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NEW JERSEY COMMUNITY OF CARE CONSORTIUM FOR

CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

AND THEIR FAMILIES

HEALTHCARE FINANCING FACTSHEET SERIES

Updated April, 2013

The NJ Community of Care Consortium for CYSHCN
Health Care Financing Work Group

This document was a collaboration of the Statewide Parent Advocacy Network (SPAN), American Academy of Pediatrics-NJ, NJ Department of Health, NJ Department of Human Services, NJ Department of Children and Families, parents of CYSCHN, and other non-profit agencies and organizations committed to improving health outcomes for children and adolescents with special healthcare needs and their families.

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NJ Family Care: SCHIP and Medicaid

Children age 18 and younger may be eligible for NJ FamilyCare/Medicaid if their family's total income before taxes is at or below 350% of the Federal Poverty Level ($6,432/month for a family of 4). Parents may also be eligible if earned income is at or below 133% of the Federal Poverty Level ($2,444 monthly for a family of four). Applicants must be uninsured (although there are exceptions) and must be either citizens or legal immigrants who have documents that allow them to remain in the United States permanently. Parents must be legal permanent residents for at least 5 years to be eligible. (This does not apply to children or pregnant women).

Are you eligible? To determine if you or your children meet the general and financial eligibility requirements for NJ FamilyCare/Medicaid or to get additional information, you can (a) self-screen for this and other social service programs on www.njhelps.org; (2) refer to the "Income Eligibility and Cost" page on www.njfamilycare.org for eligibility; (3) contact your County Welfare Agency (www.state.nj.us/humanservices/dfd/programs/foodstamps/cwa/); or (4) call NJ FamilyCare at 800-701-0710.

Parents whose income exceeds the eligibility limits for NJ FamilyCare can purchase health insurance for their children at reasonable rates through the ***NJ FamilyCare ADVANTAGE*** program administered by Horizon NJ Health, if they qualify. The cost is $143 per month for one child; $286 per month for two children; and $429 per month for three or more children. To learn more, go to www.horizonnjhealth.com/members/advantage.html or call 1-800-637-2997.

How to apply: You can: (1) apply online through www.njfamilycare.org or www.njhelps.org; (2) download an application for NJ FamilyCare/Medicaid from www.njfamilycare.org or call 1-800-701-0710 to request a mailed application; or (3) apply at your local County Welfare Agency.

Other Medical Programs for Children Under the Age of 21

Children who have "aged out" of the programs described above, or who have other special circumstances, may be eligible for one of the programs described below.

Medicaid Special: Children under the age of 21 who do not qualify for other NJ FamilyCare/ Medicaid programs may be eligible for the Medicaid Special program. Family income for all family members living in the same household is used to determine financial eligibility. For instance, children 19 or 20 years old who have "aged out" of NJ FamilyCare/Medicaid may be eligible if their family has earned income at or below 133% of the federal poverty level.

Medically Needy: This program provides limited health coverage to children under 21 who do not qualify for regular NJ Medicaid because their family income or financial resources are too high. It includes a "spend down" provision that allows documented medical expenses to be used to reduce monthly income to meet eligibility limits. Children who qualify for this program receive most Medicaid services except in-patient hospital care. Find more information at www.state.nj.us/humanservices/dmahs/clients/medicaid/medically_needy_fact_sheet.pdf and www.state.nj.us/humanservices.dmahs/clients/medicaid/medically_needy_checklist.pdf.

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MEDICAID: DENTAL CARE AND CHILDREN WITH SPECIAL NEEDS

What special provisions exist for enrollees with developmental disabilities?

