

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

**autism**

navigating through  
the maze



**A Family Guide to Navigating the  
NJ Service Systems for Individuals with  
Autism Spectrum Disorder and other  
Developmental Disabilities**

**Third Edition**

**State of New Jersey**  
Phil Murphy, *Governor*  
Sheila Oliver, *Lt. Governor*

**Department of Human Services**  
Carole Johnson, *Commissioner*

[www.state.nj.us/humanservices/ddd/home/ooa](http://www.state.nj.us/humanservices/ddd/home/ooa)



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**May 2018**

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*This publication is the result of the collaborative work of the **Interdepartmental Work Group on Autism Spectrum Disorder**.*

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*Produced by the the NJ DHS*

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

	Page
1. Background	1
2. Purpose of Guide	1
3. What is Autism Spectrum Disorder (ASD)?	2
4. Autism Spectrum Disorder in New Jersey	2
5. Diagnosing ASD in New Jersey	3
6. Professionals Who Are Working with Individuals with ASD	4
7. Following an ASD Diagnosis	5
a. How should I feel?	5
b. Who should I tell?	5
c. Next Steps/Seeking Services	5
8. Learning About Available Interventions	7
Questions for Providers	7
Parent-to-parent advice	8
9. State Agencies Providing Services to Individuals with Autism and other Developmental Disabilities	10
10. Life Stages and Autism	13
A. The Importance of Early Intervention - Birth to 3	13
B. School Years age - 3 – 21	13
C. Transition Planning from School to Adult Life	17
11. Adult Services and Supports	22
A. Division of Developmental Disabilities	22
- Employment Services	23
- Day Services	24
- Individual/Family Support Services	26
B. Department of Labor and Workforce Development/ Division of Vocational and Rehabilitation Services	27
12. Funding for Services and Supports	28
13. Housing	31
14. Additional Information and Support Resources	35
15. Registries	36
16. New Jersey Resources	38
17. Key Acronyms	43

## 1. Background

Through the work of multiple state agencies, New Jersey has taken significant steps to address the needs of individuals with Autism Spectrum Disorder (ASD) and other Developmental Disabilities 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 New Jersey's lead resource agency since 1959 for individuals with developmental disabilities who are seeking programs and services. DDD has a broad scope – addressing individual diagnoses that fall collectively within the definition of intellectual and developmental disabilities. DDD's mission is to assure the opportunity for individuals it serves to receive quality services and supports, participate meaningfully in their communities and exercise their right to make choices.

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 [www.nj.gov/humanservices/ddd/boards/AATFrpt.pdf](http://www.nj.gov/humanservices/ddd/boards/AATFrpt.pdf). Acting upon one of the recommendations, DHS established an Office on Autism (OOA) within DDD. The purpose of the OOA is to provide a one-stop, single resource to address issues associated with ASD within DDD.



One of the first acts of the OOA was the establishment of an Interdepartmental ASD Workgroup for the purpose of enhancing and improving communication, collaboration and coordination among state agencies that are charged with providing services to qualifying residents with ASD. The Workgroup departments include: Human Services, Children and Families, Community Affairs (Housing and Mortgage Finance Agency), Education, Labor and Workforce Development, and Health. The first edition of the family guide, ***Through the Maze: A Family Guide for Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorders and other Developmental Disabilities*** was the result of a concentrated effort by representatives of the ASD work group to capture virtually all state based programs and services in one manual. This third edition of "Through the Maze"

provides an update regarding the continuing work of New Jersey's state systems that are intended to serve individuals and families living with autism, as well as other developmental disabilities.

## 2. Purpose of Guide

This third edition of ***Through the Maze: A Family Guide to Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorder and other Developmental Disabilities*** remains the same as its two prior iterations: assist anyone in need of ASD related services to find their way through New Jersey's state system of programs and services for individuals with ASD. "Through the Maze" is a starting point for anyone interested in developing an understanding of the way New Jersey has arranged its governmental services for individuals and families affected by ASD; it is not intended to represent every ASD service available in New Jersey. The state has local non-profit organization partners that run intensive and comprehensive programs that fill service needs, which are not addressed by state government.

### 3. What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a neurobiological disorder that becomes evident during early childhood. ASD impacts a person's social and communication skills. People with ASD process information and perceive the world differently. An ASD is not caused by an emotional disturbance; and it is definitely not caused by any particular parenting style. A great deal of research is now occurring that explores the possible causes of ASD. For additional information regarding some of this research, please go to page 32.



In May 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM), 5th edition was released by the American Psychiatric Association. The DSM contains the official criteria for ASD that is used by diagnosticians. The previous edition, listed four separate disorders: Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS).<sup>(1)</sup> The newly revised DSM-5 includes all of these separate diagnoses under the single term, Autism Spectrum Disorder. The DSM-5 criteria place greater emphasis on the two core symptom domains of ASD (social communication and restrictive, repetitive behaviors), and no longer consider verbal abilities as a diagnostic feature.

Under the new DSM-5 criteria, a person must have problems with social communication and interaction, and display restricted repetitive behaviors, interests and activities. A diagnostician will rank the characteristics based on level of severity and describe the support the individual needs.<sup>(2)</sup> Please visit <http://aapnews.aappublications.org/content/early/2013/06/04/aapnews.20130604-1> for more details regarding the new criteria.

ASD affects people in different ways. Individuals with ASD each have their own interests, abilities, strengths, and challenges. There is a wide variety in levels of intelligence, ways of communicating, social skills, creativity and challenging behaviors associated with these diagnostic categories. This is why ASD is called a "spectrum" disorder.

### 4. Autism Spectrum Disorder in New Jersey

According to the Centers for Disease Control and Prevention's (CDC) most recent data, an average of 1 in 59 individuals have an ASD. The latest estimate of 1.7 percent (1 in 59) is higher than the previous ADDM estimate released in 2016, which found a prevalence of 1.5 percent or 1 in 68 children. <sup>(3)</sup> The reason for the increase in all states is not yet known.

New Jersey's rate of ASD, as described by the New Jersey Autism Study (NJAS), appears to be the highest rate of autism across the study sites and is estimated to be 1 in 34.<sup>(4)</sup> The NJAS is a multisource public health surveillance system established to monitor the number of 8-year-old children in the population with ASD or other developmental disabilities. This surveillance system tracks changes in the expression of autism over time. NJAS is a joint undertaking of researchers at the Rutgers Medical School, working in cooperation with the New Jersey Departments of Education and Health, the CDC and numerous New Jersey developmental health centers and school districts.

1. [www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf](http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf)
2. [autismnj.org/understanding\\_autism/diagnosis](http://autismnj.org/understanding_autism/diagnosis)
3. [www.cdc.gov/media/releases/2018/p0426-autism-prevalence.html](http://www.cdc.gov/media/releases/2018/p0426-autism-prevalence.html)
4. [www.cdc.gov/ncbddd/autism/addm-community-report/new-jersey.html](http://www.cdc.gov/ncbddd/autism/addm-community-report/new-jersey.html)

## 5. Diagnosing ASD in New Jersey

### Child Evaluation Centers

Through a statewide network, New Jersey provides support for ten Child Evaluation Centers (CECs), which provide comprehensive, multidisciplinary evaluations of children with congenital or acquired neurodevelopmental 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 individual 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:

### New Jersey's Child Evaluation Centers

#### **Children's Regional Hospital at 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  
FAS Diagnostic Center  
1825 John F. Kenney Blvd. 3rd Floor  
Jersey City, NJ 07305  
Phone: (201) 915-2059

#### **Jersey Shore University Medical Center**

FAS Diagnostic Center  
Child Evaluation Center  
FSA Diagnostic Center  
Medical Arts Building  
81 Davis Ave, Suite 4  
Neptune, NJ 07753  
732-776-4178 ext 3

#### **John F. Kennedy Medical Center**

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

#### **Children's Specialized Hospital**

FAS Diagnostic Center  
6106 Black Horse Pike  
Egg Harbor Twp, New Jersey 08234  
Phone: (888) 244-5373 or (908) 233-3720

#### **St. Joseph's Children's Hospital**

Child Evaluation Center  
DePaul Ambulatory Care Center  
11 Getty Ave, Patterson, New Jersey, 07503  
Phone: 973 754-2510

#### **Morristown Memorial Hospital**

Child Evaluation Center  
435 South St. Suite 250  
Morristown, NJ, 07962  
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 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

#### **Rutgers/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 Who Are Working with Individuals with ASD

Professionals from many medical and allied health fields will participate in the evaluation process to diagnose 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. These professionals will also register your child with the DOH Autism Registry. For more information on the Registry please go to <http://nj.gov/health/fhs/autism/public/registry/>. The Registry will link your child with important resources through its Special Child Health Services program. The most common professionals working with individuals with ASD, 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 the New Jersey Early Intervention System. (See Early Intervention Section on Page 14). 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 15).

Who Can Be of Help	How They Can Help
<b>Psychiatrist</b>	A medical doctor who can diagnose ASD as well as other illnesses and treat the mental health issues associated with ASD. 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.
<b>Neurologist</b>	A medical doctor who can diagnose ASD 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.
<b>Developmental Pediatrician</b>	A medical doctor who is a pediatrician with special training and certification in developmental-behavioral pediatrics. A developmental pediatrician is skilled in diagnosis of ASD and developmental disorders. This doctor looks at the whole child and can recommend treatments, including medication.
<b>Psychologist <sup>(1)</sup></b>	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 ASD and other developmental disorders. He or she may address coping skills, behavior management, social skills, and strategies for improving functioning.
<b>Behavior Analyst</b>	A credentialed professional who has specific training and expertise in the analysis and treatment of behaviors.
<b>Speech-Language Pathologist (SLP)</b>	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.
<b>Occupational Therapist (OT)</b>	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.
<b>Child Study Team</b>	A team of professionals that include a school psychologist, learning disabilities teacher consultant, school social worker, and at times, a speech language pathologist who are a resource for parents when they have education-related concerns and will evaluate a child to determine eligibility for special education services.
<b>Special Educator</b>	A highly qualified teacher of students age 3 through 21 who is licensed by the State of New Jersey to work with students who have a wide range of learning, intellectual, emotional and/or physical disabilities. Special Educators adapt instruction and assessments to meet the individual needs of students as well as provide instruction on state standards. Services must be provided in the least restrictive environment which may be the general education classroom, resource classroom, special class, special school, at home or hospital and community depending on the needs of the student.
<b>General Educator</b>	An educator who provides instruction and educational supports to a student within the general education environment.
<b>Physical Therapist (PT)</b>	A therapist who specializes in assessing and treating gross motor skills (jumping, ball skills, using stairs), strength, and coordination.

