

NJ Department of Human Services
Division of Developmental Disabilities
Office on Autism



A Family Guide to Navigating the
New Jersey Service Systems
for Individuals with
Autism Spectrum Disorders

State of New Jersey
Chris Christie, *Governor*
Kim Guadagno, *Lt. Governor*

Department of Human Services
Jennifer Velez, *Commissioner*

www.state.nj.us/humanservices/ddd/home/ooa

Interdepartmental Work Group on Autism Spectrum Disorders

Department of Human Services (Host Agency)

Dawn Apgar
Julie Caliwan
Deborah Cohen
Pam Ronan
Jonathan Sabin

Department of Children and Families

Jeffrey Guenzel
Deborah Filler

Department of Community Affairs

Bruce Blumenthal (New Jersey Housing and Mortgage Finance Agency)
Anthony Marchetta
Pam McCrory

Department of Education

Barbara Gantwerk

Department of Health and Senior Services

Susan Evans
Martin T. Zanna

Department of Labor and Work Force Development

Richard Constable
Alice Hunicutt

***This publication is the result of the collaborative work of the
Intergovernmental Work Group on Autism Spectrum Disorders.***

A Family Guide to Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorders and other Developmental Disabilities

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1. Background

Through the work of multiple state agencies, New Jersey has taken significant steps to address the needs of individuals with Autism Spectrum Disorders (ASD) and their families. Among these actions was the statutory establishment of the Adults with Autism Task Force (AWATF). The Department of Human Services (DHS) was charged with administering the Task Force, with support provided by its Division of Developmental Disabilities (DDD). DDD has been the lead resource agency for individuals with developmental disabilities and families who are seeking programs and services since 1959. The Division has a broad scope - addressing individual diagnoses that fall collectively within the definition of intellectual and developmental disabilities. The Division's mission to protect the health and safety of the individuals it serves, promote equity and fairness among diagnoses and expend state tax dollars responsibly and efficiently continues today.

The AWATF was charged with making recommendations to the Governor and Legislature about programs and services that would meet the needs of adults with ASD. The AWATF released its report in October 2009. The report is available at <http://www.nj.gov/humanservices/ddd/boards/AATFrpt.pdf>. Acting upon one of the recommendations, DHS established an Office on Autism (OOA) in the DDD. The purpose of the OOA is to provide a centralized place to address issues associated with ASDs within DDD.

One of the first acts of the OOA was the establishment of an Interdepartmental ASDs Workgroup for the purpose of enhancing and improving communication, collaboration and coordination among state agencies that are charged with providing services to persons with ASDs. The Workgroup departments include: Human Services, Children and Families, Community Affairs (Housing and Mortgage Finance Agency), Education, Labor and Workforce Development, and Health and Senior Services. This family guide, ***Through the Maze: A Family Guide for Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorders***, is the result of a concentrated effort by representatives of the ASDs work group to capture virtually all state based programs and services in one manual. The Interdepartmental ASDs Workgroup would like to extend its thanks to the Missouri Office on Autism Services whose publication, "Navigating Autism Services: A Community Guide for Missouri", served as a template for this document.

2. Purpose of Guide

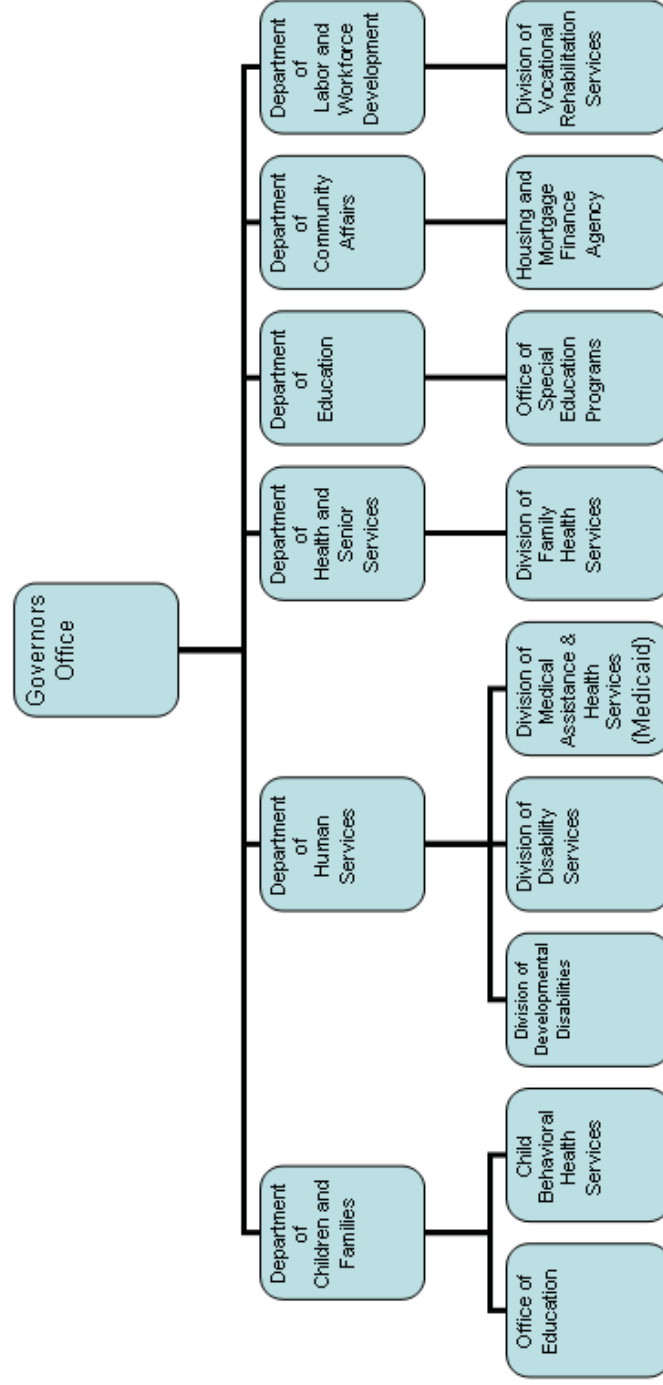
Through the Maze: A Family Guide to Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorders and other Developmental Disabilities is intended to assist anyone in need of ASD related services to find their way through the often confusing realm of New Jersey's state system of programs and services for individuals contending with ASDs. "***Through the Maze***" should be viewed as a starting point for anyone interested in developing an understanding of the way our state has arranged its governmental services for individuals and families affected by ASDs; it is not intended to represent every ASD service available in New Jersey. State Government is fortunate to have non-profit partners that run intensive and comprehensive programs that fill service needs, which are not addressed by state government.

We hope that this guide eases your way through New Jersey's maze of governmental services for people with ASDs.



State of New Jersey Departments with Primary Responsibility for Providing Services to Individuals with Autism and other Developmental Disabilities

Organization Chart





3. What are Autism Spectrum Disorders?

Autism Spectrum Disorders (ASDs) are a cluster of neurobiological disorders that become evident during early childhood. People with ASDs process information and perceive the world differently. An ASD is not caused by an emotional disturbance; and it is definitely not caused by your approach to parenting. A great deal of research is now occurring that explores the possible causes of ASDs. For additional information regarding some of this research, please go to page 26.

Your child may receive a diagnosis that is among those included in the spectrum. These include:

- Asperger Syndrome
- Autistic Disorder
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Occasionally, you may find that two other diagnoses, Rett Syndrome and Childhood Disintegrative Disorder, are included under the ASD umbrella.

ASDs affect people in different ways. Like all of us, individuals with ASDs each have their own interests, abilities and strengths and challenges. A wide variety in levels of intelligence, ways of communicating, social skills, creativity and challenging behaviors are associated with these diagnostic categories. This is why ASD is called a “spectrum” disorder.

