



Statewide Parent Advocacy Network
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Empowered Parents: Educated, Engaged, Effective!

Healthcare “Transition” Summary for Teens with Special Needs

If you presently see a pediatrician for your child’s health care, they are trained to care for children. When your child becomes an adult, they will want to see someone who is trained to care for adults. Moving from your pediatrician to adult health care services for a teen or young adult with special needs involves more than switching to adult specialists, which can be difficult enough, but also to new programs. As a parent you must not only continue to advocate on behalf of your teen, but also to help your teen to speak up for themselves to the best of their ability, including talking to their doctors (see Talk to Your Doctor video for children at <http://hctransitions.ichp.edu/gladd/>.)

Planning ahead, learning what you need to do to stay healthy and having the health care provider and people to support you will make it much easier to transition to adulthood and a life in the community. It is important to start applying for adult services and programs several months before a youth turns age 18. Keep copies of health, education and social services records handy, i.e., medical records, individualized education plan, habilitation plan, etc., since you may be asked to submit them in applying for adult services. In general, when applying for any programs or services remember to jot down the names and contact information of agency representatives, and to keep copies of applications that you submit. When mailing important documents, use a return receipt method and follow-up, as you should get a letter stating your child’s eligibility status and/or start date.

The following are examples of programs and services that you and your teen may choose to explore in planning for transition to adulthood and some helpful hints in making the transition to adult care.

Medical Insurance through Your Job: If your child has a developmental disability (DD) and is covered under your family health plan, ask your employer or insurance company about a “Certification of Disability for the Handicapped Children Provision” form. This provision may continue insurance for your child into adulthood at no extra cost for as long as you continue to work there. Certain eligibility criteria apply, for instance your child’s inability to conduct “self-sustaining employment”, their age/dependent status at time of application and whether they are enrolled in your health plan. Also, explore whether your employer has separate plans for dental, vision, or prescription coverage, as you may need to apply for each of these individually.

Another resource is the federal Consolidated Omnibus Budget Reconciliation Act (COBRA) regulations which mandate that parents be given the option of continuing to cover their child by paying the full cost of the coverage. However, if your child has a permanent disability, you may be able to continue coverage for that child at no extra cost by submitting the designated form at the proper time.

Regardless of whether your child has a special need or disability, coverage for young adults is available in NJ through the Dependent Under 31 (DU31) law. The DU31 allows young adults to continue coverage or to become covered under a parent’s group plan as an over-age dependent until the youth’s 31st birthday. Eligibility requirements and coverage limits may apply. More information about NJ health plans is available at: http://www.state.nj.us/dobi/division_consumers/index.htm.

Social Security/Medicare/Medicaid: *Supplemental Security Income (SSI)* is a federal program that provides monthly cash payments to people in need. SSI is for people who are 65 or older, as well as for blind or disabled people of any age, including children. To qualify you also must have little or no income and few resources. This means that the value of the things you own must be less than \$2,000 if you are single or less than \$3,000 if you are married. The value of your home does not count. Usually, the value of your car does not count. And the value of certain other resources, such as a burial plot, may not count either. To get SSI, you also must apply for any other cash benefits you may be able to get, you must live in the United States and in some instances if you are not a U.S. citizen, but you are a resident, you still may be able to get SSI. If a young adult (age 18 or older) was previously denied SSI, he/she can reapply based upon their current income level, not their family income. For more information on SSI you may call 1-800-772-1213. *Medicare* is another federal health insurance program for people age 65 or older, some disabled people under age 65, and people of all ages with End-Stage Renal Disease (permanent kidney failure treated with dialysis or a transplant). You can call (800) 772-1213 to get more information about SSI and Medicare for End-Stage Renal Disease.

