



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

Transition to Adult Life Resources for Health Practitioners



Statewide Parent Advocacy Network (SPAN)

In Partnership with the Champions for Progress Advisory Committee:

American Academy of Pediatrics-New Jersey Chapter

New Jersey Academy of Family Physicians

New Jersey Council on Developmental Disabilities

New Jersey Department of Health and Senior Services-SCHS

New Jersey Department of Labor-DVRS

New Jersey Family Voices/Family to Family Health Information Resource Center

Robert Wood Johnson AIDS Program

TRANSITION OVERVIEW

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NEW JERSEY TRANSITION RESOURCES: OVERVIEW OF TRANSITION TO ADULT LIFE

What is Transition to Adult Life? The federal Individuals with Disabilities Education Act (IDEA) and state special education code define transition services as a “coordinated set of activities for a student designed within an outcome-oriented process that promotes movement from school to post-school activities including postsecondary education, related services, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.”

Who is eligible for transition services? By the year in which the student turns 14, each student’s Individualized Education Program (IEP) must include a Statement of Transition Service Needs. Prospective courses, based on the student’s desired outcome upon graduation from high school, should be included (even though students often change their minds during their high school years!) These Transition Services needs must be based on the student’s interests and preferences, and not be limited by their disability or needs. By the year in which a student turns 16, the IEP must include a Statement of Needed Transition Services. This is the coordinated long range plan for life that includes instruction, related services, community experiences, the development of employment and other post-school living objectives, and if appropriate, acquisition of daily living skills and functional evaluation.

What is the role of the youth with a disability? For the IEP that is developed for the year in which the student turns 14, every student with a disability must be invited to their IEP meeting. The notice letter to the student’s parents must include that transition will be discussed at this meeting.

Further, at least three years prior to the student reaching the age of majority (18), the IEP team must meet with the student and provide him/her with information about his/her rights upon reaching age 18. Unless the parent(s) are appointed as the young adult’s legal guardian, a student makes his/her own IEP decisions at age 18.

Students pursuing college or work must choose to identify that they need support, and they must learn their support needs and be able to effectively articulate what those needs are based upon their disability. College and work settings must only provide appropriate support and accommodations if they are asked for.

Who provides transition services? The student’s local school district provides all needed transition services, either directly by school staff or through contract with other providers. The school district’s obligation to provide needed transition services does not end until the student graduates from high school or ages out at 21 without graduating. (Just because a student has met the credit requirements for graduation does not mean that his/her eligibility for services ends if they have not yet met their transition goals.) The student’s *Case manager* is responsible for transition planning and ensuring appropriate implementation.

What other agencies may be involved? The *Division of Vocational Rehabilitation Services (DVRS)* will provide consultation to a student at age 14 and can determine eligibility for services up to two years prior to graduation. For information on DVRS, or to contact the local area office, go to <http://www.state.nj.us/labor/dvrs/vrscontact.html> or call 609-292-5987. The *Division of Developmental Disabilities (DDD)* can determine eligibility from birth. DDD can put a student on a wait list for day programming five years prior to exiting the school if appropriate. However, DDD “day programs” for individuals do not begin to be funded until the student has reached age 21 and has aged out of school. To reach DDD, go to <http://www.state.nj.us/humanservices/ddd/hotlines.html> or call 800-832-9173. *Centers for Independent Living (CILS)* can provide support to a young person in the transition process and as adults with disabilities. For information on the relevant county CIL, call 609-581-4550 or go to http://www.njsilc.org/list_alt.html. For more information and technical assistance on transition, contact the *Statewide Parent Advocacy Network* at 800-654-SPAN or go to www.spannj.org.

STATE AGENCY RESOURCES

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TRANSITION RESOURCES: STATE AGENCY RESOURCES FOR FAMILIES OF TRANSITIONING YOUTH WITH DISABILITIES

Overview: New Jersey has a multitude of resources, both public and private, for families of transitioning youth with disabilities. This fact sheet provides an overview of these resources as well as contact information.

Government Agencies: Services for transitioning youth with disabilities and their families are housed at several different state agencies, including the Departments of Education; Health and Senior Services; Human Services; Labor; and Children and Families. A fact sheet is available for each of the following agencies.

The *Department of Human Services* houses several divisions that are important to transitioning youth with disabilities and their families, including the *Division of Developmental Disabilities*; the *Division of Disability Services*; the *Catastrophic Illness in Children Relief Fund*; and the *Division of Medical Assistance* (including Medicaid and the State Child Health Insurance Program.) Information on the Department of Human Services can be found by calling 609-292-3717 or by going to <http://www.state.nj.us/humanservices/>.

The *Department of Children and Families* is the home of the *Division of Child Behavioral Health Services*, which funds the county Care Management Organizations and Family Support Organizations for children and youth with mental/behavioral health challenges, as well as the *Office of Educational Services* for children/youth in DYFS group homes, residential placements, etc. Information on the Department of Children and Families can be found by calling 609-984-4500 or by going to <http://www.state.nj.us/dcf/>.

The *Office of Special Education Programs* is part of the *Department of Education*. OSEP enforces the requirements, including transition to adult life requirements, of the Individuals with Disabilities Education Act and the state special education code. Information on the Office of Special Education Programs can be found by calling 609-292-4469 or by going to <http://www.nj.gov/njded/specialed/>.

The *Department of Labor* houses several divisions that are important to transitioning youth with disabilities. The *Division of Vocational Rehabilitation Services (DVRS)* is part of the Department of Labor. The mission of DVRS is to enable individuals with disabilities to achieve employment outcomes consistent with their strengths, priorities, needs, abilities and capabilities. DVRS can be reached by calling 609-292-2919 or by going to <http://www.state.nj.us/abor/dvrs/vrsindex.html>. The *One-Stop Career Centers* can help youth with disabilities develop job skills, strengthen job search skills, get vocational counseling or training, and improve reading and other basic skills. OSCCs can be reached by calling 877-872-5627 or by going to <http://www.state.nj.us/labor/oscc/OSCC.html>. *New Jersey Next Stop* is a program aimed specifically at New Jersey teens. The easy-to-navigate website allows students to match skills and interests with occupations that will be highly marketable when they are ready to enter the workforce. For more information, go to <http://www.njnextstop.org/>.

The *Department of Health and Senior Services' Division of Family Health Services* administers programs that enhance the health, safety and well-being of families and communities in New Jersey. The *Family Health Line*, at 800-328-3838, can help families locate health information and services. *Special Child Health Services* funds county-based Case Management Units that serve children of all ages (through age 21) who have complex medical conditions. For information on SCHS CMUs, call 609-777-7778 or go to <http://www.state.nj.us/health/fhs/sch/sccase.shtml>. Through a statewide network, Child Evaluation Centers provide a comprehensive multidisciplinary evaluation of children with congenital or acquired neuro-developmental and behavioral disorders. For information on the Child Evaluation Centers, go to <http://www.state.nj.us/health/fhs/sch/cec.shtml>. Information on the Department of Health and Senior Services Division of Family Health Services can be found by calling 800-367-6543 or by going to <http://www.state.nj.us/health/fhs/index.shtml>.

STATEWIDE NON-PROFIT RESOURCES

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Non-Profit Agencies: Services for transitioning youth with disabilities and their families are also available from a range of non-profit organizations.