The New Jersey Medicaid contract requires specific policies for the provision of services to enrollees with developmental disabilities including:

1. Consultations with patient caregivers.

2. Reimbursement for initial and follow-up visits which may require up to 60 minutes to allow for a comprehensive exam and other services, including but not limited to: *a visual exam; appropriate radiographs; dental prophylaxis (including extra scaling and topical applications, such as fluoride); non-surgical periodontal treatment (including root planing and scaling; dental sealants; thorough inquiries of patient medical histories; and consultations with patient caregivers).*

3. Standards for visits that recognize additional time may be required.

4. Up to four visits annually without prior authorization.

5. Provision for home visits when medically necessary and where available.

6. Policies to ensure providers of care for enrollees with developmental disabilities have adequate support staff to meet the needs of patients.

7. Provisions for use and replacement of fixed and/or removable prosthetic devices as medically necessary.

8. Reimbursement for the costs of pre/post-operative evaluations.

9. Preauthorization cannot be required for procedures performed during surgery on patients for restorative care provided under anesthesia. Informed consent, signed by the enrollee or authorized person, must be obtained prior to such surgery or placement under anesthesia.

10. Reimbursement for providing oral hygiene instructions to caregivers to maintain a patient's oral health between visits. Such provisions must include designing and implementing a "dental management" plan, coordinated by the care manager.

11. The care manager must coordinate authorizations for dentally required hospitalizations by consulting with the plan's dental and medical consultants in an efficient and time-sensitive manner.

For more information on Medicaid and dental care for children, see www.state.nj.us/humanservices/dmahs/clients

Special thanks to Beverly Roberts, Director-AR C of NJ Mainstreaming Medical Care Program.

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New Jersey's Federally Qualified Health Centers

What are Federally Qualified Health Centers (FQHCs)?
FQHCs are community-based organizations that provide comprehensive primary care and preventive care, including health, oral, and mental health/substance abuse services to persons of all ages. Federally Qualified Health Centers (FQHCs) provide care specifically to medically underserved areas where healthcare access is otherwise limited or non-existent, especially for those who are uninsured and underserved.

Where does funding for FQHCs come from?
Funding for FQHCs comes from the US Department of Health and Human Services' Bureau of Primary Health Care (BPHC) and the Center for Medicare and Medicaid Services (CMS) as well as the state of NJ. This funding is provided to help FQHCs provide healthcare to children and adults who are uninsured or medically underserved.

Who do FQHCs provide services to?
FQHCs provide medical services to all persons with and without insurance regardless of immigration status and ability to pay.

What is the cost for care at FQHC's? Do they accept insurance?
FQHCs accept payment for services through the following: •Medicaid • Medicare • Some commercial / private insurances • Self-pay • Sliding fee scale and discounts for those who demonstrate the ability to qualify.

What types of comprehensive health services are provided?
FQHCs provide health care services from pre-birth through full age, including obstetrics/ gynecology, prenatal care, pediatrics, well-child visits, vaccines for children, adolescent health, family practice, internal medicine, and geriatrics. FQHCs offer nutrition care, pregnancy testing, social services, pharmacy discounts, and family dental care. Most FQHCs offer bilingual services in English and Spanish.

FQHCs provide comprehensive primary care that includes physical, behavioral, and oral health, either directly on site, or by referral. FQHCs also provide chronic illness treatment through a Chronic Care Model that includes diabetes care, Chronic Obstructive Pulmonary Disease (COPD), cardio-vascular disease, Laboratory Services, referral for mental health services, and cancer screenings, among other diseases.

How can you access care from your local FQHC?
Visit or call one of the county based locations with clinic hours that include nights and weekends. Visit the website to find a FQHC near you at www.njpca.org/FQHC/directory.aspx.

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New Jersey "Charity Care"

What is the hospital care payment assistance program?
The New Jersey Hospital Care Payment Assistance Program (Charity Care Assistance) is free or reduced charge care which is provided to patients who receive inpatient and outpatient services at acute care hospitals throughout the State of New Jersey.

Where does funding for hospital care payment assistance come from?
The source of funding for hospital care payment assistance is through the Health Care Subsidy Fund administered under Public Law 1997, Chapter 263.

