

NJ Department of Human Services
Division of Developmental Disabilities

FASD

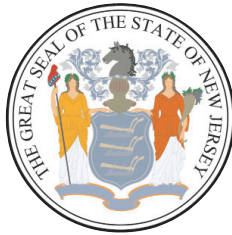
**A Family Guide for Individuals with
Fetal Alcohol Spectrum Disorders**

First 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



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2019

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A Family Guide for Individuals with Fetal Alcohol Spectrum Disorders and other Developmental Disabilities

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1. Background

Multiple New Jersey state agencies are committed to address the needs of individuals with Fetal Alcohol Spectrum Disorders (FASD) and their families. To assist and organize these state efforts, the Governor's Council on the Prevention of Developmental Disabilities (Council) created the Fetal Alcohol Spectrum Disorders Task Force (FASDTF). In partnership with the Department of Human Services (DHS) and its Division of Developmental Disabilities (DDD) the Office for the Prevention of Developmental Disabilities (OPDD) was charged with administering the Council and FASDTF.

DDD has been New Jersey's lead resource agency since 1959 for individuals with developmental disabilities who are seeking programs and services. Its mission is to assure the opportunity for the individuals it serves to receive quality services and supports, participate meaningfully in their communities and exercise their right to make choices.

Established by legislation in 1987, the mission of the OPDD is to reduce the occurrence of severe chronic mental or physical disabilities that originate during pregnancy or childhood. Its work on issues related to FASD has primarily been accomplished via the funding of community FASD prevention projects and the activities of the FASDTF.



The Council and FASDTF was charged with making recommendations to the Governor and Legislature regarding programs and services that would meet the needs of individuals with FASD. It released its most recent report in 2012. The report is available at [www.state.nj.us/humanservices/opmrrdd/fasd/5%20yr%20plan-%20FINAL%2010-17-12%20\(2\).pdf](http://www.state.nj.us/humanservices/opmrrdd/fasd/5%20yr%20plan-%20FINAL%2010-17-12%20(2).pdf)

During June and July 2017, a Needs Assessment Survey was implemented across all 9 Child Evaluation Centers. All Child Evaluation Center Providers (Developmental Pediatricians, Social Workers, Psychologists, Occupational Therapists, Physical Therapists, Nurses, Coordinators etc.) were invited to participate. The purpose of the survey was to assess the learning needs of Child Evaluation Center Staff who work with patients with a Fetal Alcohol Syndrome diagnosis, other Fetal Alcohol Spectrum Disorder or either a confirmed or possible history of prenatal alcohol exposure and develop training materials to meet those needs. The results of the survey indicated a need for additional information/training regarding available treatment services for patients with FAS/FASD, transition to community supports, and state government agency partners.

Purpose of Guide

This first edition of **FASD: A Family Guide for Individuals with Fetal Alcohol Spectrum Disorders** is available to assist anyone in need of FASD related services to access New Jersey's state system of programs and services for individuals with FASD. "**FASD: A Family Guide**" 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 FASD; it is not intended to represent every FASD 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.

2. What are Fetal Alcohol Spectrum Disorders?

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in when a fetus is exposed to alcohol during pregnancy. Outcomes associated with fetal alcohol exposure can include physical, learning, behavioral and adaptive problems across the lifespan. These conditions can affect each person in different ways and can range from mild to severe. Some of the descriptive terms under the FASD “umbrella” include: Fetal Alcohol Syndrome (FAS); Partial Fetal Alcohol Syndrome (pFAS); Alcohol-related Neurodevelopmental Disorder (ARND); and Alcohol-related Birth Defects (ARBD).

A person with an FASD might have:

- Distinct facial features, including a smooth philtrum or small head size;
- Shorter-than-average height or low body weight;
- Poor coordination;
- Difficulty with attention and hyperactive behavior;
- Difficulty in school (especially with math) and poor memory;
- Learning disabilities;
- Speech and language delays;
- Intellectual disabilities or low IQ;
- Poor reasoning and judgment skills;
- Sleep and sucking problems as a baby;
- Problems with vision, hearing, heart, kidneys, or bones.