*(1) N.J.A.C. 6A:14-3.5(c)2 requires an assessment by a speech-language specialist and an assessment by a physician trained in neurodevelopmental assessment in order to determine eligibility for special education and related services.*

## 7. Following an ASD Diagnosis

### a. How Will I Feel?

There is no right or wrong way to react to a diagnosis. Parents and family members 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 the journey. Some people are ready to jump into services right away and others need more time. Talking with another parent may be a source of support and a reminder that other family's are going through the same thing. Several agencies offer support groups to New Jersey families. Support groups can be found through one of the partner agencies featured in the box on the left.

### Partner Agencies

#### The Arc of NJ

732-246-2525 or  
[www.arcnj.org](http://www.arcnj.org)

#### Autism Family Services of NJ

877-237-4477 or  
[www.autismfamilyservicesnj.org](http://www.autismfamilyservicesnj.org)

#### Autism New Jersey

1-800-4autism or  
[www.autismnj.org](http://www.autismnj.org)

#### Mom2Mom

1-877-914-MOM2 or  
[www.njarch.org/images/  
M2M%20brochure.pdf](http://www.njarch.org/images/M2M%20brochure.pdf)

#### Parents of Autistic Children

(POAC) 732-785-1099 or  
[www.poac.net](http://www.poac.net)

#### Parent Advocacy Network

1-800-654-SPAN or  
[www.spanadvocacy.org](http://www.spanadvocacy.org)

### b. Who Do I Tell?

It is your decision as to whom and when to tell other people that your child has been diagnosed with 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 families may be 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:

Below are some initial steps you can take to learn about and access available services

- If a child is under the age of 3, contact the New Jersey Early Intervention System at 888-653-4463. Staff there will assess your child and provide appropriate intervention services.
- Consult with your county based Special Child Health Services (SCHS), Case Management Unit (CMU) 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 at 609-777-7778 or referring to Department's website at: [www.state.nj.us/health/fhs/sch/sccase.shtml](http://www.state.nj.us/health/fhs/sch/sccase.shtml).

- The Department of Children and Families (DCF), Children's System of Care (CSOC) offers a wide range of services for children up to age 21 with behavioral health, substance use, or developmental disability needs. To provide access, DCF contracts with PerformCare which is a private entity that administers this service system. **24-hour, toll-free Access Line at: 1-877-652-7624**

- Learn more about Special Education:
  - Visit the Department of Education, Offices of Special Education: [www.state.nj.us/education/specialed/](http://www.state.nj.us/education/specialed/); and/or
  - Reach out to state partner agencies that have experience helping families navigate the educational system (see partner agency box on page 6).
- Contact the Department of Human Services, Division of Disability Services at 1-888-285-3036 for live assistance in navigating State services from an Information & Referral specialist and to request **New Jersey Resources**, DDS' annually updated resource directory.
- Learn about eligibility requirements as well as possible costs associated with specific services since they vary from program to program. Be sure to visit each department's website or directly be in touch with staff associated with the services in order to ensure that you qualify for the program or service. Links to each department's website can be found on pages 11-13.
- Start a system for organizing reports and notes.
- Review section 12 of this guide, "Funding for Services and Supports", found on page 26. Ensuring that your child is registered with the Autism Registry will help you link to important resources.
- Work toward a routine schedule for your child at home. Try making a list of your daily activities using pictures or words in order to assist your child with ASD.
- Consult a behavior therapist who can teach you strategies for increasing desired behaviors. Your child's doctor, New Jersey's Child Evaluation Centers, and agencies that provide family support services, including those listed under Partner Agencies on page 6, can assist you with this process..
- Find a Support Group or connect with a Support Parent (see partner agency box on assistance on page 6).
- Talk with a parent of someone with autism who has volunteered to support/mentor other parents (see partner agency box on page 6).



## 8. Learning About Available Interventions

Although there are still unanswered questions, more is understood today about ASD than at any other time. In fact there are many therapeutic interventions available. It is important to ask questions before embarking on any therapeutic approach. Keep in mind that a child's and family's needs will change over time. Intervention plans for an individual with autism should be flexible, with the ability to evolve as the child's and family's needs evolve. Planning must be individualized because what is appropriate for your child and your family may be different from other individuals with autism and their families.

Evidence-based practice (EBP) is a term that many therapeutic interventions associated with autism like to use to describe their programs. A definition that captures the critical components of what makes an EBP an EBP is the following; "The nature of EBP is defined as the integration of best available research evidence with clinical expertise and patient values."<sup>(5)</sup> True EBP can provide an individual or family with some assurances regarding the possible effectiveness of a selected intervention.

To learn more about EBP as it relates to autism spectrum disorder, you can refer to:



- The National Autism Center's National Standards Project [www.nationalautismcenter.org/national-standards-project/phase-2/](http://www.nationalautismcenter.org/national-standards-project/phase-2/) or [www.nationalautismcenter.org/resources/for-families/](http://www.nationalautismcenter.org/resources/for-families/)
- The National Professional Development Center's Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder: <http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/imce/documents/2014-EBP-Report.pdf>

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

### Questions to Ask Providers

What is this treatment and what does it do?

Is this something I could do with my child and maintain? Will this cause more stress for our family or reduce stress?

Is there real science to support this treatment? Who or what are your scientific sources?

Can I afford the treatment? Are insurance options available? How will I be involved in the therapy?

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?

<sup>5</sup> DiCenso A, Guyatt G, Ciliska D, editors. St Louis, Missouri: Elsevier Mosby; 2005. *Evidence-based nursing: a guide to clinical practice.*

## Parent-to-Parent Advice

Have hope about treatments, but use common sense. Be cautious when you see or hear claims of cures.

Use caution with treatments that require payment before the treatment begins.

Think about the source of the information you read. Is someone trying to sell you something?

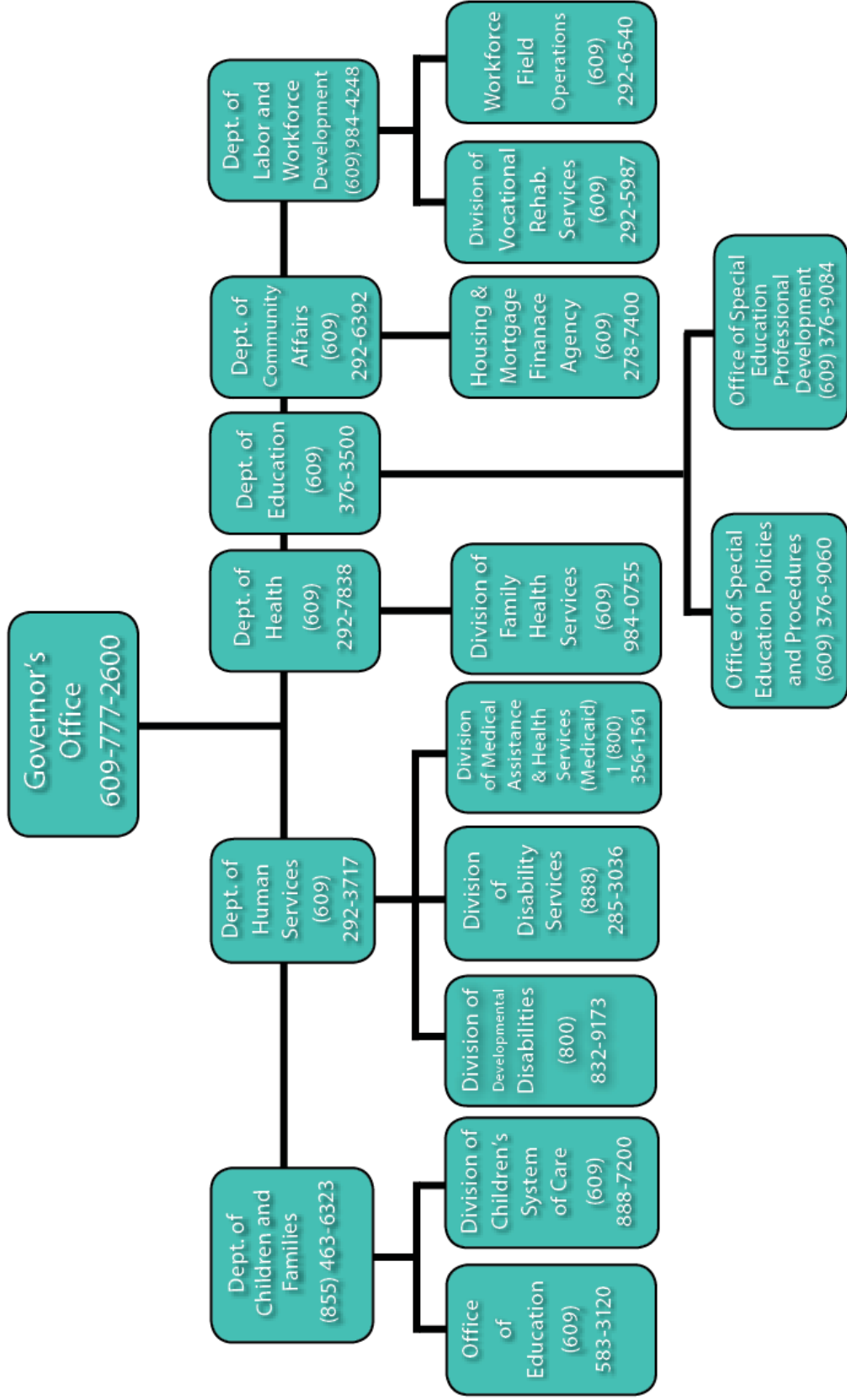
Double-check things you read on the Internet by consulting other trusted sources of information, i.e. nonprofit agencies such as those listed on page 5 or by utilizing EBP information sources such as those listed on page 7.