Statewide Parent Advocacy Network: The Statewide Parent Advocacy (SPAN) houses several transition projects, including the Transition to Adult Life Training and Technical Assistance Project, which provides county-based trainings and statewide information and technical assistance to families, youth with disabilities, and the professionals who work with them; the Transition Camp, which works intensively with regional cohorts of transitioning youth with disabilities, their parents, and professionals who work with them, and which sponsors New Jersey's Kids As Self-Advocates chapter; and Champions for Progress, which develops and disseminates tools (such as a Transition Roadmap CD for youth and one for parents and fact sheets for health professionals) for youth, parents and professionals to make the transition process more effective. SPAN's Transition projects are directed by Alice Hunnicutt, 800-654-SPAN x 103. For more information about SPAN's transition projects and resources, go to www.spannj.org.

Family Support Center: The Family Support Center has partnered with the New Jersey Division of Developmental Disabilities to offer a web-based *Real Life Choices Resource Database* of services for transitioning youth and adults with disabilities. This directory provides families with information about agencies that have been qualified through DDD to provide services and receive payment for those services. The directory can be accessed by calling 800-FSC-NJ10 or at <http://www.fscnj.org/rlc>. DDD's *Pathways to Adult Life* project, another partnership with the Family Support Center, provides information, education and ongoing communication to young adults, their families and school personnel in developing more individualized transition planning. Contact is now made with the family of every graduating student with a developmental disability to offer supports and services. For more information, contact Lorraine D'Sylva-Lee, Director of Transition, at 800-FSC-NJ10 or email pathways@dhs.state.nj.us. To find out about upcoming information sessions for families, go to <http://www.fscnj.org/docs/pathwaysschedule.doc>.

The Guardianship Association of NJ: GANJI is a not-for-profit organization of professionals, families, and individuals committed to supporting guardians and other surrogate decision makers in enhancing the lives of persons who require assistance. The Guardianship Association sponsors an annual

conference and they have resources that can help families make important decisions about whether to apply for guardianship for their transitioning youth and if so, what type of guardianship may be appropriate. More information can be obtained by calling 877-GUARDNJ or at <http://www.ganji.org/>.

Centers for Independent Living: New Jersey's Centers for Independent Living provide information and referral, including access to comprehensive resources on accessible housing, transportation, personal assistance, and other community supports; individual and community-wide advocacy for individuals with disabilities and for improving systems for people with disabilities; person-centered peer to peer support; and independent living skills training on topics such as managing a budget, understanding the Americans with Disabilities Act, and self-advocacy. Through a State Improvement Grant, the Centers for Independent Living are funded by the NJ Department of Education to provide transition support to students and families. For more information, go to

The Boggs Center (University Center of Excellence on Developmental Disabilities): The Boggs Center provides the community training and technical assistance component for New Jersey's efforts in *self directed supports* coordinated by the New Jersey Division of Developmental Disabilities (DDD), responding to requests from individuals and families and providing technical assistance and training and information sessions on self directed services and person-centered planning. The Boggs Center has been involved in training and technical assistance for the current DDD program, *Real Life Choices*. As part of this process, The Boggs Center is providing training in Essential Lifestyle Planning, the planning process being used by families, individuals, and support coordinators in the development of a plan of care. The Boggs Center continues to provide training and technical assistance for the *self determination initiative*, an alternative to traditional residential placements, providing periodic regional networking meetings, an annual conference for the participants in self-determination, the maintenance of a self-directed supports listserv and support broker directory, and other activities to assist the maintenance and improvement of the self determination process. Products include a Resource Manual, and a short video, *The New Jersey Self-Determination Process: It Makes Life Worth Living*, available from The Boggs Center. The Boggs Center has also developed a transition curriculum. For more information, call 732-235-9300 or go to <http://rwjms.umdnj.edu/boggscenter>.

OFFICE OF SPECIAL EDUCATION PROGRAMS

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TRANSITION RESOURCES: NJ DEPARTMENT OF EDUCATION: OFFICE OF SPECIAL EDUCATION PROGRAMS

The Office of Special Education Programs of the NJ Department of Education implements state and federal laws and regulations governing special education to ensure that pupils with disabilities in New Jersey receive full educational opportunities. It provides statewide leadership through the development of policy and implementation documents and provides guidance to school districts and parents regarding the implementation of special education programs and services.

OSEP issues *policy guidance* on issues impacting children and youth with disabilities. Guidance relating to youth with disabilities includes a model Individualized Education Program (IEP) form that addresses *transition to adult life requirements* (this form can be found at <http://www.nj.gov/njded/specialed/iep.htm>); a model form to provide for students with disabilities at graduation or upon aging out of the special education system, summarizing their present levels of academic and functional performance and providing recommendations to help the student achieve post-secondary goals (this form can be found at http://www.nj.gov/njded/specialed/form/sop_temp_ate.doc); and guidance on high school students who are not yet graduating from high school but who wish to *walk at graduation* with their class (this guidance can be found at <http://www.nj.gov/njded/specialed/memos/graduation.pdf>).

This memo notes districts may allow a special education student who will not receive a diploma to participate in the graduation ceremony or prom with his or her classmates, and adds that such a policy enhances graduation ceremonies by including students with special needs who, by virtue of their disability, will continue their education beyond that of their classmates. Allowing such participation could lessen disputes over when students will complete their educational career and ensure that such decisions are not guided by non-educational considerations such as a student's desire to participate in graduation with friends.

OSEP is responsible for *administering all federal funds* received by the state for educating pupils with disabilities ages 3 through 21. It also *monitors the delivery of special education programs* operated under state authority, provides mediation services to parents and school districts, processes hearings with the Office of Administrative Law, and conducts complaint investigations requested by the public. The forms to *request mediation, a hearing, or complaint investigation* can be found at <http://www.nj.gov/njded/parights/mediation.doc>. The Parents Rights in Special Education Booklet can be found at <http://www.nj.gov/njded/parights/pocketprise.pdf>, and a short summary of parental procedural safeguards is at <http://www.nj.gov/njded/parights/spss.pdf>.

OSEP funds *four learning resource centers (LRCs)* that provide schools and parents with information services, materials circulation, technical assistance, consultation services and production services. Information on LRC programs can be found at <http://www.nj.gov/njded/lrc/toc.htm>. The office also plans and implements program and personnel development activities in areas such as implementing the least restrictive environment provision, planning the transition of students with disabilities from school to adulthood, planning programs and services for preschool children with disabilities, developing Individualized Education Programs (IEPs) and accessing individual rights and entitlements, including the right to transition services for youth with disabilities age 14 through 21.

OSEP also coordinates regional *Dare to Dream Student Leadership Conferences* for youth with disabilities each year.

Through its State Improvement Grant, OSEP funds the Centers for Independent Living to provide transition support to students and families, and the Statewide Parent Advocacy Network to conduct free transition teleconferences and conferences.

The office can be reached by calling 609-292-0147 or by going to <http://www.nj.gov/njded/specialed/>.

DEPARTMENT OF LABOR

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TRANSITION RESOURCES: NJ DEPARTMENT OF LABOR: DVRS, ONE-STOP CAREER CENTERS, & NJ NEXT STOP

The *Department of Labor* houses several divisions that are important to transitioning youth with disabilities.

The mission of the *Division of Vocational Rehabilitation Services (DVRS)* is to enable individuals with disabilities to achieve employment outcomes consistent with their strengths, priorities, needs, abilities and capabilities. DVRS can be reached by calling 609-292-2919 or by going to <http://www.state.nj.us/abor/dvrs/vrsindex.html>. Information on vocational rehabilitation services by county is available at <http://www.state.nj.us/labor/dvrs/vrdirectory.html>. DVRS's confidential referral form can be accessed at <http://www.state.nj.us/labor/dvrs/vrsrefer.html>.

