and those that provide them with services and support. [www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)
- **Youthood.org:** A dynamic, curriculum-based tool that can help young adults plan for life after high school. [www.ncset.org/websites/youthhood.asp](http://www.ncset.org/websites/youthhood.asp)

Please call the hospital with any questions at (801) 536-3500. If you are unable to reach the hospital and you feel it is an emergency, call 911 or go to the nearest Emergency Room.

Questions about Transition? Call your Care Coordinator:

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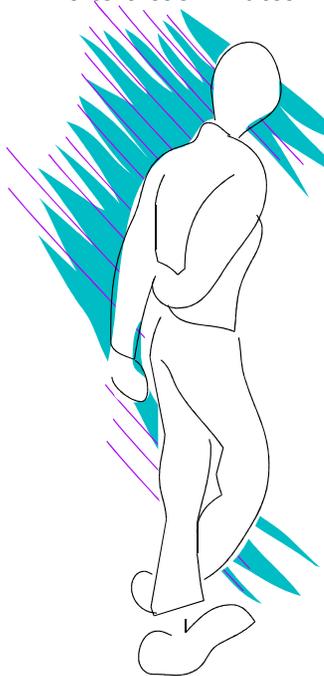
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- **DisabilityInfo.gov:** Federal government website that serves as a starting point for all government services and information sites. [www.disabilityinfo.gov](http://www.disabilityinfo.gov)
- **Health Finder:** Key resource for finding the best government and nonprofit health and human services information on the Internet. [www.healthfinder.gov](http://www.healthfinder.gov)
- **Healthy and Ready to Work National Dissemination Center:** This site provides various tools and resources to assist youth with special health care needs in the transition to adulthood. [www.hrtw.org](http://www.hrtw.org)
- **National Center on Secondary Education and Transition:** This site disseminates information related to secondary education and transition for youth with disabilities. [www.ncset.org](http://www.ncset.org)



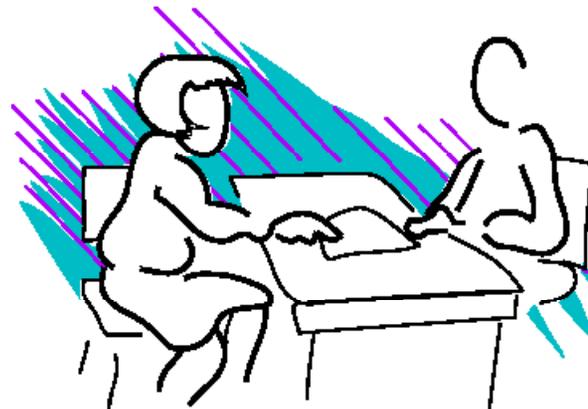
- **National Dissemination Center for Children with Disabilities (NICHCY):** Central source of information on disabilities in children and youth, programs and services for youth with disabilities and special education laws and rights. [www.nichcy.org/index.html](http://www.nichcy.org/index.html)

- **Parent Advocacy Coalition for Educational Rights (PACER):** This site offers educational materials, information about resources and services, online training and individual assistance for parents of children with disabilities. [www.pacer.org](http://www.pacer.org)

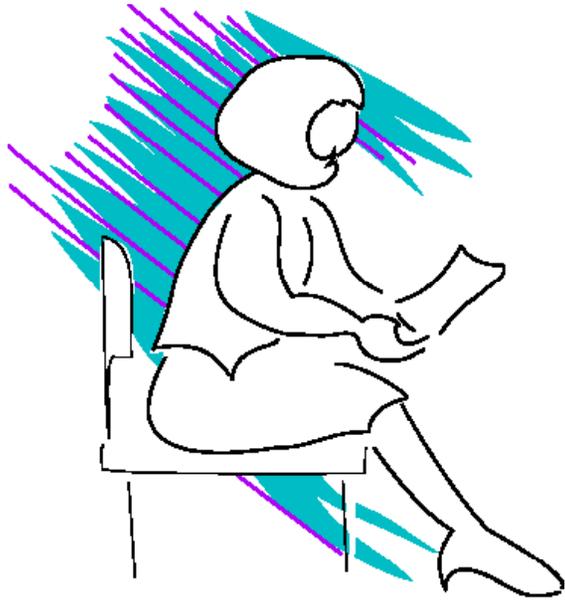
- **National Collaborative on Workforce and Disability for Youth:** Information and resources geared toward increasing understanding of policy and practice issues regarding youth with disabilities in the workplace. [www.ncwd-youth.info/who\\_Are\\_You/youth\\_and\\_Family/index.html](http://www.ncwd-youth.info/who_Are_You/youth_and_Family/index.html)