Pay special attention to studies that are published in high-quality scientific journals (those reviewed positively by other researchers – or “peer-reviewed” – and aligned with findings from similar studies).



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

Organizational Charts - May 2018



## 9. State Agencies Providing Services to Individuals with Autism and other Developmental Disabilities

Individuals with autism, 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. Following is a list of these agencies and a general overview of the services provided by each. Becoming familiar with these agencies and how they differ, with regard to autism services, can be very helpful for families.

### ■ Department of Children and Families (DCF)

[www.state.nj.us/dcf/](http://www.state.nj.us/dcf/)

On June 28, 2012, Governor Christie signed P.L. 2012, c. 16, into law. The provisions of that law took effect immediately and transferred responsibility for providing services for persons with developmental disabilities under age 21 from the Division of Developmental Disabilities (DDD) within the Department of Human Services (DHS) to the Division of Children's System of Care (CSOC) within the Department of Children and Families (DCF).

The focus of the Department of Children and Families (DCF), New Jersey's state child welfare agency, is on strengthening families and achieving safety, well-being and permanency for all New Jersey's children. Within the Department, the Children's System of Care offers a wide range of services for children up to age 21 with behavioral health, substance use, or developmental disability needs. This includes community-based services, intensive in-home, out-of-home residential treatment services, and family support services.

### ■ Department of Community Affairs (DCA)

[www.state.nj.us/dca/](http://www.state.nj.us/dca/)

The Department of Community Affairs (DCA) provides 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 an affiliate agency of DCA, and is the largest affordable rental housing, purchase housing, and permanent supportive housing financing agency in the state. People with ASD or other developmental disabilities may qualify for assistance with housing issues through the HMFA or the Department of Community Affairs.

### ■ Department of Education (DOE)

[www.state.nj.us/education/](http://www.state.nj.us/education/)

The Department of Education (DOE) is New Jersey's primary educational oversight body, and is committed to setting standards that ensure all children receive the highest quality education. DOE works with local school systems to provide supports and services to all school aged children and youth. Within DOE, the Office of Special Education Policies and Procedures and the Office of Special Education Professional Development oversee the systems that provide educational supports and services to students with disabilities, including students with ASD.

## ■ Department of Health (DOH)

[www.state.nj.us/health/](http://www.state.nj.us/health/)

The mission of the Department of Health (DOH) is to improve health through leadership and innovation. DOH works 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. In addition, DOH provides special needs assistance to children with ASD and other special health needs through the Early Intervention System and Title V programs, including Special Child Health Services Case Management Units (SCHS CMU). DOH's Autism Registry directly connects families with these 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 who can provide information and guidance regarding:

- 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)

[www.state.nj.us/humanservices/](http://www.state.nj.us/humanservices/)

The Department of Human Services (DHS) serves about 1.5 million New Jersey citizens in need of assistance (about one in six). 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)

[www.state.nj.us/humanservices/ddd/home/index.html](http://www.state.nj.us/humanservices/ddd/home/index.html)

The Division of Developmental Disabilities (DDD) funds a variety of services and supports for eligible individuals with developmental disabilities in New Jersey. These supports and services are provided by more than 250 agencies in communities throughout the state, or in residential settings that are administered by DDD. Since its inception, DDD has changed and grown significantly. Today, nearly 25,000 adults are eligible to receive services funded through DDD.

### • DHS Division of Disability Services (DDS)

[www.state.nj.us/humanservices/dds/home/index.html](http://www.state.nj.us/humanservices/dds/home/index.html)

The Division of Disability Services (DDS) is designated as New Jersey's single point of entry for people seeking disability related information. DDS provides information and referral services and administers programs designed to promote maximum independence and community participation for individuals with disabilities. Through the use of active information exchange, community outreach, and program advocacy, DDS works to support and foster the coordination of services



among government and community agencies. Certified Information and Referral Specialists are available by phone to confidentially discuss issues, provide information, assist with problem solving, and refer to agencies or services as appropriate. Annually, DDS publishes New Jersey Resources, a comprehensive directory listing services available for individuals with disabilities throughout the state. The Division of Disability Services can be reached at 888-285-3036.

■ **Department of Labor and Workforce Development (DLWD)**

The Department of Labor and Workforce Development (DLWD) is committed to helping persons with barriers to employment to become a skilled and productive workforce competing successfully in the marketplace. Under the DLWD, the mission of the Division of Vocational Rehabilitation Services (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 in obtaining and maintaining employment. DVRS Field Services staff provide job seekers with those services and tools necessary to raise occupational skill levels to increase the employment, retention, and earnings of participants and improve the quality of the workforce.



## 10. Life Stages and Autism

### A. The Importance of Early Intervention - Birth to age 3

The New Jersey Early Intervention System (NJEIS) is administered by the DOH 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. The DOH 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.

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

### B. The School Age Years - 3 to 21

The New Jersey Department of Education (DOE) Office of Special Education Policies and Procedures (OSEPP) 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 guidance documents. The office is responsible for administering all federal funds received by the state for educating pupils with disabilities ages 3 through 21. Visit the OSEPP at [www.state.nj.us/education/specialed](http://www.state.nj.us/education/specialed).

The Office of Special Education Professional Development (OSEPD) works in tandem with the OSEPP to provide technical assistance to school districts and parents regarding the implementation of special education programs and services.

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, or other Developmental Disabilities, 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 <https://homeroom5.doe.state.nj.us/directory/>. 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 (LDTTC).



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 [www.state.nj.us/education/specialed/info/process.pdf](http://www.state.nj.us/education/specialed/info/process.pdf). The IEP team is responsible for identifying appropriate programs and services for students who are eligible to receive special education and related services. The IEP team also determines where students with IEPs receive their education. The IEP team must ensure that a continuum of alternate placements is available, such as instruction in general education classes, special education classes, specialized schools, home instruction, and instruction in hospitals and institutions. The IEP team can consider placement in special classes or in a different school only when the nature or severity of the educational disability is such that education in the student's general education class, with the use of appropriate supplementary aids and services, cannot be achieved satisfactorily.

The OSEPD also has an Autism and Multiple Disabilities Specialist who provides supports and services statewide. This specialist provides technical assistance, support and training to teachers, administrators and parents regarding autism programming, services and supports. In addition, this specialist is responsible for gathering and disseminating resources for families and educators in areas critical to improving instruction and positive outcomes for students with autism and multiple disabilities, including evidence-based practices, functional behavior assessment, positive behavioral supports and IEP development. For additional resources, you may visit the autism program improvement page on the NJDOE website at [www.nj.gov/education/specialed/autism/](http://www.nj.gov/education/specialed/autism/) behavioral supports and IEP development.

Learning Resource Centers (LRCs) are library and training centers that support the educational needs of students with disabilities ages 3 through 21. The LRC staff provides regional workshops, training institutes, statewide conferences, LRC orientations, and technical assistance to educators and parents of students with disabilities age 3 to 21 years. Current special education information is available at the LRCs through library media, professional journals, video/DVD collections, and access to online research relevant to educators and parents having responsibility for children and youth with disabilities. Learn more about the LRCs at [www.state.nj.us/education/lrc](http://www.state.nj.us/education/lrc)

The OSEPD 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) [www.state.nj.us/education/specialed/form](http://www.state.nj.us/education/specialed/form).

Finally, it is the OSEPP, not the OSEPD that 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.

### ***Educational Resources***

**Assistive Technology** – DOE's Office of Special Education Professional Development works collaboratively with a variety of organizations to develop and present information and guidance to families of children with disabilities and educators on assistive technology. More information can be found at [www.state.nj.us/education/specialed/tech/](http://www.state.nj.us/education/specialed/tech/).

**Parental Rights in Special Education (PRISE)** – This is an important guide for parents working with their local school system can be found at [www.state.nj.us/education/specialed/form/prise/prise.pdf](http://www.state.nj.us/education/specialed/form/prise/prise.pdf).

**Abledata** – This web site provides a searchable database of 19,000 assistive technology products, [www.abledata.com](http://www.abledata.com).

**Council for Exceptional Children** – This Council provides links with updated information on the Individuals with Disabilities Education Act (IDEA). It can be visited at [www.cec.sped.org](http://www.cec.sped.org)

**United States Society for Augmentative and Alternative Communication (USSAAC)** - This organization gives information on AAC, disabilities, advocacy, and the companies that produce AAC devices. You can visit USSAAC at [www.ussaac.org](http://www.ussaac.org).



## Children's System of Care

The Department of Children and Families, Children's System of Care (CSOC) offers a wide range of services for children up to age 21 with behavioral health, substance use, or developmental disability needs. These services include community-based services, intensive in-home services, out-of-home residential treatment services, and family support services. Individuals up to the age of 21 who receive a diagnosis of ASD may qualify for services established under CSOC and/ or the Office of Education. The DCF provides families with a single point of contact that registers, tracks, and coordinates care for children who are screened – at any level - into its Children's System of Care. To provide this simplified access, DCF contracts with PerformCare 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:

- Determination of eligibility for CSOC Functional Services\* (formerly DDD eligibility)
- Family Support Services - are a coordinated system of on-going public and private supports, services, resources, and other assistance, which are designed to maintain and enhance the quality of life of a young person with a developmental disability and his or her family. Family Support Services are designed to strengthen and promote families that provide care at home for a child or young adult. Family Support Services fall into two main categories:
  1. Respite care for families, including recreational programs for youth and
  2. Assistive Technology.
- Comprehensive Waiver Demonstration Home and Community Based Services - Sections of the demonstration waiver will provide additional community support and coordination of services for individuals that meet the clinical criteria for services through the Department of Children and Families (DCF), Children's System of Care (CSOC). This includes services for certain NJ FamilyCare eligible individuals that have been diagnosed with a Serious Emotional Disturbance (SED) or Autism Spectrum Disorder (ASD), and individuals with Intellectual/Developmental Disabilities and a co-occurring Mental Illness (ID/DD-MI).
- Mobile Response and Stabilization Services (MRSS)– intended to help children and youth who are experiencing emotional or behavioral crises. The services are designed to defuse an immediate crisis, keep children and their families' safe, and maintain the children in their own homes or current living situation (such as a foster home, treatment home or group home) in the community.
- Care Management Organizations (CMOs) - agencies that provide a full range of treatment and support 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.
- Family Support Organizations (FSO's) - 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.