Who is eligible for hospital care payment assistance?
Hospital care payment assistance is available to New Jersey residents who:

1. Have no health coverage or have coverage that pays only for part of the bill: **and**
2. Are ineligible for any private or governmental sponsored coverage (such as Medicaid); **and**
3. Meet **both** the income and assets eligibility criteria
4. Hospital assistance is also available to non-New Jersey residents, subject to specific provisions.

How are individuals made aware of the availability of hospital care payment assistance?
Hospitals post signs in English, Spanish and any language which is spoken by 10% or more of the population in the hospital's service area.

What are the screening procedures for third party payers and Medicaid?
All charity care applicants must be screened to determine the potential eligibility for any third party insurance benefits or medical assistance programs that might pay towards the hospital bill.
Patients may not be eligible for the hospital care payment assistance program until they are determined to be ineligible for any other medical assistance programs.

How does someone apply for hospital care payment assistance?
The patient or prospective patient must apply for hospital care payment assistance at the hospital from which he/she plans to obtain or has obtained services. The patient should apply at the business office or admissions office of the hospital. The patient or responsible party must answer questions related to his/her income and assets, as well as provide documentation of the income and assets. The hospital will make a determination of whether the applicant is eligible as soon as possible, but no more than ten working days from the time a complete application is submitted.

The Department of Health and Senior Services has a toll-free number to assist with any questions or concerns. Please call the Health Care for the Uninsured Program during business hours at 1-866-588-5696 or email us Charity.Care@doh.state.nj.us .

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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? 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, 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; and 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:

- 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
- Medical transportation
- Experimental medical treatment or pharmaceuticals following special review
- Other medical expenses.

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.

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.

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NJ Health
New Jersey Department of Health

Department of Children and Families

Cover our Kids Community Campaign
NJ FAMILYCARE
Affordable health coverage. Quality care.
1-800-701-0710
department of human services DHS

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
New Jersey Chapter

Mental Health Parity

There are two federal laws that protect the right of children and adults who need mental health care: the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) and Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), as well as a state law, the New Jersey Biologically-Based Mental Illness Mandate.

Federal Law: ***MHPAEA*** applies to employers with 50 or more workers whose group health plan *chooses* to offer mental health or substance use disorder benefits. Businesses with 50 or fewer employees are exempt from this law but small employers are still covered by state mental health parity law. The law requires mental health "parity" in group health plans offered by private employers as well as plans sponsored by state and local governments. Covered disorders include depression, autism, schizophrenia, eating disorders, and alcohol and drug abuse.

Group health insurance plans may not restrict access to mental health care by limiting benefits and requiring higher patient costs than those that apply to general medical or surgical benefits. Employers and group health plans cannot provide less coverage for mental health care than for the treatment of physical conditions such as cancer and heart disease. Insurers cannot set higher co-payments and deductibles or stricter limits on treatment for mental illness and addiction disorders. Insurers can't establish separate deductibles for mental health care and for the treatment of physical illnesses. There can't be a cap on the number of outpatient visits allotted per year for mental health care if there are no caps for physical health-related visits. For more information, go to www.dol.gov/ebsa/newsroom/fsmhpaea.html or http://federalregister.gov/a/2010-2167.

CHIPRA: Children who are covered by NJ Family Care (State Children's Health Insurance Program and Medicaid) are protected by the provisions of CHIPRA 2009. Qualifying financial requirements and treatment limitations for mental health or substance use disorder benefits can't be more restrictive than those applied to medical surgical benefits. No separate qualifying criteria may be applied to mental health/substance use disorder benefits. When out-of-network coverage is available for medical surgical benefits, it must also be available for mental health or substance use disorder benefits.