The *One-Stop Career Centers* can help youth with disabilities develop job skills, strengthen job search skills, get vocational counseling or training, and improve reading and other basic skills. The centers, in 29 locations throughout New Jersey, offer many services that can be accessed both in person and online. One-Stop Career Centers offer a wide range of tools to help youth with disabilities find a job. Career counselors keep in touch with employers throughout the state, and they frequently post new job opportunities. Job seekers are cross-matched to openings in their desired field or occupation when they register.

Workforce information, job listings, training providers, career advice and a computer system to match job seekers' skills and aptitudes with current job openings, training programs (including skills and basic education classes in public or private vocational and trade schools), and on-the-job training and apprenticeships in many fields are examples of available job-search tools.

Youth with disabilities can use free self-help public access areas including phones, fax machines, photocopiers and personal computers to conduct their job search. Assistance with the equipment is always available. The OSCCs can be reached by calling 877-872-5627 or by going to <http://www.state.nj.us/labor/oscc/OSCC.html>.

The *New Jersey Job Bank* contains thousands of jobs that are posted daily by employers seeking to hire. Youth can access the New Jersey Job Bank by going to <http://www.ajb.org/nj/>.

New Jersey Next Stop is a program aimed specifically at New Jersey teens. The easy-to-navigate website allows students to match skills and interests with occupations that will be highly marketable when they are ready to enter the workforce. Njnextstop.org tells students the skills they will need to be in demand in New Jersey industries, including health care, finance, construction, utilities, manufacturing, tourism, transportation, and information technology. Njnextstop.org lists and describes occupations within an expanding industry and provides overviews that identify weekly earnings and projected growth within the industry. Youth can read articles, interviews and advice from other young people as well as from some of the state's top employers about their professions, and how to get their first job. The site has advice about writing a résumé, learning to overcome poor work habits and tackling job interviews.

The site is a product of the New Jersey State Employment & Training Commission, the New Jersey Department of Labor & Workforce Development and Department of Education with the John J. Heldrich Center for Workforce Development at Rutgers University. For more information, go to <http://www.njnextstop.org/>.

The New Jersey job seeker web site provides resources that help youth search for job opportunities, find employment-related events, list their resume, access job search tools and resources, and find out about New Jersey's job training systems. Go to <http://wnjpin.net/jobseeker.html>.

To find more job info, youth can visit the Occupational Information Network at http://online.onetcenter.org/gen_search_page, or the Career Information Section of WNJPIN at <http://wnjpin2.dol.state.nj.us/wnjpin/index.htm>.

DIVISION OF DEVELOPMENTAL DISABILITIES

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TRANSITION RESOURCES: DIVISION OF DEVELOPMENTAL DISABILITIES

The Division of Developmental Disabilities of the NJ Department of Human Services serves more than 35,000 people with developmental disabilities such as mental retardation, cerebral palsy, autism, epilepsy, spina bifida, traumatic brain injuries and neurological impairments, most of whom live at home with their families. DDD coordinates and/or provides a wide variety of services to help people with developmental disabilities live as independently as possible. DDD offers case management, residential services, and various family support services that help both people with developmental disabilities and their families. Most services are provided through state contracts with private organizations or individuals. The availability of services depends on current resources; the types of services may vary in each county.

Case Management: A trained case manager is assigned to each individual with developmental disabilities and his/her family to coordinate services and supports for that person.

Family Support Services: Family support services, provided under the Family Support Act of 1993, are offered to families caring for relatives with disabilities (typically children) at home. Family support services include in-home and out-of-home respite, cash stipends to pay for such things as home modifications, assistive devices, and recreation. Available services include:

- Cash subsidies
- Communication and interpreter services
- Counseling and crisis intervention
- Day care
- Equipment and supplies
- Home and vehicle modifications
- Homemaker assistance
- Medical and dental care
- Personal assistance services
- Respite care
- Self-advocacy training
- Therapeutic or nursing services
- Vouchers for services.

Real Life Choices: This major change to DDD is aimed at establishing equity in the distribution of resources and services; allowing for more family and individual decision-making; allocating comparable resources for comparable levels of need; and developing individual budgets based on support needs.

DDD has partnered with The Family Support Center of New Jersey to offer a *Real Life Choices Resource Database* through the Internet. This directory provides families with information about agencies that have been qualified through DDD to provide services and receive payment for those services. The directory can be accessed at <http://www.fscnj.org/rlc> or by calling 800-FSC-NJ10, the Family Support Center of New Jersey.

DDD's *Pathways to Adult Life* project, another partnership with the Family Support Center, provides information, education and ongoing communication to young adults, their families and school personnel in developing more individualized transition planning. Contact is now made with the family of every graduating student with a developmental disability to offer supports and services. For more information, contact Lorraine D'Sylva-Lee, Director of Transition, at 800-FSC-NJ10 or email pathways@dhs.state.nj.us. To find out about upcoming Pathways to Adult Life information sessions for families, go to <http://www.fscnj.org/docs/pathwaysschedule.doc>

Guardianship Services: DDD provides *guardianship services* for individuals, in order to protect their rights and to ensure appropriate care and treatment. Guardianship services are provided to help people with developmental disabilities, should it become necessary to act on their behalf because they do not have the capacity to make informed decisions regarding health, living arrangements, etc. DDD also guides parents through the process to become legal guardians of their adult children. For more information about Guardianship, contact The Guardianship Association of New Jersey at 877-GUARDNJ or go to <http://www.ganji.org/index.htm>.

DIVISION OF DEVELOPMENTAL DISABILITIES

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Residential Programs: When it is no longer possible for a person with a developmental disability to remain living at home, DDD helps the family make other living arrangements that best meet the individual's needs. Individuals who receive residential services may be required to contribute toward the cost from their disability benefits or other personal resources.

There currently is a "Community Services Waiting List" for residential programs and for adult day programs. Individuals are served in the order in which their names were added to the list. When individuals on the list are about to receive services, they may choose to develop their own plans for services through the Self-Determination Initiative. For more information on Residential Services, see the back of this fact sheet.

Day Programs: DDD services also include the provision of day programs which help the consumer develop vocational skills and learn how to use community resources; supported employment services, which help the consumer develop job skills, such as group interaction, teach the consumer about volunteerism, and offer job coaching to help consumers remain employed. DDD also helps with guardianship procedures. Day Programs include *adult training services*, which help individuals with basic vocational skills, such as those needed to develop social skills, manage money, and take care of their homes; extended employment at *sheltered workshops*, where individuals receive work-related training, such as learning how to package and assemble products, as well as job counseling and job referrals; and *supported employment services*, including on-site job coaches; crew work, in which an individual works as part of a peer group; and arrangements in which a consumer can sample different jobs to find a good "fit."