All services will be prior authorized through PerformCare.

Additional information may be found at: [www.performcarenj.org/families/](http://www.performcarenj.org/families/)

*\* Youth already determined eligible for Division of Developmental Disabilities (DDD) services need not re-apply for a determination of eligibility for CSOC functional services. CSOC will accept a DDD eligibility determination regarding a youth's developmental disability status.*

Application for eligibility for functional services from CSOC for young adults between the ages of 18 and 21 should be made to DDD. CSOC will accept the DDD determination regarding whether the young adult has a developmental disability and meets the residency requirements for the receipt of functional services, but independently determines the most appropriate services. Services are provided until the young adult reaches 21 years of age.

### **Department of Children and Families, Office of Education**

The Department of Children and Families, Office of Education (OOE) 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.

OOE regular and special education programs are individually designed and provided to students in the least restrictive environment. These 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).

Learn more about OOE at [www.nj.gov/dcf/about/divisions/oe/](http://www.nj.gov/dcf/about/divisions/oe/)



### ***C. Transition Planning from School to Adult Life***

Planning a child's successful transition from school to adult life requires a multiyear, long-range collaborative process that involves the student, family members, school staff, agency staff, employers, and other community members. The first step in the transition planning process involves the student, school staff and family working together to develop and identify the child's strengths, preferences, and interests related to past and future activities and environments. While transition planning involves steps that can begin as early as birth, it begins to be addressed in the IEP during the school year in which the child reaches 14 years of age. Some youth start planning their transition when they are younger than 14, if determined appropriate by the IEP team. Transition planning continues to be addressed in the student's IEP each year until graduation or exit from high school.

Starting in the years prior to your son/daughter turning age 16, the school should use a variety of formal and informal methods (referred to as Transition Assessment) to identify the student's post-secondary goals in the areas of education, training, employment, and independent living. When the child is age 16 and older, the IEP must include post-secondary goals based upon the results of transition assessments related to training, education, employment, and, if appropriate, independent living. A combination of school courses and transition services (a coordinated set of activities and strategies) is planned for and provided to prepare the student to obtain his or her post-secondary goals. While still in school, the student should also be referred for eligibility determinations from agencies such as the New Jersey Division of Developmental Disabilities and the New Jersey Division of Vocational Rehabilitation Services if he or she will likely need adult services and supports to be successful as an adult. Information about adult services and supports is included on the next several pages of this guide.

OSEPD provides regional workshops, in-district training and technical assistance, and conferences on the topic of transition from school to adult life. A broad range of resources and information on the topic of transition can be found on the web at: [www.nj.gov/education/specialed/transition/](http://www.nj.gov/education/specialed/transition/)

OSEPD also sponsors training initiatives for school districts on the transition-related topics of Community-Based Instruction, and Person-Centered Approaches through a partnership with The Boggs Center on Developmental Disabilities at Rutgers.

### **Community-Based Instruction**

Community-Based Instruction (CBI) is a critical component of a successful transition from school to adult life for many students with disabilities. CBI training and technical assistance efforts assist school districts in providing instruction for students in community-based settings. These efforts include: providing information to districts through workshops, sharing successful efforts currently occurring in New Jersey school districts, and offering direct technical assistance to school districts addressing CBI strategies, training needs, and necessary administrative supports. All activities are designed to create positive, observable outcomes for students.

### **Person-Centered Approaches**

The New Jersey Department of Education, Office of Special Education Programs, in partnership with The Boggs Center, conducts planning, development, and pilot activities aimed at promoting effective transitions for students with disabilities through the use of person-centered approaches. The Boggs Center provides expertise in these approaches to the critical process of planning for effective transitions from school to adult life, including employment and engaging with adult service systems. The project aims to identify strategies to positively impact post-school outcomes.

Students and 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.

In order to assist young adults between the ages of 16-21 and their families in gathering this information and planning for life after school, the Planning for Adult Life project was established. Planning for Adult Life activities, events, and materials are conducted and developed in partnership with The Arc of New Jersey and Community Access Unlimited with funding from DDD. A variety of resources including informational sessions, webinars, and resource guides/materials address the following core areas: Postsecondary Education/Employment, Housing, Legal/Financial Planning, Self-Direction, Health/Behavioral Health, Building/Maintaining Community Ties and Friendships, and Planning/Visioning a Life Course. Information about upcoming information sessions, webinars, preparatory groups for students and parents, opportunity expos, and other training opportunities or transition planning related materials can be found at the Planning for Adult Life website at [www.planningforadulthood.org](http://www.planningforadulthood.org).

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?
- What work experience/training can the student participate in to prepare for employment upon graduation or after post-secondary education?
- 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?

### **Legal Issues**

As the child nears age 18, it is important to explore protections within and outside of the legal system for managing his or her affairs. Families will want to consider the areas in which the 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 legal information at [www.drnj.org](http://www.drnj.org).

### **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 [www.state.nj.us/humanservices/ddd/services/guardianship/](http://www.state.nj.us/humanservices/ddd/services/guardianship/).



## **NJ Department of Labor and Workforce Development, Division of Vocational Rehabilitation Services Involvement with Transition**

**Pre-Employment Transition Services.** The Rehabilitation Act of 1973 (the Act), as amended by the Workforce Innovation and Opportunity Act (WIOA) emphasizes the provision of services to students and youth with disabilities to ensure they have opportunities to receive the training and other services necessary to achieve competitive integrated employment. WIOA expands the population of students with disabilities who may receive services and the kinds of services that VR agencies may provide to youth and students with disabilities who are transitioning from school or home-schooling to postsecondary education and employment. A student with a disability is an individual who is in an educational program, meets certain age requirements, and is eligible for and receiving special education or related services under the Individuals with Disabilities Education Act (IDEA) or is an individual with a disability for purposes of section 504 of the Act.

WIOA requires the vocational rehabilitation programs to provide pre-employment transition services to students with disabilities; in New Jersey pre-employment transition services begins at the beginning of the school year in which the student turn 14, and ends at graduation or aging out of secondary education.

Pre-employment transition services are an early start at job exploration that assist students with identifying career interests. The five required activities are:

- Job exploration counseling;
- Work-based learning experiences;
- Counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs;
- Workplace readiness training to develop social skills and independent living; and
- Instruction in self-advocacy, including peer mentoring.

**Individualized Transition Services.** The next step in the continuum of services from DVRS is individualized transition services that can be provided to students who have been determined eligible for the VR program and in accordance with an approved individualized plan for employment (IPE).

A student may have a case opened with DVRS when determined appropriate by the DVRS counselor, and this is done on a case-by-case basis.

Neither pre-employment transition services nor individualized transition services reduce the school district's obligation to provide appropriate transition services under IDEA.

For more information about DVRS services to students with disabilities please go [http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational\\_rehabilitation\\_services.shtml](http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational_rehabilitation_services.shtml) or [http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/students\\_with\\_disabilities.shtml](http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/students_with_disabilities.shtml)

**Limitation on the Use of Subminimum Wage for youth.** WIOA places additional restrictions on employers who hold a special wage certificate described in section 14(c) of the Fair Labor Standards Act of 1938 that authorizes payment of subminimum wages. Facilities are prohibited from hiring and paying youth with disabilities at a subminimum wage unless certain conditions are met.

## Extended Employment Requirements For Youth 24 Years Of Age And Under

Individuals with autism under the age of 24 must receive documentation that demonstrates completion of these services prior to beginning work that will be paid at less than the federal minimum wage. The services include the following:

- Receipt, as applicable of pre-employment transition services under DVRS or transition services under the Individuals with Disabilities Education Act (IDEA);
- Application for DVRS services that results in a determination of either ineligibility or eligibility; and
- Receipt of career counseling, and information and referral services. If determined eligible for DVRS, you must have:
  - An approved individualized plan for employment (IPE);
  - Been working toward the employment outcome in the IPE for a reasonable period of time with appropriate supports without success; and
  - A closed VR service record.

A youth with a disability must receive career counseling, and information and referral services regardless of DVRS eligibility prior to obtaining employment at subminimum wage with an entity holding a section 14(c) certificate.

If a youth with a disability or, as applicable, the youth's parent or guardian, refuses, through informed choice, to participate in the activities required by section 511 of the Rehabilitation Act and its implementing regulations in part 397, documentation will be provided to the youth and you will be advised that refusal to participate will also result in the youth not being eligible for employment at a subminimum wage with a section 14(c) certificate holder.



## 11. Adult Services and Supports

As the young adult grows and families continue to develop the Person-Centered Plan, consider the places that offer the assistance he or she will need. A very helpful step to assist an individual's transition to this new phase of life is the program Planning for Adult life ([www.planningforadulthood.org](http://www.planningforadulthood.org)) which is described on the bottom of page 19 in this guide.

There are many doors to assistance. Most communities offer an array of services that may meet the needs of the individual and his/her family. The type and availability of aid will vary, but utilizing these community resources can increase the amount of services an individual receives and may provide options that are not available through State agencies. Each individual's unique strengths, abilities and needs will help determine which doors to choose. Each State agency also has its own service criteria.

### EMPLOYMENT FIRST INITIATIVE

In April 2012, Governor Chris Christie declared New Jersey an 'Employment First' state, embracing the philosophy – implemented through policies, programs, and services – that promotes competitive employment in the general workforce as the first and preferred post-education outcome for every resident.

- Supports to pursue competitive employment in the general workforce shall be considered the primary service option for working age adults with intellectual and developmental disabilities who are receiving services and supports from the New Jersey Division of Developmental Disabilities. Integrated employment is more valuable than non-employment, group employment, segregated employment, facility-based employment, or day habilitation in terms of outcomes for individuals.
- For all individuals receiving services/supports from DDD, including those not yet achieving employment, annual service planning shall include outcomes related to achieving employment. A facilitated discussion regarding employment pathways must be conducted at least annually and lead toward identified employment outcome(s), planning goals associated with the outcome(s), and needed services/supports to assist the individual in establishing/maintaining employment or removing barriers that may be preventing the individual from pursuing employment opportunities in fully integrated work settings.