NJ Biologically Based Mental Illness Mandate (1999): This requires all health insurers in the state who are covered by the NJ Department of Banking and Insurance to cover treatment of "biologically-based mental illness" according to the same conditions for other illnesses and diseases. This also covers small employers. Biologically-based mental illness means a mental or nervous condition that is caused by a biological disorder of the brain and results in a clinically significant or psychological syndrome or pattern that substantially limits the functioning of the person with the illness, including but not limited to schizophrenia, schizoaffective disorder, major depressive disorder, bipolar disorder, paranoia and other psychotic disorders, obsessive-compulsive disorder, panic disorder, and pervasive developmental disorder or autism. Copayments, deductibles, and benefit limits for behavioral health services must be the same as for medical and surgical benefits. For more information, go to www.njleg.state.nj.us/9899/Bills/s2500/2277_i1.pdf or www.state.nj.us/dobi/division_insurance/ihcseh/bulletins/seh9906.htm.

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The NJ Children's System of Care – Child Behavioral Health

Overview: The *Children's System of Care (CSC)* of the New Jersey Department of Children and Families (DCF) serves children and adolescents with emotional and behavioral health care challenges or developmental disabilities and their families. This fact sheet addresses child behavioral health services.

What services are available? The following is a list of some of the key services.

***Mobile Response and Stabilization Services*:** Children's Mobile Response and Stabilization Services are available to children and youth with escalating emotional or behavioral issues that need to be addressed quickly to keep them at home, safely. 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, school, etc. Mobile Response provides time-limited, intensive behavioral services designed to defuse, mitigate and resolve an immediate crisis. To access Mobile Response services, contact Perform Care at **(877) 652-7624** for a referral. A list of organizations that provide this service in the family's community can be found at www.state.nj.us/dcf/families/csc/mobile/.

Care Management Organizations (CMOs): 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 Perform Care at **(877) 652-7624** for a referral. To view the list of Care Management Organizations, go to www.state.nj.us/dcf/families/csc/care/.

Family Support Organizations (FSOs): 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 Perform Care at **(877) 652-7624** for a referral. To view the list of Family Support Organizations, go to www.state.nj.us/dcf/families/support/support/.

Youth Case Management Services (YCM): YCM Services are available to children in the Child Behavioral Health System who do not need the most intensive supports. YCM advocates for the needs and views of the child and their family and helps to coordinate and integrate services. To access Youth Case Management services, contact Perform Care at **(877) 652-7624** for a referral. For a list of local YCM, go to www.state.nj.us/dcf/families/csc/case/.

How to access services: Perform Care, the Contracted Systems Administrator, registers, tracks and coordinates care for children and youth who are screened into the Child Behavioral Health Service System of Care. For questions about or to access these services or other available services, call Perform Care at their 24-hour, toll free Access Line at 877-652-7624.

More Information: For more information, go to www.state.nj.us/dcf/families/csc/.

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The NJ Children's System of Care – Intellectual/Developmental Disabilities

Overview: The *Children's System of Care (CSOC)* of the New Jersey Department of Children and Families (DCF) serves children and adolescents with emotional and behavioral health care challenges or developmental disabilities (DD) and their families. This fact sheet addresses services for children and youth with intellectual and developmental disabilities.

The NJ DCF CSOC determines eligibility of individuals under age 18 for DD services, and provides support and services, deemed "clinically and functionally appropriate," for individuals under the age of 21 with DD.

What services are available? The following is a list of some of the key services.

- Group home placements
- In-Home supports
- Assistive technology devices
- Respite
- Camp
- Home and vehicle modifications

The goal is to best meet the needs of children with developmental and intellectual disabilities that are not being met through school related services, medical services reimbursable by health insurance, or by other existing supports or services. Developmental Disability (DD) Family Support services are intended to help support uncompensated caregivers for children and youth eligible for DD services and living in their own homes. Under the direction of the NJ Developmental Disabilities Council, the Regional Family Support Planning Councils assist the Children's System of Care to allocate funding for these services by making recommendations based on family input.