Residential Services: In consultation with the individual and his family, the Division provides a variety of community residential options, including:

- **Supervised apartments**, where a consumer lives with a roommate and receives 24-hour help from staff living nearby.
 - **Supportive living**, where a consumer lives alone or with a roommate, and help is available through a 24-hour hotline and assistance is provided on an as-needed basis.
 - **Sponsor families**, where the individual lives as part of the family of a trained caretaker, and receives 24-hour care and assistance from that person, with other support services available as needed.
 - **Private homes** are another option. By combining personal and Division funds, and/or by pooling funds with other residents, individuals can purchase or rent a house or condo.
 - **Full home ownership** is an option for individuals and/or families with sufficient resources. They can tap funding from the state Housing and Mortgage Finance Agency to purchase a home.
- Developmental Centers:** DDD also provides personal and medical care, training, therapy and supervision to individuals with the most significant disabilities in seven developmental centers statewide. Residents live as part of a community, receive training, medical care and therapy and, as needed, receive training in preparation for community life.
- To apply for services from DDD, contact the *Community Services Office* that serves the county in which the youth/young adult with disabilities lives. A list of Offices can be found at <http://www.state.nj.us/humanservices/ddd/help.html>. A DDD representative will guide the family and/or youth/young adult through the application process, eligibility will be determined and service recommendations that include appropriate information and referrals specific to the youth/young adult's circumstances will be made.
- More Information:** For more information on DDD, call 800-832-9173 or go to http://www.state.nj.us/humanservices/ddd/about_dd.html.
- **Group homes** that feature on-site, 24-hour staffing and serve the individual and several roommates.

DIVISION OF DISABILITY SERVICES & MEDICAID WAIVERS

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TRANSITION RESOURCES: THE DIVISION OF DISABILITY SERVICES & MEDICAID WAIVERS

The mission of the Division of Disability Services (DDS) of the NJ Department of Human Services is to “promote and facilitate the maximum independence and participation of people with disabilities in community life through information and access to services and supports,” and to “foster coordination and cooperation among government agencies.”

Office of Information and Assistance Services: A DDS Certified Information Specialist can provide disability-related information at 888-285-3036.

Office of Home and Community Services: DDS administers several of New Jersey’s Medicaid Waiver programs serving people with disabilities, some of which are available for transitioning youth and young adults with disabilities. These include:

Traumatic Brain Injury Waiver: This waiver is available for people with traumatic brain injury age 18 and older. It provides full Medicaid benefits plus additional services including case management, structured day programs, personal care assistance, community residential services, transportation, respite care, and cognitive therapy.

AIDS Community Care Alternative Program: This waiver serves people of any age with AIDS and children up to age 13 who are HIV positive, providing Medicaid benefits, case management, private-duty nursing, medical day care, personal care assistance, narcotic and drug abuse treatment at home, and hospice care.

Community Resources for People with Disabilities: This waiver is available for individuals with disabilities of all ages who meet the “nursing facility level of care,” financial eligibility for Medicaid waiver coverage, and who require the services offered under the waiver, including case management and Medicaid State Plan services. Individuals meeting certain specific clinical criteria can receive private duty nursing services of up to 16 hours per day.

Medicaid Personal Care Assistance: This waiver is available to people eligible for Medicaid services in the community. The purpose of personal care is to accommodate long-term chronic or maintenance health care as opposed to short-term skilled care (which is available under Medicaid’s home health program). PCA services are health-related tasks done by qualified staff in the beneficiary’s home, such as assistance with activities of daily living and household duties essential to the individual’s health and comfort.

NJ Workability Program: This program offers people with disabilities over age 16 who are working, and whose income would otherwise make them ineligible for Medicaid, the opportunity to pay a small premium and receive full NJ Medicaid coverage. It is available for people with an annual gross earned income up to \$48,500.

Personal Assistance Services Program: PASP provides routine, non-medical assistance to adults with disabilities who are employed, involved in community volunteer work, or attending school. Personal assistants help with tasks such as light housekeeping, bathing, dressing, preparing meals, shopping, driving, or using public transportation. The number of hours a person receives depends on individual need up to 40 hours per week.

Personal Preference: Cash and Counseling: This project allows disabled Medicaid recipients to direct their own care through a monthly cash allowance. A consultant works with the participant to develop a cash management plan in which s/he decides the services s/he needs and the individuals or agencies to provide the services, providing control, flexibility and choice for the participant.

Resource Directory: DDS also maintains a Resource Directory of supports for families and individuals with disabilities, available online at <http://www.state.nj.us/humanservices/dds/publications>.

Other Services: DDS also operates the *Traumatic Brain Injury Fund*, which provides supports and purchases services for individuals with acquired brain injury to foster independence when insurance, personal resources, and/or public programs cannot meet all needs; the *Disability Health and Wellness Initiative*; and the *Real Choice Systems Change grant* from the Centers for Medicare and Medicaid Services, which is supporting projects including a web-based accessible housing registry and a model curriculum to assist students with disabilities to transition from school to work.

For more information: A brochure about the services available through the Division of Disability Services is available at <http://www.state.nj.us/humanservices/dds/publications/ABOUT%20DDS.pdf>. For more information about DDS, call 888-285-3036 or go to www.state.nj.us/humanservices.dds.

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TRANSITION RESOURCES: SOCIAL SECURITY DISABILITY INCOME

Social Security pays benefits to people who cannot work because they have a medical condition that is expected to last at least one year or result in death. Federal law requires this very strict definition of disability. While some programs give money to people with partial disability or short-term disability, Social Security does not. In addition, certain family members of disabled workers also can receive money from Social Security. This is called “Family benefits.”

How does an individual meet the earnings requirement for disability benefits? In general, to get disability benefits, an individual must meet two different earnings tests: a “recent work test” based on his/her age at the time s/he became disabled, and a “duration of work” test to show that s/he worked long enough under Social Security. The charts indicating the rules for work needed to meet these two tests are at <http://www.ssa.gov/pubs/10029.html#part>.

What are family benefits and who is eligible? Certain members of the family of an individual who qualifies for SSDI may qualify for benefits based on that individual's work. Eligible family members include his/her spouse, if s/he is 62 or older; his/her spouse if s/he is caring for a child who is younger than age 16 and disabled; his/her unmarried child, including an adopted child and in some cases a stepchild or grandchild, if the child is under age 18 or under age 19 if in elementary or secondary school full time; and his/her unmarried child, age 18 or older, if s/he has a disability that started before age 22.

What are “child’s benefits” and who is eligible? An adult who was disabled before age 22 may be eligible for “child’s benefits” if a parent is deceased or starts receiving retirement or disability benefits. This is considered a “child’s” benefit because it is paid on a parent’s Social Security earnings record. The Social Security Administration makes the disability decision using the disability rules for adults. The “adult child”—including an adopted child, or, in some cases, a stepchild, grandchild, or step-grandchild—must be unmarried, age 18 or older, and have a disability that started before age 22.

What if the adult child never worked? It is not necessary that the adult child ever worked because benefits are paid on the parent’s earnings record.

What if the adult child is currently working? The adult child must not have substantial earnings. In 2007, this means working and earning more than \$900 a month. Certain expenses the adult child incurs in order to work may be excluded from these earnings. For more information about work and disability, refer to Working While Disabled-How We Can Help, a publication of the Social Security Administration.

What if the adult child is already receiving SSI benefits? An adult child already receiving SSI benefits should still check to see if benefits may be payable on a parent’s earnings record. Higher benefits might be payable, and entitlement to Medicare may be possible.

What if the adult child is already receiving disability benefits on his or her own record? An adult child already receiving disability benefits should still check to see if benefits may be payable on a parent’s earnings record. It is possible for an individual disabled since childhood to attain insured status on his/her own record and be entitled to higher benefits on a parent’s record.

What if the parent never worked? No benefits would be payable on the record of a parent who never worked.

How does SSA decide if an adult “child” is disabled for SSDI benefits? If a child is age 18 or older, SSA will evaluate his or her disability the same way they would evaluate the disability for any adult. For detailed information about how SSA evaluates disability for adults, see *Disability Benefits* (Publication No. 05-10029) at <http://www.ssa.gov/pubs/10029.html>.

