



Connecting the Dots...

A Guide to Finding Services for
Children and Adults with Disabilities and
Special Health Care Needs in Delaware

Second Edition



Center for Disabilities Studies
Delaware Family Voices Inc.
Family to Family Health Information Center

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Additional copies of *Connecting the Dots* are available by contacting:

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The electronic version of *Connecting the Dots* can be found at www.udel.edu/cds and www.delawarefamilytofamily.org.

Care Notebook pages and information can be found at www.delawarefamilytofamily.org or by contacting Delaware Family Voices/ Family to Family Health Information Center.

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What's Inside

The purpose of this guide is to help individuals with a newly-diagnosed disability or special health care need and their family members find available supports and services. It was developed with the support of parents of children with disabilities and special health care needs and adults with disabilities and special health care needs. The guide is intended to give you hope, a belief in yourself, your child and the future, and the feeling that anything is possible. You are not your diagnosis; your child is not a diagnosis. Your dreams and goals may change, but finding available supports and services can lead to positive outcomes. The first step in accepting a diagnosis is realizing that you are not alone in your experience.

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First Steps

Where to turn? What to do?

This guide will help you identify the first steps in finding the supports and services you and your family members may need. Some sections of this guide may be more relevant to you now, while other sections will help you later, depending on your needs.

Remember: You are not alone.

People are willing and able to help you. They may help by informing you about services you are qualified for or by providing emotional support and advice because they have gone through this process before.

Learning about the disability or special health care need that you or a family member has, and hearing about it again and again, can be overwhelming. You may not know where to begin, and yet so much needs to happen.

Pace yourself.

You don't have to learn everything at once.

Determine the most important priorities and focus on finding these supports and services.

How can *Connecting the Dots* help me?

Connecting the Dots can help you navigate the maze of services and supports available to you. The use of this guide is a first step in orienting you to the many state agencies and organizations that provide services to individuals with disabilities and special health care needs. Being prepared and equipped with the right questions to ask—so you can receive the information you need—can be your first step toward positive results. This guide will provide you with advice and resources, along with examples of questions to ask, as you prepare to make those first calls.

The resource section of the guide is divided into categories of services and supports you may need, including advocacy, assistive technology/home modification, caregiving/respite, early intervention, education, emergency preparedness, employment, federally qualified health centers, financial and insurance resources, home visitation organizations, hospitals, information and referral, legal services, medical and dental preparation and treatment services, mental health resources, military family resources, outpatient therapies, postsecondary education, protective services, residential skilled nursing, skilled child care and schooling, skilled pediatric nursing care, transition and transportation. The guide also includes a glossary of terms and a list of acronyms that will help familiarize you with commonly-used terminology.

Note: To make it easier to read Connecting the Dots, the word "you" is used to refer both to the person using the guide—whether you are a parent, caregiver or a person with a disability or special health care need—and the person on whose behalf it is being used. You will sometimes find a reference to "your family member" or "your loved one," but more often, the word "you" will be used to refer to that person.

Getting Started

Redefining Normal

Life may feel like it has been turned upside down for you and your family. After new routines are established and services and supports have been found that meet your needs, you will find that some normalcy will return to your household.

Remember, if you have a child with a disability, you are raising a child—not a disability. And if you are the family member with a disability, your life is more than your disability.

Are You a Caregiver?

You are a caregiver if you provide physical or emotional care for a loved one. When you are providing care for another person the emotional and physical strain is significant. However, you must maintain both your physical and mental well-being if you are going to be of any use to your loved one. You cannot and should not do it all by yourself. Recognize your own strengths and limitations and ask for help when you need it. You may find support by contacting Delaware Family Voices/ Family to Family Health Information Center (DE FV/F2F) (see page 16) or looking to one or more of the following resources:

- Support groups, online or in-person
- Other parents/caregivers
- Advocacy groups
- Family counseling
- Respite care (see page 26)

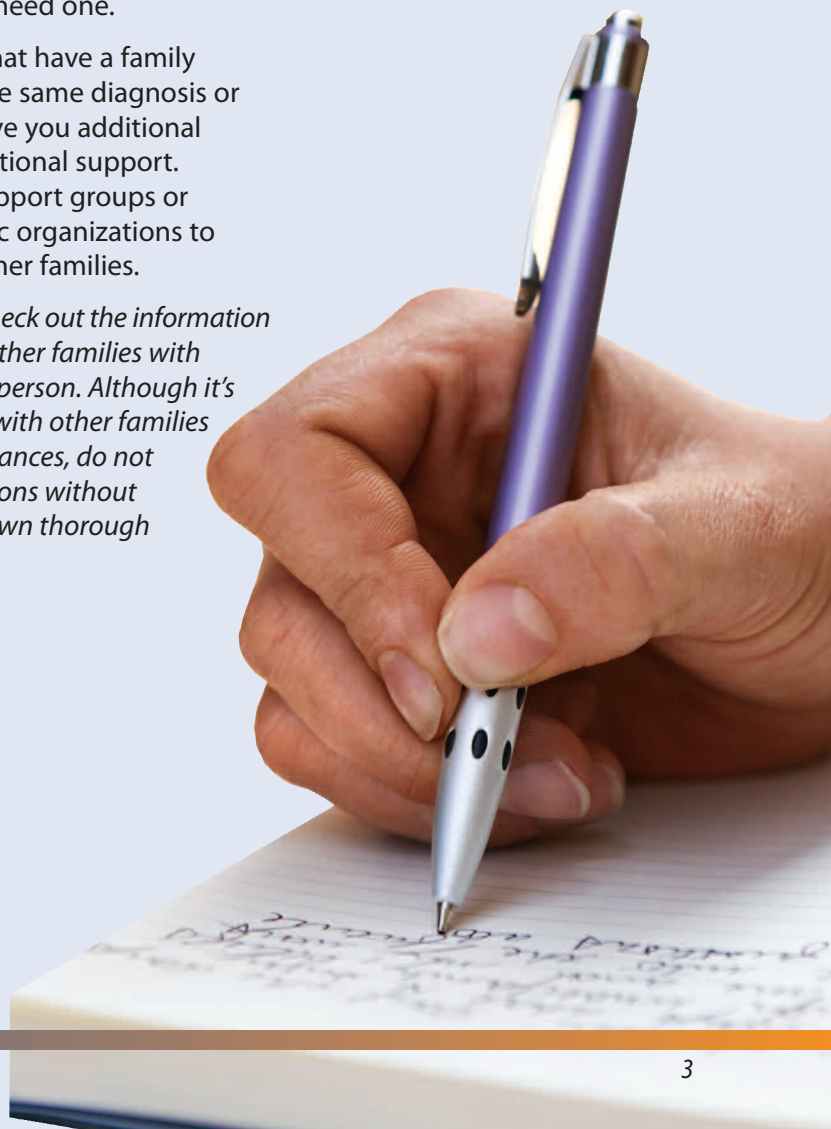
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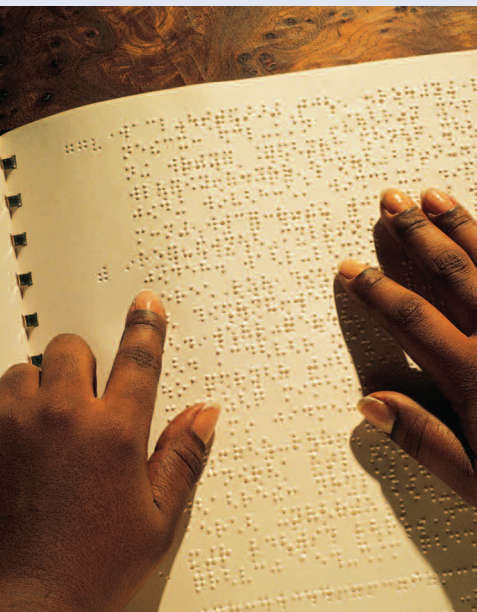
Get prepared. It's important to gain a thorough understanding of your disability or special health care need and learn how to work within the system of services. Knowing about the disability can help you gain some level of control over a situation that often can feel overwhelming and confusing.

- Knowledge is power, but be careful not to become weighed down by the avalanche of available information.
- Take plenty of time going through the information you find until you understand it.
- Do not be afraid or embarrassed to ask for help. Asking for help is a sign of strength and will help to ensure that you locate the appropriate services.
- Find out as much as you can about the disability or special health care need. Search the Internet and contact national and local organizations and support groups. Make certain to use reputable sources when you search the Internet.
- Ask your primary care physician for information and a referral to a specialist if you need one.
- Other families that have a family member with the same diagnosis or disability can give you additional insight and emotional support. Contact local support groups or disability-specific organizations to connect with other families.

Caution: Always check out the information you receive from other families with another source or person. Although it's important to talk with other families in similar circumstances, do not make major decisions without conducting your own thorough investigation.

Find the courage to express yourself in an honest and thoughtful manner with health care professionals and service providers. Speak as calmly and clearly as possible. Take a family member or friend to meetings for support and to take notes. You can review these notes together to make sure you have a correct understanding of what the health care professional or service provider said.





Insurance

Where to begin: Find out what public or private insurance coverage you have or are eligible for, including employer-related coverage, Medicaid and Medicare, and the type of benefits your insurance covers. Ask if it pays for speech therapy, physical therapy, occupational therapy, home care, durable medical equipment and assistive technology, nursing visits, mental health services, dental services and the supports your physicians, therapists and specialists have said you will need. Also ask if the services require prior authorization and how the process works to obtain approval.

What you should know: You may qualify for additional benefits that won't affect insurance or assets that you have. Ask your private insurer to assign a case manager to you to help you obtain any additional services that are required. You or your child may qualify for Medicaid even if you currently have insurance. There are other options and programs available that will supplement your primary insurance.

- There are two types of **Medicaid** that you may qualify for: One is based on

income and the other is based on disability. Medicaid provides medical assistance to eligible people who are elderly, blind or have disabilities and whose income is not large enough to pay the costs of adequate medical services. Medicaid pays for doctor visits, hospital care, labs, x-rays, prescription drugs, durable medical equipment and assistive technology, therapies, transportation, routine shots for children, dental care for children and mental health and substance abuse services.

- **Medicare** is health insurance for people who have been defined by the Social Security Administration as having a disability and qualifying for Social Security retirement or disability benefits.
- The **Delaware Healthy Children Program** is Delaware's Children's Health Insurance Program (CHIP). It is a low-cost health insurance program for uninsured children that features the same high-quality coverage provided by Medicaid and some of the best private insurance plans. This program is for children under the age of 19 who do not qualify for Medicaid.