#### A. New Jersey Division of Developmental Disabilities

Approximately 25,000 Medicaid-eligible adults with developmental disabilities age 21 and older, including those with ASD, are served by the New Jersey Division of Developmental Disabilities. Most DDD-eligible individuals live in the community, in their own homes or apartments; with family; in a licensed community residence such as a group home or supervised apartment; or in a Community Care Residence with a family caregiver. Supports and services to assist individuals living in the community are offered by more than 250 agencies or more than 600 individual providers. You can learn more about DDD at [www.nj.gov/humanservices/ddd/home/index.html](http://www.nj.gov/humanservices/ddd/home/index.html).

- o In addition to the Support Coordination services that help individuals access needed program and State plan assistance including needed medical, social, educational, and other services, DDD can provide other services to eligible families. These services include but are not limited to Employment Services, Day Services, and Individual/Family Supports.

Information about current DDD services can be found by clicking on the “Services and Supports” tab on DDD’s website. The following services are available in the Supports Program and the Community Care Program:

## **Employment Services**

### **■ Supported Employment – Individual Support**

Activities needed to help a participant obtain and maintain an individual job in competitive or customized employment, or self-employment, in an integrated work setting in the general workforce. The individual is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals without disabilities. The service may be delivered for an intensive period upon the participant’s initial employment to support the participant who, because of their disability, would not be able to sustain employment without supports. Supports during the intensive period are delivered in a face-to-face setting, one-on-one. The service may also be delivered to a participant on a less intensive, ongoing basis (“follow along”) where supports are delivered either face-to-face or by phone with the participant and/or his or her employer. Services are individualized and may include but are not limited to: training and systematic instruction, job coaching, benefit support, travel training, and other workplace support services including services not specifically related to job-skill training that enable the participant to be successful in integrating into the job setting.



### **■ Supported Employment – Group Support**

Services and training activities provided to participants in regular business, industry and community settings for groups of two to eight workers with disabilities. Services may include mobile crews and other business-based workgroups employing small groups of workers with disabilities in employment in the community. Services must be provided in a manner that promotes integration into the workplace and interaction between participants and people without disabilities. Services may include but are not limited to: job placement, job development, negotiation with prospective employers, job analysis, training and systematic instruction, job coaching, benefit support, travel training and planning.

### **■ Career Planning**

Career planning is a person-centered, comprehensive employment planning and support service that provides assistance for program participants to obtain, maintain, or advance in competitive employment or self-employment. It is a focused, time-limited service engaging a participant in identifying a career direction and developing a plan for achieving competitive, integrated employment at or above the state’s minimum wage. The outcome of this service is documentation of the participant’s stated career objective and a career plan used to guide individual employment support. If a participant is employed and receiving supported employment services, career planning may be used to find other competitive employment more consistent with the person’s skills and interests or to explore advancement opportunities in his or her chosen career.

### **■ Prevocational Training**

Services that provide learning and work experiences, including volunteer work, where the individual can develop general, non-job-task-specific strengths and skills that contribute to employability in paid employment in integrated community settings. Services may include training in effective communication with supervisors, co-workers and customers; generally accepted community workplace conduct and dress;

ability to follow directions; ability to attend to tasks; workplace problem solving skills and strategies; and general workplace safety and mobility training. Prevocational Training is intended to be a service that participants receive over a defined period of time and with specific outcomes to be achieved in preparation for securing competitive, integrated employment in the community for which an individual is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals without disabilities. Prevocational Training services cannot be delivered within a sheltered workshop. Supports are delivered in a face-to-face setting, either one-on-one with the participant or in a group of two to eight participants.

## **Day Services**

### **■ Community Based Supports**

Services that provide direct support and assistance for participants, with or without the caregiver present, in or out of the participant's residence, to achieve and/or maintain the outcomes of increased independence, productivity, enhanced family functioning, and inclusion in the community, as outlined in his/her Individualized Service Plan. Community-Based Supports are delivered one-on-one with a participant and may include but are not limited to: assistance with community-based activities and assistance to, as well as training and supervision of, individuals as they learn and perform the various tasks that are included in basic self-care, social skills, and activities of daily living.

### **■ Individual Supports**

Individual support services are self-care and habilitation-related tasks performed and/or supervised by service provider staff or an approved individual caregiver in an individual's own or family home or in other community-based settings, in accordance with approved Service Plans. Assistance to, as well as training and supervision of, individuals as they learn and perform the various tasks that are included in basic self-care, social skills, activities of daily living and behavior shaping will be provided. The Service Plan will specify the actual tasks to be performed and the anticipated outcomes. Individual support services may include personal assistance, including attendant care, household chores, errand services and training.

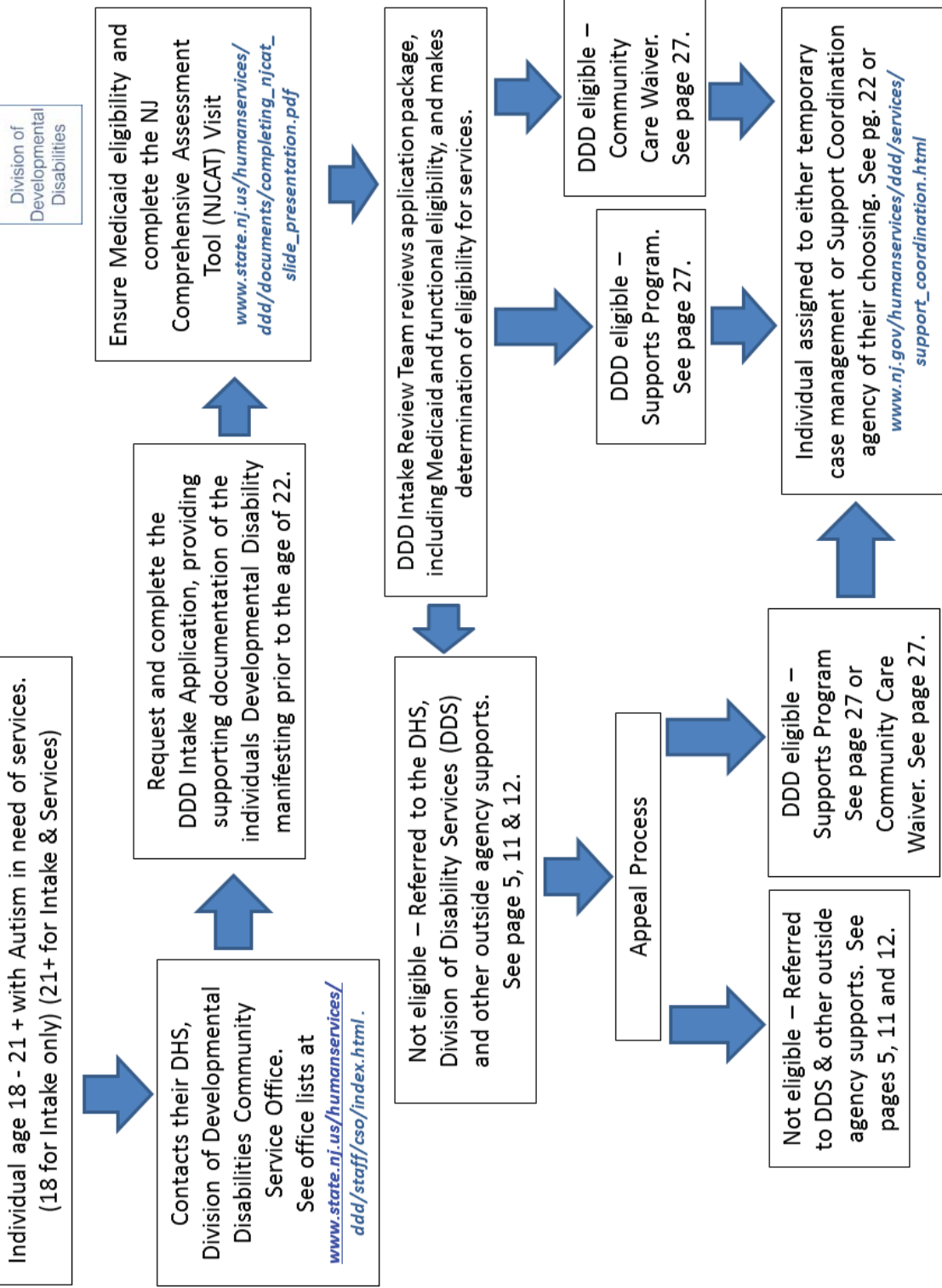
### **■ Community Inclusion Services**

Services provided outside of a participant's home that support and assist participants in educational, enrichment, or recreational activities as outlined in his/her Service Plan that are intended to enhance inclusion in the community. Community Inclusion Services are delivered in a group setting not to exceed six (6) individuals.

### **■ Day Habilitation**

Services that provide education and training to acquire the skills and experience needed to participate in the community, consistent with the participant's Service Plan. This may include activities to support participants with building problem-solving skills, self-help, social skills, adaptive skills, daily living skills, and leisure skills. Activities and environments are designed to foster the acquisition of skills, building positive social behavior and interpersonal competence, greater independence and personal choice. Services are provided during daytime hours and do not include employment-related training. Day Habilitation may be offered in a center-based or community-based setting.

# DDD Intake Flow Chart



## Individual/Family Support Services

DDD funds a wide array of services intended to help support individuals with developmental disabilities who reside in the community. Additionally, families caring for relatives with developmental disabilities, on an ongoing basis, often struggle to meet their caregiving responsibilities. To help address these concerns, DDD will provide self-directed individual and family supports such as adaptive technology, behavioral supports, environmental and vehicle modifications, respite, etc. via a self-directed model based upon assessed need. Individuals will choose from approved providers using established budgets.