Another diagnostic option is listed in the Diagnostic and Statistical Manual 5 (DSM-5, 2013) as Neurodevelopmental Disorder associated with prenatal alcohol exposure or ND-PAE (315.8/ F88). This applies to “neurodevelopmental disorders that cause impairment in social, occupational, and other important areas of function”. Neurobehavioral disorder associated with Prenatal Alcohol Exposure is included as a condition for further study in the DSM-5. A child or youth with this condition will have problems in three areas: (1) Impaired neurocognitive function: thinking and memory, where the child may have trouble planning or may forget material he or she has already learned, (2) Impaired self-regulation: behavior problems, such as severe tantrums, mood issues (for example, irritability), and difficulty shifting attention from one task to another, and (3) Impaired adaptive functioning: trouble with day-to-day living, which can include problems with bathing, dressing for the weather, and playing with other children. In addition, to be diagnosed with ND-PAE, a fetus must have been exposed to more than minimal levels of alcohol before the child’s birth, which is defined as more than 13 alcoholic drinks per month of pregnancy or more than 2 alcoholic drinks in one sitting.

FASD affects people in different ways. Individuals with FASD 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 FASD is called a “spectrum” disorder.

3. Diagnosing FASDs in New Jersey

Child Evaluation Centers

Through a statewide network, New Jersey provides support for nine Child Evaluation Centers (CECs), which provide comprehensive, multidisciplinary evaluations of children with congenital or acquired neurodevelopmental and behavioral disorders. Following evaluation, the CEC's develop an individualized service plan (ISP) in collaboration with families. The cost of 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.

Child Evaluation Centers with FASD Diagnostic Expertise

Children's Specialized Hospital (Greenville)

Center for Children with Special Needs
FAS/FASD Diagnostic Center
1825 John F. Kennedy Blvd 1st Floor
Jersey City, NJ 07305
Phone: (201)-204-0044

Rutgers/New Jersey Medical School

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

Children's Specialized Hospital (Mountainside)

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

Jersey Shore University Medical Center

Child Evaluation Center
FAS/FASD Diagnostic Center
81 Davis Ave, Suite 4
Neptune, NJ 07753
Phone: (732) 776-4178 ext 2

Children's Specialized Hospital (Egg Harbor Township)

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

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

Child Evaluation Center
FAS/FASD Diagnostic Center
4009 Black Horse Pike Mays Landing, NJ 08330
Phone: (609) 677-7895 ext. 33466

Child Evaluation Centers

St. Joseph's Children's Hospital

Child Evaluation Center
DePaul Ambulatory Care Center
11 Getty Avenue
Paterson, New Jersey, 07503,
Phone: (973) 971-5227

Morristown Medical Center

Child Evaluation Center
435 South St., Suite 250
Morristown, NJ 07960
Phone: (973) 971-5227

John F. Kennedy Medical Center

Child Evaluation Center
2050 Oak Tree Road
Edison, New Jersey 08820
Phone: (732) 548-7751

Children's Regional Hospital at Cooper University Hospital

Child Evaluation Center
Three Cooper Plaza, Suite 200
Camden, New Jersey 08103-1489
Phone: (856) 342-2257



4. Professionals Who Are Working with Individuals with FASD

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 link your child with important resources through its Special Child Health Services program. The most common professionals working with individuals with FASD, as well as their areas 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
Obstetrician/Midwife	The obstetrician/midwife's role is to screen women for high risk conditions and behaviors, including alcohol intake. Any alcohol intake during pregnancy warrants brief intervention at every visit. Referral to treatment with follow-up to assure linkage are also made as appropriate.
Pediatrician	A primary care physician that provides a medical home for the child. In addition to preventive care, a pediatric medical home coordinates care among all of the specialists that are involved in a child's care, maintaining records and following up on all referrals.
Psychiatrist	A medical doctor who can diagnose FASD or ND-PAE as well as other illnesses and treat the mental health issues associated with FASD. A psychiatrist can prescribe medication or other treatments to treat issues such as depression and anxiety, aggression, ADD/ADHD, obsessive-compulsive behavior, tic disorders, and more.
Neurologist	A medical doctor who can diagnose FASD and other neurological disorders. A neurologist also checks the neurological functioning of the body and may order tests such as MRIs or EEGs. A neurologist can prescribe medication or other treatments to treat issues such as depression and anxiety, aggression, ADD/ADHD, obsessive-compulsive behavior, tic disorders, seizure disorders, and more.
Developmental Pediatrician	A medical doctor who is a pediatrician with special training and certification in developmental-behavioral pediatrics. A developmental pediatrician is skilled in diagnosis of FASD and developmental disorders. This doctor looks at the whole child and can recommend treatments, including medication.
Psychologist	A licensed psychologist with specialized training in developmental disorders, such as a clinical psychologist or neuropsychologist. A psychologist or neuropsychologist can diagnose or recommend treatment for FASD and other developmental disorders. He or she may address coping skills, behavior management, social skills, and strategies for improving functioning.
Behavior Analyst	A credentialed professional who has specific training and expertise in the analysis and treatment of behaviors.
Speech-Language Pathologist (SLP)	A therapist that 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. Speech therapists also support social speech skills. The therapist may recommend a referral to Dental or Ear Nose and Throat (ENT) specialists for evaluation of oral or hearing issues.
Occupational Therapist (OT)	A therapist who specializes in assessing and treating fine motor skills, play and social skills, handwriting, sensory integration, and daily living skills such as dressing and feeding.
Child Study Team	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. Parent advocacy skills are also important.
Special Educator	A 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.
General Educator	An educator who provides instruction and educational supports to a student within the general education environment.
Physical Therapist (PT)	A therapist who specializes in assessing and treating gross motor skills (jumping, ball skills, using stairs), strength, and coordination.