Get Started with a Care Notebook

You have work to do to get prepared. Be organized, be persistent and be positive. It is best to write down information and save it. Information you have now may not seem important, but it might be relevant later. You will be glad to know that it is within reach in a file when you need it.

Consider using a care notebook to keep your information and documents organized. This record-keeping system will allow you to have all pertinent information about your needs in one place. Use your care notebook to record your communications with service providers and the information you find as you learn about services and supports. This notebook should go with you to all appointments, tests, therapies and other interactions with professionals.

The care notebook will help in the coordination of care, as each professional will see all interactions with other professionals involved in your care. The care notebook will reduce the burden of remembering everything and give you the confidence to talk with others about your specific needs.

Delaware Family Voices/Family to Family Health Information Center (DE FV/F2F) can provide you with a free care notebook and assistance on the many ways to use it (*see page 16*).

- Some children with significant disabilities who require the level of skilled medical care that would make them eligible for an institutional setting (hospitalization, intermediate or skilled care) will qualify for Medicaid's **Children's Community Alternative Disability Program (CCADP)**, which lets them stay at home with their families. Parents may apply for this program for their child, regardless of income, by contacting the nearest Division of Medicaid and Medical Assistance Long Term Care Service Delivery unit.

Be informed about insurance changes: Visit www.healthcare.gov and/or connect with Delaware Family Voices/Family to Family Health Information Center (see page 16) as well as your personal insurance carrier. See *Financial & Insurance Resources* on page 22 for additional information.

A Medical Home/ The Doctor's Office

A family-centered medical home is not a building, house, hospital or home health care service; it is an *approach* to providing comprehensive primary care. In a family-centered medical home the pediatric care team works in partnership with a child and the child's family to assure that all of the medical and non-medical needs are met.

The first stop on your journey is often your primary care physician or your child's pediatrician. Your doctor is an integral partner in your care. This relationship is too important for you to settle for a doctor if it appears that she will impede your ability to seek out answers and take an active role in your child's care. Trust your instincts and look for a new doctor if you feel your doctor cannot provide everything you need.

- Find a primary care doctor or pediatrician who you feel supports you and your journey, is easy to reach by phone, will work with your specialists, provides you with clear instructions and written materials when asked, and

whose staff understands that you will probably visit the office frequently and need numerous referrals and copies of medical records.

- When you have an appointment, come prepared with a list of written questions, bring your care notebook, and offer copies of medical records to the doctor or nurse to confirm they have current information on your chart.
- Prioritize your concerns in case the doctor does not have time to address all of them. Ask when she can discuss your concerns.
- Do not put on a brave face. Your doctor can connect you to the necessary supports for you, if you are the caregiver, or for the patient.
- Ask for copies of test results and written instructions regarding medications and treatments and add them to your care notebook.

Doctors and their staff are responsible for completing paperwork for medical equipment and services. They will inform insurance companies and agencies about any equipment, medical supplies, therapies, nursing visits or other home care you need. Written prescriptions also are provided by the doctor's office. It is very important to communicate effectively with your doctor so she can get a clear picture of what you need.

REMEMBER—You are the person responsible for communicating and explaining what you need to your doctors. Follow your instincts. No one knows you or your family member better than you. Become knowledgeable by educating yourself, then share your information with your doctor and with other families. Although you may have no formal training, you are a member of the health care team. If you are objective about the needs and abilities of your family member and demonstrate knowledge of the disability, you will be viewed as a valued member of the team. As a result, when you make a request, doctors and other professionals are more likely to listen to you.



Attitude . . .

Some Words of Advice

Prepare before you call.

Don't make calls when you are rushed. Have pen and paper or your care notebook ready and set aside a reasonable amount of time. Don't give up. You have the right to receive information and respectful service.

Be persistent and patient. Realize that it will sometimes take many calls to find an answer, and no one person or organization has all the answers.

. . .

Be persistent, not combative.

Try to remember that you will "catch more flies with honey than with vinegar." If your level of frustration is high, try making the call another day when you are refreshed and reenergized.

Getting Your Point Across: Helping Agencies Understand What You Really Need

Learn the terminology used by agencies. Words may have different meanings for different agencies. You may find that you have to describe your specific needs, particularly when you don't understand the terms an agency is using. For example, if you need assistance with personal care in your home, the person providing such care may be called a home health aide, personal attendant or home care provider, depending on the agency providing the service. Do not be afraid or embarrassed to ask the meaning of terms that are unfamiliar to you. Asking for explanations or definitions demonstrates a desire for knowledge and encourages those you are speaking with to help you.

When making calls, avoid phrasing questions that will elicit only a "yes" or "no" answer; this type of question limits the amount of information you will receive. Provide specific information about your family member's disability or special health care needs to learn if she qualifies for more than one service or can receive services from a number of agencies and organizations. Doing so will increase your chances of getting all the services that your family member needs. Refer to the Glossary on page 32 and the Acronyms on page 36 for help in understanding terms that you will hear.

When calling for information, tell your story in as few words as possible. Before you call, think about the services you may need. Make a list of questions. Ask if there are waiting lists for specific services and how long it might be until you receive services. Ask for an assessment to be done in person so you can learn if you qualify for services. Ask if there is a cost for the services. Your income level may be irrelevant; do not assume you will be denied services if you cannot afford to pay for them.

Document all phone calls and the information and promises you receive. Always ask for the name of the person who is speaking to you. Don't take "no" for an answer.

A good attitude influences action. A positive attitude will help you be more successful in having your needs met. Try not to put people on the spot; it makes them defensive. Try to enlist their support. Framing your questions without an argumentative or judgmental tone will help engage the support of others. For example, if you are talking to your insurance company after you were denied coverage for a medication, don't express your anger; instead, ask what information is needed from you or your doctor to obtain approval for payment for the medication. Ask for an explanation about why a service is not covered and how you can qualify for that service.

That First Call – And All the Ones That Will Follow

This guide includes contacts for many resources in Delaware—agencies, organizations, facilities and programs—you may want to contact as you begin your search for information and services. Here are some suggestions about how to make the most of your phone calls.

HINT—Do not be misled by the names of agencies; they do not always convey all of the services they provide. An agency's name might lead you to believe it caters to a certain disability or age group, but that is not always the case. Ask if the agency provides services for your disability. The agency might surprise you with a "yes" answer or be able to provide you with other resource options. If told "no," then ask for suggestions about places to call to get the services you need.

1) Prepare yourself to make the call

- Do not make assumptions before you gather the facts. While you need to become knowledgeable about the disability or special health care needs, realize that much information on the Internet may have a slanted view because of the source. Try to use only reputable sources of information and confirm the accuracy of the information from at least one source other than the Internet.
- Make calls when you have time to talk, when you have a pen and paper or

your care notebook available, and when you are not rushed to meet some other demand.

- Write down your questions in a clear and to-the-point manner before you call a physician, therapist or other service provider.
- Always write down the name of the person with whom you are speaking.
- When calling an agency, tell your story as clearly and in as few words as possible. Maintain a calm manner whenever possible. Focus on the details that will provide the information the agency staff needs in order to help you. When strong emotions accompany your questions, physicians and other professionals sometimes hear only the emotion and not the content of your questions.
- Document all phone calls, information and promises of services discussed. Take notes. It is important to date the notes as well as the subject you discuss. Use your care notebook to keep documents and information in one place.
- Ask the person you are talking with to tell you about the services and supports provided by the program or agency; avoid asking questions that will be answered with just “yes” or “no.”
- Ask about eligibility for services and if you might qualify through more than one category or program.
- If an agency representative says he will call back, ask when; if he does not return your call, call again.
- Realize that it will sometimes take many calls to learn what you need and what services you can receive.
- Ask for brochures or written policies about the agency’s services.
- Ask if there is a website address for the agency or its services.
- You may need to contact an agency again at a later date because policies and services may change over time.

- Most of all—do not give up! If told “no,” then ask for the names of other places to call to get what you need. Be persistent but not combative. You have the right to information and respectful service.

2) Organize your needs and concerns and ask questions that clearly reflect these needs and concerns, such as...

- How do I qualify for services? If you are told you do not qualify, ask for suggestions of other agencies to call; you may learn of another agency that is able to provide you with services.
- Does your agency provide case management? Ask for an explanation of the case management services that are available for each agency you contact, including your insurance company. These services will vary among service providers.
- Is there a cost for services? You will find that fees for some services are based on income, other services may be provided at no cost, and certain services always have a cost. Asking about fees will help you plan.
- Who will pay for...?
- Are there waiting lists for specific services?
- How do I get transportation?
- How do I get the therapies that are needed?
- How can I get help in my home?
- Who can care for my loved one while I am working?
- How can I make my home more accessible?
- Do you provide respite services or funding for respite services?

3) Be prepared to answer questions

- Although it can be overwhelming, try to determine what you want from an agency before you call. Know as much as possible about the disability and special health care

needs so you can give better answers to questions from agency staff.

- Assess your family member’s ability to function independently, both physically and mentally. Determine if the physical surroundings are accessible. Do you need help to make your home accessible?
- State what you want and what would be helpful to you as you learn about the disability and services. Being clear and honest goes a long way toward establishing a mutually respectful relationship with health care and service professionals.
- Know what financial resources and insurance options are available to you.
- Be prepared to provide the information the agency needs to assist you or your family member in receiving appropriate services:
 - How much care is needed? If you do not know how to answer this question, request an in-home evaluation or assessment. Be honest about your needs and abilities.
 - Do you require a nurse?
 - Do you use a ventilator, wheelchair, etc.?
 - Is assistance needed with dressing or bathing?
- You should be aware that even if you qualify for long-term nursing care, it does not mean you have to go to a nursing home. If a person meets the criteria for a nursing home, then he also meets the criteria for certain at-home help.
- Keep records in your care notebook of doctors’ names and numbers, names and doses of medications, diagnoses, hospitalizations and names of agencies with which your family member has been registered.

Transition

You may find that the resources you need from this guide will change over time, as you transition between service systems. Transitions have different meanings for different ages and settings. Transitions take place as a person moves from the early intervention program to preschool, from preschool to kindergarten through high school, and from high school to adult services. Transferring from pediatric medical care to adult medical care is another type of transition. You may also transition from a nursing home to the community and from a hospital setting to your home.

Planning and coordination are vital to achieving successful transition. Services and supports are available to help you move through different stages.