Support services include, but are not limited to, the following:

- Assistive Technology
- Behavioral Management
- Cognitive Rehabilitation
- Environmental Modifications
- Interpreter Services
- Natural Supports Training
- Occupational Therapy
- Personal Emergency Response System (PERS)
- Physical Therapy
- Respite
- Speech, Language, and Hearing Therapy
- Supports Brokerage
- Transportation
- Vehicle Modifications
- Goods and Services



## **B. New Jersey Division of Vocational Rehabilitation Services**

The New Jersey Division of Vocational Rehabilitation Services (DVRS) provides a variety of services for adults with disabilities attempting to succeed in the working world. Services can include:

- 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. Pre-Employment Transition Services** - Services to students begin at age 14 until graduation or the student ages out of the school system.
- 3. 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).
- 4. Job Seeking Skills/Job Clubs** – Guidance in work search activities such as resume writing, interviewing skills, job search organization.
- 5. 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.
- 6. Time Limited Placement and Coaching** – The first two categories of Supported Employment Services without periodic follow-along.
- 7. 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.
- 8. Skills Training** – Attendance at a vocational school, technology or trade School, business school, etc.
- 9. College Training** – Attendance at 2 or 4 year higher education programs leading to a degree.
- 10. 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 aids, and eyeglasses (in some instances).
- 11. 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.
- 12. Mobility Equipment** – Assessment and evaluation of mobility needs.
- 13. Driver Training** – Assessment of driving ability and equipment needed to drive safely.
- 14. Vehicle Modification** – Assessment of adaptive/modification needs related to employment.
- 15. Home Modifications** – Assessment of adaptive/modification needs related to employment.

For more information on DVRS services for adults please go to: <http://careerconnections.nj.gov/>

LWD Workforce Field Services provides services to individuals with all abilities through their One Stop Career Centers (OSCC). For more information on services for jobseekers please go to: <http://lwd.dol.state.nj.us/>



## 12. Funding for Services and Supports

### The Comprehensive Medicaid Waiver

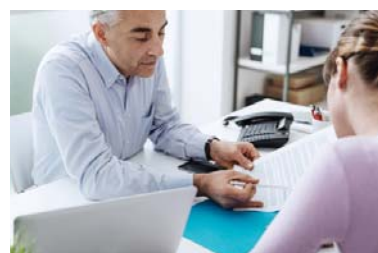
The Comprehensive Medicaid Waiver (CMW) was approved by the Centers for Medicare & Medicaid Services (CMS) on October 1, 2012. The CMW provides statewide reform for Medicaid services, shifts the focus of services and supports to community-based, and allows New Jersey to draw down increased federal funds.

The Community Care Program (CCP) is intended for:

- Individuals who exhibit substantial functional limitations in 3 or more major life areas due to an intellectual or physical impairment, or combination of intellectual or physical impairments, that manifest before the age of 22 and are likely to continue indefinitely;
- demonstrate deficiencies in self-care; and
- need the CCP support services so that they may reside in the community, thus preventing the need for long-term institutional placement.

In order to be eligible for the CCP an individual must:

- Be a resident of NJ, be a U.S. citizen or qualified alien;
- Be 21 Years of age or older.
- Be DDD and Medicaid eligible;
- Need and utilize at least one CCP services;
- Meet clinical level of care; and
- Meet DDD's "emergency" criteria, reach the top of the CCW waiting list, be part of Olmstead



An individual on the CCP will receive waiver services that meet his/her needs as determined through an assessment and outlined/authorized in the individual's Service Plan. The needs of individuals on the CCP are re-assessed at least annually.

For more information regarding CCP eligibility please go to:  
[www.state.nj.us/humanservices/ddd/services/ccw/index.html](http://www.state.nj.us/humanservices/ddd/services/ccw/index.html).

### New Jersey's Supports Program

The Supports Program provides needed supports and services for adult individuals, 21 and older, living with their families or in other unlicensed settings. It has been designed to help New Jersey better serve adults with developmental disabilities and significantly reduce the number of individuals waiting for supports and services. The Supports Program will provide all enrolled participants with employment/day services and individual/family support services based on their assessed level of need. Individuals and their families will have the flexibility to choose the options and opportunities for support services that will best meet their needs with the assistance of Support Coordinators who will assist them in developing an Individualized Service Plan and link them to appropriate services.

Additional information about the Supports Program may be found at:  
[www.nj.gov/humanservices/ddd/programs/supports\\_program.html](http://www.nj.gov/humanservices/ddd/programs/supports_program.html)

The Comprehensive Medicaid Waiver also encompasses supports and services administered by the DCF CSOC for children with developmental disabilities up to the age of 21.

## Department of Children and Families – Children’s System of Care

The Department of Children and Families, Children’s System of Care (DCF CSOC) is responsible for three components of the Comprehensive Medicaid Waiver:

- The Intellectual Developmental Disability/Mentally Ill Dually Diagnosed Children Service Program has the primary goal of providing a safe, stable, and therapeutically supportive environment for children with developmental disabilities and co-occurring mental health diagnoses, ages five (5) up to twenty-one (21), with significantly challenging behaviors. This program provides both in-home intensive and out-of-home services. It is the purpose of this program to serve and stabilize the child with ID-DD/MI in the least restrictive environment. The optimum goal is for the child to remain, or return, home with their natural supports. This program is intended to assist families/caregivers by working with qualified agencies and consultants skilled in positive behavior supports to develop appropriate and safe ways to redirect the child to a more productive, safe and involved lifestyle. As the family/caregiver gains knowledge and becomes more skilled in working with their child, the level of supports will be decreased to match the level of intensive behavioral need. The ultimate goal is to return the family home to an environment requiring minimal, if any, outside intervention.
- Children with Pervasive Developmental Disabilities Program (Renamed Children with Autism Spectrum Disorder) provides habilitation services to children with a diagnosis of Autism Spectrum Disorder (ASD), as per the DSM 5, up to their 13th birthday. Evidence-based habilitation services will support the child’s functional development, and enhance his/her inclusion in the community with improved adaptive behavior, language, and cognitive outcomes. ASD Habilitation services are available to the extent that they are not available under a program funded by the Individuals with Disabilities Education Act and the Rehabilitation Services Act of 1973.
- Children with Severe Emotional Disturbance (SED) – The SED program provides behavioral health services for youth, ages five (5) up to twenty-one (21) who have been diagnosed as seriously emotionally disturbed which places them at risk for hospitalization and/or out-of-home placement.

### NJ Medicaid

Medicaid provides health insurance to parents/caretakers and dependent 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 [www.state.nj.us/humanservices/dmahs/clients/medicaid/](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.
  - NJ FamilyCare also includes certain programs for pregnant women. Go to [www.njfamilycare.org](http://www.njfamilycare.org) for more information.
- meet specific standards for financial income and resources  
Please visit [www.state.nj.us/humanservices/ddd/services/medicaideligibility.html](http://www.state.nj.us/humanservices/ddd/services/medicaideligibility.html)

## Private Insurance

Some private insurance companies cover evaluation and therapy services related to the care of people with ASD; others do not. Families should call their insurance company to ask about covered services.

- 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 [www.nj.gov/health/fhs/eis/documents/autism\\_dd\\_insurance\\_factsheet.pdf](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 [www.spannj.org/cyshcn/core\\_outcome\\_3/Maximizing%20Coverage%20ASD%20&%20Other%20DD.pdf](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 a person can get SSI, it considers his/her income and resources. It also considers the income and resources of family members living in the child's household. These rules apply if the child lives at home. They also apply if he or she is away at school but returns home from time to a dependent or has guardianship.

If the 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.

It is highly recommended that individuals apply for SSI as soon as possible after his/her 18th birthday. Individuals receiving SSI will automatically receive Medicaid - required for DDD eligibility. Establishing SSI eligibility at 18 can help an individual maintain Medicaid eligibility as a "1634 DAC" (Disabled Adult Child) even if the individual later receives Social Security Disability (SSD) through a parent who has retired, become disabled, or died.

For more information, please visit [www.ssa.gov/pubs/10026.html#ssi-benefits](http://www.ssa.gov/pubs/10026.html#ssi-benefits).

## Catastrophic Illness in Children Relief Fund Commission

The Catastrophic Illness in Children Relief Fund (CICRF) is a financial resource to help New Jersey families, regardless of income, cope with medical expenses for their children that are not fully covered by insurance, state or federal programs, or any other source, such as fundraising. The Fund provides a financial safety net to families struggling with a child's previously incurred medical expenses. The definition of a catastrophic illness in this program is economic and is measured in terms of the financial impact of health care expenses on the family, rather than on the diagnosis or severity of the illness.

Eligibility criteria include:

- Uncovered medical expenses in any prior, consecutive, 12 month period, dating back to 1988
- Eligible expenses must exceed 10% of the first \$100,000 of a family's annual income, plus 15% of any income over \$100,000.
- The child must have been 21 years or younger when the medical expenses were incurred.
- The child's family or legal guardian have been residents of New Jersey for at least 3 months prior to the date of application. Temporary residents of any type are not eligible to apply.

The Fund pays traditional medical expenses such as physician, hospital and pharmacy services. The Fund also assists with non-traditional expenses such as home modifications, modified vans and funeral expenses not usually covered by insurance. All expenses are subject to established caps and program regulations.

You can contact the Catastrophic Illness in Children Relief Fund Program at 1-800-335-FUND (3863) or visit their web site at [www.njcatastrophicfund.org](http://www.njcatastrophicfund.org)

## 13. Housing

### Division of Developmental Disabilities (DDD)

As a disability services agency, DDD strives to provide support services that allow individuals to live in their own homes or in their family homes and be part of their communities. DDD encourages individuals to use all available services, including mainstream affordable housing and/or their own resources, to live independently. For some individuals who cannot be supported in their family home and are eligible for the Community Care Program (CCP), DDD can provide supports in licensed residential settings, such as group homes or supervised apartments. Housing assistance through a transitional rental voucher may also be available based on annual appropriations to DDD.



## 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 people with disabilities and those with special housing needs; and formulate partnerships to foster the economic development of New Jersey and the personal development of its residents. Funding for rent and operating subsidies and supportive services is not available through HMFA.



- **Supported Housing and Special Needs Programs** – HMFA’s Supported Housing and Special Needs Programs Division administers capital financing 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 Agency works to improve the housing situation for some citizens of New Jersey with the most needs, including people with ASD and other developmental and intellectual 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, individuals 18 years of age and overcoming out of nursing homes, and other under-served communities.
- **Housing Resource Center (HRC)** – The HRC is an award winning website and online registry, located at [www.nj.gov/njhrc](http://www.nj.gov/njhrc), designed to assist households in search of affordable and/or accessible housing that allows folks the ability to search thousands of affordable units. 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) are 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](http://www.nj-hmfa.com).