4. ASDs in New Jersey

According to the Centers for Disease Control and Prevention’s (CDC) most recent data, an average of 1 in 110 individuals have an ASD. This is a prevalence of about 1 percent of children.¹ It is estimated that between 12,000 and 18,000 New Jersey residents have an ASD.² New Jersey’s rate of ASD, however, is one of the highest in the nation and is estimated to be 1 in 94.³ Unfortunately, the reasons for this high rate in our state are not yet known.

5. Diagnosing ASDs in New Jersey

Child Evaluation Centers

Through a statewide network, New Jersey provides support for eleven Child Evaluation Centers (CECs), which provide comprehensive, multidisciplinary evaluations of children with congenital or acquired neuro-developmental and behavioral disorders. Following evaluation, the CECs develop an individualized service plan (ISP) in collaboration with families. Cost of a diagnostic evaluation is the responsibility of the patient and each clinical site varies in their fees. However, no child is denied access to these services due to the absence of third party health insurance coverage or an inability to pay. Families should contact the evaluation team directly to determine their options regarding insurance, sliding scale fees, private pay or other funding sources. Contact information for the CEC located in your region is as follows:

¹ Centers for Disease Control, CDC Study: An average of 1 in 110 children have an ASD.

<http://www.cdc.gov/Features/CountingAutism/>.

² Division of Family Health Services Special Child Health and Early Intervention Services, Autism Spectrum Disorders. <http://www.nj.gov/health/fhs/documents/autism0904.pdf>.

³ *MMWR*, Vol. 56/SS-1, Feb 9, 2007, *Prevalence of Autism Spectrum Disorders - Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002*





New Jersey's Child Evaluation Centers

Cooper University Hospital

Child Evaluation Center
Three Cooper Plaza
Camden, New Jersey 08103-1489
Phone: (856) 342-2257

Jersey City Medical Center

Center for Children with Special Needs
953 Garfield Avenue, 1st Floor
Jersey City, New Jersey 07304
Phone: (201) 915-2059

Jersey Shore University Medical Center

FAS Diagnostic Center
Child Evaluation Center
Medical Arts Building
1944 Rt. 33 Suite 101 A
Neptune, New Jersey 07753
Phone: (732) 776-4178 ext. 2

John F. Kennedy Medical Center

Child Evaluation Center
2050 Oak Tree Road
Edison, New Jersey 08820
Phone: (732) 548-7610

South Jersey Healthcare

FAS Diagnostic Center
Child Evaluation Center
1138 East Chestnut Ave., 3B
Vineland, New Jersey 08360-4893
Phone: (856) 696-1014 or 1035

St. Joseph's Children's Hospital

Child Evaluation Center
703 Main Street
Paterson, New Jersey 07503
Phone: (973) 754-2500

Morristown Memorial Hospital

Child Evaluation Center
100 Madison Avenue
Morristown, New Jersey 07960-6095
Phone: (973) 971-5227

Children's Seashore House of the Children's Hospital of Philadelphia

FAS Diagnostic Center
Child Evaluation Center
4009 Black Horse Pike
Mays Landing, NJ 08330
Phone: (609) 677-7895 ext. 33463

Children's Hospital of New Jersey at Newark Beth Israel

FAS Diagnostic Center
Child Evaluation Center
201 Lyons Avenue
Newark, New Jersey 07112
Phone: (973) 926-4544

Children's Specialized Hospital

FAS Diagnostic Center
Phone: (908) 301-5511
Child Evaluation Center
150 New Providence Rd.
Mountainside, New Jersey 07092
Phone: (888) 244-5373 or (908) 233-3720

UMDNJ New Jersey/New Jersey Medical School

FAS Diagnostic Center
Child Evaluation Center
185 South Orange Avenue, F509
Newark, New Jersey 07107
Phone: (973) 972-8930





6. Professionals Working With ASDs

Professionals from many medical and allied health fields will participate in the evaluation process to diagnosis your child. These professionals are often referred to as the Interdisciplinary Evaluation Team. Following the assessment and as part of developing an Individualized Service Plan (ISP), individuals could be referred to different types of specialists. The most common professionals working with individuals with ASDs, as well as their area of expertise are summarized in the following table.

If children are younger than three years of age, the CEC may also refer them to an Early Intervention Program (EIP). (See Early Intervention Section on Page 12) If your children are school age (3-21 years), they may be referred to your school district’s Child Study Team (see School Years Section Page 13).

Who Can Be of Help	How They Can Help
Psychiatrist	A medical doctor who can diagnose ASDs as well as other illnesses and treat the mental health issues associated with ASDs. A psychiatrist can prescribe medication or other treatments to treat issues such as depression and anxiety, aggression, ADD/ ADHD, obsessive-compulsive behavior, tic disorders, and more.
Neurologist	A medical doctor who can diagnose ASDs and other neurological disorders. A neurologist also checks the neurological functioning of the body and may order tests such as MRIs or EEGs. A neurologist can prescribe medication or other treatments to treat issues such as depression and anxiety, aggression, ADD/ADHD, obsessive-compulsive behavior, tic disorders, seizure disorders, and more.
Developmental Pediatrician	A medical doctor who is a pediatrician with special training and certification in developmental-behavioral pediatrics. A developmental pediatrician is skilled in diagnosis of ASDs and developmental disorders. This doctor looks at the whole child and can recommend treatments, including medication.
Psychologist	A licensed psychologist with specialized training in developmental disorders, such as a clinical psychologist or neuropsychologist. A psychologist, or neuropsychologist, can diagnose or recommend treatment for ASDs and other developmental disorders. He or she may address coping skills, behavior management, social skills, and strategies for improving functioning.
Behavior Analyst	A psychologist or therapist who is specially trained to analyze and treat behaviors that interfere with learning and functioning.
Speech-Language Pathologist (SLP)	A therapist who specializes in understanding and use of language, and the pronunciation of speech sounds. A speech-language pathologist may address understanding and use of words, grammar, social skills, reading comprehension, and written language.
Occupational Therapist (OT)	A therapist who specializes in assessing and treating fine motor skills, play and social skills, handwriting, sensory integration, and daily living skills such as dressing and feeding.
Physical Therapist (PT)	A therapist who specializes in assessing and treating gross motor skills (jumping, ball skills, using stairs), strength, and coordination.





7. Following an ASD Diagnosis

a. How Should I Feel?

There is no right or wrong way to react to a diagnosis. You may have feelings of sadness, fear, guilt, denial, confusion, anxiety, or even relief about having an answer. These feelings will come and go in no particular order throughout your journey. Some people are ready to jump into treatment right away, and others need more time. Talking with another parent may be a source of support and a reminder that you are not alone. Several agencies offer support groups to New Jersey families. You can find support groups at Autism Family Services of New Jersey, <http://www.autismfamilyservicesnj.org/content/services/#> or to connect with a Support Parent, contact the Statewide Parent Advocacy Network at 1-800-654-SPAN or <http://www.spannj.org/>.

b. Who Should I Tell?

It is your decision as to whom and when to tell other people that your child has been diagnosed with an ASD. The people who provide health and therapeutic services to your child will likely find it helpful to have this information as soon as possible. When you share the news with family members, you may find they respond with a range of reactions and feelings. Keep in mind that everyone copes differently with the news of a diagnosis. Find other parents with similar experiences who can help support you.

c. Next Steps/Seeking Services?