Many agencies provide a variety of services, each of which may be needed at different stages of life; therefore, you may need to contact them more than once over the years. Make sure you plan ahead for transitions before they actually occur; giving yourself time to plan will make the transition process go much more smoothly. In the Resources section of this guide, you will find listings in several categories for agencies that provide services across the lifespan.

Hint: You may have a gap in services as you transition between service systems. It is important to understand that, although your family member's diagnosis may not change, the providers of services will change through the course of her life. Be aware of changes to services based on age or a change in your situation. For example, early intervention services are provided through age three; services after this age are available through your local school district. Your insurance coverage may change with your status of employment and your child's insurance coverage may change when she becomes an adult. Understanding when these transitions will occur will ensure smoother transitions and fewer gaps in care.

The Verlinghieri Family

Welcoming a new baby comes with both expectations and anxieties. For families of children who are born with severe disabilities, these feelings are further complicated by the challenges of navigating a complex medical and social service system. For one Delaware family, the opportunity to develop a support system that includes other families with children with disabilities, therapists, teachers, family and friends has been invaluable.

Lori and Ray Verlinghieri welcomed their first child, a full-term baby boy they named Jacob, in October 2003 at Lankenau Hospital in Pennsylvania. Jacob was born with a cleft lip and low muscle tone and had difficulty feeding. Extensive genetic testing found no diagnosis for Jacob's disabilities and provided few answers for Lori and Ray despite Jacob's complex needs. Jacob began receiving physical therapy, occupational therapy, speech therapy and other services. Lori and Ray learned everything they could about his needs, and Lori sought out parents and families through online support groups and by connecting with other families with children with a variety of disabilities. Attending forums, conferences and workshops is another way Lori learned about services and supports for Jacob and made connections with other families.

The Verlinghieri family learned that finding supportive doctors, therapists and teachers is also important. Lori stresses the importance of finding the right pediatrician, especially for the newly diagnosed. She says, "Find a pediatrician who you feel supports you and your journey, is easy to reach by phone, will work with your specialists, and whose staff understands that you'll probably be in and out and need lots of referrals and medical records."

The family moved to Delaware so Jacob could attend Leach



School, which uses the MOVE program, a specialized education and mobility program for children with severe disabilities. Jacob has flourished in this program and is improving his communication and motor skills. At home, Jacob's twin sisters, Jenna and Zoe, adore him and make him laugh.

Since Jacob's birth, Lori and Ray have become advocates for children with severe disabilities. Ray joined the Governor's Advisory Council for Exceptional Citizens. To connect with other families who have children with disabilities, Lori volunteers with the Delaware Family Voices/Family to Family Health Information Center and is active with the Parent Information Center, two Delaware parent advocacy organizations. Lori sees her involvement with these organizations as an opportunity to take the knowledge she has learned and share it with other families.

Lori advises new parents of children with complex medical needs to surround their child with people who understand their situation and the needs of their child. "Most importantly," she says, "find people who celebrate and appreciate your child as much as you do."

Resources

While the list of resources in this guide is extensive, it does not represent every resource available in the state of Delaware for individuals with disabilities and special health care needs. Inclusion of a resource does not indicate an endorsement by the organizations that compiled and published *Connecting the Dots*. Exclusion of an agency or organization does not imply that it may not be a valuable resource for you.

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- DART First State: Delaware Transit Corporation



State Agencies

This guide includes information about many of Delaware's state-run agencies because they will be valuable resources in your search for information and services. Most agencies are known as "divisions" and are part of a "department" that serves a particular purpose for the residents of Delaware. The guide also lists some relevant programs within a particular division or department.

Department of Education (DOE)

Special Education (Exceptional Children Resources)

What information do you ask for?

Special education services for children ages 6 through 21.

Why do you need this information?

If you suspect your child has a disability or you need information about your rights under the Individuals with Disabilities Education Act.

Who do you need to make contact with?

First contact your local school district. If the local school district does not have the information you need, contact Exceptional Children Resources.

302-735-4210

www.doe.k12.de.us/infosuites/students_family/specialed/default.shtml
401 Federal Street, Suite 2
Dover, DE 19901



Department of Health and Social Services (DHSS)

Division of Developmental Disabilities Services (DDDS)

What information do you ask for?

Ask how to apply to DDDS to find out if your family member is eligible for services. It is recommended that you register as soon as the developmental disability is diagnosed in order to secure respite services for your young child through adulthood. Your family member should be registered with DDDS at least five years before high school graduation so the division can secure funding to provide the respite services as well as other services during adulthood.

Why do you need this information?

Services provided by DDDS will make it easier for you to care for a family member with a developmental disability. The family support services section of DDDS provides parent training, reimbursement, respite services, crisis intervention, in-home care, recreation, social supports and substance abuse services to individuals who are residing in the community. DDDS services can help in the development of work skills, self-care skills, community living skills, leisure/social skills and academic/communication skills. Services are arranged according to each person's special needs and available to help families continue to care for their family members at home.

Who do you need to make contact with?

For eligibility and application information, ask for the DDDS Intake Coordinator.

1-866-552-5758 (24 hours)
www.dhss.delaware.gov/dhss/ddds

New Castle County:
302-836-2100
Fox Run
2540 Wrangle Hill Road, Suite 200
Bear, DE 19701

Kent County:
302-744-1110
Thomas Collins Building
540 South DuPont Highway, 1st Floor
Dover, DE 19901

Sussex County:
302-933-3100
Stockley Center
101 Lloyd Lane, 26351 Patriots Way
Georgetown, DE 19947

Division of Medicaid and Medical Assistance (DMMA)

What information do you ask for?

Ask about services that DMMA offers to meet your family member's needs and if you qualify for them. Among DMMA services are Medicaid, Healthy Children (CHIP), Prescription Assistance (DPAP) and Children's Community Alternative Disability Program.

Why do you need this information?

Medicaid provides payment for health care to low-income individuals and families and people with disabilities whose income is insufficient to meet the cost of necessary medical services. Medicaid pays for doctor visits, hospital care, labs, prescription drugs, transportation, routine shots for children, and mental health and substance abuse services.

Who do you need to make contact with?

You can find out if you qualify for Medicaid or other medical assistance and social service programs by speaking with a representative at your local State Service Center. Call Medicaid Customer Relations at one of the numbers listed below to be directed to the appropriate office where someone can help you.

1-800-372-2022
302-255-9500
302-255-2022 TTY
www.dhss.delaware.gov/dhss/dmma

Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)

What information do you ask for?

Ask for information about programs and services that will benefit your family member with physical disabilities who is over age 18. The Aging and Disabilities Resource Center (ADRC) of DSAAPD is a one-stop access point for information and services for adults with physical disabilities and older Delawareans.

Why do you need this information?

ADRC staff can help you determine the services you need and connect you to available services, including home modification, legal services, medical transportation, personal care and respite care.

Who do you need to make contact with?

Contact ADRC call center staff for assistance or a referral to a social worker if needed. Bilingual services are available.

1-800-223-9074
302-255-9390
302-391-3505 TDD
www.dhss.delaware.gov/dsaapd/adrc.html

New Castle (Administrative Office):
Herman M. Holloway, Sr. Campus
Main Administration Building, First Floor
Annex
1901 N. DuPont Highway
New Castle, DE 19720
302-255-9390

Newark:
University Plaza
256 Chapman Road
Oxford Building, Suite 200
Newark, DE 19702
302-391-3500
302-391-3505 (TDD)

Milford:
Milford State Service Center
18 N. Walnut St., First Floor
Milford, DE 19963
302-424-7310
302-424-7141 (TDD)

Division of Social Services (DSS)**What information do you ask for?**

The Division of Social Services (DSS) administers Delaware's Temporary Assistance for Needy Families (TANF), Food Stamps, Subsidized Child Care, General Assistance and Refugee Cash Assistance programs. The DSS website includes charts and forms so you can see if your household may be eligible for Delaware's social service programs. There is a tool on the website to assist you in applying for assistance.

Why do you need this information?

By speaking with someone from DSS, you can find out about financial support for child care, cash assistance, food stamps, medical coverage and other programs. Financial eligibility guidelines vary from program to program.

Who do you need to make contact with?

Use the numbers listed below to connect with a representative in your county.

1-800-372-2022
302-255-9498 TTY
<http://dhss.delaware.gov/dhss/dss/>

Division of Substance Abuse and Mental Health (DSAMH)**What information do you ask for?**

Information about community mental health treatment, counseling and support services, supported housing services that promote independent living and community integration, mobile crisis intervention services, in-patient psychiatric evaluation, diagnosis and treatment, substance abuse treatment and prevention services and problem gambling services.

Why do you need this information?

The Division of Substance Abuse and Mental Health provides services to Delaware adults with mental illness, alcoholism, drug addiction or gambling addiction.

Who do you need to make contact with?

An intake coordinator can connect you to DSAMH services in your area. If you are in crisis, the toll-free Crisis Intervention Services number will connect you to immediate assistance.

1-800-652-2929 (Crisis Intervention Services)
302-255-9399
www.dhss.delaware.gov/dhss/dsamh

Division for the Visually Impaired (DVI)**What information do you ask for?**

Information about early diagnosis and intervention, education in the least restrictive environment, family and individual counseling, independent living skills, training and equipment, vocational training and related job placement, employment opportunities, advocacy, and low-vision evaluation and enhancement. Services are developed and provided for three groups of consumers: educational age (0-21); primary employment age (21-65); and older Delawareans (66+).

Why do you need this information?

Services can help a person with a vision disability to achieve the highest level of independence possible.

Who do you need to make contact with?

Call the office in your county and ask to speak with an intake representative. Bilingual services are available.

New Castle County:
302-255-9807
www.dhss.delaware.gov/dvi
Herman M. Holloway, Sr. Campus
Biggs Building
1901 N. DuPont Highway
New Castle, DE 19720

Kent and Sussex Counties:

302-424-7240
Milford Annex
13 S. W. Front Street
Milford, DE 19963

Home and Community-Based Services Ombudsman Program**What information do you ask for?**

The Ombudsman can listen, mediate, negotiate, facilitate and propose solutions on behalf of people with disabilities. Ask the disability advocate for help with a broad range of issues—such as medical equipment issues, Medicare/Medicaid difficulties, medical/legal/counseling information and referrals, termination, or appeals of services and payment issues.

Why do you need this information?

People with disabilities and community service consumers have a right to be treated fairly and respectfully and to participate in the planning of their care. An ombudsman serves as an information specialist for consumers and families and can help individuals find resources to improve the quality of their lives (e.g., guardianship, home health care, and durable medical equipment). Referrals can be made by consumers, friends, relatives or professionals in the community.