How much will the benefits be? The amount of the monthly disability benefit is based on average lifetime earnings. The Social Security Statement provided to workers each year displays lifetime earnings and provides an estimate of disability benefit. It also includes estimates of retirement and survivors benefits that the worker and his/her family may be eligible to receive in the future. An estimate of the disability benefit can be requested at www.socialsecurity.gov or the toll-free number, 1-800-772-1213.

For more information, go to <http://www.ssa.gov/pubs/10029.html#part7>.

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TRANSITION RESOURCES: SUPPLEMENTAL SECURITY INCOME (SSI)

What is SSI? Supplemental Security Income (SSI) makes monthly payments to people with low income and limited resources who are blind or disabled, or 65 or older. A child under age 18 (or 22 if regularly attending school) may qualify for SSI if s/he meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits. A young adult age 18 and over may also qualify based on blindness or disability.

Who is eligible? First, the child/young adult must not be working and earning more than \$860 a month, and must have countable resources of not more than \$2,000. Two, s/he must have a physical or mental condition, or a combination of conditions, that seriously limit life activity. Third, the condition(s) must have lasted, or be expected to last, at least 12 months, or to result in death.

SSI has a Benefit Eligibility Screening Tool (BEST) tool that applicants can use to find out if they could be eligible for benefits. However, **BEST is not an application for benefits.** Applicants can access this tool by going to <https://s044a90.ssa.gov/apps12/best/benefits/>. It is available in English and Spanish.

How to apply? The SSI application is not intended to be completed by the parent or young adult alone. They call SSI and make an appointment for an SSI representative to help them apply for benefits on the phone or in person at the local Social Security office.

During the application process, parents or the young adult will be asked detailed information about their child's medical condition and how it affects his or her ability to function on a daily basis. If the parents are applying on behalf of a disabled child, SSI needs the names, addresses, and telephone numbers of people (teachers, caregivers) who can provide information about how the disabled child's medical condition affects his or her day-to-day activities. If they have access to the Internet, they can complete the disability report before they visit the Social Security office.

Completing the report before they visit the office can help make the office visit shorter. They will have to sign consent for medical providers to release all medical records for SSI review. They will also be asked to provide documentation such as the applicant's birth certificate, social security number, proof of citizenship or permanent resident card, medical records, and proof of income, expenses, and living arrangements. SSI will help get the documents needed to show SSI eligibility and will complete the application forms based on the information provided.

For applications based on [disability or blindness](#), SSI may decide that the medical information needed to make a decision is not available from existing sources and pay for a doctor's examination as well as the travel costs to get to this exam. If this exam is needed, the applicant must attend the exam to be eligible for SSI benefits.

Once the information is provided, Social Security sends the information to Disability Determination Services where doctors and other trained staff decide if the child is disabled. This process takes three to five months. However, there are certain conditions that Social Security believes to be so severe, that the child will receive payments right away and up to 6 months while the agency decides if the child is disabled. These conditions may include HIV infection, total blindness, total deafness, cerebral palsy, Down syndrome, muscular dystrophy, severe mental retardation, and birth weight below 2 pounds 10 ounces.

How to contact SSI? There are two ways to contact Social Security. The first way is to visit www.socialsecurity.gov, their website, where you can receive information on all of Social Security's programs. The second way to contact Social Security is to call them at their toll-free number, 800-772-1213, or the local Social Security Office.

More information: For more information on SSI, you can access the Understanding SSI guide at <http://www.ssa.gov/notices/supplemental-security-income/text-understanding-ssi.htm>.

SUPPLEMENTAL SECURITY INCOME

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How much will they receive? How much the child/young adult will receive in SSI benefits depends on their income and expenses, up to a maximum federal payment of \$603/month which New Jersey supplements with an additional \$27/month. Generally, the more income, the less the SSI benefit will be. If the countable income is over the allowable limit, they cannot receive SSI benefits. Some income may not count as income for the SSI program.

What is income? *Earned Income* is wages, earnings from self-employment, certain royalties and honoraria, and sheltered workshop payments. *Unearned Income* is all income that is not earned, such as Social Security benefits, pensions, State disability payments, unemployment benefits, interest income, and cash from friends and relatives. *In-Kind Income* is food or shelter received for free or less than its fair market value. *Deemed Income* is the part of the income of their parent(s) with whom they live, which SSI uses to compute the benefit amount. (When a disabled or blind child under age 18 lives with parent(s), and at least one parent does not receive SSI benefits, SSI may count some of the parents' income in figuring the child's SSI benefit. Once the child turns 18, their parent's income is not deemed to them even if they are still living at home.)

What income doesn't count? Examples of income SSI doesn't count as income include:

- The 1st \$20 of most monthly income;
- The 1st \$65 of earnings and one-half of earnings over \$65 received in a month;
- The value of food stamps;
- Income tax refunds;
- Home energy assistance;
- Assistance based on need funded by a state or local government;
- Small amounts of income received irregularly or infrequently;
- Grants, scholarships, fellowships or gifts used for tuition and educational expenses;
- Interest or dividends earned on countable resources or resources excluded under other federal laws;
- Loans that they have to repay;
- Food or shelter based on need provided by nonprofit agencies;
- Money someone else spends to pay their expenses for items other than food or shelter (e.g., telephone or medical bills);
- Income set aside under a Plan to Achieve Self-Support (PASS);
- Earnings up to \$1,460/month to a maximum of \$5,910/year for a student under age 22;
- The value of impairment-related work expenses for items or services that a person with a disability needs in order to work;
- Disaster assistance.

How does income affect benefit rate?

Step 1: SSI subtracts any income that they do not count from total gross income. The remaining amount is "countable income". *Step 2:* SSI subtracts the "countable income" from the SSI Federal benefit rate (currently \$603/month).

What are resources? Resources are things the applicant owns such as cash, bank accounts, stocks, savings bonds, land (excluding the home they live in and the land the home is on), life insurance valued over \$1500, personal property, vehicles, anything else that could be changed to cash and used for food and shelter, and *deemed resources*. (Sometimes, SSI "deems" a portion of the resources of a parent as belonging to the child who files for SSI benefits. If a child under age 18 lives with one parent, \$2000 of the parent's total countable resources do not count, and if the child lives with two parents, \$3000 doesn't count. SSI counts amounts over these limits as part of the child's \$2,000 resource limit.) Resources do not include household furnishings and personal effects, burial space or funds up to \$1500/person, one vehicle per household, retroactive SSI benefits, grants, scholarships, or gifts for educational expenses, or dedicated accounts for children who are blind or disabled. If the value of resources that SSI counts is over the allowable limit at the beginning of the month, they cannot receive SSI benefits for that month. If they decide to sell the excess resources, they may receive SSI benefits beginning the month after sale of excess resources.

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**TRANSITION RESOURCES:
NEW JERSEY DEPARTMENT OF HEALTH & SENIOR SERVICES**

The **Department of Health and Senior Services'** *Division of Family Health Services* administers programs that enhance the health, safety and well-being of families and communities in New Jersey.

Special Child Health Services funds county-based Case Management Units (CMU) that serve children of all ages (birth through age 21) who have complex medical conditions. Each of the state's 21 counties has CMU jointly funded by SCHS and the county freeholders. With parental consent, SCHS Case Managers work with parents and physicians to evaluate an affected child's strengths and needs and develop an individual service plan for the child and family. Case managers help families access medical, educational, developmental, social and other services, including health care, family support, and services from other state agencies. In 11 counties, part-time Family Resource Specialists, parents of children with special needs who work for the Statewide Parent Advocacy Network (SPAN), are housed at CMUs to provide families with information and support. For information on SCHS CMUs, call 609-777-7778 or go to <http://www.state.nj.us/health/fhs/sch/sccase.shtml>.