The world of ASD and other developmental disabilities is, most likely, one with which you are entirely unfamiliar. Finding appropriate services for your family member is often dependent upon their age at the time of diagnosis. It is important to remember that New Jersey's departments and services operate under federal and state laws and regulations which may result in some constraints in the delivery of services. The information below provides the general steps that families can take to obtain needed services:

Determine eligibility for services:

- Eligibility requirements as well as possible costs associated with specific services vary from program to program. If you are interested in Early Intervention services from the Department of Health and Senior Services, housing assistance from the NJ Housing Mortgage Finance Agency, Family Support Services from the Department of Human Service's Division of Developmental Disabilities or any other service or program, make sure to visit the department's web site or directly be in touch with staff associated with the services in order to ensure that you qualify for the program or service. (You will find links to each department's website on pages 10 and 11.)
- Begin intervention services: Under age 3: see Early Intervention section on page 12.
- Find a Support Group or connect with a Support Parent. Contact Autism Family Services of New Jersey at <http://www.autismfamilyservicesnj.org/content/services/#> or to access a support network for mothers of children with special needs, contact Mom2Mom at 1-877-914-MOM2 or <http://www.njarch.org/images/M2M%20brochure.pdf>.





- To connect with a Support Parent, contact the Statewide Parent Advocacy Network at 1-800-654-SPAN or <http://www.spannj.org/>. You can also talk with a parent who has volunteered to be a mentor for other parents at SPAN.
- Educate yourself about ASDs.
- Consult with your county based Special Child Health Services (SCHS), Case Management Unit about community based, State and/or federal services and supports for your child age birth to 21 years of age. You may find your county's CMU by calling the Department of Health and Senior Services at 609-777-7778, or referring to Department's website at: <http://www.state.nj.us/health/fhs/sch/sccase.shtml>.
- Learn more about Special Education:
 - Visit the Department of Education, Office of Special Education Programs at <http://www.state.nj.us/education/specialed/>; and/or
 - Contact The Arc of New Jersey's Department of Education Advocacy at 732-246-2525 and http://www.arcnj.org/programs/education_advocacy.html and/or
 - Contact the Statewide Parent Advocacy Network at 1-800-654-SPAN or <http://www.spannj.org/>.
- Start a system for organizing reports and notes.
- If you need resources, please be sure to review section 12 "Funding for Services and Supports" on page 22.
- Work toward a routine schedule for home. Try making a schedule of your daily activities, using pictures or words in order to assist your child with an ASD.
- Find a behavior therapist to teach you strategies for increasing the behaviors you want to see. Your child's doctor, the CECs or agencies that provide family support services, such as Autism New Jersey (<http://www.autismnj.org>) may be able to help find a behavior therapist.





8. Intervention Decisions

We know more about what works in treating ASD than we did 10 or 20 years ago, but there are still many questions to be answered. Today, hundreds of treatment options are available. It is important to ask questions about which therapeutic approach might be the most effective for your child.

Here are some examples:

- Early Intensive Behavior Intervention (EIBI)/Applied Behavior Analysis (ABA)
- Relationship Development Intervention (RDI) Developmental, Individual-Difference, Relationship-Based (DIR) Model (Floortime)
- Structured Teaching – TEACCH Model (Treatment and Education of Autistic and Communication Related Handicapped Children)

Knowing what questions to ask is just as important as asking them. Parents who have gone down this path have compiled some important issues that you may want to raise with your service providers and these parents offer some advice:

Questions to Ask Providers	Parent-to-Parent Advice
What is this treatment and what does it do?	Have hope about treatments, but use common sense. Be cautious when you see or hear claims of cures.
Is this something I could do with my child and stay with it? Will this cause more stress for our family or reduce stress?	Use caution with treatments that require payment before the treatment begins.
Is there real science to support this treatment?	Think about the source of the information you read. Is someone trying to sell you something?
Can I afford the treatment?	Double-check things you read on the Internet.
How will I be involved in the therapy?	Pay special attention to studies that are published in high-quality scientific journals with peer-reviewed research. Do other studies show the same findings?
How will I know whether my child is making progress?	
Could I talk with another family about their experience with this therapy and this provider?	





9. New Jersey Departments Primarily Responsible for Providing Services to Individuals with Autism and other Developmental Disabilities

Individuals with ASDs, living in New Jersey, may receive services and assistance from a number of different departments and agencies within state government. Seeking information and assistance for a family member with an ASD can be very confusing. The purpose of this section is to provide the names of the various state departments and to give you some general information about the services they offer. It is not intended to be an all-inclusive description of what each agency provides. Visiting each department's website to obtain more in-depth information about these services is encouraged. The following state departments include agencies that provide one or more services to individuals with ASDs and their families:

- **Department of Children and Families (DCF)** <http://www.state.nj.us/dcf/> - The DCF is New Jersey's state child welfare agency. DCF is focused on strengthening families and achieving: safety, well-being and permanency for all New Jersey's children. Children with ASD or other developmental disabilities and co-occurring mental health needs may qualify for assistance via the DCF Office of Education or the Division of Child Behavioral Health Services (DCBHS).
 - Individuals between the ages of 5 and 21 who receive diagnoses of both ASD as well as a mental health disorder may qualify for services established under the DCF DCBHS. DCF provides families with a virtual single point of contact that registers, tracks and coordinates care for children who are screened - at any level - into its Children's Behavioral Health Service System of Care. To provide this simplified access, DCF contracts with Perform Care which is a private entity that administers this service system.
24-hour, toll-free Access Line at: 1-877-652-7624
The following services are available:
 - Mobile Response and Stabilization Services
 - Care Management Organizations
 - Youth Case Management Services
 - Family Support Organizations
- **Department of Community Affairs (DCA)** <http://www.state.nj.us/dca/> - The DCA is charged with providing administrative guidance, financial support and technical assistance to local governments, community development organizations, businesses and individuals to improve the quality of life in New Jersey. DCA offers a wide range of programs and services that respond to issues of public concern including fire and building safety, housing production, community planning and development, and local government management and finance. The New Jersey Housing and Mortgage Finance Agency (HMFA) is associated with DCA. People with ASDs or other developmental disabilities may qualify for assistance with housing issues through the HMFA.
- **Department of Education (DOE)** <http://www.state.nj.us/education/> - The DOE is New Jersey's primary educational oversight body. DOE is committed to setting standards associated with providing children with the highest quality education. DOE works with local school systems to provide supports and services to all school aged children and youth. The Office of Special Education Programs within DOE addresses systems which provide educational supports and services to students with disabilities, including students with ASD.





- **Department of Health and Senior Services (DHSS)** – <http://www.state.nj.us/health/>
 - The mission of the DHSS is to foster accessible and high-quality health and senior services to help all people in New Jersey achieve optimal health, dignity and independence. They work to prevent disease, promote and protect well-being at all life stages and encourage informed choices that enrich quality of life for individuals and communities. DHSS provides special needs assistance to children with ASDs and other special health needs through Early Intervention Services and Title V programs including Special Child Health Services Case Management Units. Funded in part through the county Boards of Social Services, there is a SCHS CMU in each county staffed by nurses and social workers that will speak with you about:
 - information related to your child’s medical/dental, developmental, rehabilitative, educational and socioeconomic needs,
 - development of an individual service plan and periodic monitoring,
 - referrals to related services; i.e., Social Security Income (SSI), Medicaid, transition, Catastrophic Illness in Children Relief Fund, family support, Child Evaluation Centers and Early Intervention Services.

- **Department of Human Services (DHS)** – <http://www.state.nj.us/humanservices/>
 - The DHS serves more than one million of New Jersey’s most vulnerable citizens, or about one of every eight New Jersey residents. DHS serves individuals and families with low incomes; people with mental illnesses, developmental disabilities, or late-onset disabilities; people who are blind or visually impaired, deaf or hard of hearing, or deaf-blind; parents needing child care services, child support and/or healthcare for their children; and families facing catastrophic medical expenses for their children.
 - **DHS Division of Developmental Disabilities (DDD)** – The New Jersey Division of Developmental Disabilities funds services for eligible individuals with DD.
 - **DHS Division of Disability Services (DDS)** – DDS is designated as New Jersey’s single point of entry for all people who are seeking disability-related information.