Who do you need to make contact with?

Call one of the numbers listed below.

1-800-223-9074
302-391-3505 (New Castle County TDD)
302-424-7141 (Kent/Sussex Counties TDD)

Delaware Health and Social Services
Main Administration Building
1901 N. DuPont Highway
New Castle, DE 19720

Department of Services for Children, Youth and their Families (DSCYF)**Division of Prevention and Behavioral Health Services (DPBHS)****What information do you ask for?**

DPBHS (formerly known as Child Mental Health) provides voluntary services to children up to age 18 and to the families of children who have mental health or substance abuse problems. The division responds to all child mental health emergencies.

Why do you need this information?

DPBHS has a variety of services for your child including crisis services, outpatient

services, support services, day treatment services, residential treatment services, and hospital treatment services. These services are managed by licensed mental health professionals.

Who do you need to make contact with?

For non-emergencies, outpatient facilities are located in each county. Use the main number to make contact with your local office outpatient service provider. Use the crisis line for emergency help with a child's emotional problem. Bilingual counselors are available.

302-633-2571 (main number)
1-800-969-4357 (crisis hotline)
www.kids.delaware.gov/pbhs/pbhs.shtml
1825 Faulkland Road
Wilmington, DE 19805

Division of Family Services (DFS)

• Foster Care

What information do you ask for?

If you are a foster parent with a child with disabilities or special health care needs, ask the foster care staff for information on how they help foster families to protect and nurture children.

Why do you need this information?

You may need assistance in meeting the child's developmental needs and addressing the developmental delays. You will learn about special support available to help your child to succeed educationally and socially.

Who do you need to make contact with?

Call the toll-free number, which is also the help line, or the office in your county.

1-800-464-4357 (Help Line)
www.kids.delaware.gov/fs/fostercare.shtml
302-451-2800 (New Castle County)
302-739-4800 (Kent County)
302-422-1400 (Sussex County)
1825 Faulkland Road
Wilmington, DE 19805

• Office of Children's Services

What information do you ask for?

If your family is having problems, ask for an assessment and supportive services to empower you to protect and nurture your children. If you suspect child abuse, neglect or dependency in a family you know, ask for an investigation.

Why do you need this information?

When an investigation confirms abuse, neglect or dependency, or significant risk of its occurrence is identified,

treatment workers will assess a family's needs and connect the family with appropriate resources/services to address the identified areas. The goal is to provide services to minimize the risk, keep children safe and strengthen families.

Who do you need to make contact with?

All reports of child abuse and neglect in Delaware should be made to the toll-free number, which is staffed at all times.

1-800-292-9582 (24-hour Child Abuse and Neglect Hotline)
1-800-969-HELP (1-800-969-4357)
(24-hour emergency help with a child's emotional problem)
www.kids.delaware.gov/fs/ocs.shtml

Department of Safety and Homeland Security

Developmental Disabilities Council (DDC)

What information do you ask for?

Information about current legislative activity, information and referrals.

Why do you need this information?

DDC advocates for change and educates communities to be responsive and sensitive to the needs, preferences and choices of all people with developmental disabilities and their families. DDC supports the Partners in Policymaking advocacy training program (which is conducted in even-numbered years), conferences and studies of interest to people with disabilities and their families and advocates.

Who do you need to make contact with?

The Senior Administrator or Office Administrator can answer general questions regarding the council's activities and how you or your child can help advocate for improved systems change.

302-739-2232
www.ddc.delaware.gov
Margaret M. O'Neill Building, 2nd Floor
410 Federal Street, Suite 2
Dover, DE 19901

State Council for Persons with Disabilities (SCPD)

What information do you ask for?

The mission of the State Council for Persons with Disabilities is to unite, in one council, disability advocates and state agency policy makers to ensure that individuals with disabilities are empowered to become fully integrated within the community. Ask about laws,

policies and regulations, either proposed or passed, that are pertinent to Delaware's disabilities community.

Why do you need this information?

This information is important because laws, policies and regulations outline the services and supports that are available to people with disabilities. SCPD is mandated by state law to monitor these programs and assure they are meeting the community's needs.

Who do you need to make contact with?

The Program Administrator.

302-739-3620
302-739-3699 (TTY/TDD)
www.scpd.delaware.gov
410 Federal Street, Suite 1
Dover, DE 19901

Department of Labor

Delaware Office for the Deaf and Hard of Hearing (DODHH)

What information do you ask for?

Ask for information about assistive technology, workshops and sensitivity training, finding and working with a sign language interpreter and other auxiliary aids such as assistive listening devices and Computer Aided Realtime Translation (CART).

Why do you need this information?

This office, which serves children and adults, works to ensure that deaf and hard of hearing citizens have equal access to services and programs in Delaware.

Who do you need to make contact with?

Contact the coordinator for resources and referrals.

302-761-8275 (TTY and voice)
302-761-8336 (TTY)
www.delawareworks.com/dvr/dodhh.shtml
4425 North Market Street
Wilmington, DE 19802

Division of Vocational Rehabilitation (DVR)

What information do you ask for?

Information about DVR services, including supplies and supports, that are required to assist an individual with a disability to obtain or retain employment. This includes assessment, counseling and guidance, information and referral, rehabilitation technology, skill training, job placement assistance, interpreter

Beth and Lizzy MacDonald

People with disabilities and their families understand the importance of making connections when planning for the future. Both Beth and Lizzy MacDonald have taken active roles in seeking resources and support for 21-year-old Lizzy, who was born with spondyloepiphyseal dysplasia congenita, a form of dwarfism.

When Lizzy was 8 years old, Beth participated in Partners in Policymaking through the Developmental Disabilities Council. Partners in Policymaking is a leadership training program that educates participants about the legislative process and local, state and national issues that affect people with disabilities. Beth's experiences with the program improved her ability to advocate for her daughter and introduced her to others who share similar interests. One of the most important lessons she learned was to make connections to people with disabilities and other parents—and to make those connections early.

"It is so vital to have other parents you can call on for advice, or just to listen, because they 'get it' without needing explanation," Beth said, highlighting the support she has found through Family Voices, an organization dedicated to achieving family-centered care for all children and youth with special health care needs and/or disabilities. Beth was a founding member of Delaware Family Voices in 1996, volunteering as the state coordinator for many years and also serving as the Family Voices Region III coordinator. Delaware Family Voices, also known as the Delaware Family to Family Health Information Center, continues to provide families with the tools they need to make informed decisions and advocate for their children. Beth remains active in the organization, serving on its Delawareans with Special Needs Medicaid Managed Care Panel.

Beth currently works as the program coordinator of the Delaware Special Needs Alert Program (SNAP), a pre-hospital notification program for any child who has special emergency care needs. The program alerts emergency responders to medical information and appropriate emergency care for each individual child. Beth's involvement with Family Voices, SNAP and other organizations has provided her with opportunities to share her experiences with other parents and individuals.

Parents need to ask questions about available supports while their child is still in high school, emphasized Beth. By the time a child is 14 years old, parents should start becoming familiar with transition and post-secondary education resources, including those available through the Division of Vocational Rehabilitation (DVR). Among other things, DVR provides financial support for books and other expenses for individuals pursuing higher education opportunities. Students may also receive on-campus support, such as a tutor and other accommodations as needed, all provided by DVR.

Lizzy MacDonald is a graduate of Caesar Rodney High School and currently is a student at Delaware Technical and Community College. She is taking courses in the human services field, and her studies have taught her about "counseling, asking the right questions and group dynamics."

Although Lizzy has made connections through the national Little People of America, attendance at national conferences, and social networking resources such as Facebook and Skype, she sees the need for additional services and community supports. Just as her interest in human services grew stronger through her own experiences as a little person, Lizzy was convinced that her first-hand knowledge of available services and supports could help others. To that end, Lizzy started a nonprofit organization called Uplift, dedicated to finding supports to help families with financial needs not covered by insurance or other means.

"My dream is to focus on the organization full time once I'm out of school," Lizzy says. "For now, I enjoy the classes with lots of people of different ages and different experiences that Del Tech provides."



services, supported employment services and other services. DVR also administers the Consortium Leadership and Independence through Managing Benefits (CLIMB) program and offers counseling about the impact of employment on an individual's TANF, SSI, SSDI and other benefits. (See *Acronyms* section on page 36 for the meaning of these acronyms.)

Why do you need this information?

DVR services help people with physical

and intellectual disabilities obtain or retain employment. DVR provides disability determination services for SSI and SSDI. An Independent Living Program helps people with disabilities function in the community. Parents of school-aged children should contact DVR by the time a child is 16 years old.

Who do you need to make contact with?

DVR has six offices statewide. To obtain services, or for further information, contact the office that is most convenient for you.

www.delawareworks.com/dvr

New Castle County and Statewide
Admissions Offices:
302-761-8275 (Voice/TTY)
4425 North Market Street
Wilmington, DE 19802

Pencader Corporate Center:
302-368-6980 (Voice/TTY)
225 Corporate Boulevard, Suite 204
Newark, DE 19702

(continued)

Appoquinimink State Service Center:
302-378-5779 (Voice/TTY)
122 Silver Lake Road
Middletown, DE 19709

Kent County:
302-739-5478 (Voice/TTY)
Carroll's Plaza, Suite 105
1114 DuPont Highway
Dover, DE 19901

Sussex County:
302-856-5730 (Voice/TTY)
20793 Professional Park Boulevard
Georgetown, DE 19947

Delaware Insurance Commissioner's Office

Consumer Services Division

What information do you ask for?

The Delaware Insurance Commissioner's Office assists Delawareans in resolving conflicts with insurance companies, health coverage providers and agents.

Why do you need this information?

The goal of the Insurance Commissioner's Consumer Services Division is to protect, advocate for and inform consumers of their rights and options when it comes to insurance. The Insurance Commissioner's Office can assist you if you are having difficulties with your insurance coverage.

Who do you need to make contact with?

Contact the Consumer Services Division with general questions about insurance or if you have problems or complaints.

1-800-282-8611
www.delawareinsurance.gov



First Steps Resources

The main focus of *Connecting the Dots* is on the first steps you need to take to find the supports and services available when you or a member of your family has a newly-diagnosed disability or special health care need. This section includes several categories of resources that will be of value to you as begin this journey.

ADVOCACY

The agencies and organizations listed in this section can assist you with information and resources that help you educate yourself about services for people with disabilities in Delaware and advocate for yourself or your family member. They can help you connect with family members of other people with disabilities, find out about workshops and conferences, and get to know the services within the community. Some organizations are disability-specific and others provide services for multiple disabilities. A listing of disability-specific agencies follows the general advocacy agency listings.