5. Following an FASD Diagnosis

a. How Do I Get Support?

Support can be found in local and state agencies, on-line support groups and helpful websites, to learn what is available and accessible. Support is important for parent/caregiver's mental and physical health. There will be challenges and obstacles to manage. Self-care is essential for physical, spiritual and mental health. Learning and growing with your child can also be fun and filled with pride.

b. Who Do I Talk To About FASD?

It is a personal decision as to whom and when to tell other people that your child has been diagnosed with an FASD. Education plays an integral function in making these decisions. Many resources and websites are available throughout this document. FASD is particularly complex. Everyone affected has a unique set of difficulties and disabilities, along with strengths and talents. Service providers will vary throughout the person's lifespan.

It is strongly recommended that you give a comprehensive history to everyone providing services to your child because obtaining effective services is based on accurate information.

c. Next Steps

Parents and caregivers can be a child's strongest advocate. Working in tandem with the school system is necessary. A child can be misdiagnosed with a different disorder such as ADHD and, as a result, not receive the interventions that she/he requires. If the school system is not meeting your child's needs, follow up with your school's child study team supervisor, school principal or, if necessary, school system superintendent. County numbers are located in the PRISE booklet listed in the resources. The diagnostic centers, previously listed, provide diagnosis through extensive testing by a panel of experts on FASD, up until age 21. They will help identify what needs to be addressed. Home environment greatly impacts the ability to self-regulate and increase level of function. Some suggestions can be found on the panel to the right.

d. Seeking Services - 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 impacts 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.

Partner Agencies

The Arc of NJ
732-246-2525 or
www.arcnj.org

National Organization on Fetal
Alcohol Syndrome (NOFAS)
The Circle of Hope: A Mentor-
ing Network for Birth Mothers
201-785-4585 or
www.nofas.org/circleofhope/

Mom2Mom
1-877-914-MOM2 or
www.mom2mom.us.com/

SPAN Advocacy Network
973-642-8100 or
www.spanadvocacy.org/

"Tips For Home Life"

- Establish a routine
- Have lists, pictures, videos to help child with activities of daily living
- Changes in routine should be noted ahead of time with child to help with adjustment
- Create calm, positive environment
- Decrease clutter and stimuli
- Find ways to improve organizational and sequencing skills, task completion, self-regulation, money management, time, etc.
- Understand that what works today may not work tomorrow
- Communicate with literal vs abstract language
- Break instructions down to simple steps
- Check level of child's understanding of what is being said or done
- Healthy eating throughout the day and proper hydration matter
- Use humor
- Understand level of function and controlled behavior often changes within an instant
- Play to strengths with regular positive reinforcement
- Provide creative support to help with executive functions, which are necessary for improving level function and negotiating life

- 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/; 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 contact their office to speak with a staff member directly in order to ensure that you meet the qualification requirements for the programs or services you are seeking. 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 Birth Defects 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 FASD.
- Consult a behavior therapist that 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 FASD who has volunteered to support/mentor other parents (see partner agency box on page 6).



6. Learning About Available Interventions

Although there are still unanswered questions, more is understood today about FASD 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 FASD 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 FASD and their families.