## Department of Community Affairs



The Division of Housing and Community Resources is committed to strengthening and revitalizing communities through the delivery of affordable housing, supportive services and the provision of financial and technical assistance to communities, local government and community based organizations.

### Section 8 Housing Choice Voucher

The Section 8 Housing Choice Voucher (HCV) Program assists in making safe and quality housing in the private rental market affordable to low and very low-income households by reducing housing costs through direct rent subsidy payments to landlords. The program is funded by the U.S. Department of Housing and Urban Development.

The Section 8 HCV program is based on the premise that housing costs (rent and utilities) should not exceed 30 percent of a household's income. The statewide program is available to residents of all New Jersey counties. Section 8 Existing Housing programs are administered throughout the State by a number of municipal and county authorities. To see the list of County Authorities and find the one closest to you, please check this link [www.state.nj.us/dca/divisions/dhcr/offices/docs/fieldofficedirectory.pdf](http://www.state.nj.us/dca/divisions/dhcr/offices/docs/fieldofficedirectory.pdf).

### State Rental Assistance Program

The State Rental Assistance Program provides tenant-based and project-based rental assistance grants comparable to the Federal Housing Choice Voucher Program, and shall be terminated upon the award of a Federal subsidy to the same individual or household. The program has a "Disabled set-aside" which is reserved for a head of household or spouse with a disability. For more information please call (609) 292-4080.



## **Additional Assistance**

### **Supplemental Nutrition Assistance Program (SNAP)**

Formerly known as Food Stamps, SNAP helps eligible New Jersey residents receive benefits that help them afford a nutritionally balanced diet. Local County Welfare Agencies/Boards of Social Services determine who is eligible for SNAP. To find a specific County Welfare Agency (Board of Social Services) please check this link [www.nj.gov/humanservices/dfd/programs/njsnap/cwa/index.html](http://www.nj.gov/humanservices/dfd/programs/njsnap/cwa/index.html).

### **Energy Assistance**

The New Jersey Board of Public Utilities provides a number of programs intended to help NJ citizens that are having trouble affording their utility bills. These programs include:

- TRUE and PAGE Programs
- Comfort Partners
- LIHEAP (NJ DCA)
- Universal Service Fund-Energy
- Winter Termination Program
- Lifeline Program (Energy Assistance)
- NJSHARES
- Telephone Assistance
- NJ EASE



For more information regarding these programs please visit [www.state.nj.us/bpu/assistance/programs/](http://www.state.nj.us/bpu/assistance/programs/).

### **[www.mynjhelps.org](http://www.mynjhelps.org)**

The site offers a free and easy screening tool to identify if you may be eligible for food assistance, cash assistance, and health care. Following the screening, individuals can then continue on to actually apply for the program or service.

## 14. Additional Information and Support Resources

### Learn the Signs. Act Early.

One important key to a child's ability to develop to his or her greatest potential is to obtain help and support as early as possible. "Learn the Signs. Act Early" is a national initiative undertaken by the 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 Rutgers - Robert Wood Johnson Medical School. Important informational resources for parents are also available. Learn more about this initiative at [http://rwjms.rutgers.edu/boggscenter/projects/Act\\_Early.html](http://rwjms.rutgers.edu/boggscenter/projects/Act_Early.html) and obtain helpful materials at [www.cdc.gov/ncbddd/actearly/](http://www.cdc.gov/ncbddd/actearly/).

### Research

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

### Governor's Council for Medical Research and Treatment of Autism

The Governor's Council for Medical Research and Treatment of Autism (Council) was created by State appropriation in 1999 and has been issuing research, clinical and educational enhancement grants since 2000. In 2012 the Council established the New Jersey Autism Center of Excellence (NJ ACE) with a mission to research, apply and advance best practices in the understanding, prevention, evaluation and treatment of autism spectrum disorder, enhancing the lives of individuals across their lifespans. 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 [www.state.nj.us/health/autism/](http://www.state.nj.us/health/autism/)

### Wandering Prevention Efforts

Autism Shield Project – Parents of Autistic Children (POAC) provides safety training for police, fire fighters, EMTs, caregivers, teachers, and child study team members in every New Jersey County. These workshops are intended to give participants the information needed to keep individuals with autism safe, and include a safety kit full of resources. An additional facet of Autism Shield is POAC's School Bus Driver and Personnel Training.

Project Lifesaver - is a national program that uses technology to help locate missing persons. Participants wear a bracelet, equipped with a transmitter, which can aid specially trained Sheriff's Officers in locating them once reported missing. The bracelet requires daily monitoring by the caregiver. Any NJ resident that is prone to wandering is eligible for the program. Project Lifesaver is run through county sheriff's departments. The initial cost for the bracelet transmitter and battery is approximately \$285. There is a monthly cost of \$9-\$15. There are some funds available for families in need who cannot afford the cost. Families apply through their county Sheriff's office. For more information, visit [www.projectlifesaver.org/](http://www.projectlifesaver.org/)



## 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 [www13.state.nj.us/SpecialNeeds](http://www13.state.nj.us/SpecialNeeds).

### New Jersey Autism Registry

Legislation was enacted in 2007 mandating that the DOH maintain a registry of individuals diagnosed with ASD who are under the age of 22. Licensed health care professionals are required to register any child whom they have diagnosed or whom they follow with ASD. They must notify parents of the registration process. Once a child is registered, a letter of notification and information pamphlets regarding available services will be received. The Autism Registry is a confidential registry with three main missions:

1. Connects families to the Special Child Health Services Case Management Unit in their county of residence.
2. Provides aggregate information to policy makers to help them better plan for needed services and resources throughout the state.
3. Examines epidemiological factors to better understand the prevalence of autism in New Jersey.



For more information about the Autism Registry, please call 609-292-5676 or visit <http://nj.gov/health/fhs/autism/public/registry/> for more information. Information about services available from DOH to children with special needs is available at [www.state.nj.us/health/fhs/sch/](http://www.state.nj.us/health/fhs/sch/).

### The New Jersey Autism Registry: Facts and Myths

**Myth:** *I can refuse to have my child registered with the Autism Registry.*

**False.** You cannot refuse to be part of the Autism Registry. Health care providers must tell the parent/guardian about the Registry and their right to request an anonymous registration. You can only choose to be in the Registry without identifiers such as name, full date of birth, address etc. However, if you choose this option, you will not automatically be linked to special child health services case management services.

**Myth:** *If I don't give consent, my health care provider cannot register my child because of Health Insurance Portability and Accountability Act (HIPAA).*

**False.** A provider does not need consent because this is a public health surveillance activity. All states require the reporting of certain conditions so that they can better plan for and provide services. Both health care providers who diagnose ASD and primary care providers are required to register so that children diagnosed previously or out-of-state are not missed.

**Myth:** *There is no benefit to me or my child to be registered.*

**False.** Once your child is registered, you will receive a letter and informational pamphlets telling you that your child has been registered, and about services that may be available for you and your family. The Special Child Health Services Case Management Unit will contact your family and inform you of available family-centered services in your community. County-based case management units are a free resource for families of children from birth to 21 years of age with special health care needs. If your child's personal information is not included, we will not be able to link your child to important services and resources, many at no charge to the families.

**Fact:** *Your child's personal identifying information is CONFIDENTIAL.*

**True.** Children's personal information such as their name, address, diagnosis, etc. is NOT shared with other agencies such as the Division of Motor Vehicles, schools and colleges. We recognize the sensitivity of your information and respect the rights of all individuals with ASD and their families. We take seriously our obligation to protect the privacy and confidentiality of individuals and we keep all personal information in a tightly secured location.



## 16. New Jersey Resources

### **Abledata**

[www.abledata.com/](http://www.abledata.com/)

### **Alliance for the Betterment of Citizens with Disabilities (ABCD)**

<http://abcdnj.org>

### **The Arc of New Jersey**

[www.arcnj.org](http://www.arcnj.org)

### **Arts Unbound**

[www.artsunbound.org](http://www.artsunbound.org)

### **Asperger Syndrome Education Network (ASPEN)**

[www.aspennj.org](http://www.aspennj.org)

### **Advocates for Children of New Jersey**

[www.acnj.org](http://www.acnj.org)

### **Autism Family Services of NJ**

[www.autismfamilyservicesnj.org](http://www.autismfamilyservicesnj.org)

### **Autism NJ**

[www.autismnj.org](http://www.autismnj.org)

### **Autistic Self Advocacy Network (ASAN)**

<http://autisticadvocacy.org/>

### **Autism Speaks**

[www.autismspeaks.org](http://www.autismspeaks.org)

### **Centers for Disease Control and Prevention (CDC)**

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

### **Children's Specialized Hospital**

[www.childrens-specialized.org](http://www.childrens-specialized.org)

### **Council for Exceptional Children**

[www.cec.sped.org/](http://www.cec.sped.org/)

### **Daniel Jordan Fiddle Foundation**

[www.djfiddlefoundation.org](http://www.djfiddlefoundation.org)

### **Dental Care for Persons with Developmental Disabilities in New Jersey**

[www.disabilityhealth.org/dental/index.html](http://www.disabilityhealth.org/dental/index.html)

## **New Jersey Resources - continued**

### **Department of Children and Families**

[www.state.nj.us/dcf/](http://www.state.nj.us/dcf/)

### **DCF Office of Education**

[www.state.nj.us/dcf/divisions/education/](http://www.state.nj.us/dcf/divisions/education/)

### **Department of Community Affairs**

[www.state.nj.us/dca/](http://www.state.nj.us/dca/)

### **Department of Education**

[www.state.nj.us/education/](http://www.state.nj.us/education/)

### **Department of Health**

[www.state.nj.us/health/](http://www.state.nj.us/health/)

### **Department of Human Services**

[www.state.nj.us/humanservices/](http://www.state.nj.us/humanservices/)