Services and Resources for Specific Conditions
The New Jersey Division of Family Health Services supports statewide referral networks that enhance quality of services and extensive support to families. Members of each network provide comprehensive diagnosis, treatment, patient and family education, and counseling for children and adults living with autism, cleft lip/palate, hemophilia, HIV/AIDS, Phenylketonuria (PKU), sickle cell disease, developmental and behavioral issues, and pediatric ambulatory tertiary services.

Child Evaluation Centers provide a comprehensive multidisciplinary evaluation of children with congenital or acquired neuro-developmental and behavioral disorders. Six of the eleven centers provide diagnostic services for children with or suspected of having Fetal Alcohol Syndrome. For information on the Child Evaluation Centers, go to <http://www.state.nj.us/health/fhs/sch/cec.shtml>.

Regional Cleft/Lip Palate Centers provide a comprehensive team approach to the care of infants and children with cranio-facial anomalies. Medical/health related experts evaluate the child and develop long term care plans, in collaboration with the child's primary physician and parents, to correct or reduce craniofacial disorders. Go to <http://www.state.nj.us/health/fhs/sch/scleft.shtml>.

Hemophilia services can be accessed through a statewide network of centers that provide comprehensive diagnosis, treatment/management, patient/family education, and psychosocial counseling for children and adults with hemophilia or other disorders of bleeding or coagulation. Related services are also available or can be coordinated for their family members. More information is available at <http://www.state.nj.us/health/fhs/sch/schemo.shtml>

New Jersey's *Family Centered HIV Care Network* provides a full range of high quality, culturally sensitive and coordinated HIV/AIDS medical and social support services to women, children, and adolescents throughout the state. Resources can be accessed at <http://www.njfamilyhiv aids.org>.

The *Family Health Line*, at 800-328-3838, can help families locate health information and services. Trained telephone counselors provide information and referrals for health screening and treatment and have access to an interpreter service that enables them to respond to callers in 140 languages.

New Jersey Health Link, accessible at <http://www.nj.gov/njhealthlink/>, provides access to health information and details about services and eligibility, as well as contact names and phone numbers in a single-page printable format.

Additional information on the Department of Health and Senior Services Division of Family Health Services can be found by going to <http://www.state.nj.us/health/fhs/index.shtml> or by calling 800-367-6543.

CHILD BEHAVIORAL HEALTH SERVICES

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TRANSITION RESOURCES: DIVISION OF CHILD BEHAVIORAL HEALTH SERVICES

Overview: The *Division of Child Behavioral Health Services (DCBHS)* of the New Jersey Department of Children and Families serves children and adolescents with emotional and behavioral health care challenges and their families in a family-centered, community-based environment. DCF involves families throughout the planning and treatment process to create a service system that values and promotes the advice and recommendations of the family, a system that is friendly to families and one which provides them the tools and support needed to create successful life experiences for their children with emotional and behavioral problems.

How to access services: DCF provides families with a virtual single point of contact that registers, tracks and coordinates care for children and youth who are screened – at any level - into its Children's Behavioral Health Service System of Care. To provide this simplified access, DCF contracts with Value Options, the systems administrator. For questions about or to access services, call the 24-hour, toll free Access Line at 877-652-7624.

What services are available? Through Value Options families can access the following services in their county.

Mobile Response and Stabilization Services: Children's Mobile Response and Stabilization Services is a single, comprehensive system of mobile response available to children and youth whose escalating emotional or behavioral issues require timely interventions to prevent disruption of their current living arrangement, including out-of-home placement. Primarily, the mobile response system is a face-to-face delivery of service at the site of the escalating behavior, whether this is the child's home, a group home or another living arrangement, including foster and adoption family homes. Mobile Response provides time limited, intensive, preventive services that include behavioral and rehabilitative interventions designed specifically to defuse, mitigate and resolve an immediate crisis.

To access Mobile Response services, contact Value Options at (877) 652-7624 for a referral. A list of organizations that provide this service in the family's community can be found at <http://www.state.nj.us/dcf/behavioral/links/mobile.html>.

Care Management Organizations: Care management organizations (CMO's) are non-profits that provide a full range of treatment and support (wrap-around) services to children with the most complex needs. They work with child-family teams to develop individualized service plans. The CMO's goals are to keep children in their homes, their schools and their communities. To access Care Management services, contact Value Options at (877) 652-7624 for a referral. To view the list of Care Management Organizations, go to <http://www.state.nj.us/dcf/behavioral/links/care.html>.

Family Support Organizations: Family Support Organizations (FSO's) are family-run, county-based organizations that provide direct family-to-family peer support, education, advocacy and other services to family members of children with emotional and behavioral problems. The FSOs also have a Youth Partnership program to support youth with behavioral health challenges and build their leadership skills. To access Family Support services, contact Value Options at (877) 652-7624 for a referral. To view the list of Family Support Organizations, go to <http://www.state.nj.us/dcf/behavioral/links/family.html>.

Youth Case Management Services: Youth Case Management (YCM) is the supportive relationship that case managers develop with the children and families they serve. YCM advocates for the needs and views of the child and their family. YCM has a leadership role in the coordination and integration of services designed to optimize care for children and families. To access Youth Case Management services, contact Value Options at (877) 652-7624 for a referral. For a list of local YCM, go to <http://www.state.nj.us/dcf/behavioral/links/youth.html>.

More Information: For more information, go to <http://www.state.nj.us/dcf/behavioral/>.

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**TRANSITION RESOURCES:
CONTINUING HEALTH COVERAGE FOR DEPENDENTS UNDER 30**

Federal COBRA and the New Jersey Small Group Continuation Right (NJSOCR, a state law that applies to employers with fewer than 20 employees not governed by COBRA) allow an adult child who ages-out of coverage under a group health plan to elect to continue coverage with the group for up to 36 months. New Jersey Public Law 2005 Chapter 375 allows an adult child who ages-out under a group health plan to elect to continue coverage on his/her parent's group health coverage until his or her 30th birthday, if s/he meets all other Chapter 375 eligibility standards. A young adult eligible to choose continuation under both Chapter 375 and COBRA or NJSOCR will have to make a choice.

Chapter 375 only applies to group health insurance policies issued in the State of New Jersey, and to the State Health Benefits Plan (SHBP). The law does not apply to group health insurance policies issued in other states, or self-funded group health plans (other than the SHBP). It applies differently to the SHBP than it does to other groups with group health insurance policies.

An adult child under 30 who is a New Jersey resident (or a full time student at an accredited public or private institution of higher education wherever located) is permitted to make a Chapter 375 election only if several conditions are met. The young adult must have already aged-out of a parent's group health benefits plan, or be about to age-out of a parent's group health benefits plan issued in New Jersey or under the SHBP. The young adult may not have any children; be covered under an individual health benefits plan, a group health plan, or church plan (a young adult can be covered immediately prior to the Chapter 375 election, so it is not necessary to have a break in coverage, only that the young adult not be covered under two policies); or be entitled to coverage under Medicare. The adult child's parents must be covered under a group health benefits plan issued in New Jersey or under the SHBP that covers dependents. It is not required that the young adult demonstrate economic dependence on their parent (through tax returns or anything else).