Evidence-based practice (EBP) is a term that many therapeutic interventions associated with FASD like to use to describe their programs. A definition that captures the critical components of what makes a program/practice 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." ⁽⁵⁾ 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 FASDs, you can refer to:



Government Resources

- www.cdc.gov/ncbddd/fasd/treatments.htm

Professional Advocacy Resources

- www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Evidence-Based.aspx
- www.nofas.org/treatments-support/

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.

Learning from Providers

What is this treatment and what does it do?

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?

Can FASD look like other developmental disabilities?

⁵ 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).



7. State Agencies Providing Services to Individuals with FASD and other Developmental Disabilities

Individuals with FASD, 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 FASD 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 FASD services, can be very helpful for families.

■ Department of Children and Families (DCF)

www.state.nj.us/dcf/ P. (855) 463-6323

Individuals with developmental disabilities under age 21 are served by the Division of Children's System of Care (CSOC) within the Department of Children and Families (DCF); with developmental disabilities under age 21 are served by 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) is on strengthening families and achieving safety, well-being and permanency for all of 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/ P. (609) 292-6392

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, including fire and building safety, housing support and community planning and development. 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 FASD 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/ P. (609) 376-3500

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 an FASD.

■ Department of Health (DOH)

www.state.nj.us/health/ P. (609) 292-7838

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 FASD 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 NJ Birth Defects 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/ P. (609) 292-3717

The Department of Human Services (DHS) serves about 1.7 million New Jersey citizens in need of assistance (about one in five New Jerseyans). 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 health care for their children.



• DHS Division of Developmental Disabilities (DDD)

www.state.nj.us/humanservices/ddd/home/index.html
P. (800) 832-9173

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 funded by DDD. 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 P. (888) 285-3036

The Division of Disability Services (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)**

www.nj.gov/labor/ P. (609) 984-4248

The Department of Labor and Workforce Development (DLWD) is committed to helping persons with barriers to employment participate in the workforce. 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.



8. Life Stages and FASD

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 all children.
- 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. 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.



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 diagnosed your child between the ages three and five as an individual with an FASD, 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. 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 are 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 and other disabilities 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/ 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.

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.

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/.

Parental Rights in Special Education (PRISE) – This is an important guide for parents working with their local school system and can be found at 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.

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

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.



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 an FASD 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*
- 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
 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 an FASD, Serious Emotional Disturbance (SED), 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 (FSOs) - 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.



Prior to receiving services, PerformCare must provide authorization.

Additional information may be found at: www.performcarenj.org/families/

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.

**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.*

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/

C. Transition Planning from School to Adult Life

Planning a child's successful transition from school to adult life requires a 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 students IEP each year until graduation or exit from high school.

Starting in the years prior to your family member 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 are 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/

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 by 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.

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

- What are the student's dreams and visions 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/.

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.

Supported Decision Making/Guardianship

At age 18, all individuals, including those with 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. Supported decision-making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making.

Supported decision-making is an alternative to guardianship. Guardians make decisions for the person with a disability. However, supported decision-making allows the person with the disability to make his or her own decisions instead of having someone else make them for him or her. For more information on Supported Decision Making, please visit <http://supporteddecisions.org/>. For information about the guardianship process please go to www.state.nj.us/humanservices/ddd/services/guardianship/.

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/.

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. New Jersey’s pre-employment transition services start at the beginning of the school year in which the student turns 14 and ends at graduation or when he/she ages 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 utilize the following links 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

9. 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. 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

New Jersey supports policies, programs, and services that promote employment.

- Supports to pursue competitive employment, such as Supported Employment, Career Planning, and Prevocational Training, in the general workforce are available for working age adults with intellectual and developmental disabilities who are receiving services and supports from the New Jersey Division of Developmental Disabilities.
- 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

Adults with developmental disabilities age 21 and older, including those with FASDs, may be eligible for services from by the New Jersey Division of Developmental Disabilities. Most DDD-eligible individuals live in the community, in their own homes or apartments; with family; or a licensed community residence such as a group home or supervised apartment. 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.

- 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 such as 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 the DDD 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 are 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 with 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.

Individual/Family Support Services

DDD funds a wide array of services intended to help support individuals with developmental disabilities who reside in the community. DDD provides 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
- 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. Placement Services – Development of job leads both with and for the consumer and support during the job search; could include On the Job Training (OJT), Supported Employment (SE) or Time Limited - Placement and Coaching (TLPC).