- **Department of Labor and Workforce Development (DLWD)** – <http://lwd.state.nj.us/labor/index.html> – The DLWD is committed to helping New Jersey’s skilled and productive workforce gain the right job so that they can help high quality employers compete successfully in the world marketplace.
 - **DLWD Division of Vocational Rehabilitation Services (DVRS)** – The mission of DVRS is to enable eligible individuals with disabilities to achieve employment outcomes consistent with their strengths, priorities, needs, abilities, and capabilities. DVRS provides a wide range of vocational rehabilitation services to people with disabilities in order to assist eligible individuals to obtain employment.





10. Life Stages and and ASDs

A. The Importance of Early Intervention (Birth to age 3)

The New Jersey Early Intervention System (NJEIS) is administered by the DHSS' Division of Family Health Services which implements New Jersey's statewide system of services for infants and toddlers, birth to age three, with developmental delays or disabilities, and their families. DHSS is the Governor's designated lead agency for the Early Intervention System. The goals of the NJEIS are:

- Promote collaborative partnerships among the family, their community, service and health care providers, schools and child care programs that strengthen and enhance family competence to develop and use lasting networks of natural support.
- Provide a family-centered approach which will be based upon the uniqueness of the family and its culture.
- Promote prompt service and support delivery in settings most natural and comfortable for the child and family and which foster opportunities for the development of peer relationships with children without disabilities.
- Reflect the current best practices in the field of early intervention in order to ensure uniformity of service delivery standards and yield the most positive outcome for the child and family.
- Recognize and respect the knowledge, beliefs, aspirations, values, culture and preference of families and utilize these for planning and delivery of supports and services.
- Facilitate ongoing, system-wide, participatory evaluation to ensure an effective and efficient Early Intervention System.

Please be aware that there may be costs associated with some services provided to families through the NJEIS. You can call the statewide toll free referral number 888-653-4463 for information about accessing EIS in your community. More information can be found at <http://www.nj.gov/health/fhs/eis>.

Life Line for the Journey

The Division of Developmental Disabilities (DDD) hosts a unique educational and informational presentation called "Life Line for the Journey." It is specifically designed for Parents and Guardians of children with developmental disabilities. Life Line for the Journey aims to help families consider the appropriate steps in planning for children with developmental disabilities, from birth through age 14. At these sessions, families can talk about problems they might encounter, such as, how to ask for and get assistance from large organizations or how to get the most from the education system.

You may register by contacting the Family Support Center at 732-528-8080. Online registration and directions are available at www.fscnj.org.





B. School Years age 3 – 21

DOE Office of Special Education Programs (OSEP) – <http://www.state.nj.us/education/specialed/> OSEP is responsible for implementing 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. The office is responsible for administering all federal funds received by the state for educating pupils with disabilities ages 3 through 21. Visit OSEP at <http://www.state.nj.us/education/specialed/>.

If you are concerned that your preschool child (ages 3-5) is developing differently or a physician has recently diagnosed your preschool child as an individual with an autism spectrum disorder, you can contact your local school district for educational evaluations and support. Each district has a Director of Special Education listed on the New Jersey Department of Education's School Directory web page at <http://www.state.nj.us/education/directory/districts.shtml>.

If you have questions regarding a referral to access an evaluation for special education and related services, you can contact the district's child study team, which can include a school psychologist, a social worker and a learning disabilities teacher consultant (LDTC).

The process used to identify, refer, evaluate and determine a student's eligibility for special education and related services, as well as the required steps for developing an Individualized Education Program (IEP) can be found at <http://www.state.nj.us/education/specialed/info/process.pdf>.

In addition, the office funds four Learning Resource Centers (LRCs) <http://www.state.nj.us/education/lrc/> which are library and training centers that support the educational needs of students with disabilities ages 3 to 21 years. The LRC staff provides regional workshops, training institutes, statewide conferences, LRC orientations, and technical assistance to educators and parents of students with disabilities aged 3 to 21 years. Current special education information is available at the LRCs through library media, professional journals, video/DVD collections, and access to on-line research relevant to educators and parents having responsibility for children and youth with disabilities. The centers have a variety of resources pertaining to students with ASDs. The centers offer ideas for the development of teacher and parent-made learning materials for use at home or in the classroom. The production service at each of the LRCs includes lettering machines, laminating, transparency making, button making, poster making and photocopying. Learn more about the LRCs at <http://www.state.nj.us/education/lrc/>.

OSEP also plans and implements program and professional development activities related to a variety of areas including the implementation of the least restrictive environment provision, planning programs and services for preschool children with disabilities, designing programs to support students with challenging behaviors, planning the transition of students with disabilities from school to adult life and developing Individualized Education Programs (IEPs) <http://www.state.nj.us/education/specialed/form/>.





Additionally, OSEP is responsible for monitoring the delivery of special education programs operated under state authority, providing mediation services to parents and school districts when there is a disagreement, processing hearings with the Office of Administrative Law, and conducting complaint investigations as requested by the public.

Charter Schools – A charter school is a public school that operates independently of a local school district’s board of education under a charter granted by the Commissioner of DOE. Once a charter is approved and established, the school is managed by a board of trustees with status as a public agent authorized by the State Board of Education to supervise and control the school. A charter school is a corporate entity with all the powers needed to carry out its charter program. All charter schools provide services to students with disabilities, as well as typical students.

Assistive Technology – The NJDOE Office of Special Education Programs (OSEP) works collaboratively with the Statewide Parent Advocacy Network in developing and presenting information and guidance to families of children with disabilities and educators on assistive technology. More information can be found at <http://spannj.org/START/tools.htm>.

Educational Resources:

Parental Rights in Special Education (PRISE) – Important guide for parents working with their local school system can be found at <http://www.state.nj.us/education/specialed/form/prise/prise.pdf> .

Abledata – Web site with a searchable database of 19,000 assistive technology products, <http://www.abledata.com/>.

Council for Exceptional Children – Links with updated information on IDEA, Individuals with Disabilities Education Act can be visited at <http://www.cec.sped.org//AM/Template.cfm?Section=Home> .

United States Society for Augmentative and Alternative Communication (USSAAC) – The national chapter of ISAAC, the International Society for Augmentative and Alternative Communication. This page of links gives information on AAC, disabilities, advocacy, and the companies that produce AAC devices. This website can be found at <http://www.ussaac.org/>.

DCF Office of Education (OOE) – <http://www.state.nj.us/dcf/divisions/education/>
The DCF Office of Education provides intensive 12 month educational services and supports to children and young adults ages 3 through 21. In some cases, the severity or uniqueness of individual needs requires removal from the public school setting for a period of time. A successful return to school and participation in community life are goals for all OOE students. Learn more about the DCF OOE at <http://www.state.nj.us/dcf/divisions/education/>.

These State and federally compliant education programs are designed for students who:

- Exhibit severe cognitive, physical, behavioral and emotional disabilities;
- Exhibit a variety of moderate to severe learning disabilities;
- Are at risk of school failure; and/or
- Are pregnant/parenting teens (programs are available for infant/toddlers of parenting teens).
- Regular and special education programs are individually designed and provided to these students in the least restrictive environment.





Interagency Collaboration Addressing Children's Needs

- *Dual Diagnoses* – In January, 2008, DHS Commissioner Jennifer Velez convened New Jersey's first ever task force charged with creating a plan for developing services and supports for individuals with co-occurring developmental disabilities and mental health needs. The Task Force members represented all areas of the dual diagnosis community including individuals and family members, advocates, professionals and state officials. DDD, DCF Division of Children's Behavioral Health Services (DCBHS) and the DHS Division on Mental Health Services (DMHS), with advice from individuals and groups from New Jersey's non-profit agencies serving those with developmental disabilities, developed recommendations regarding how New Jersey can best serve persons with dual diagnoses (mental health and developmentally disabilities). The Dual Diagnoses Task Force report can be found at <http://www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/DDTFreport.pdf>.