How to access services: Perform Care, the Contracted Systems Administrator, registers, tracks and coordinates care for children and youth who are screened into the System of Care for Intellectual and Developmental Disabilities. Families are asked to provide insurance information to PerformCare; families that are not already Medicaid or NJ Family Care eligible are required to complete a NJ Family Care Application. Families requesting services for DD-eligible youth must apply for all benefits to which their youth may be entitled, including but not limited to Supplemental Security Income (see SSI fact sheet in this series). While all families are required to apply for Medicaid and/or Family Care, if families are not eligible for this health insurance, CSOC services may still be available. Eligibility for Medicaid is not a prerequisite to obtaining most services. (Note: Services for adults with DD under the NJ Department of Human Services are limited to those with Medicaid coverage. For more information, go to www.nj.gov/humanservices/ddd/services/medicaideligibility.html).

For questions about or to access these services or other available services, call Perform Care at their 24-hour, toll free Access Line at 877-652-7624.

More Information: For more information, go to www.performcarenj.org/families/disability/index.aspx.

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NEW JERSEY EARLY INTERVENTION SYSTEM

The New Jersey Early Intervention System (NJEIS) is a statewide system of services for infants and toddlers, birth to age three, with developmental delays or disabilities and their families. A referral is made by calling the Regional System Point of Entry toll-free number at **1-888-653-4463.** Following referral, a service coordinator is assigned to assist the family with determining eligibility for early intervention services.

Who is Eligible?

In New Jersey, a child is considered eligible for early intervention services if he or she is under the age of three and either (a) demonstrates measured delays in development of at least 2.0 standard deviations below the mean in one developmental area, or 1.5 standard deviations below the mean in two or more developmental areas, including Physical; including gross motor, fine motor, and sensory (vision and hearing); Cognitive; Communication; Social or emotional; and/or Adaptive; (b) has a diagnosed physical or mental condition with a high probability of resulting in developmental delay, confirmed in a signed statement or report from a physician, advanced practice nurse, or licensed clinical psychologist (chromosomal abnormalities, genetic or congenital disorders, sensory impairments, inborn errors of metabolism, disturbance of the development of the nervous system, congenital infections, severe attachment disorders, or disorders secondary to exposure to toxic substances such as fetal alcohol syndrome); or (c) has a presumptive eligibility diagnosis (Down syndrome, fetal alcohol syndrome, hearing or vision impairment, autism spectrum disorder, spina bifida, cerebral palsy, Trisomy 13, 18, etc., Fragile X, or hydrocephalus).

What are the Costs of the Services?

Federal law requires that specific services be provided to eligible children and families at public expense. These include Child find/referral; Evaluation/assessment; Service coordination; IFSP development and review; and Procedural safeguards (family rights).

Beyond these required services, a family may have to assume some or all of the cost of services, depending on the parents' resources (e.g., Medicaid/Private Insurance) and ability to pay. The Family Cost Participation co-payment for services is on a sliding fee scale based on the family's income and size. Families with adjusted incomes below 300% of the Federal Poverty Level do not have a family cost share.

What are Family Rights?

Parents have specific procedural safeguards (parent rights) under the NJEIS. These include parent consent, written prior notice, confidentiality, record review and dispute resolution. The NJEIS offers several options for formal resolution of disputes including mediation, impartial due process hearings, and administrative complaints.

More information on procedural safeguards is available at http://nj.gov/health/fhs/eis/procsafeguards.shtml

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SPECIAL CHILD HEALTH SERVICES
New Jersey Department of Health and Senior Services

Our mission is focused on providing family-centered, community-based services that are individualized and accessible. Children age birth to 21 years of age and individuals infected and/or affected by HIV/AIDS who have any of a broad range of disabilities or chronic illnesses may benefit from the available special child health services as listed below. Our main telephone number is **609-984-0755**. Please visit our website at http://nj.gov/health/fhs/sch/index.shtml

Case Management Services……(609) 777-7778
This program, together with individual County Boards of Chosen Freeholders, funds case management units in each of New Jersey's 21 counties. Special Child Health Case Managers work with families of children with special health care needs to find medical, dental, rehabilitative, social, emotional, and economic resources for the care and treatment of their child. More information can be found at their website: http://nj.gov/health/fhs/sch/sccase.shtml

Birth Defects and Autism Registry System….. ……(609) 292-5676
This confidential system maintains the Special Child Health Services Registry and the Autism Registry. Families are informed of the registration and are provided information about available services in their area.