General Advocacy Organizations

Center for Disabilities Studies at the University of Delaware (CDS)

What information do you ask for?

Information about the ways in which CDS supports the well-being, inclusion and empowerment of people with disabilities and their families. The Center engages in projects that influence policy and practice and improve the quality of life for persons with disabilities. One of the CDS units, the Transition, Education and Employment Model (TEEM), offers services, supports and opportunities to enable young adults and adults with disabilities to develop the skills needed to increase their independence, gain employment, lead productive lives and participate in the community as adults. Employment services and postsecondary employment programs are included, as well as a leadership development/recreational program. The Health and Wellness unit promotes programs that help people with disabilities and special health care needs lead healthier lives and reduce the occurrence of further health issues.

Why do you need this information?

To increase your knowledge about

programs, services and research related to disabilities, and find ways to be more fully included in the community.

Who do you need to make contact with?

Call the main number to learn which staff member can be of help to you.

302-831-6974
302-831-4689 (TTY)
www.udel.edu/cds
University of Delaware
461 Wyoming Road
Newark, DE 19716

Delaware Family Voices/Family to Family Health Information Center (DE FV/F2F)

What information do you ask for?

Information about navigating the health care system, accessing resources and services and finding the answers to your questions about services for children and young adults with special health care needs and disabilities.

Why do you need this information?

DE FV/F2F provides information and emotional support to families new to the world of special health care needs and disabilities. DE FV/F2F is staffed by families who are raising a child with special health care needs, disabilities, chronic illness and/or physical or mental health conditions. DE FV/F2F also offers workshops and trainings for families and professionals.

Who do you need to make contact with?

An agency staff member. Bilingual services are available.

1-877-235-3588
302-221-5360
302-221-5363 (Spanish)
www.delawarefamilytofamily.org
61 Corporate Circle, Rooms 135 and 136
New Castle, DE 19720

Developmental Disabilities Council (DDC)

See DDC information in State Agencies on page 14.

Disabilities Law Program (DLP), Community Legal Aid Society, Inc.

What information do you ask for?

The DLP includes eight advocacy programs serving individuals with disabilities, including programs for persons with developmental disabilities, mental illness, physical disabilities and traumatic brain injury. DLP provides protection and advocacy related to individual rights, assistive technology,

education, social security and other areas.

Why do you need this information?

Services include individual advocacy, general information, referral services, community education and self-advocacy training.

Who do you need to make contact with?

If you have a legal problem that is related to your disability, you should call the office nearest you or use the toll-free number.

1-800-773-0606
www.declasi.org

New Castle County:
302-575-0660
302-575-0696 (TTY)
Community Service Building
100 West 10th Street, Suite 801
Wilmington, DE 19801

Kent County:
302-674-8500
302-674-9430 (TTY)
840 Walker Road
Dover, DE 19904

Sussex County:
302-856-3742
302-856-0038 (TTY)
20151 Office Circle
Georgetown, DE 19947

Freedom Center for Independent Living (FCIL)

What information do you ask for?

Information about advocacy methods, how to contact public officials, civil rights under the Americans with Disabilities Act and other legislation, and effective letter writing, phone calls and other communication. FCIL is a nonprofit organization created by and for people with disabilities. As a resource and advocacy organization, the Freedom Center promotes independent living and equal access for people of any age with all types of disabilities.

Why do you need this information?

FCIL provides core services in advocacy, information and referral, independent living skills and peer support.

Who do you need to make contact with?

An independent living specialist.

1-866-687-3245
302-376-4399
302-449-1487 TTY
www.fcilde.org
400 North Broad Street
Middletown, DE 19709

Governor's Advisory Council for Exceptional Citizens (GACEC)

What information do you ask for?

GACEC is a volunteer council appointed by the governor. The council holds meetings to review regulations, policies and laws that affect children and adults with disabilities. The meetings are open to the public.

Why do you need this information?

The council serves as the State Advisory Panel for the Individuals with Disabilities Education Act (IDEA) and as a general advocacy group for all state disability issues.

Who do you need to make contact with?

Ask for an agency staff member.

302-739-4553
www.gacec.delaware.gov
George V. Massey Station
516 W. Loockerman Street
Dover, DE 19904

Independent Resources, Inc. (IRI)

What information do you ask for?

Evaluation and guidance to develop an independent living plan, training in homemaking skills, financial management, and information on the ADA, technical assistance and training.

Why do you need this information?

IRI provides services in independent living, advocacy, information and referral, outreach and community education. IRI provides other services to the community such as: sensitivity training, community education and outreach, services for the deaf and hard of hearing, computer training for the blind, a transition program and an employment network.

Who do you need to make contact with?

An agency staff member in your county.

www.iri-de.org

New Castle County:
302-765-0191
302-504-4754 (video phone)
1-866-571-7594 (for hearing to connect with Deaf & Hard of Hearing Coordinator)
302-765-0194 (TTY)
Two Fox Point Centre
6 Denny Road, Suite 101
Wilmington, DE 19809

Kent County:
302-735-4599
302-735-5629 (TTY)
32 W. Loockerman Street, Suite 104
Dover, DE 19904

Sussex County:
302-732-9500
302-732-9562 (TTY)
31038 Country Gardens Boulevard,
Suite D - 4
Dagsboro, DE 19939

Interagency Coordinating Council (ICC)

What information do you ask for?

Ask how ICC members, who are appointed by the governor, assist and advise the Department of Health and Social Services to develop, implement and improve Delaware's early intervention system. Ask if the Delaware Central Directory of Services for Young Children with Special Needs has current information.

Why do you need this information?

You can contact ICC members to share concerns or ideas about the early intervention system. ICC welcomes parents of children birth to three to share their story with the council. Council members include parents, state agency personnel, private providers, insurance providers, legislators and professionals involved in personnel preparation.

Who do you need to make contact with?

Call the Birth to Three Office and ask to speak with the chair of the Interagency Coordinating Council.

302-255-9134
DHSS/DMS/Birth to Three Office
1910 N. DuPont Highway
New Castle, DE 19720

State Council for Persons with Disabilities (SCPD)

See SCPD information in State Agencies on page 14.

Disability-specific Advocacy Organizations

The Arc of Delaware (for intellectual and developmental disabilities)

www.thearcofdelaware.org

New Castle County:
302-996-9400
2 South Augustine Street, Suite B
Wilmington, DE 19804

Kent and Sussex Counties:
302-736-6140
E. Loockerman Street & Federal Street
Dover, DE 19901

Autism Delaware

www.delautism.org

New Castle County:

302-224-6020

924 Old Harmony Road, Suite 201

Newark, DE 19713

Kent and Sussex Counties:

302-644-3410

16394 Samuel Paynter Boulevard, Suite 201

Milton, DE 19968

Brain Injury Association of Delaware

1-800-411-0505

302-346-2083

www.biausa.org/Delaware

840 Walker Road, Suite A

Dover, DE 19904

Children and Adults with Attention Deficit Disorders (CHADD)

www.chadd.org

Newark Chapter:

302-737-5063

9 Maple Avenue

Newark, DE 19711

Sussex County Chapter:

302-841-4447

Delaware Association for the Blind

302-655-2111

302-654-1376 (Peer Support)

1-888-777-3925

www.dabdel.org

800 West Street

Wilmington, DE 19801

Delaware Foundation Reaching Citizens with Intellectual DisAbilities (DFRC)

www.blue-gold.org/index.html

302-454-2730

640 Plaza Drive

Four Seasons Center

Newark, DE 19702

Delaware Hands & Voices (support to families of children who are deaf and hard-of-hearing)

302-378-4979

www.delawarehandsandvoices.org

22 Peoples Plaza

Newark, DE 19702

Down Syndrome Association of Delaware

302-995-1004

www.dsadelaware.org

P. O. Box 747

Middletown, DE 19709

Epilepsy Foundation of Delaware

302-999-9313

1-800-422-3653 (for people in Kent and Sussex Counties)

www.epilepsyfoundation.org/delaware/

240 North James Street, #208

Newport, DE 19804

Hearing Loss Association of America (HLAA), Delaware Chapters

www.hlade.org

Delaware Chapter (Wilmington):

302-292-3066 (Voice/Relay)

Kent & Sussex Counties Chapter (Dover):

302-674-3272 (Voice/Relay)

Mental Health Association of Delaware (MHA)

1-800-287-6423

302-654-6833

www.mhainde.org

100 West 10th Street, Suite 600

Wilmington, DE 19801

National Alliance on Mental Illness Delaware (NAMI)

1-888-427-2643

302-427-0787

www.namide.org

2400 W. 4th Street

Wilmington, DE 19805

National Kidney Foundation of Delaware Valley

1-215-923-8611

www.nkfddv.org

111 S. Independence Mall E., Suite 411

The Philadelphia Bourse Building

Philadelphia, PA 19103

National Multiple Sclerosis Society, Delaware Chapter

1-800-344-4867

302-655-5610

www.MSDelaware.org

2 Mill Road, Suite 106

Wilmington, DE 19806

Prader-Willi Syndrome Association USA

1-800-926-4797

www.pwsausa.org

8588 Potter Park Drive, Suite 500

Sarasota, FL 34238

Spina Bifida Association

1-800-621-3141

www.spinabifidaassociation.org

4590 MacArthur Boulevard, NW, Suite 250

Washington, D.C. 20007



United Cerebral Palsy, Delaware Chapter

302-764-2400

www.ucpde.org

700A River Road

Wilmington, DE 19809

Assistive Technology and Home Modification

Assistive technology (AT) is broadly defined as any device that assists people with disabilities. A variety of agencies provide AT services in Delaware, including the Delaware Assistive Technology Initiative (DATI) of the Center for Disabilities Studies (see below). Other agencies provide AT and home modification as part of their services. If you are in need of funding for assistive technology and home and vehicle modification, contact the independent living centers listed in the Advocacy section on page 16 and local charitable organizations. Ask disability-specific agencies if they provide AT services or funding for AT.

Delaware Assistive Technology Initiative (DATI), Center for Disabilities Studies

What information do you ask for?

Information about funding, workshops, no-cost equipment loans, technical assistance for device selection, the AT Exchange Program and the quarterly newsletter. The website and newsletter include AT Exchange listings.

Why do you need this information?

To help connect and identify technology options needed to learn, work, play and participate in community life safely and independently. Services are free of charge.

Who do you need to make contact with?