The SSI application process will require forms to be filled out, submission of medical and financial documentation and likely a visit to your local Social Security office. If your child has complex needs, ask about Social Security “presumptive eligibility.” You may find it easier to follow-up on an application by telephone rather than in-person visits whenever possible. Also, when you call Social Security, ask them to narrow down what they want mailed in such as medical records, because you can perhaps list whom your child sees now noting that there is a long history with that doctor or specialist, and you can send more information if needed. If eligible for SSI, it may take several months to receive benefits. You also can get medical assistance (*Medicaid*). You will receive a separate acceptance letter and a NJ Medicaid ID card. NJ Medicaid is a State program. If you have questions about Medicaid, you may call the Medicaid hotline at (800) 356-1561 or contact your local Medical Assistance Customer Center <http://www.state.nj.us/humanservices/dmahs/info/resources/macc/index.html>.

Families with very low income can apply for “Special Medicaid,” called *Jersey Care*, through their County Board of Social Services: www.state.nj.us/humanservices/dfd/programs/foodstamps/cwa/index.html. Medicaid provides unique services to persons with a variety of disabilities through home and community-based waiver programs. For more information on waiver programs you may contact the Department of Human Services (DHS), Division of Disability Services at 888-285-3036. Likewise, The NJ WorkAbility Program offers full New Jersey Medicaid health coverage to people with disabilities who are working, and whose earnings would otherwise make them ineligible for Medicaid. More information on NJ WorkAbility can be found by calling the DHS, Division of Disability Services at 1-888-285-3036.

Guardianship: If you think that your child will need support in exercising his/her legal capacity when s/he turns 18, you'll need to explore partial or full guardianship and its alternatives before s/he turns 18. For more information, see www.ganji.org and www.plannj.org. If parents need legal assistance, the Statewide Parent Advocacy Network also has a list of lawyers who practice guardianship law. (This list includes any attorney who asks to be placed on the list and is not an endorsement of any lawyer).

Helpful Hints: Most adult program applications require relatively recent health information, and will provide you with the medical exam forms you need. For guardianship, there must be two doctor’s exams within 30 days of the date your child turns 18. Because many doctors have waiting lists, you can plan ahead setting up visits within this timeframe. You can also have the doctors fill out the forms for guardianship, Medicaid, and SSI (can copy guardianship/Medicaid forms) at the same visit.

If your teen is not going to be a driver, it may be helpful to get a “non-driver handicapped id” (identification card) at age 17 from the NJ Department of Motor Vehicles (see www.state.nj.us/mvc/Licenses/NonDriverID.htm). To obtain this ID, bring your teen’s birth certificate, social security card, school ID with report card, and other photo ID like child safety card to the DMV. This DMV card can be used anytime your teen needs proof of identity.

Others who can help with health care transition:

- ✦ Special Child Health Services County Case Management Units www.state.nj.us/health/fhs/sch/sccase.shtml or State office at 609-777-7778
- ✦ Family Support Coalition www.familysupportcoalition.org
- ✦ Centers for Independent Living www.njsilc.org
- ✦ NJ Department of Human Services, Division of Disability Services (888) 285-3036, or Division of Developmental Disabilities at (800) 832-9173
- ✦ Boggs Center resources http://rwjms.umdnj.edu/boggscenter/projects/keep_real_more.html and <http://rwjms.umdnj.edu/boggscenter/products/BeingaHealthyAdultHowtoAdvocateforYourHealthandHealthCare.html>

A special note on preparing for natural disasters and other emergencies:

There are many things you can do to keep your teen safe in a natural disaster or other emergency (see www.familyvoices.org/pub/general/Disasters_&_Emergencies.pdf). There are county offices of emergency management at www.state.nj.us/njoem/about/association.html that can help you plan ahead. For example, you may need an “emergency generator” for refrigerated medicine or medical equipment when the power goes out. Check with your electric company if they provide generators for life threatening situations. You may also wish to contact Emergency Medical Services for Children at (609) 633-7777. NOTE: DDD may help cover medical equipment if it’s not covered by your insurance.

SPAN Resources on Transition:

- ✦ Transition Resources for Health Professionals (also useful for parents!) www.spannj.org/keychanges/TransitionResourcesHealthPractitioners.pdf
- ✦ Champions for Progress-interactive CD for students (work, school, health) www.spannj.org/transition/TransitionCD/start.htm