Newborn Screening and Genetic Services (NSGS)……(609) 292-1582
Every baby born in New Jersey is screened for 54 disorders that can cause serious health problems. Several drops of blood are taken from the baby's heel and the sample is sent to the Newborn Screening Laboratory for testing. NSGS staff ensure that newborns with abnormal screening results are followed by the baby's health care provider and if necessary, by pediatric specialists. If the baby is found to have one of these disorders, the baby's health care provider and specialist work together with the family to treat and manage the condition.

Early Hearing Detection and Intervention (EHDI)……(609) 292-5676
The EHDI program ensures all children born in New Jersey are screened for possible hearing loss. Children with any level of hearing loss are offered services through Case Management Services and the Early Intervention System **(1-888-653-4463)**. Diagnostic hearing services are available on a sliding fee scale through the Child Evaluation Centers.

Fee-For-Service ……(609) 777-7778
Fee-For-Service may provide financial assistance toward the purchase of orthopedic braces, prostheses and hearing aids for families who meet eligibility criteria. In addition, a special pharmaceutical assistance program is available for children who have cystic fibrosis or asthma. Families are screened for insurance status and eligibility for State and Federal programs.

Ryan White Part D Family-Centered HIV Care Network……(609) 777-7778
This Network provides comprehensive, culturally sensitive, coordinated care for women, children, youth and families infected with or affected by HIV disease. The Network offers HIV specialty care, outreach, counseling and testing, medical case management, social support services as well as access to clinical drug trials, and referral to ancillary care services.

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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 at https://s044a90.ssa.gov/apps12/best/benefits in English and Spanish. However, ***BEST is not an application for benefits.***

How to apply? The parent or young adult calls SSI to 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 process, parents or the young adult will be asked detailed information about their child's medical condition and how it affects daily functioning. If the parents are applying on behalf of a child with a disability, SSI needs contact information for people (teachers, caregivers) who can provide information about how the 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. 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. SSI may decide that a medical exam is needed, 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.

Social Security sends the information to Disability Determination Services. This process takes 3-5 months. However, there are certain conditions that are 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 much will they receive? How much the child/young adult will receive in SSI benefits depends on their income, resources, and expenses, up to a maximum federal payment of $603/month which New Jersey supplements with an additional $27/month. Generally, the more income and resources, the less the SSI benefit.

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

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Social Security Disability Insurance (SSDI)

SSDI is a federal program that pays benefits to people who *cannot* work because of a medical condition expected to last at least one year or result in death. It is not for people with partial or short-term disability. Certain family members of disabled workers can receive "family benefits."

How does an individual meet the earnings requirement for benefits? To get disability benefits, an individual must meet two earnings tests: a "recent work test" based on age at the time of disability, and a "duration of work" test to a long enough work record under Social Security. The charts with the rules for these two tests are at www.ssa.gov/pubs/10029.html#part.

What are *family benefits* and who is eligible? 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 a spouse who is 62 or older; a spouse who is caring for a child younger than age 16 and disabled; an 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 school full time; and an unmarried child, age 18 or older, with 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. A "child's" benefit is paid on a parent's Social Security earnings record. The disability decision is based on the disability rules for adults. The "adult child" must be unmarried, age 18 or older, and have a disability that started before age 22.

What if the adult child is currently working? The adult child can't have earnings above $900 a month, excluding certain work-related expenses. For more information about work and disability, refer to Working While Disabled-How We Can Help, www.ssa.gov/pubs/10095.pdf.