## How do I assist my young adult in becoming more independent?

- Do not do for your young adult what he can do for himself. Encourage him to ask for your help once he has tried on his own and has done as much as he can.
- Explore independent living options and supports. Options range from living independently without any assistance to living in a supported environment.
- If your young adult will continue to live in your home, expect him to help out just as you would any adult living in your home. Give him as much responsibility as he can manage. Do not treat him as a child simply because he is living at home.
- Now that your child is an adult, you will no longer be his primary decision maker. Instead, take on the role of “consultant,” assisting your young adult in making good decisions.
- For many young adults with disabilities, the transition out of high school means losing their primary contact with friends. Encourage your young adult to stay involved with his former friends and to meet new friends by participating in recreation, church groups, volunteer and work activities, classes and clubs.



- Help your young adult look into personal care assistant services. Personal care assistants can help with personal care needs at home, school or work. It can be difficult for young adults to feel a sense of independence when they have to rely on their parents to meet their personal needs. Contact your state's developmental disabilities program for more information (See page 6).

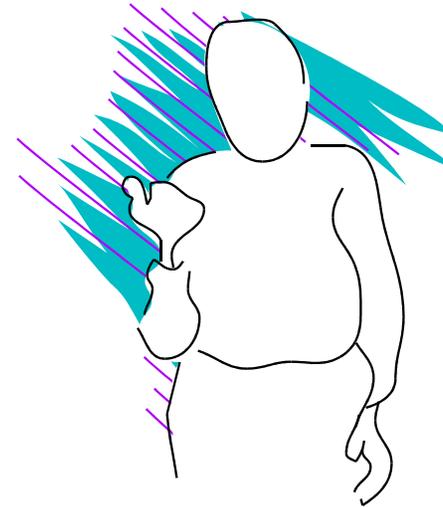


## How do I help my young adult obtain health insurance?

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- If your young adult is covered under your family health insurance plan, contact your provider to find out how long she will be covered and under what conditions. In some states, policies provide for coverage of adult dependent children. Check with your insurance plan prior to your child's 18<sup>th</sup> birthday.
- Assist your young adult in looking into Medicaid coverage or other state health insurance benefits for uninsured adults. Be aware that at age 18, SSI redetermination may affect your young adult's Medicaid benefits.

- Adaptive recreation programs provide sports and other forms of recreation to people with disabilities. Programs may include skiing (snow or water), horseback riding, sled hockey, bowling and team sports, among many others. Contact your local Parks and Recreation, Disabled Sports USA [www.dsusa.org](http://www.dsusa.org), Special Olympics [www.specialolympics.org](http://www.specialolympics.org), or your Care Coordinator for more information.



## What websites are available to help with transition?

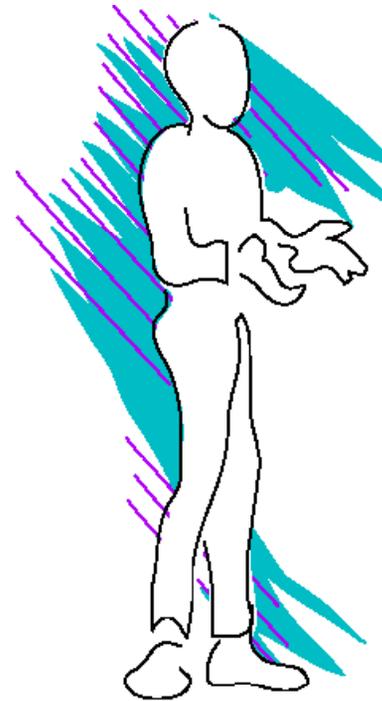
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- **American Medical Association Doctor Finder:** Online physician locator that provides basic professional information on licensed physicians in the United States. <http://webapps.ama-assn.org/doctorfinder/home.html>
- **Bright Futures for Families:** Developmentally focused information for infancy, childhood, adolescence and transition. <http://brightfuturesforfamilies.org/home.htm>