3. Job Seeking Skills/Job Clubs – Guidance in work search activities such as resume writing, interviewing skills, job search organization.

4. Supported Employment – Through referral to an SE provider, one-on-one assistance in job searching, interviewing, applying for jobs; followed by coaching on the job to facilitate learning job duties and adjusting to the work environment; followed by periodic follow-up to ensure job retention.

5. Time Limited Placement and Coaching – The first two categories of Supported Employment Services without periodic follow-along.

6. Job Accommodations – Guidance on changing the worksite's physical environment or adding equipment that will allow an individual to do more work tasks independently, effectively and safely.

7. Skills Training – Attendance at a vocational school, technology or trade School, business school, etc.

8. College Training – Attendance at 2 or 4 year higher education programs leading to a degree.

9. Physical Restoration – Equipment or therapies which improve physical or cognitive functioning so that a person is able to work. These services may include physical, occupational, or speech therapy; cognitive therapy which includes those modalities; prosthetics or orthotics such as artificial limbs, braces, special shoes, hearing aids and eyeglasses (in some instances).

10. Emotional Restoration Services – Short-term individual, group or other types of counseling to reduce symptoms of mental health problems and improve work-tolerance and the ability to get and keep a job.

11. Mobility Equipment

12. Driver Training – Assessment of driving ability and equipment needed to drive safely; assistance in purchasing driver training lessons if needed to reach a specific work goal.

13. Vehicle Modification

14. Home Modifications – services if needed to reach a specific work goal.

For more information on DVRS services for adults please go to:

<http://jobs4jersey.com/jobs4jersey/jobseekers/disable/index.html>

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/>



10. Funding for Services and Supports

The Medicaid Community Care Program

The Medicaid Community Care Program (CCP) provides specialized services to support eligible individuals with developmental disabilities in the least restrictive setting. This person-driven, long-term support system offers choice and access to services which aid in diverting and/or transitioning individuals from institutional settings to community living arrangements. The CCP is funded by the state, and federal government's Medicaid program. DDD administers the CCP.

The CCP is intended for individuals that need 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 eligible for DDD services. This includes:

- Being a resident of NJ, be a U.S. citizen or qualified alien;
- Being 21 Years of age or older;
- Being DDD and Medicaid eligible.

CCP eligibility includes that an individual:

- Need and utilize at least one CCP service each month;
- Meet clinical level of care; and
- Meet DDD's "emergency" criteria, or be at the top of the CCW waiting list.



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 Individualized Service Plan. The needs of individuals on the CCP are reviewed at least annually.

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

The Medicaid Supports Program

The Supports Program provides services for DDD eligible individuals who are 21 and over, live in their own home, or family home (unlicensed DDD settings), and are not on the CCP.

Additional information about the Supports Program may be found at:
www.nj.gov/humanservices/ddd/programs/supports_program.html

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 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/.

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 arrive after August 22, 1996 are barred from Medicaid for five years, but could be eligible for NJ FamilyCare and certain programs for pregnant women.)
- Meet specific standards for financial income and resources.
Please visit 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 an FASD; others do not. Families should call their insurance company to ask about covered services.

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. A child, younger than age 18, can qualify if he or she meets Social Security's definition of a disability for children and if his or her income and resources fall within the eligibility requirements.

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 occasionally 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.



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 yet 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



11. 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. Individuals not eligible for the CCP will be eligible for the Supports Program.



Launched in July 2015, the Supports Program offers a variety of services and supports based on an assessed level of need, that include, but are not limited to, assisting an individual in preparing for, finding and maintaining employment; developing skills used in daily living; and integrating and participating in the community; as well as behavioral supports; physical, occupational, and speech therapies; and respite. Unless enrolled in another Waiver program, all individuals who are eligible for both Division services and Medicaid are able to access the Supports Program. In addition to a variety of services, DDD partnered with New Jersey Department of Community Affairs to create the Supportive Housing Connection (SHC). SHC vouchers provide eligible individuals, seeking to live independently, with the financial assistance needed to support the cost of renting in NJ. Vouchers administered through the SHC are based on annual funding appropriations to DDD and criteria set forth by the Division.

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.