Call or use the website to connect with an AT specialist in your area.

1-800-870-DATI (1-800-870-3284)
www.dati.org

Administrative office and New Castle
County AT Resource Center:

302-651-6790

302-651-6794 (TDD)

Nemours/Alfred I. duPont Hospital for
Children

Administration and Research Building,
Suite 203

1600 Rockland Road

Wilmington, DE 19803

Kent County office and AT Resource Center:
302-739-6885

302-739-6886 (TDD)

Easter Seals Kent County Center

100 Enterprise Place, Suite 1

Dover, DE 19904

Sussex County office and AT Resource
Center:

302-856-7946

302-856-6714 (TDD)

20123 Office Circle

Georgetown, DE 19947

Delaware Office for the Deaf and Hard of Hearing (DODHH)

See DODHH information in State Agencies
on page 14.

Department of Education (DOE) Special Education, Accessible Instructional Materials (AIM)

Children with disabilities who need
supports in order to participate in
education services may be eligible for
assistive technology devices and services.
These AT services may be available to
you or your family member through the
Individuals with Disabilities Education Act
(IDEA), Section 504 of the Rehabilitation
Act of 1973, and the Americans with
Disabilities Act of 1990. Information
about Accessible Instructional Materials
(AIM) is available at [www.doe.k12.de.us/
infosuites/students_family/specialed/
aim.shtml](http://www.doe.k12.de.us/infosuites/students_family/specialed/aim.shtml).

See more DOE information in State
Agencies on page 12.

Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), Home Modification Program

The Home Modification Program pays
for modifications (or changes) to be
made to the home of a person with a
physical disability. The changes are
made to allow a person to move around
more freely in the home. Information is

available at [http://dhss.delaware.gov/
dsaapd/homemod.html](http://dhss.delaware.gov/dsaapd/homemod.html).

See more DSAAPD information in State
Agencies on page 12.

Division for the Visually Impaired (DVI)

See DVI information in State Agencies on
page 13.

Division of Vocational Rehabilitation (DVR)

State vocational rehabilitation agencies
are often a major funding source of AT
for working-age individuals with
disabilities.

See more DVR information in State
Agencies on page 14.

Easter Seals Delaware and Maryland's Eastern Shore, Resource Technology Demonstration Center

Easter Seals houses a Resource and
Technology Demonstration Center in its
New Castle County building. Assistive
technology devices are available for trial
use at the center. The center also provides
home and work assessments to help
determine assistive technology needs,
wheelchair seating assessments,
communication device assessments and
workshops about assistive technology.

See more Easter Seals information in
Outpatient Therapies on page 25.

Goodwill Durable Medical Equipment

What information do you ask for?

Ask about the availability of refurbished,
previously-owned durable medical
equipment (DME) and assistive technol-
ogy (AT), including commode chairs,
crutches, walkers, wheelchairs, scooters,
communication devices and others, that
are for sale. You may also ask about
donating such devices to the program.

Why do you need this information?

To help you obtain the DME or AT that
you might not otherwise be able to
afford.

Who do you need to make contact with?

Call or use the website to connect with a
staff person who will assist you with
your DME/AT needs.

302-463-1465

www.goodwillde.org/DME.asp

311 E. Lea Boulevard

Wilmington, DE 19802

Early Intervention/ Home Visiting Programs

Birth to Three – Child Development Watch

What information do you ask for?

Child Development Watch is the
statewide early intervention program for
children from birth to 36 months of age.
Child Development Watch helps you
answer the question, "Is my child
developing and learning like other
children?" Your child may be growing
and changing, yet have difficulty hearing,
seeing, talking, moving or learning the
way other children do. This is called a
developmental delay.

Why do you need this information?

You want to learn about a developmental
delay as early as possible so your child
can receive services at an early age.
Services are designed to meet the
developmental needs of the child and
the needs of the family in enhancing
that child's development. Services
include assistive technology, audiology,
family training and counseling, health
services, nutrition plans, nursing services,
occupational therapy, physical therapy,
psychological services, social work,
special instruction related to the child's
skill development, speech-language
therapy, transportation and visual services.

Who do you need to make contact with?

For information or to make an appoint-
ment, call the service center nearest you.
Your doctor may also make a referral to
Child Development Watch, although you
can call directly if you are concerned
about your child's development.
Bilingual services are available.

[www.dhss.delaware.gov/dph/chs/
chscdw.html](http://www.dhss.delaware.gov/dph/chs/chscdw.html)

New Castle County:

1-800-671-0050

302-283-7240

University Plaza - Chopin Building

258 Chapman Road

Newark, DE 19702

Kent and Sussex Counties:

1-800-752-9393

302-424-7300

Milford Walnut Street Building

18 N. Walnut Street

Milford, DE 19963

Delaware Early Childhood Center (DECC)

What information do you ask for?

Ask about the many programs DECC offers for young children with developmental delays or disabilities and their families.

- The Early Intervention program offers early intervention services assisting children from birth to three years old.
- New Directions Early Head Start (Kent County) provides home-based services to families, with home visits weekly for each participating family.
- Early CHOICES (Children Having Options In a Continuum of Educational Services) offers special education and related services for 3-year olds with developmental delays and 3- and 4-year olds with speech delays and provides support for their families.
- Parents as Teachers (*See separate listing on this page.*)

Why do you need this information?

Services offered by DECC, both in centers and in your home, will provide your child with services to improve development, while you receive the information and education you need to help your child.

Who do you need to make contact with?

Call the administration office to find a location that is convenient for you. DECC is administered through the Lake Forest School District.

302-398-8945 or 302-424-7552
www.lf.k12.de.us/decc

Early Head Start

What information do you ask for?

Ask if your child is eligible for Head Start based on your income. Children from families receiving public assistance (TANF or SSI) are eligible for Head Start and Early Head Start services regardless of income. Ask about home visitor and center programs.

Why do you need this information?

You and your child will benefit from involvement in an Early Head Start program. It provides quality care and family services to pregnant women and children between the ages of birth and 36 months and their families. Programs at the centers give children with and without disabilities an equal opportunity to learn together. The home visiting program helps parents learn about

caring for their young children and assures that the children are receiving medical attention and services that may be needed for developing language, motor and other skills.

Who do you need to make contact with?

For enrollment information, contact the Early Head Start program serving your community; a list is on the Department of Education's website. Your local Head Start program will provide the required forms, answer questions about the program, and help you find the program closest to your home.

302-735-4244

www.doe.k12.de.us/infosuites/students_family/earlychildhood/programdir.shtml

Parents as Teachers (PAT)

What information do you ask for?

The Parents as Teachers Program (PAT) provides parent education services to first-time parents. Parents receive monthly home visits from a trained parent educator from the time the child is born through age 3, and in cases of multiple risk, through age 5. The purpose of each visit is to provide information to parents about their child and strategies to encourage and assist in their child's development.

Why do you need this information?

Services are available statewide with programs operating in all three counties. PAT serves children most at-risk for later learning challenges. They provide families with the information and resources necessary to allow them to support their child. This support results in families acquiring the skills to become nurturers of their child's development and be their child's first teachers.

Who do you need to make contact with?

For more information on how to contact your local PAT program, call the Department of Education, Early Development Office at 302-735-4295.

Smart Start (Division of Public Health)

What information do you ask for?

Ask for education and support in your home for a child (through age 3) who has medical or developmental needs or when you need extra help to provide the special care your child needs. Services include nutrition education, parent education, nursing and developmental assessments, health education, case

management and assistance with social concerns for children through age 3 who meet eligibility requirements.

Why do you need this information?

Parent education and support is important for keeping your child healthy, helping you know what to expect as your child grows and develops, and strengthening parenting and coping skills. You and your family will receive home visits from a registered nurse, social worker or nutritionist.

Who do you need to make contact with?

Contact the Maternal Child Referrals Intake line in your county.

302-283-7140 (New Castle County)

302-424-7300 (Kent and Sussex Counties)

<http://dhss.delaware.gov/dph/chs/chssmartstart.html>

EDUCATION

All children in Delaware are entitled to a free appropriate public education. Special education services are provided by individual public school districts. The districts are supported by the Department of Education's Exceptional Children and Early Childhood Group. Each school district has a special education coordinator (title may be different) who can assist you. Other agencies provide assistance in navigating the education system.

The Arc of Delaware

What information do you ask for?

Ask for help so you can understand special education system in Delaware. The Arc's Parent Mentor Program has a network of trained parents that provides support to families for education. The Arc also provides information about systems advocacy and direct services to help ensure that persons with disabilities can live, work, go to school and enjoy leisure activities within the communities of their choice. The Arc of Delaware also provides referrals, training and assistance to individuals, their families and the community to promote better understanding and better lives.

Why do you need this information?

The Arc of Delaware promotes and protects the rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

Who do you need to make contact with?

Call your local office.

www.thearcofdelaware.org

New Castle County:
302-996-9400
2 South Augustine Street, Suite B
Wilmington, DE 19804

Kent and Sussex Counties:
302-736-6140
E. Loockerman Street & Federal Street
Dover, DE 19901

Delaware Autism Program**What information do you ask for?**

Information about services, eligibility and application processes.

Why do you need this information?

The Delaware Autism Program (DAP) is the statewide, public school program for students with autism. The program provides comprehensive educational, vocational, respite and residential services to students with autism between 2 and 21 years of age in three centers across the state—the Sussex Elementary Consortium (Lewes), Charlton School (Camden) and the Brennen School (Newark).

Who do you need to make contact with?

Contact the statewide office.

302-454-2202
<http://www.christina.k12.de.us/Schools/DAP/>
144 Brennen Drive
Newark, DE 19713

Delaware School for the Deaf**What information do you ask for?**

Parents can get a referral from Child Development Watch or their current school or can contact the school directly for information about services, eligibility and application processes and to schedule a tour of the school.

Why do you need this information?

This public school serves deaf and hard of hearing students and deaf/blind students from birth through 21 years of age from throughout the state. Its mission is to educate students with rigorous achievement standards, to develop their linguistic competence in both American Sign Language and English, and to prepare them to be contributing citizens, by providing access to language and information in a safe and supportive learning environment. Dormitories are available at the school.

Who do you need to make contact with?

Contact the statewide coordinator. All staff are fluent in sign language.

Toll-free statewide: 1-800-292-9590
302-454-2301
302-297-8637 (video phone)
www.christina.k12.de.us/DSPDHH/DSD/index.htm
630 E Chestnut Hill Road
Newark, DE 19713

**Department of Education (DOE),
Special Education (Exceptional
Children Resources)**

See DOE information in State Agencies on page 12.