- Your young adult may be eligible at age 18 for Supplemental Security Income (SSI) benefits while in the transition from school to work. SSI provides monthly payments to persons who have disabilities and have limited income and resources. SSI may be used as a financial support during periods that your young adult is only able to work minimum hours or is in the process of finding employment. SSI benefits can also be received while in vocational training or attending post-secondary institutions. [www.ssa.gov](http://www.ssa.gov)
- Work incentives are special rules that make it possible for people with disabilities receiving Social Security or Supplemental Security Income (SSI) to work and still receive monthly payments and Medicare. Contact your young adult's Social Security caseworker, Medicaid caseworker or Vocational Rehabilitation counselor for more information. [www.ssa.gov/disabilityresearch/wi/generalinfo.htm](http://www.ssa.gov/disabilityresearch/wi/generalinfo.htm)
- Community work incentive coordinators provide SSI recipients with valuable information to help them make informed choices about work. They can provide information about how employment will affect Social Security and other public benefits, make referrals to various agencies that can assist with employment issues and assess health benefits coverage. [www.socialsecurity.gov/work/ServiceProviders/wipafactsheet.html](http://www.socialsecurity.gov/work/ServiceProviders/wipafactsheet.html)
- Independent Living Centers offer classes and activities to help people with disabilities to become more independent. Sometimes they can help pay for equipment or assistive technology needed for independence. [www.ilru.org/html/publications/directory/index.html](http://www.ilru.org/html/publications/directory/index.html)

- If your young adult is attending college or a university, encourage or assist her in looking into student health insurance offered through the school.
- Encourage your young adult to pursue jobs and careers that offer health insurance as a benefit.
- Check in your community for health clinics that charge patients based on their income.

## How do I help my young adult transition to adult health care?



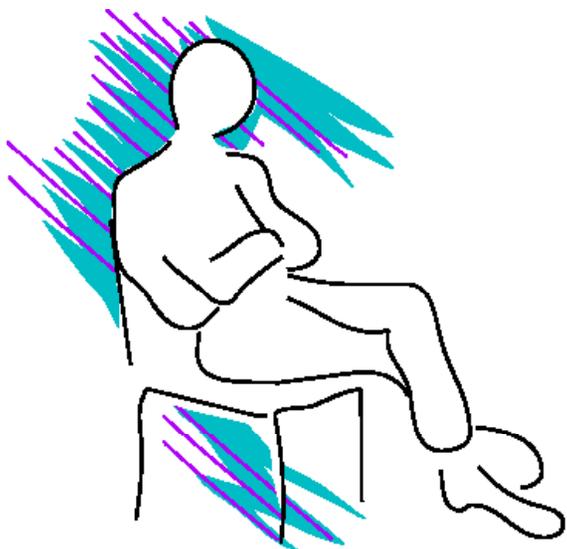
- Start early. Finding appropriate adult doctors and other services can take time. Do not wait until a crisis or until your young adult's last pediatric appointment to start looking.
- Encourage your young adult to ask his current providers how long they can treat him. Most pediatric providers will not see patients beyond age 18 or 21.
- Remind your young adult that although it may be hard to let go of doctors he has known for years, an adult healthcare provider will be better able to address adult medical issues.
- Encourage or assist your young adult to ask current healthcare providers, other young adults with disabilities and local referral agencies for referrals to adult healthcare providers.

- Encourage or assist your young adult in making phone calls to find out if potential providers have the experience and willingness to work with people with his disability.
- Encourage or assist your young adult in making appointments to interview prospective providers.
- Encourage your young adult to arrange for at least one appointment with an adult healthcare provider before his last appointment with his pediatric care provider. This gives the pediatric and adult healthcare providers the opportunity to share information and work together.

## What is guardianship and does it apply to my situation?

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- In the United States, once young adults turn age 18, they are of “legal age” and considered an adult for all intents and purposes, regardless of whether or not they have disabilities. You will no longer be able to sign official documents, access medical or legal records or make major decisions on your young adult’s behalf.



- If you are concerned that your young adult is unable to make sound medical, financial, legal and/or residential decisions, you may want to consider taking legal action that will give you decision making power on her behalf. There is a range of legal intervention from serving as an advocate to your young adult, to limited guardianship (decision making power in only a few areas of his life) to full guardianship. Ask your Care Coordinator for referrals.
- If you do take legal guardianship of your young adult, you as guardian have the final say in all major decisions. However, your young adult deserves to be heard and to have her thoughts and feelings taken into consideration regarding any decision that will be impacting her life.

## What resources are available to my young adult?

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- If your young adult is capable of working independently with some training and support, he should connect with Vocational Rehabilitation (VR). VR provides a variety of services including vocational testing and training, job counseling and guidance, assistive technology, job placement and other services. [www.jan.vwu.edu/SBSES/VOC\\_REHAB.HTM](http://www.jan.vwu.edu/SBSES/VOC_REHAB.HTM)
- Young adults with disabilities who will need a more structured work setting such as a sheltered workshop, day services or supported employment should connect with the developmental disabilities program in your state immediately, as the waiting list for services can be very lengthy. Check with your state’s Department of Human Services via [www.healthfinder.gov](http://www.healthfinder.gov) or NICHCY’s state resource sheets [www.cichcy.org/states.htm](http://www.cichcy.org/states.htm) for contact information.