DHS Division of Developmental Disabilities – Today, more than 40,000 individuals, including those with ASDs, are eligible to receive services funded by DDD. A growing number of these recipients are under the age of 22. Most DDD-eligible individuals live in the community, either with family or in a community residence, such as a group home or supervised apartment or in a Community Care Residence with a family caregiver. Community residential services are offered by more than 250 agencies or by more than 600 individuals. Fewer than 2,700 individuals reside in one of the seven developmental centers administered by DDD. More information is available at <http://www.nj.gov/humanservices/ddd/home/index.html>.

DDD can provide a number of services to eligible families. These services include:

- *Case Management* – Case management services help individuals learn about and gain access to any services that can help address their needs. These include, but are not limited to, Medicaid waiver and Medicaid State Plan services as well as medical, social, educational, county and municipal services.

DDD provides different levels of case management, depending on the assessed need of the individual, to help coordinate services and supports. In some cases, individuals may be assigned to the Office of Information and Assistance Services (OIAS) at DDD's sister agency, the Division of Disability Services (DDS). DDS, which is also part of the New Jersey Department of Human Services, works closely with DDD to make sure individuals who are eligible for services funded by DDD are able to access them if the need arises.

- *Self-Directed Services* – A growing number of individuals who live and receive services in the community are choosing to self-direct those services. Self-direction gives individuals and families greater control over the services they receive, how they receive them and who provides them. At the same time, people who self-direct must be willing to take on the responsibility of managing their services. Individuals who self-direct services tend to share certain characteristics. Learn about these characteristics at <http://www.state.nj.us/humanservices/ddd/programs/selfdirected/>.





- *Family Support Services* – Family Support services are intended to help support adults and children who are DDD eligible and living in their own homes. DDD evaluates requests for Family Support based on individual need, the services and supports already available and/or being used, and the availability of DDD resources. Family Support is not an entitlement and cannot be guaranteed. Budget allocations dictate the availability of services. Families must exhaust any other services to which they are entitled before they can receive assistance through Family Support.

Individual regions may have different options but the following services generally are offered in all regions of the state: respite, camp, assistive technology devices, home and vehicle modifications, tutoring, and family-facilitated networking. For more information regarding Family Support Services, please go to <http://www.state.nj.us/humanservices/ddd/services/fss/>.

C. Life Stages and ASDs (Transition to Adulthood)

Transition Planning from School to Adult Life:

It is important to understand that planning for your child's successful transition from school to adult life requires a multiyear, long-range collaborative process that involves families, school staff, agency staff, employers, and other community members. The first step in the transition planning process involves school staff and families working together to develop and identify your child's strengths, preferences, and interests related to past and future activities and environments. Transition planning is part of the IEP, and begins to be addressed in the IEP that will be in place for the school year that your child turns age 14, or younger if determined appropriate by the IEP team. Transition planning continues to be addressed in your child's IEP each year until graduation or exit from high school.

When your child is approaching age 16, the school should conduct a transition assessment, which is an ongoing process that uses a variety of formal and informal methods to identify your child's post-secondary goals in areas such as further education and training, employment, and independent living. When your child is age 16 and older, the IEP should include at least one post-secondary goal based upon the results of the transition assessment. A combination of school courses and transition services (a coordinated set of activities and strategies) is planned for and provided to prepare your child to obtain his or her post-secondary goals. While still in school, your child should also be determined eligible to receive the adult services and supports he or she will need to be successful as an adult from agencies such as the New Jersey Division of Developmental Disabilities and the New Jersey Division of Vocational Rehabilitation Services. Information about adult services and supports is included on the next several pages of this guide.

Families benefit from gathering as much information about transition services and adult services as possible and thoroughly participating throughout the planning and implementation of the IEP.





The following are some questions to be answered during the transition process:

- What are the student's dreams and vision for his/her life as a young adult?
- What are the student's strengths? How will the student use them to build success during and after high school?
- What is the motivation and investment of the student and family in the process?
- Will the student participate in a vocational training program?
- Does the student have a career interest now? If not, when and how can the student be helped to discover his/her interests and preferences?
- Does the IEP team believe that the student will remain in school through the maximum age of 21? If so, what age-appropriate experiences may be available after age 18?
- What skills need to be developed or improved to help the student make progress toward his or her post-secondary goals?
- In what school and community activities will the student participate?
- What does the IEP team think the student's high school course of study will look like?
- What transition services, supports and accommodations does the student need for success in high school?

Person-Centered Planning is a process that takes place across the lifespan but is especially important in laying out a road map for services and supports needed for adulthood. You will want your son or daughter's person-centered plan to include needs that match their age and interests. Through the person-centered plan, you will explore the interests your young adult has, how they can be pursued, and what supports may be needed for Continued Education, Career Exploration, Residential Living, Recreation and Leisure, and more.

Legal Issues

Legal Protections — As your child nears age 18, it is important to explore protections within and outside of the legal system for managing his or her affairs. You will want to consider the areas in which your young adult can manage responsibility and areas where assistance may be needed. Learn about options of conservatorship, power of attorney, guardianship, and other alternatives. Disabilities Rights New Jersey, the State's protection and advocacy agency for persons with developmental disabilities, may be able to provide you with legal information. You can visit them at <http://www.drnj.org>.

Estate Planning

Estate Planning—Special needs trusts are designed for individuals with disabilities. If properly structured and administered, special needs trusts do not affect an individual's eligibility for benefits such as Social Security Income (SSI) or Medicaid.





Guardianship

At age 18, all individuals, including those with ASD and developmental disabilities, reach the legal age of majority. This means that parents can no longer make decisions legally on behalf of their children, regardless of the nature of their disability and regardless of whether or not they still live with their family. Some families may want to consider guardianship as an option for their family member. A guardian is defined as “a person or agency appointed by a court to act on behalf of an individual.” Establishing guardianship is a legal process, and many families turn to the Bureau of Guardianship Services at the Department of Human Services for help with the process. Guardianship, however, can be established without the Bureau’s involvement. For more information about the guardianship process please go to <http://www.state.nj.us/humanservices/ddd/services/guardianship/>

NJ State Services to Assist Transition

Pathways to Adult Life

To meet the needs of individuals with disabilities more efficiently, DDD has partnered with the following state agencies to provide current transition-related information: DVRS (Division of Vocational Rehabilitation Services), DDS (Division of Disability Services), DOE (Department of Education-Office of Special Education Programs). This information is geared specifically to families with a child who is 14 to 19 years old. The transition program is called Pathways to Adult Life.

To learn more about Pathways to Adult Life, you are encouraged to attend workshops and educational forums. For more information or help regarding these workshops and forums, please call the Family Support Center of New Jersey @ 1 (800) 372-6510 or you may register online at www.fscnj.org.

Preparation for Life After 21

Life After 21 is a two-part training series addressing the concerns of students with developmental disabilities ages 19 to 21, and their families, as they approach the adult service systems.

Life After 21 Part I provides:

- Skills and tools to plan supports and services based on individual needs;
- A brief overview of New Jersey Work Incentives Support (NJWINS), DDD Day Services and Division of Vocational Rehabilitation Services (DVRS);
- Resource information regarding DDD Day Program/Day Service options; and
- DVRS contact information, is distributed to participants.

This session also includes “The Provider Marketplace” which is an opportunity for families to become acquainted with Adult Agencies/Service Organizations providing local supports and services.

Life After 21 Part II provides:

- Skills and tools to plan supports and services based on individual needs.
- Current information on DDD Day Services including traditional Day Programs,
- Self-Directed Day Services, DVRS information, and DDS.
- Resource information for adult services are distributed.