**Disabilities Law Program (DLP),
Community Legal Aid Society, Inc.**

Contact DLP if you have difficulty finding the appropriate educational setting for your child.

See DLP information in Advocacy on page 16.

Division for the Visually Impaired (DVI)

DVI staff members work closely with the Delaware Department of Education, Child Development Watch and other organizations involved with children who have visual impairments. The division provides services to families and to personnel in Delaware school districts, charter schools and private schools serving visually impaired students in the classroom.

See more DVI information in State Agencies on page 13.

**Parent Information Center of
Delaware (PIC)****What information do you ask for?**

The Parent Information Center provides information and consultation about disabilities and special education rights, consultation about obtaining appropriate services for children with disabilities, and helps parents prepare for Individualized Education Plan (IEP) and other school meetings.

Why do you need this information?

The Parent Information Center can assist you to better understand your child's rights and opportunities in education, obtain information about all types of disabilities, find solutions to problems and concerns about educational services, and learn about programs and services that promote growth and independence.

**Who do you need to make contact with?**

Contact your local area office or use the toll-free number to talk to a parent consultant.

1-888-547-4412
www.picofdel.org

New Castle County:
302-999-7394
5570 Kirkwood Highway
Orchard Commons Business Center
Wilmington, DE 19808

Kent County:
302-678-0300
100 Enterprise Place, Suite 1
Dover, DE 19904

Sussex County:
302-856-9880
13 Bridgeville Road
Georgetown, DE 19947

FEDERALLY QUALIFIED HEALTH CENTERS

Federally Qualified Health Centers (FQHC) are community-based and patient-directed organizations that serve populations with limited access to health care. These include low-income populations, the uninsured, those with limited English proficiency, migrant and seasonal farm workers, individuals and families experiencing homelessness, and those living in public housing. FQHCs accept Medicare, Medicaid and most private insurance, as well as provide services for the uninsured on a sliding scale based on income and family size. Contact the FQHC nearest you for information about available primary care services and to make an appointment. All centers have some staff members who speak Spanish.

Henrietta Johnson Medical Center

www.hjmc.org

Southbridge location:
302-655-6187
601 New Castle Avenue
Wilmington, DE 19801

Riverside location:
302-761-4610
700 Lea Boulevard, Suite 201
Wilmington, DE 19802

LaRed Health Center

www.laredhealthcenter.org

Dover location:
302-730-0633
1057 South Bradford Street
Dover, DE 19904



Georgetown location:
302-855-2130
505 W. Market Street
Georgetown, DE 19947

Seaford location:
302-628-7752
1340 Middleford Road, Suite 401
Seaford, DE 19973

Westside Family Healthcare

www.westsidehealth.org
For information: 302-655-5822

To schedule an appointment:
302-224-6800 (New Castle County)
302-678-4622 (Kent and Sussex Counties)

New Castle County locations:
1802 W. 4th Street
Wilmington, DE 19805
302-655-5822

908-B East 16th Street
Wilmington, DE 19802
302-575-1414

404 Fox Hunt Drive
Fox Run Shopping Center
Bear, DE 19701
302-836-2864

27 Marrows Road
Newark, DE 19713
302-455-0900

Kent County location:
1020 Forrest Avenue
Dover, DE 19904
302-678-4622

FINANCIAL AND INSURANCE RESOURCES

The federal and state agencies listed in this section provide financial assistance to individuals with disabilities. Eligibility requirements and applications for each program vary. If you have private insurance, contact your insurance company and ask to speak with a case manager about the benefits you have. With the passage of the Affordable Care Act in March 2010, ongoing changes to Medicaid and Medicare and private insurance will affect eligibility, policies and costs. To stay informed of these changes, visit www.healthcare.gov and/or connect with Delaware Family Voices/Family to Family Health Information Center and your personal insurance carrier. (See DE FV/F2F information in Advocacy on page 16.)

Delaware Insurance Commissioner's Office

See Insurance Commissioner's Office information in State Agencies on page 16.

Division of Medicaid and Medical Assistance (DMMA)

See DMMA information in State Agencies on page 12.

Division of Social Services (DSS), ASSIST

ASSIST is the State of Delaware's Application for Social Service Programs. The self-screening questionnaire can tell you which programs you and the members of your household may be eligible to receive.

See more DSS information in State Agencies on page 13.

Social Security Administration

What information do you ask for?

Ask about eligibility and benefits through the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs. Some adults and children with disabilities may be eligible for one or both of these programs. SSDI provides benefits to people with disabilities who are "insured" by workers' contributions to the Social Security trust fund. An adult whose disability began before age 22 may be eligible for benefits if a parent is deceased or receiving retirement or disability benefits. SSI makes cash assistance payments to people with disabilities and individuals who are blind (including children under age 18) who have limited income and resources.

Why do you need this information?

Eligibility for health and medical services are often connected to Social Security.

Who do you need to make contact with?

For information about medical and financial eligibility requirements for SSI and SSDI, to apply for benefits, or to ask any questions about services, contact your local office or the toll-free number. Some application services are also available on the Social Security website.

1-800-772-1213 (National toll-free)
1-800-325-0778 (Statewide, TTY)
www.socialsecurity.gov

New Castle County:
1-888-377-7019
920 W. Basin Road, Suite 200
New Castle, DE 19720

Kent County:
1-877-701-2141
500 W. Lookerman Street, Suite 100
Dover, DE 19904

Sussex County:
1-866-864-1803
20105 Office Circle
Georgetown, DE 19947

HOSPITALS

Children's Hospital

Nemours/Alfred I. duPont Hospital for Children

This hospital provides intensive and acute inpatient and outpatient care for children beginning at birth. Children can continue to see specialists at the hospital until they turn 21 if they were already a patient in that specialty before age 18.

302-651-4000
www.nemours.org
1600 Rockland Road
Wilmington, DE 19803

Clinics also are available throughout the state. Call for more information.

General Hospitals

Bayhealth Medical Center - Milford Memorial Hospital

302-422-3311
www.bayhealth.org
21 West Clarke Avenue
Milford, DE 19963

Bayhealth Medical Center - Kent General Hospital

302-674-4700
www.bayhealth.org
640 South State Street
Dover, DE 19901

Beebe Medical Center

302-645-3300
www.beebemed.org
424 Savannah Road
Lewes, DE 19958

Christiana Care Health System - Christiana Hospital

302-733-1000
www.christianacare.org
4755 Ogletown Stanton Road
Newark, DE 19718

Christiana Care Health System - Wilmington Hospital

302-733-1000
302-733-3500 TTY
www.christianacare.org/Wilmington
Hospital
501 W. 14th Street
Wilmington, DE 19801

Nanticoke Memorial Hospital

302-629-6611
www.nanticoke.org
801 Middleford Road
Seaford, DE 19973

St. Francis Hospital

302-421-4100
www.stfrancishealthcare.org
701 N. Clayton Street
Wilmington, DE 19805

Wilmington VA Medical Center

1-800-461-8262
302-994-2511
www.wilmington.va.gov
1601 Kirkwood Highway
Wilmington, DE 19805

See more Wilmington VAMC information in Military Resources on page 24.

INFORMATION & REFERRAL

Information and referral agencies provide connections to other agencies and resources. The agencies listed in this section will help you find the right agency for the services and supports you need.

2-1-1 Delaware Helpline

What information do you ask for?

2-1-1 Delaware Helpline provides information and referrals for financial assistance, emergency housing and food, utilities assistance, legal services, child support, transportation, mental health counseling, family issues and other areas of need.

Why do you need this information?

2-1-1 Delaware Helpline can help you assess your situation and connect you with a human service agency or program where you can get the help you need.

Who do you need to make contact with?

A Referral Specialist will answer your call and assist you from 8:00 a.m. to 8:00 p.m. weekdays. Bilingual services are available. Check the 2-1-1 website, which serves as an online guide to human services.

2-1-1

1-800-560-3372 (from outside Delaware)
www.delaware211.org

Children & Families First (CFF)

What information do you ask for?

Children & Families First provides information and services for families across the lifespan. CFF staff provide social, educational and mental health programs throughout the state, as well as connect families to appropriate services within their communities and provide referrals for child care and respite care.

Why do you need this information?

Children & Families First can assist you to find services to meet your family's needs.

Who do you need to make contact with?

The person answering the phone can assist you.

1-800-220-3092
302-658-5177 (New Castle County)
302-674-8384 (Kent County)
302-856-2388 (Sussex County)
www.cffde.org
2005 Baynard Boulevard
Wilmington, DE 19802

Delaware Family Voices/Family to Family Health Information Center (DE FV/F2F)

See DE FV/F2F information in Advocacy on page 16.

Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), Aging and Disabilities Resource Center (ADRC)

See DSAAPD and ADRC information in State Agencies on page 12.

Parent Information Center of Delaware (PIC)

See PIC information in Education on page 21.

LEGAL SERVICES

People with disabilities and their families need to know and understand their rights, including how to access needed services. Legal assistance is available through a variety of resources in Delaware, including the two listed in this guide.

Home and Community-Based Services Ombudsman Program

See *Home and Community-Based Services Ombudsman Program* information in *State Agencies* on page 13.

Disabilities Law Program (DLP), Community Legal Aid Society, Inc.

See *DLP* information in *Advocacy* on page 16.

MENTAL HEALTH RESOURCES

ContactLifeline, Inc.

ContactLifeline staffs the following 24-hour free, confidential helplines for emotional stress and personal crises, including suicide and rape, and connects Delawareans with relevant community resources.

1-800-262-9800
www.contactlifeline.org

New Castle County:
302-761-9100 (Crisis Helpline and Rape Crisis Program)
302-761-9700 (TDD)
302-761-9800 (Administrative Office)

Kent and Sussex Counties:
1-800-262-9800 (Crisis Helpline and Rape Crisis Program, office)
302-422-1154 (Administrative Office)

Delaware Guidance Services for Children & Youth (DGS)

What information do you ask for?

Ask for information about mental health services for children and their families. Delaware Guidance offers programs and services for every level of need, including outpatient clinical services, intensive outpatient treatment programs, day treatment programs, crisis intervention services, school-based treatment services and behavioral interventions. Services include evaluations, counseling, play therapy, medication management and educational resources.

Why do you need this information?

Quality mental health services are important to treat and reduce the incidence of emotional problems in

children. Services are available regardless of ability to pay.

Who do you need to make contact with?