Like other State departments, the HMFA does not provide services specifically designed to meet the needs of adolescents and adults with a specific disability. However, HMFA offers a wide range of programs and services that respond to the general issues of housing production, community planning and development, accessibility, home ownership and housing finance. HMFA administers capital financing programs for housing for people with special needs. Funding for rent and operating subsidies and supportive services are 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 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 over coming 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, 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.

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.

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/Boards of Social Services can help you determine if you are eligible. To find a specific County Board of Social Services please check this link 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/.

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.

12. Registries

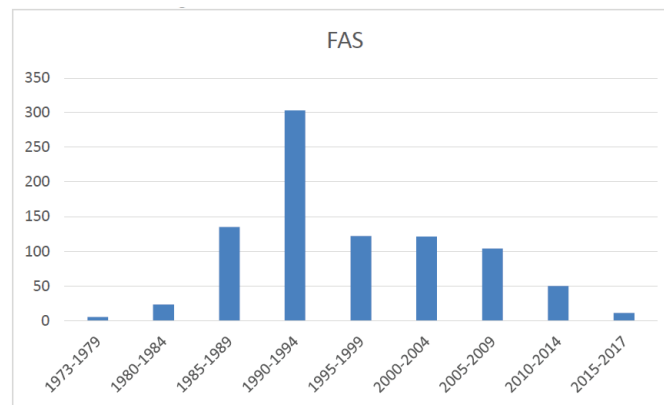
Emergency Preparedness Registry

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.

New Jersey FASD Registry

In 1985, the Birth Defects Registry began collecting FAS/FASD as a mandated condition for children 0 through 1 year of age. In 2009, the rules were changed to mandate the reporting of FAS for children 0 through 5 years of age. Children with FAS who were identified after the mandated age, could also be voluntarily registered until they reached their 22 birthday.

The figure below shows the number of children registered by birth year. To date, the total number of FAS/FASD children reported to the NJ Birth Defects Registry is 847. The average number of children for this period is 25.67 per year. Of the total, 376 children are eligible for case management because they are between the ages of birth through 21 years.



There are various factors affecting the number of children who are registered. First, the earlier mandate, to only register children 0 through 1, restricted who was required to be registered to only those children who met the narrow definition of FAS meaning that they met the definitive diagnosis of FAS made by a geneticist, developmental, and/or other specialized physician at or around the time of birth. As the age group expanded, children who have fetal alcohol exposure as well as definitive FAS are required to be registered. Even the expanded age continues to result in underreporting of FAS as many children are not diagnosed until much later after the developmental effects of FAS are present and evaluated.

The figure does show that the highest number of FAS cases reported was for children born in the 1990s. This may be due to or because of educational activity/public awareness/medical education. Additionally, the addition of the diagnosis of autism and comorbidities associated with autism in 2009, may be resulting in older children being now registered with FAS/FASD.

It is important to note that lower numbers reported for birth cohorts from 2010 through 2017 are more likely the results of the children's age and not having been evaluated yet, rather than a decrease in the incidence of FAS. These early cases more likely reflect those children who meet the more narrow definitive diagnosis which resulted in more pronounced facial dysmorphia rather than subtler symptoms of developmental delays.

13. New Jersey Resources

(Government, Non-Profit, Advocacy, Professional Associations)

Abledata

www.abledata.com/

Alliance for the Betterment of Citizens with Disabilities (ABCD)

<http://abcdnj.org>

The Arc of New Jersey

www.arcnj.org

Arts Unbound

www.artsunbound.org

Advocates for Children of New Jersey

www.acnj.org

Centers for Disease Control and Prevention (CDC)

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

Central Jersey Family Health Consortium (CJFHC)

<http://www.cjfhc.org/index.php/en/>

Council for Exceptional Children

www.cec.sped.org/

Dental Care for Persons with Developmental Disabilities in New Jersey

www.disabilityhealth.org/dental/index.html

Department of Children and Families

www.state.nj.us/dcf/

DCF Office of Education

www.state.nj.us/dcf/divisions/education/

Department of Community Affairs

www.state.nj.us/dca/

Department of Education

www.state.nj.us/education/

Department of Health

www.state.nj.us/health/

New Jersey Resources - continued (Government, Non-Profit, Advocacy, Professional Associations)