What if the adult child is already receiving Supplemental Security Income (SSI) benefits? An adult child already receiving SSI benefits should check to see if benefits may be payable on a parent's earnings record. Higher benefits and/or entitlement to Medicare might 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.

How does SSA decide if an adult "child" is disabled for SSDI benefits? If a child is age 18 or older, SSA will evaluate disability the same way they would evaluate the disability for any adult. For detailed information, see Disability Benefits at 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. 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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New Jersey's Health Insurance Exchange

The federal ***Patient Protection and Affordable Care Act*** (ACA) requires each state to establish a Health Care Exchange by January 1, 2014. A state ***health insurance exchange*** gives you and small employers the same purchasing power as large corporations. You will be able to buy your health insurance with a "wholesale discount" instead of at retail "take-it-or-leave-it" prices. Every employer will have to offer health insurance coverage, and every individual will ***have to*** purchase a health plan if they are not already covered through another plan. If you cannot afford a plan, even at the Exchange prices, there will be federal financial assistance to help you buy a plan.

What is a Health Care Exchange?
A health care, or health insurance, exchange is like a marketplace. It gives individuals and small businesses the information and tools you need to compare different health care plans in terms of costs and plan benefits. The exchange will help you decide which coverage option is best for you and your family, and small businesses to obtain the best coverage for their employees. The exchange will give individuals and small businesses the opportunity to join together to negotiate for high-quality health plan options at affordable prices the way larger companies do. Participating in the Exchange is voluntary if you already have an insurance plan that you like. Members of the US Congress will have to get their insurance through the Exchange – so you will have the same options they have!

Who Will Run the Exchange? What Will They Do?
The purpose of the Exchange is to benefit the people of New Jersey who can't afford insurance on the open market, and who aren't eligible for public insurance like Medicaid or NJ Family Care. New Jersey's healthcare exchange, or "marketplace," will be a federally-facilitated marketplace. You can find out information about how the federally-facilitated marketplace will operate at http://cciio.cms.gov/resources/factsheets/ffe.html.

The Exchange will set rules about the quality and type of coverage that has to be included in an Exchange health coverage plan. Only health plans that meet these criteria will be accepted into the Exchange. The Exchange will offer plans that provide a comprehensive and high-quality package of health care services, including dental and mental health services, for children and adults, including those with special healthcare needs. Health care delivery networks will include essential community providers such as Federally Qualified Health Centers and community clinics. Patients should have access to providers who speak their native language, and information materials in their language.

How Will You Find the Right Plans?
The Exchange will be easily accessible to all consumers and small businesses, using plain, easy-to-understand terms in multiple languages. The Exchange must adopt a "no wrong door" approach, meaning people can access insurance through the exchange no matter how they come to seek assistance. It will provide in-person, telephone and online assistance and access. Those providing assistance need to understand diverse populations, such as people with disabilities, mental health needs or low-income. It will have an easy-to-use website, like Travelocity or Consumer Reports, that you can access for information and to purchase insurance. The website will be closely monitored by the Exchange to prevent fraud and protect consumers.

The Exchange will contract with independent organizations to help consumers and small groups "navigate" health insurance plans and services. ***Navigators*** must be independent, knowledgeable, and have a history of working with diverse communities to ensure that they can help consumers and small businesses determine which coverage is best for them. Navigators can be community nonprofit organizations, unions, chambers of commerce, or other organizations that are trusted in the community and equipped to help the consumers in New Jersey find and access the right plans.

For more information, go to www.spannj.org/healthcarematerials or www.njforhealthcare.org or call 800-654-SPAN (7726).

The NJ Community of Care Consortium for CYSHCN
Health Care Financing Work Group

This document was a collaboration of the Statewide Parent Advocacy Network (SPAN), American Academy of Pediatrics-NJ, NJ Department of Health, NJ Department of Human Services, NJ Department of Children and Families, parents of CYSCHN, and other non-profit agencies and organizations committed to improving health outcomes for children and adolescents with special healthcare needs and their families.