### **Department of Labor and Workforce Development**

<http://lwd.state.nj.us/labor/index.html>

### **Disability Rights New Jersey - NJ ADD Network**

[www.drnj.org](http://www.drnj.org)

### **Division of Children's System of Care**

[www.nj.gov/dcf/families/csc/](http://www.nj.gov/dcf/families/csc/)

### **Division of Developmental Disabilities**

[www.state.nj.us/humanservices/ddd/home/index.html](http://www.state.nj.us/humanservices/ddd/home/index.html)

### **Division of Disability Services**

[www.state.nj.us/humanservices/dds/home/](http://www.state.nj.us/humanservices/dds/home/)

### **DOE Office of Special Education Programs**

[www.nj.gov/education/specialed/overview.shtml](http://www.nj.gov/education/specialed/overview.shtml) [index.html](#)

### **Elizabeth M. Boggs Center for Excellence in Developmental Disabilities**

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

### **Emergency Preparedness Resources from the NJ Council on Developmental Disabilities**

[www.njcdd.org/EmergencyPreparedness/emergencypreparednesshome.htm](http://www.njcdd.org/EmergencyPreparedness/emergencypreparednesshome.htm)

### **Epilepsy Foundation of New Jersey**

[www.efnj.com](http://www.efnj.com)

## **New Jersey Resources - continued**

### **Family Crisis Handbook**

[www.sccatnj.org/misc/Family\\_Crisis\\_handbook.pdf](http://www.sccatnj.org/misc/Family_Crisis_handbook.pdf)

### **Family Resource Network**

[www.familyresourcenetwork.org](http://www.familyresourcenetwork.org)

### **Family Support Center of New Jersey**

[www.fscnj.org/](http://www.fscnj.org/)

### **Family Support Coalition of New Jersey**

[www.familysupportcoalition.org](http://www.familysupportcoalition.org)

### **Family Voices of New Jersey**

[www.spannj.org/familywrap/familyvoices.htm](http://www.spannj.org/familywrap/familyvoices.htm)

### **Find a Ride: NJ public and private transportation**

[www.njfindaride.org](http://www.njfindaride.org)

### **Housing & Community Development Network of NJ**

[www.hcdnnj.org](http://www.hcdnnj.org)

### **Housing Resource Center (HRC)**

[www.nj.gov/njhrc](http://www.nj.gov/njhrc)

### **Lead Safe NJ Program**

[www.njleadsafe.info/](http://www.njleadsafe.info/)

### **Learning Resource Centers**

[www.state.nj.us/education/lrc/](http://www.state.nj.us/education/lrc/)

### **Mom2Mom - Support line for mothers 1-877-914-MOM2**

[www.njarch.org/images/M2M%20brochure.pdf](http://www.njarch.org/images/M2M%20brochure.pdf)

### **National Institutes of Health (NIH)**

[www.nih.gov/](http://www.nih.gov/)

### **NJ APSE - The Network on Employment**

<http://www.apse.org/>

### **New Jersey Association of Community Providers**

[www.njacp.org](http://www.njacp.org)

### **NJ Coalition for Inclusive Education**

<http://njcie.net>

## **New Jersey Resources - continued**

### **NJ Council on Developmental Disabilities**

[www.njcdc.org](http://www.njcdc.org)

### **NJ Dept. of Community Affairs' Div of Housing and Community Resources**

[www.state.nj.us/dca/divisions/dhcr/](http://www.state.nj.us/dca/divisions/dhcr/)

### **NJ Division of Medical Assistance and Health Services**

[www.state.nj.us/humanservices/dmahs/home](http://www.state.nj.us/humanservices/dmahs/home)

### **NJ Division of Mental Health and Addiction Services**

[www.nj.gov/humanservices/dmhs/home/index.html](http://www.nj.gov/humanservices/dmhs/home/index.html)

### **NJ Department of Health, Title V Children with Special Health Care Needs programs**

[www.state.nj.us/health/fhs/sch/index.shtml](http://www.state.nj.us/health/fhs/sch/index.shtml)

### **NJ Early Intervention System**

<http://nj.gov/health/fhs/eis/index.shtml>

### **NJ Foundation of Dentistry for Persons with Disabilities**

<http://nfdh.org>

### **NJHelps.org**

<http://njhelps.org>

### **NJ Housing and Mortgage Finance Agency (HMFA)**

[www.nj.gov/dca/hmfa/](http://www.nj.gov/dca/hmfa/)

### **NJ Parent Link: The Early Childhood, Parenting, and Professional Resource Center**

[www.nj.gov/njparentlink/](http://www.nj.gov/njparentlink/)

### **NJ Positive Behavior Support in Schools**

[www.njpbs.org](http://www.njpbs.org)

### **NJ Rehabilitation Association**

[www.newjerseyrehabassociation.org/mission.htm](http://www.newjerseyrehabassociation.org/mission.htm)

### **NJ Self Advocacy Project**

[www.njselfadvocacyproject.org](http://www.njselfadvocacyproject.org)

### **NJ Self Help Clearinghouse**

[www.njgroups.org](http://www.njgroups.org)

### **NJ State Home Page**

[www.state.NJ.us/index.htm](http://www.state.NJ.us/index.htm)

### **NJ State Legislature**

[www.njleg.state.nj.us](http://www.njleg.state.nj.us)

## **New Jersey Resources - continued**

### **NJ Statewide Independent Living Council**

[www.njsilc.org](http://www.njsilc.org)

### **NJ Statewide Network for Cultural Competence**

[www.nj.gov/njsncc/](http://www.nj.gov/njsncc/)

### **NJ Transit Accessible Services**

[www.njtransit.com/tm/tm\\_servlet.srv?hdnPageAction=AccessibleServicesTo](http://www.njtransit.com/tm/tm_servlet.srv?hdnPageAction=AccessibleServicesTo)

### **NJ Work Incentive Network Support (NJWINS)**

[www.njwins.org](http://www.njwins.org)

### **Northeast ADA & IT Center**

<http://northeastada.org>

### **Parents Of Autistic Children (POAC)**

[www.poac.net](http://www.poac.net)

### **Parental Rights in Special Education (PRISE)**

[www.state.nj.us/education/specialed/form/prise/prise.pdf](http://www.state.nj.us/education/specialed/form/prise/prise.pdf)

### **PerformCare**

[www.performcarenj.org/families/disability/index.aspx](http://www.performcarenj.org/families/disability/index.aspx)

### **Rewarding Work/New Jersey - A website for direct support professionals, personal assistants, and their employers**

[www.rewardingwork.org/NewJersey](http://www.rewardingwork.org/NewJersey)

### **Special Olympics of New Jersey**

[www.sonj.org](http://www.sonj.org)

### **Statewide Clinical Consultation & Training (SCCAT)**

[www.sccatnj.org](http://www.sccatnj.org)

### **Statewide Parent Advocacy Network (SPAN)**

[www.spannj.org](http://www.spannj.org)

### **Supportive Housing Association of NJ**

[www.shanj.org](http://www.shanj.org)

### **Supplemental Nutrition Assistance Program (SNAP)**

[www.nj.gov/humanservices/dfd/programs/njsnap/cwa/index.html](http://www.nj.gov/humanservices/dfd/programs/njsnap/cwa/index.html)

### **United States Society for Augmentative and Alternative Communication (USAAC)**

[www.ussaac.org/](http://www.ussaac.org/)

## 17. Key Acronyms

ABA	Applied Behavior Analysis
ABCD	Alliance for the Betterment of Citizens with Disabilities
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASAN	Autistic Self Advocacy Network
ASD	Autism Spectrum Disorder
ASPEN	Asperger Syndrome Education Network
AWATF	Adults With Autism Task Force
CBI	Community Based Instruction
CBVI	Commission for the Blind and Visually Impaired
CCP	Medicaid Community Care Program
CDC	Centers for Disease Control and Prevention
CEC	Child Evaluation Centers
CICRF	Catastrophic Illness in Children Relief Fund
CMS	Centers for Medicare and Medicaid Services
CMW	Comprehensive Medicaid Waiver
DAC	Disabled Adult Child
DCA	Department of Community Affairs
DCF	Department of Children and Families
DCSOC	Division of Children's System of Care
DDD	Division of Developmental Disabilities
DDS	Division of Disability Services
DHS	Department of Human Services
DOH	Department of Health
DIR	Developmental, Individual-Difference, Relationship-Based Model
DLWD	Department of Labor and Workforce Development
DMHAS	Division of Mental Health and Addiction Services
DOE	Department of Education
DSM	Diagnostic and Statistical Manual of Mental Disorders
DVRS	Division of Vocational Rehabilitation Services
EBP	Evidence Based Practice
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



IPE	Individualized Plan for Employment
ISAAC	International Society for Augmentative and Alternative Communication
ISP	Individualized Service Plan
LDTC	Learning Disabilities Teacher Consultant
LHCA	Lead Hazard Control Assistance
LRCs	Learning Resource Centers
MCHB	Maternal and Child Health Bureau
NIH	National Institutes of Health
NJ ACE	New Jersey Autism Center of Excellence
NJAS	New Jersey Autism Study
NJEIS	New Jersey Early Intervention System
NJWINS	New Jersey Work Incentive Network Support
NON-DAC	Non Disabled Adult Child
OOA	Office on Autism
OJT	On the Job Training
OSCC	One Stop Career Centers
OTSSS	Office of Tiered Supports and Specialized Services
OOE	Office of Education
OIAS	Office of Information and Assistance Services
OT	Occupational Therapist
PDD	Pervasive Developmental Disorders
PDDNOS	Pervasive Developmental Disorder - Not Otherwise Specified
PERS	Personal Emergency Response System
POAC	Parents Of Autistic Children
PT	Physical Therapist
RDI	Relationship Development Intervention
SCHS	Special Child Health Services Case Management Units
SE	Supported Employment
SLP	Speech-Language Pathologist
SNAP	Supplemental Nutrition Assistance Program
SPAN	Statewide Parent Advocacy Network
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TEACCH	Treatment and Education of Autistic and Communication Related Handicapped Children
TLPC	Time Limited Placement and Coaching
USSAAC	United States Society for Augmentative and Alternative Communicat
WIOA	Workforce Innovation and Opportunity Act



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



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