Department of Human Services

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

Division of Children's System of Care

www.nj.gov/DCF/families/csc/

Division of Developmental Disabilities

www.state.nj.us/humanservices/ddd/home/index.html

Division of Disability Services

www.state.nj.us/humanservices/dds/home/

DOE Office of Special Education Programs

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

Family Crisis Handbook

www.sccatnj.org/misc/Family_Crisis_handbook.pdf

Family Resource Network

www.familyresourcenetwork.org

Family Support Center of New Jersey

www.fscnj.org/

Family Support Coalition of New Jersey

www.familysupportcoalition.org

Family Voices of New Jersey

www.spannj.org/familywrap/familyvoices.htm

Find a Ride: NJ public and private transportation

www.njfindaride.org

New Jersey Resources - continued
(Government, Non-Profit, Advocacy, Professional Associations)

Housing & Community Development Network of NJ

www.hcdnnj.org

Housing Resource Center (HRC)

www.nj.gov/njhrc

Learning Resource Centers

www.state.nj.us/education/lrc/

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

www.njarch.org/images/M2M%20brochure.pdf

National Institutes of Health (NIH)

www.nih.gov/

NJ APSE - The Network on Employment

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

New Jersey Association of Community Providers

www.njacp.org

NJ Coalition for Inclusive Education

<http://njcie.net>

NJ Council on Developmental Disabilities

www.njcdd.org

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

www.state.nj.us/dca/divisions/dhcr/

NJ Division of Medical Assistance and Health Services

www.state.nj.us/humanservices/dmahs/home

NJ Division of Mental Health and Addiction Services

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

NJ Early Intervention System

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

NJ Foundation of Dentistry for Persons with Disabilities

<http://nfdh.org>

New Jersey Resources - continued (Government, Non-Profit, Advocacy, Professional Associations)

NJHelps.org

<http://njhelps.org>

NJ Housing and Mortgage Finance Agency (HMFA)

www.nj.gov/dca/hmfa/

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

www.nj.gov/njparentlink/

NJ Positive Behavior Support in Schools

www.njpbs.org

NJ Rehabilitation Association

www.newjerseyrehabassociation.org/mission.htm

NJ Self Advocacy Project

www.njselfadvocacyproject.org

NJ Self Help Clearinghouse

www.njgroups.org

NJ State Home Page

www.state.NJ.us/index.htm

NJ State Legislature

www.njleg.state.nj.us

NJ Statewide Independent Living Council

www.njsilc.org

NJ Statewide Network for Cultural Competence

www.nj.gov/njsncc/

NJ Transit Accessible Services

www.njtransit.com/tm/tm_servlet.srv?hdnPageAction=AccessibleServicesTo

NJ Work Incentive Network Support (NjWINS)

www.njwins.org

Northeast ADA & IT Center

<http://northeastada.org>

Parental Rights in Special Education (PRISE)

www.state.nj.us/education/specialed/form/prise/prise.pdf

New Jersey Resources - continued **(Government, Non-Profit, Advocacy, Professional Associations)**

Partnership for Maternal & Child Health of Northern New Jersey

<http://partnershipmch.org/>

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

www.rewardingwork.org/NewJersey

Special Olympics of New Jersey

www.sonj.org

Statewide Clinical Consultation & Training (SCCAT)

www.sccatnj.org

Statewide Parent Advocacy Network (SPAN)

www.spannj.org

Supportive Housing Association of NJ

www.shanj.org

Supplemental Nutrition Assistance Program (SNAP)

www.nj.gov/humanservices/dfd/programs/njsnap/cwa/index.html

United States Society for Augmentative and Alternative Communication (USAAC)

www.ussaac.org/

14. Key Acronyms

ABA	Applied Behavior Analysis
ABCD	Alliance for the Betterment of Citizens with Disabilities
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
FASD	Fetal Alcohol Spectrum Disorder
ASD	Autism Spectrum Disorder
CBI	Community Based Instruction
CBVI	Commission for the Blind and Visually Impaired
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
FASD	Fetal Alcohol Spectrum Disorder
HMFA	Housing and Mortgage Finance Agency
FASD	Fetal Alcohol Spectrum Disorder
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
ND-PAE	Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure
NIH	National Institutes of Health
NJEIS	New Jersey Early Intervention System
NJWINS	New Jersey Work Incentive Network Support
NON-DAC	Non Disabled Adult Child
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
PFAS	Partial Fetal Alcohol Syndrome
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 for the Prevention of
Developmental Disabilities*

FASD

**A Family Guide for Individuals with
Fetal Alcohol Spectrum Disorders**

First Edition

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

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