To learn more about Preparation for Life After 21, please attend these Workshops and Educational Forums. For more information or help regarding these workshops and forums, please call the Family Support Center of New Jersey at 1-800-372-6510 or you may register online at www.fscnj.org.

DLWD Division of Vocational Rehabilitation Services

DVRS provides important information on their web site pertaining to a child's transition from school to work. The site provides a link to common misconceptions about working with DVRS. Information is found at <http://lwd.dol.state.nj.us/labor/dvrs/disabled/Transition.html>.

11. Adult Services and Supports

As your child grows and you continue to develop the Person-Centered Plan, you will want to consider the places that offer the services he or she will need. There are many doors that you can enter for services. Your youth's unique strengths, abilities and needs will help determine which doors you choose. Each agency also has its own service criteria.

A. Day Services

Day services allow individuals to remain active outside their home and develop social relationships with others. They also provide families and caregivers with time to pursue their own interests and activities, including a job. Day Services is a general term used to describe the programs and activities in which individuals participate for 25 to 35 hours per week.

To participate in DDD-funded day services, an individual must be:

- DDD eligible
- at least 21 years old
- have completed their educational entitlement
- have already taken advantage of any other day program options such as those offered by DVRS, Commission for the Blind and Visually Impaired (CBVI), the Division of Mental Health Services (DMHS) or the Department of Health and Senior Services (DHSS), which administers Adult Day Health Services.

B. Residential Services

DDD strives to support individuals by providing services that allow them to live in their own homes and be a part of their community. Sometimes, however, it is not possible to continue to support an individual at home. In those cases, DDD can help an individual move to a place where services and individual supports can be provided. Residential options include:

- **Group homes** – in which individuals share a home with no more than three other residents and receive services from staff who is on-site 24-hours a day.
- **Supervised apartments** – in which an individual lives alone or with a roommate in an apartment that is leased or owned by a DDD-contracted provider agency, which also employs staff that is available to serve the individual 24-hours a day.
- **Supportive Housing** – in which an individual leases his or her own apartment and receives services on an as-needed basis either in person or through phone contact up to a total of 24 hours a day, seven days a week.
- **Community Care Home** – in which an individual lives as part of the family of a caretaker and receives assistance from that person and/or from an agency on a routine basis.





C. Supported Employment Services for DDD Clients

DDD supports the principles that people with developmental disabilities shall pursue meaningful and productive lives. DDD seeks to have them achieve full integration and inclusion in society through relationships and work--- in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, and abilities of each individual.

In 1985, DDD established Supported Employment (SE) as an alternative to conventional day programs for any DDD-eligible individual who expressed a desire to become employed. Initially, emphasis was placed on the movement of individuals from extended employment and adult day services into community-based jobs with supports from an employment specialist/job coach.

In 2003, DDD revised the manner in which services and supports were being delivered by adopting a self-directed approach to service provision. With this approach, services and supports are built around the individual promoting choice, which in turn fosters independence, integration, individualization, and productivity within the community for each person, while honoring the individual's cultural background and diversity.

In keeping with the concept of self-direction, DDD's Supported Employment Services enable individuals to find jobs that suit their aspirations and abilities, teach the skills necessary to perform the job, and provide ongoing support to maintain and strengthen the individual in competitive employment.

Additional information can be found at <http://www.state.nj.us/humanservices/ddd/services/ses/>.

D. DLWD Division of Vocational Rehabilitation Services (DVRS)

DVRS provides a variety of services for adults with disabilities attempting to succeed in the working world. Many of their client services are as follows:

1. Vocational Counseling and Guidance - Providing assistance to the consumer in handling the job search issues that impact employability, job maintenance strategies, and developing the overall techniques needed to be successful in a work environment.
2. Placement Services - Development of job leads both with and for the consumer and support during the job search; could include On the Job Training (OJT), Supported Employment (SE) or Time Limited -Placement and Coaching (TLPC).
3. Job Seeking Skills - Guidance in work search activities such as resume writing, interviewing skills, job search organization.
4. Supported Employment - Through referral to an SE provider, one-on-one assistance in job searching, interviewing, applying for jobs; followed by coaching on the job to facilitate learning job duties and adjusting to the work environment; followed by periodic follow-up to ensure job retention.





5. Time Limited Placement and Coaching – The first two categories of Supported Employment Services without periodic follow-along.
6. Job Accommodations – Guidance on changing the worksite’s physical environment or adding equipment that will allow an individual to do more work tasks independently, effectively, and safely.
7. Skills Training – Attendance at a vocational school, technology or trade School, business school, etc.
8. College Training – Attendance at 2 or 4 year higher education programs leading to a degree.
9. Physical Restoration – Equipment or therapies which improve physical or cognitive functioning so that a person is able to work. These services may include physical, occupational, or speech therapy; cognitive therapy which includes those modalities; prosthetics or orthotics such as artificial limbs, braces, special shoes, hearing aides, and eyeglasses (in some instances).
10. Emotional Restoration Services – Short-term individual, group or other types of counseling to reduce symptoms of mental health problems and improve work-tolerance and the ability to get and keep a job.
11. Mobility Equipment
12. Driver Training – Assessment of driving ability and equipment needed to drive safely; assistance in purchasing driver training lessons if needed to reach a specific work goal.
13. Vehicle Modification
14. Home Modifications – services if needed to reach a specific work goal

For more information on DVRS services for adults please go to:
<http://lwd.dol.state.nj.us/labor/dvrs/disabled/DisIndex.html>.





12. Funding for Services and Supports

The Medicaid Community Care Waiver (CCW)

The Medicaid Community Care Waiver (CCW) is a program for individuals with developmental disabilities that pays for the services and supports they need in order to live in the community. The CCW is funded by the state, with assistance from the federal government's Medicaid program. DDD administers the CCW.

The number of individuals who can be served on the waiver is limited. When individuals are enrolled on the waiver, their "need" for services is determined through an assessment. DDD always strives to provide the services an individual needs; the difference is that individuals enrolled on the waiver are entitled to receive those services (based on their needs assessment), unlike individuals who are not enrolled on the waiver.

The CCW is a critical component of DDD's ability to provide services in the community to individuals with developmental disabilities. Without the CCW, New Jersey could only use Medicaid funding to help provide services to these individuals if they resided in an institution. The federal government allowed states to create waivers, including the CCW, as a way to help individuals, with specific needs, avoid institutionalization and return to or remain in community.

For more information regarding CCW eligibility please go to:
<http://www.state.nj.us/humanservices/ddd/services/ccw/index.html>.

NJ Medicaid

Medicaid provides health insurance to parents/caretakers and dependant children, pregnant women, and people who are aged, blind or disabled. These programs pay for hospital services, doctor visits, prescriptions, nursing home care and other healthcare needs, depending on what program a person is eligible for. Additional information may be found at <http://www.state.nj.us/humanservices/dmahs/clients/medicaid/>.


To be eligible for New Jersey Medicaid, a person must

- be a resident of New Jersey
- be a U.S. Citizen or qualified alien (most immigrants who arrived after August 22, 1996 are barred from Medicaid for five years, but could be eligible for NJ FamilyCare (NJ FamilyCare is a federal and state funded health insurance program created to help New Jersey's uninsured children and certain low-income parents and guardians to have affordable health coverage, go to www.njfamilycare.org) and certain programs for pregnant women
- meet specific standards for financial income and resources

Private Insurance

Some private insurance companies cover evaluation and therapy services related to care of people with ASDs. Others do not. Call your insurance company to ask about your family's benefits.