An adult child who continues coverage as a Chapter 375 dependent will lose coverage if s/he marries, becomes a parent, is no longer a full-time student and is not residing in New Jersey, becomes covered under an individual or group health benefits plan, group health plan or church plan, or turns 30 years old; or if required premiums are not paid, the adult child's parent is no longer covered under the group health benefits plan; or

the group health benefits plan no longer covers dependents. If a young adult loses coverage obtained through a Chapter 375 election, but later meets the eligibility requirements again, the young adult may make another Chapter 375 election, up until age 30.

The cost of coverage for a Chapter 375 dependent will depend on the cost of the adult child's parent's group coverage. The cost of coverage for a Chapter 375 dependent will be less than the cost of coverage for a single employee under the parent's group coverage, probably between 20 to 40% less. Employers are NOT required to contribute to the cost of covering a Chapter 375 dependent and the parent or continuing dependent may be required to pay the full cost of the coverage. To find out the actual cost of coverage, an adult child must contact the parent's employer, the carrier that issues the group health benefits plan, or their representatives.

An adult child who meets the eligibility standards may make a Chapter 375 election within 30 days *PRIOR* to the date a dependent is scheduled to age-out of the policy; within 30 days *AFTER* an adult child meets the Chapter 375 eligibility standards for reasons other than age (for example, an adult child who had been working in California decides to return to live in New Jersey); or either during the group's annual open enrollment period, or annually during the 30-day period following the anniversary of the adult child's loss of coverage if the adult child is seeking coverage under a Small Employer Health Benefits Plan.

If an adult child who is aging-out is not eligible to make a Chapter 375 continuation election, he or she will still be eligible to make a COBRA election to continue coverage if the employer is subject to COBRA, or make a COBRA-like election based on New Jersey law if the employer group is too small to be subject to COBRA. The conditions for making the COBRA or NJSOCR election are the same.

If an adult child was covered under NJ Family Care until age 19, their loss of coverage does not entitle him/her to elect coverage under Chapter 375, because Medicaid is not a group health benefits plan. If an adult child was covered as a dependent of a parent who was active duty military when s/he aged out, his/her loss of coverage does not entitle her/him to elect coverage under Chapter 375 because coverage through Tricare does not qualify as a group health benefits plan issued in New Jersey.

CONTINUING HEALTH COVERAGE

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If the adult child was covered as a dependent of a parent who worked for the government or worked for a university in New Jersey when s/he aged out may be eligible if the coverage was under a group health benefits plan issued in New Jersey. The best source of information will be the human resources or benefits department handling the parent's coverage.

Most people who work for the *federal government* as part of the civilian workforce receive their health benefits through the [Federal Employees Health Benefits Program](#) (FEHBP). Some coverage under the FEHBP is self-funded, some is insured, but much of the coverage is unlikely to qualify as group health benefits plans issued in New Jersey.

Most people who work for the New Jersey *state government* are covered through the [State Health Benefits Plan](#) (SHBP). Although the SHBP is self-funded, if the young adult aged-out of SHBP coverage, s/he will qualify for the Chapter 375 election.

People who work for *counties, municipalities, local authorities, or public universities* in New Jersey may have coverage through the SHBP, another group health benefits plan issued in New Jersey, or through a self-funded plan. If the young adult aged-out of a self-funded plan other than the SHBP, s/he will not qualify for the Chapter 375 election.

Most people who work for *private universities* located in New Jersey will have coverage under a group health benefits plan issued in New Jersey or a self-funded plan. If the young adult aged-out of a self-funded plan, s/he will not qualify for the Chapter 375 election.

If the young adult was covered as a dependent of a parent who received coverage through a union plan when s/he aged out, s/he will need to obtain more information about the parent's coverage at the time s/he aged-out. Many union plans self-fund the health benefits offered to members and their families. In some instances, the health benefits may be through a jointly-sponsored employer-employee self-funded welfare plan. Self-funded plans are not group health benefits plans issued in New Jersey. Even when the health benefits are insured, many unions exist across state lines, and may seek to have the insurance contract issued in a single state, which may or may not be New Jersey. If insured through an out-of-state policy, the coverage is not through a group health benefits plan issued in New Jersey and wouldn't fall under Chapter 375.

Even if an adult child is eligible to make a Chapter 375 continuation election, he or she should evaluate the COBRA (or NJSGCR) election option to determine which election option is best for his or her situation. There are some clear differences between these options. An adult child must make the COBRA or NJSGCR election when he or she first ages-out. Chapter 375 allows the adult child to make a Chapter 375 election when: (1) he or she first ages-out, (2) when he or she meets the other Chapter 375 eligibility standards, or (3) during an established open enrollment period. An adult child who exhausts the COBRA or NJSGCR election (for instance, the 36-month period ends), may make a Chapter 375 election later if he or she meets all of the Chapter 375 eligibility standards.

The premium rate for an adult child making a COBRA or NJSGCR election may be up to 102% of the group's single person rate. The premium rate for an adult child making a Chapter 375 election may be 102% of the rate applicable to the group's child dependents. Generally, the Chapter 375 charge may be a little lower than the charge for the same coverage under a COBRA or NJSGCR election.

The adult child's continuing coverage following a Chapter 375 election is contingent upon whether: (1) the parent continues to have coverage with the group, (2) the parent elects to continue dependent coverage, and (3) the group continues to offer dependent coverage. An adult child's continuing coverage with a group following a COBRA or NJSGCR election is not contingent upon his or her parent's actions, or a decision by the group policyholder to eliminate the option to cover dependents.

A person continuing coverage under Chapter 375 loses the right to such coverage if he marries, becomes a parent, moves out of state and is not a full-time student, or completes studies and does not live in New Jersey. None of these events disqualifies a person from continuing coverage under COBRA or NJSGCR.

The adult child's COBRA and NJSGCR election is restricted to the group from whose coverage the adult child aged-out. The adult child's Chapter 375 election right is not restricted to the group from which the adult child aged-out.

For more information and answers to frequently asked questions, go to the New Jersey Department of Banking and Insurance website, <http://www.state.nj.us/dobi/dependentsunder30.htm>.

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TRANSITION RESOURCES: MEDICAL RECORDS AND HIPAA

This fact sheet briefly explains the Health Insurance Portability and Accountability Act (HIPAA) regulations that apply in situations when a parent or other family member seeks health-related information or records of their young adult with a cognitive impairment. The HIPAA statute and its regulations govern the use and disclosure of individuals' health information by health service providers, including the circumstances under which a family member of a young adult with a significant disability (e.g., autism or cognitive disability) can access the individual's health information.

HIPAA provides that covered entities are required to disclose to an individual his own health information upon his request. 45 CFR § 164.502(a)(2)¹. HIPAA also provides that the individual's "personal representative" is entitled to be treated the same as the individual in terms of access to health information. 45 CFR § 164.502(g). The term "personal representative" is used to define the scope of a family member's access to the records of both adult and minor relatives with disabilities.

Access when the family member is a minor: If a parent, guardian, or other person acting as the parent has the authority to act on behalf of a minor in making health care decisions, the covered entity generally must treat that individual as the personal representative of the minor who can authorize access to the minor's records. Thus, a parent or guardian of a minor – regardless of whether the minor has a disability – generally has the right to request the minor's health care information and consent or refuse to consent to the release or sharing of that information. 45 CFR § 164.502(g)(3).

Access when the family member has an appointed guardian: If a family member has authority to act on behalf of a young adult relative in making health care decisions (e.g., a parent is the guardian of an adult daughter with autism or cognitive disability), the covered entity must treat the family member as a personal representative with respect to protected health information. In other words, if a young adult has a guardian who is authorized to make health care decisions, then the guardian is treated as the individual and has the right to request the individual's health care information. 45 CFR § 164.502(g)(2).