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- Insurance bill - P.L. 2009 c. 115 requires certain health benefits plans to provide coverage for medically necessary therapies for the treatment of autism and other developmental disabilities. However, not all insurance plans are required to provide coverage under P.L. 2009 c. 115. Insurance companies regulated by the State of NJ and state and local government plans must comply. Health plans that are self-funded or federally-regulated are not required to provide coverage. If your child is enrolled in the Family Care Program or you are enrolled in the NJ State Health Benefits Program the insurance law applies to your health benefits plan. For details regarding P.L. 2009 c. 115, please visit http://www.nj.gov/health/fhs/eis/documents/autism_dd_insurance_factsheet.pdf.
 - The Statewide Parent Advocacy Network (SPAN) and Autism NJ created a guide booklet to assist parents and professionals with understanding how Insurance bill P.L. 2009 may affect an individual or families insurance benefits. This guide booklet can be accessed at http://www.spannj.org/cyshcn/core_outcome_3/Maximizing%20Coverage%20ASD%20&%20Other%20DD.pdf.

Supplemental Security Income (SSI)

SSI makes monthly payments to people with low income and limited resources who are 65 or older, or blind or disabled. Your child younger than age 18 can qualify if he or she meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits.

When the Social Security Administration decides if your child can get SSI, they consider your child's income and resources. They also consider the income and resources of family members living in the child's household. These rules apply if your child lives at home. They also apply if he or she is away at school but returns home from time to time and is subject to your control.

If your child's income and resources, or the income and resources of family members living in the child's household, are more than the amount allowed, the Social Security Administration will deny the child's application for SSI payments.

For more information, please visit <http://www.ssa.gov/pubs/10026.html#ssi-benefits>.

Catastrophic Illness in Children Relief Fund Commission

The Catastrophic Illness in Children Relief Fund is a financial assistance program for New Jersey Families whose children have an illness or condition otherwise uncovered by insurance, State or Federal programs, or other source, such as fundraising. The Fund is intended to assist in preserving a family's ability to cope with the responsibilities which accompany a child's significant health problems. Eligibility criteria include:

- Illness in any prior, consecutive, 12 month period, dating back to 1988, eligible expenses must exceed 10% of the family's income, plus 15% of any excess income over \$100,000.
- The child must have been 21 years or younger when the medical expenses were incurred.
- The family must have lived in New Jersey for 3 months immediately prior to the date of application. Migrant workers may be eligible; temporary residents are not.

Contact the Catastrophic Illness in Children Relief Fund Program 1-800-335-FUND (3863) or visit their web site at <http://www.state.nj.us/humanservices/cicrf/home/>.



13. Housing



New Jersey Housing and Mortgage Finance Agency (HMFA)

The HMFA provides funding for affordable homeownership and housing opportunities for New Jersey residents. HMFA responds to the needs of its residents by implementing creative programs and establishing alliances that fund affordable home mortgages for first-time home buyers; promote construction, preservation and rehabilitation of rental housing; encourage mixed-income, owner-occupied housing growth as a means to stabilize urban neighborhoods; advance the growth and development of municipalities; contribute to the quality of life of older adults, the disabled and those with special housing needs; and formulate partnerships to foster the economic development of New Jersey and the personal development of its residents.

Like other State departments, the HMFA does not provide services specifically designed to meet the needs of adolescents and adults with ASDs. However, HMFA offers a wide range of programs and services that respond to the general issues of housing production, community planning and development, accessibility, home ownership and housing finance.

- **Supported Housing and Special Needs Programs** – HMFA’s Supported Housing and Special Needs Programs Division administers financing and support programs for service-enriched housing developments and housing for people with special needs and provides technical assistance and coordination within HMFA and with other state agencies. The Department works to improve the housing situation for some of New Jersey’s most vulnerable citizens, including people with ASDs and other developmental disabilities, mental health consumers, the homeless, the frail elderly, people with HIV/AIDS, youth who are aging out of foster care, youth leaving the juvenile justice system, ex-offenders re-entering communities, and other under-served communities.
- **Special Needs Housing Trust Fund** – The Special Needs Housing Trust Fund, “Trust Fund”, pursuant to the Special Needs Housing Trust Fund Act, P.L. 2005, c. 163, provides capital financing to create permanent supportive housing and community residences for individuals with special needs, with priority given to individuals with mental illness. The purpose of this special non-lapsing, revolving fund, which is administered by the HMFA, is to develop special needs housing and residential opportunities as alternatives to institutionalization or homelessness for those who would benefit from these programs and to ensure the long-term viability of such housing. The monies in the Trust Fund will be used to enable persons with special needs to live with dignity and independence within communities of their choice by providing capital funding to increase the supply of affordable and quality housing with support services and other residential opportunities. The Trust Fund provides capital financing in the form of loans, grants, and other financial vehicles and investments to eligible not-for-profit and for-profit developers, as well as government entities at the state, county, and municipal levels, for new housing units. **Funding for rent and operating subsidies and supportive services is not available through the Trust Fund.**



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- **Housing Resource Center (HRC)** – The HRC is an award winning website and online registry, located at www.nj.gov/njhrc designed to assist households in search of affordable and/or accessible housing. HRC allows folks the ability to search thousands of affordable units <http://www.state.nj.us/njhrc/>. This service is free to both users searching for housing and landlords and property owners looking to rent or sell housing units. The housing is organized in an easy to search format, with a variety of criteria tailored to narrow the search. Complete contact information as well as photos of the units (if available) is provided in the search results. Further empowering the HRC user, the system provides a private venue for people searching for housing with specific needs. In short, the user can search according to their needs without revealing personal information, thereby protecting their rights and individuality.

For additional information on HMFA Programs, please call 1-800-NJ-HOUSE or visit their website at www.nj-hmfa.com.

Department of Community Affairs Lead Safe Homes Program for Children

The Lead Hazard Control Assistance (LHCA) Program is administered by the DCA. It provides financial assistance to families whose young children are at high risk of becoming poisoned by exposure to lead in their homes. These funds are used to remediate and abate lead hazards in the homes. If you live in a home that was constructed prior to 1978, when the addition of lead to interior and exterior house paint was banned, it is likely that you have lead hazards in your home. Exposure to this toxic heavy metal may exacerbate some of the health and behavioral problems currently experienced by your child with ASD. You can learn more about ways to protect your children as well as about the various activities of the program, including the Lead-Safe Housing Registry, tips on making your home safer, consumer resources, information about recalls of toys and children accessories, and for current updates regarding the financial assistance availability and application priorities by visiting <http://www.state.nj.us/dca/dcr/leadsafe/index.shtml>.



14. Additional Information and Support Resources

One important key to your child's ability to develop to his or hers greatest potential is to obtain help and support as early as possible. "Learn the Signs. Act Early" is a national initiative undertaken by CDC and the Maternal and Child Health Bureau (MCHB). This program aims to build an informed corps of pediatricians, family practitioners, allied health providers and other professionals who work with young children to understand the signs and symptoms associated with ASD and other developmental disabilities. In New Jersey, this effort is being implemented by the Elizabeth M. Boggs Center for Excellence in Developmental Disabilities (Boggs Center) at the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School (UMDNJ-RWJ). Important informational resources for parents are also available. You can learn more about this initiative at <http://rwjms.umdnj.edu/boggscenter/> and obtain helpful materials at <http://www.cdc.gov/ncbddd/actearly/>.

Research

Many research initiatives are underway to study possible genetic and environmental links to ASD. You can read about some of these investigations at Autism Speaks at <http://www.autismspeaks.org/>, the National Institutes of Health (NIH) at <http://www.nih.gov/>, and the Centers for Disease Control and Prevention (CDC) at <http://www.cdc.gov/ncbddd/>.

Governor's Council for Medical Research and Treatment of Autism - The mission of the Governor's Council is to establish a Center of Excellence in the State where basic science and clinical research studies, and clinical diagnosis and treatment initiatives can take place. To this end, the Council awards grants and contracts to public and private nonprofit entities. To learn more about the work of the Governor's Council for Medical Research and Treatment of Autism please visit <http://www.state.nj.us/health/autism/>.