Access when the family member has no appointed guardian: A young adult – regardless of disability status – is presumed competent to control his/her health care records in the absence of a legal finding that a guardian is necessary. Thus, family members who do not have guardianship cannot control access to their relative's health care information. However, nothing precludes the individual (regardless of cognitive limitations) from authorizing release of health care information to his/her family member.

A health service provider can refuse access to a personal representative if: (1) it has a reasonable belief that the individual has been subject to abuse or neglect by the representative and that releasing the information to the representative could endanger the individual and would not be in the individual's best interests; or (2) it determines that the provision of access to the personal representative is likely to cause substantial harm to the individual or another person. 45 CFR §§ 164.502 and 164.525.

If an individual (or his personal representative) requests his records, a health service provider may request that s/he execute an authorization for the release. HIPAA regulations require that the authorization include, among other things, an expiration date or event. 45 CFR. § 164.508(c)(1)(iv). Accordingly, an individual (or his representative) can execute an authorization that governs future requests for information so long as an expiration date is included in the authorization.

Minors' rights to consent to treatment without notice to parents: In New Jersey, minors have the right to consent to contraceptive counseling and services; abortion; medical care related to pregnancy; testing and treatment for sexually transmitted infections or treatment for sexual assault; and mental health services, without notice to their parents of the health services they receive and without sharing health records related to these health services with their parents. However, if the health provider believes that the minor has been sexually assaulted, the health provider must immediately inform the parents unless they feel that it is not in the best interests of the minor to do so (for example, if they believe that the parent was responsible for the sexual assault).

¹ CFR = Code of Federal Regulations. 45 CFR Section 164 contains the federal regulations for HIPAA.

POWER OF ATTORNEY FOR MEDICAL DECISIONS

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TRANSITION RESOURCES: POWER OF ATTORNEY FOR MEDICAL DECISIONS

Youth and young adults with disabilities who are old enough to make their own medical decisions (age 18 and older) and do not have an appointed guardian may wish to identify an “agent” in case they become incapacitated and need a surrogate decision maker. A Durable Power of Attorney and a Medical Power of Attorney are legal instruments that are available to all persons with capacity as a way of planning for such an event.

The standard types of documents that attorneys use for the general population are written in such a way that they are often too complex and difficult for youth and young adults with disabilities to understand. The Community Health Law Project (973-275-1175) has developed a Medical Power of Attorney Form to meet the needs of people with developmental disabilities that is written in simple, easy to understand language. This form is attached to this Transition Resource fact sheet.

What is a Medical Power of Attorney? A Medical Power of Attorney is a document that allows a person to appoint an Agent to make medical decisions on his/her behalf and access his/her medical records. It is designed to allow the “principal’s” wishes with regard to medical care to be carried out or to be authorized by another person if they cannot authorize necessary medical treatment themselves. The Medical Power of Authority authorizes the agent to access medical records, talk with doctors, and collect information about their principal’s health. The Agent cannot make all medical decisions for the Principal but rather makes medical decisions after consulting with the Principal. If the Principal cannot be consulted due to his/her medical condition, then the Agent should make medical decisions that were previously expressed to him or her or that are in the Principal’s best interest if no prior discussions were held regarding the current situation.

How can a Medical Power of Attorney be assigned? It is not necessary to go to court to execute a Medical Power of Attorney. The Principal merely signs the form (it is best if the signing is witnessed/notarized).

What should happen to the signed document?

The Principal and the Agent should hold the originals. They should show the original to their health practitioners and ask them to make a copy of it for the medical file.

Can the health practitioner talk only to the Agent? The health practitioner must continue to talk directly to the patient about his/her healthcare even if there is an Agent, unless the patient is no longer capable of discussing his/her health care.

What can the Medical Power of Attorney include? The Medical Power of Attorney can be very broad, allowing the Agent to act on behalf of the Principal in any and all situations where the Principal lacks decision-making capacity, including general medical decisions (medical procedures, tests, treatments, surgery, hospitalization, end-of-life decisions such as Do Not Resuscitate orders or withholding/withdrawing of life-sustaining medical treatment), psychological or psychiatric care, access and release of health care information, funeral arrangements, and/or anatomical gifts. On the other hand, it may be limited to certain situations or certain types of care specified in the signed Medical Power of Attorney document.

What if the Principal wishes to change their Agent or revoke the Medical Power of Attorney? The patient/principal always has the right to change their Agent or revoke the Medical Power of Attorney by signing a Revocation of Medical Power of Attorney form, or by any other writing that clearly expresses their desire to revoke. The healthcare practitioner must honor the revocation immediately, or consistent with the terms of the revocation.

Liability of Healthcare Practitioners: A health care practitioner who relies in good faith on a consent or waiver given under a signed Medical Power of Attorney incurs no liability for any act or omission taken at the direction of the authorized Agent. However, *healthcare practitioners may be held liable if they fail to honor a revocation once it has been provided to them.*

CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND

Family to Family Health Information Resource Center/Family Voices NJ @ Statewide Parent Advocacy Network
35 Halsey Street, Newark, NJ 07102
800-654-SPAN www.spannj.org

TRANSITION RESOURCES: CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND

The *Catastrophic Illness in Children Relief Fund* of the NJ Department of Human Services provides eligible families with financial assistance to help them cover medical expenses that were previously incurred because their child became catastrophically ill or injured.

What is a catastrophic illness? In the Catastrophic Illness in Children Relief Fund Program, any illness can be "catastrophic" based on uncovered eligible medical expenses and the family's income in a prior 12-month time period.

A catastrophic illness is any illness or condition, acute or chronic, for which expenses are incurred that are not fully covered by insurance, state, federal programs, or other sources and exceed the program's eligibility threshold. There are no specific exclusions by diagnosis.

Who is eligible? To be eligible for the Catastrophic Illness in Children Relief Fund, the family must have lived in New Jersey for at least three months prior to the application; their child must have been 21 years old or younger at the time the expenses were incurred; the expenses that were not covered by insurance or state/federal programs exceeded 10% of their annual family income plus 15% of any annual family income above \$100,000.

What expenses are eligible for reimbursement? Covered expenses include, but are not limited to, special ambulatory care, acute or specialized in- or out-patient hospital care, medical equipment, medically-related home modifications, home health care and medical transportation.

The following incurred expenses will be considered and may be eligible for payment/reimbursement if found reasonable. The categories include, but are not limited to:

- Specialized pediatric ambulatory care
- Addictions/mental health services
- Acute or specialized hospital care, both in and outpatient
- Physician care in all settings
- Medical equipment or disposable medical supplies
- Pharmaceuticals
- Medically related home modifications and medical transportation
- Home health care
- Experimental medical treatment or pharmaceuticals following special review.

How does a family apply? A family first calls the toll free Family Information Line at 1-800-335-FUND (3863) for information and an application. The completed application is forwarded to the State Office of the Commission for screening and review. All applications to the Fund are confidential. The Commission reviews the application and makes the final determination on eligibility and the amount of assistance. Approved grant awards are disbursed directly to the providers to offset outstanding balances. Families may also be reimbursed for out-of-pocket expenses.

Since 1989, when the first awards were granted, more than 4100 families have been assisted and more than \$100 million has been approved in uncovered expenses.

For more information on the Catastrophic Illness in Children Relief Fund, call 609-292-0600 or go to <http://www.state.nj.us/humanservices/catill/cicrf1.htm>.