15. Registries

Emergency Preparedness Registry - This registration web site allows residents with special needs and their families, friends and associates an opportunity to provide information to emergency response agencies, so emergency responders can better plan to serve them in a disaster or other emergency <https://www13.state.nj.us/SpecialNeeds>.

Autism Registry for Children - Legislation was enacted in 2007 mandating that the DHSS maintain a registry of individuals diagnosed with ASD who are under the age of 18. Licensed health care professionals are required to register any child whom they have diagnosed with ASD. They must notify parents of the registration process. Once a child is registered, you will receive a letter of notification and informational pamphlets regarding available services. Families are then linked to the Special Child Health Services Case Management Unit in your county of residence. DHSS maintains a call center at 609-292-5676 to answer questions you may have about the registry or you can visit http://www.state.nj.us/health/fhs/documents/autism_registry_providers.pdf for more information. Information about services available from DHSS to children with special needs is available at <http://www.nj.us/health/fhs/sch/index.shtml>.

Autism Registry for Adults - The Autism Registry Legislation was amended in 2009 to include voluntary registration of adults. This portion of the registry is currently under development. You can learn when the registry is active by visiting <http://www.state.nj.us/health/>.





16. New Jersey Resources

Adults with Autism Task Force Report

www.state.nj.us/humanservices/ddd/boards/AATFrpt.pdf

Alliance for the Betterment of Citizens with Disabilities (ABCD)

<http://abcdnj.org>

The Arc of New Jersey

www.arcnj.org

Arts Unbound

www.artsunbound.org

Asperger Syndrome Education Network (ASPEN)

www.aspennj.org

Advocacy for Children of New Jersey

www.acnj.org

Autism Family Services of NJ

www.autismfamilyservicesnj.org

Autism NJ

www.autismnj.org

Autism Speaks

www.autismspeaks.org

Centers for Disease Control and Prevention (CDC)

www.cdc.gov/ncbddd/actearly/

Children's Specialized Hospital

www.childrens-specialized.org

Daniel Jordan Fiddle Foundation

www.djffiddlefoundation.org

Dental Care for Persons with Developmental Disabilities in New Jersey

www.disabilityhealth.org/dental/index.html

Disability Rights New Jersey

NJ ADD Network www.drnj.org

Elizabeth M. Boggs Center for Excellence in Developmental Disabilities, UMDNJ-RWJ

<http://rwjms.umdj.edu/boggscenter/>

Emergency Preparedness Resources from the NJ Council on Developmental Disabilities

www.njcdd.org/EmergencyPreparedness/emergencypreparednesshome.htm

Epilepsy Foundation of New Jersey

www.efnj.com

Family Crisis Handbook

www.sccatnj.org/misc/Family_Crisis_handbook.pdf

Family Resource Network

www.familyresourcenetwork.org



New Jersey Resources - continued

Family Support Center of New Jersey
www.fscnj.org/

Family Support Coalition of New Jersey
www.familysupportcoalition.org

Family Voices of New Jersey
www.spannj.org/familywrap/familyvoices.htm

Find a Ride: NJ public and private transportation
www.njfindaride.org

Lead Safe NJ Program
www.state.nj.us/dca/dcr/leadsafe/index.shtml

Mom2Mom - Support line for mothers 1-877-914-MOM2
www.njarch.org/images/M2M%20brochure.pdf

NJ APSE - The Network on Employment
www.njapse.org/index.html

New Jersey Association of Community Providers
www.njacp.org

NJ Coalition for Inclusive Education
<http://njcie.net>

NJ Council on Developmental Disabilities
www.njddc.org

NJ Dept. of Community Affairs' Div of Housing and Community Resources
www.state.nj.us/dca/divisions/dhcr/

NJ Division of Medical Assistance and Health Services
www.state.nj.us/humanservices/dmahs/home

NJ Division of Mental Health Services
www.nj.gov/humanservices/dmhs/home/index.html

NJ Department of Health and Senior Services, Title V Children with
Special Health Care Needs programs
www.state.nj.us/health/fhs/sch/index.shtml

NJ Early Intervention System
www.njeis.org

NJ Foundation of Dentistry for Persons with Disabilities
<http://nfdh.org>

NJHelps.org
<http://njhelps.org>

NJ Parent Link: The Early Childhood, Parenting, and Professional Resource Center
www.nj.gov/njparentlink/

NJ Positive Behavior Support in Schools
www.njpbs.org



New Jersey Resources - continued

NJ Rehabilitation Association
www.njrehabassociation.webs.com

NJ Self Advocacy Project
www.njselfadvocacyproject.org

NJ Self Help Clearinghouse
www.njgroups.org

NJ State Home Page
www.state.NJ.us/index.htm

NJ State Legislature
www.njleg.state.nj.us

NJ Statewide Independent Living Council
www.njsilc.org

NJ Statewide Network for Cultural Competence
www.nj.gov/njsncc/

NJ Transit Accessible Services
www.njtransit.com/as.shtml

NJ Work Incentive Network Support (NJWINS)
www.njwins.org

Northeast ADA & IT Center
<http://northeastada.org>

Parents Of Autistic Children (POAC)
<http://www.poac.net>

Rewarding Work/New Jersey - A website for direct support professionals, personal assistants, and their employers
www.rewardingwork.org/NewJersey

Special Olympics of New Jersey
www.sonj.org

Statewide Clinical Consultation & Training (SCCAT)
www.sccatnj.org





17. The Key to the State's Alphabet Soup

ABA	Applied Behavior Analysis
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorders
CBI	Community Based Instruction
CBVI	Commission for the Blind and Visually Impaired
CCW	Medicaid Community Care Waiver
CDC	Centers for Disease Control and Prevention
CEC	Child Evaluation Centers
DCA	Department of Community Affairs
DCBHS	Division of Child Behavioral Health Services
DCF	Department of Children and Families
DDD	Division of Developmental Disabilities
DDS	Division of Disability Services
DHS	Department of Human Services
DHSS	Department of Health and Senior Services
DIR	Developmental, Individual-Difference, Relationship-Based Model
DLWD	Department of Labor and Workforce Development
DMHS	Division of Mental Health Services
DOE	Department of Education
DVRS	Division of Vocational Rehabilitation Services
EIBI	Early Intensive Behavior Intervention
EIP	Early Intervention Program
FAS	Fetal Alcohol Syndrome
HMFA	Housing and Mortgage Finance Agency
HRC	Housing Resource Center
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
ISAAC	International Society for Augmentative and Alternative Communication
ISP	Individualized Service Plan
LDTA	Learning Disabilities Teacher Consultant
LHCA	Lead Hazard Control Assistance
LRCs	Learning Resource Centers
MCHB	Maternal and Child Health Bureau
NIH	National Institutes of Health
NJEIS	New Jersey Early Intervention System





The Key to the State's Alphabet Soup - continued

NJWINS	New Jersey Work Incentive Network Support
OJT	On the Job Training
OSEP	Office of Special Education Programs
OOE	Office of Education
OIAS	Office of Information and Assistance Services
OT	Occupational Therapist
PDD	Pervasive Developmental Disorders
PRISE	Parental Rights in Special Education
PT	Physical Therapist
RDI	Relationship Development Intervention
SCHS	Special Child Health Services
SE	Supported Employment
SPAN	Statewide Parent Advocacy Network
SLP	Speech-Language Pathologist
SSI	Supplemental Security Income
TEACCH	Treatment and Education of Autistic and Communication Related Handicapped Children
TLPC	Time Limited Placement and Coaching
UMDNJ	University of Medicine and Dentistry of New Jersey
USSAAC	United States Society for Augmentative and Alternative Communication



NJ Department of Human Services
Division of Developmental Disabilities
Office on Autism



www.nj.gov/humanservices/ddd/home/index.html