Contact the office in your area. If you or your child is in crisis, call the toll-free crisis hotline.

www.delawareguidance.org
1-800-969-4357 (Toll-free Crisis Hotline)

New Castle County:
302-652-3948
302-633-2571 (Crisis)
1213 Delaware Avenue
Wilmington, DE 19806

302-455-9333
302-455-9544 (Crisis)
Polly Drummond Office Park
Building 1, Suite 1208
Newark, DE 19711

Kent County:
302-678-3020
302-678-2458 (Crisis)
103 Mont Blanc Boulevard
Dover, DE 19904

Sussex County:
302-262-3505
900 Health Services Drive
Seaford, DE 19973

Division of Prevention and Behavioral Health Services (DPBHS)

24-hour Behavioral Health Crisis Services for emergency help with a child's emotional problem: 1-800-969-HELP (1-800-969-4357)

See more *DPBHS* information under *State Agencies* on page 13.

Division of Substance Abuse and Mental Health (DSAMH)

Adult Mobile Crisis Hotline:
New Castle County: 1-800-652-2929
Kent and Sussex Counties: 1-800-345-6785

See more *DSAMH* information under *State Agencies* on page 13.

Mental Health Association of Delaware (MHA)

What information do you ask for?

Information about warning signs of mental health problems and how to get help for yourself or a friend or loved one with a mental health problem. Options include support groups and education programs.

Why do you need this information?

It is important to know the signs and

symptoms of depressive and anxiety disorders in children and adults in order to get help.

Who do you need to make contact with?

Call MHA's toll-free telephone information and referral service or visit the online Mental Health Community Resources Directory when you have questions about mental health issues or services.

1-800-287-6423
302-654-6833
www.mhainde.org
100 West 10th Street, Suite 600
Wilmington, DE 19801

National Alliance on Mental Illness Delaware (NAMI)

What information do you ask for?

Information about the support available for people with serious mental illness and the resources and programs available for family members.

Why do you need this information?

To better understand and cope with the problems and realities of severe and persistent mental illness.

Who do you need to make contact with?

Contact a NAMI Delaware representative during regular business hours or complete the email contact form on the NAMI website.

1-888-427-2643
302-427-0787 (New Castle County)
302- 744-9357 (Kent County)
302-226-3334 (Sussex County)
www.namide.org
2400 W. 4th Street
Wilmington, DE 19805

MILITARY FAMILY RESOURCES

Dover Air Force Base Family Advocacy Program

Special Needs Program/EFMP
302-677-2711
436 MDOS/SGOHF
263 Chad Street
Dover Air Force Base
Dover, DE 19902

MilitaryHOMEFRONT

What information do you ask for?

MilitaryHOMEFRONT is the Department of Defense website for official Military Community and Family Policy (MC&FP) program information, policy and guidance designed to help troops and their families, leaders and service providers.

Why do you need this information?

MilitaryHOMEFRONT has the most accurate and up-to-date information about Department of Defense programs serving troops and their families.

Who do you need to make contact with?

MilitaryHOMEFRONT is an online resource. For assistance by telephone, use Military OneSource.

www.militaryhomefront.dod.mil

Military OneSource

What information do you ask for?

Military OneSource is available to help you with just about any need, including those related to health, education, relocation, parenting, financial and legal issues.

Why do you need this information?

Military OneSource provides free short-term, non-medical counseling to active duty service, National Guard and Reserve members and their families. These services are available in person, by telephone or online.

Who do you need to make contact with?

Any operator can direct you to the resources needed.

1-800-342-9647
1-877-888-0727 (En español)
1-800-787-3224 (TTY/TDD)
www.militaryonesource.com

Specialized Training of Military Parents (STOMP)

What information do you ask for?

STOMP, a parent-directed project, provides information to empower military parents, individuals with disabilities and service providers with the knowledge, skills and resources they need to access services.

Why do you need this information?

STOMP is the National Parent Training and Information Center for military families providing support and advice to military parents without regard for the type of their child's medical condition or geographic location.

Who do you need to make contact with?

An agency representative. STOMP offers bilingual services.

1-800-5-parent (1-800-572-7368)
www.stompproject.org

Wilmington VA Medical Center

What information do you ask for?

Ask if you or other family members are eligible for any benefits from the VA. For a dependent to receive benefits from the VA, the veteran needs to have been rated by the VA for a service-connected disability. If the veteran is deceased, certain minor dependents, or adult children with needs, may be entitled to VA benefits.

Why do you need this information?

You may be able to receive needed services from the Wilmington VA Medical Center or a Community Based Outpatient Clinic (CBOC).

Who do you need to make contact with?

Call the toll-free number, visit the website or, for information about family eligibility, visit www.vba.va.gov/bln/dependents/index.htm and www.vba.va.gov/benefit_facts/index.htm.

1-800-461-8262
302-994-2511
www.wilmington.va.gov
1601 Kirkwood Highway
Wilmington, DE 19805

Dover CBOC
1-800-461-8262 ext. 2400
1198 S. Governors Avenue, Suite 201
Dover, DE 19904

Georgetown CBOC
1-800-461-8262 ext. 2300
15 Georgetown Plaza
Georgetown, DE 19947

OUTPATIENT THERAPIES

Easter Seals Delaware and Maryland's Eastern Shore

What information do you ask for?

Ask for information about the type of outpatient services you need. Easter Seals provides outpatient rehabilitation therapies (physical therapy, occupational therapy and speech/language therapy), activity and employment services for adults with developmental disabilities, early intervention for children with developmental delays, adult day services, recreation programs, respite care, personal attendant services, assistive technology and services for farmers with disabilities.

Why do you need this information?

You may find several types of services you need at Easter Seals. This agency serves children and adults with physical



and mental disabilities and special needs resulting from any cause—whether diagnosed at birth or incurred through disease, accidental injury or the aging process. Easter Seals also provides support to their families.

Who do you need to make contact with?

Contact your local area office or use the toll-free number.

1-800-677-3800
www.de.easterseals.com

New Castle County:
302-324-4444
302-324-4442 (TDD)
61 Corporate Circle
New Castle, DE 19720

Kent County:
302-678-3353
100 Enterprise Place, Suite 1
Dover, DE 19904

Sussex County:
302-253-1100
22317 DuPont Boulevard
Georgetown, DE 19947

Nemours Department of Therapy and Rehabilitation

What information do you ask for?

Ask for information about the type of outpatient services you need. The Nemours Department of Therapy and Rehabilitation at Alfred I. duPont Hospital for Children evaluates and

treats children who have conditions that are present at birth, acquired through injury or occur due to disease. Services include occupational therapy, physical therapy, speech and language therapy, assistive technology, a wheelchair clinic and a cochlear implantation program.

Why do you need this information?

A complete assessment of your child's functional abilities and needs will lead to the creation of a plan of care that addresses your child's individual needs. Nemours also provides education and guidance for families to learn to carry over therapeutic techniques to everyday settings, as well as communication and referral support for families.

Who do you need to make contact with?

Contact Nemours/Alfred I. duPont Hospital for Children in Wilmington.

302-651-4000

www.nemours.org/service/medical/therapy.html

1600 Rockland Road
Wilmington, DE 19803

RESPITE/CAREGIVING

Organizations that provide respite services and personal attendant services are listed in this section. Caregivers should also look to organizations listed in Disability-specific Advocacy Organizations for other opportunities for respite care and funding of respite care. (See page 16.)

Delaware Autism Program (DAP)

DAP provides in-home respite services and at-school holiday respite services for students in the program.

See more DAP information in Education on page 21.

Delaware Lifespan Respite Care Network

What information do you ask for?

Information about financial assistance for respite care, a directory of respite care providers and tools for selecting a respite care provider.

Why do you need this information?

The network provides families with small grants to fund respite care. The grants will help pay for care for individuals of all ages and with any type of disability or special need.

Who do you need to make contact with?

Call to speak to a specialist who can help you find care and determine if you are eligible for help in paying for it.

1-888-610-5572

302-479-1690

www.delrespite.org

61 Corporate Circle
New Castle, DE 19720

Division of Developmental Disabilities Services (DDDS)

See DDDS information in State Agencies on page 12.

Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)

See DSAAPD information in State Agencies on page 12.

United Cerebral Palsy (UCP)

What information do you ask for?

Information about the respite care programs UCP provides: Community Respite Care, Weekend Respite and Rec-n-Respite programs for children and adults with various disabilities. Length of care provided, location of respite care and eligibility for the programs vary. Wheelchair-accessible transportation is available and trained staff members provide the services.

Why do you need this information?

To determine the services that best serve your needs. Respite care may be provided in the community, your home or a UCP location and is not limited to people with cerebral palsy.

Who do you need to make contact with?

An agency staff member.

www.ucpde.org

New Castle County:
302-764-2400
700A River Road
Wilmington, DE 19809

Kent and Sussex Counties:
302-335-5626
3249 Midstate Road
Felton, DE 19943

SKILLED CHILD CARE AND SCHOOLING

Some children with significant medical conditions or disabilities may benefit from skilled child care and school services to address their needs. They are placed in a Prescribed Pediatric Extended Care (PPEC) facility because their medical condition requires continuous therapeutic interventions. A PPEC center provides a less-restrictive alternative to institutionalization and reduces the isolation that medically-dependent children may otherwise experience. Each center offers an array of services focused on meeting the physiological as well as developmental, physical, nutritional and social needs of the children served.

Children's Secret Garden

What information do you ask for?

Ask for information about Prescribed Pediatric Extended Care (PPEC) services if your child has medical needs requiring skilled nursing care and the Dover location is convenient for you. A doctor's prescription is required for admission. Referrals can be made by a child's family, doctor, social worker or any community service provider.

Why do you need this information?

This comprehensive inclusive child care center offers both traditional child care services and PPEC services for children with medical needs requiring skilled nursing care on a full-time basis only. Your child will receive physical, occupational, speech and nutritional therapy as needed.

Who do you need to make contact with?

Call the office for information or to schedule an appointment.

302-730-1717

www.childrenssecretgarden.net
717 Hatchery Road
Dover, DE 19901

First State School

What information do you ask for?

Ask how your child, in kindergarten through high school, can enroll in this school and receive medical treatment as part of the program.

Why do you need this information?

First State School gives children with serious illnesses, such as cancer, sickle cell anemia and other conditions, the opportunity to attend school rather than being homebound. First State School serves children kindergarten through



high school and is a collaborative effort of Christiana Care Health System and the Red Clay School District.

Who do you need to make contact with?
Call the school's office.

302-428-5848
www.christianacare.org/firststateschool
501 W. 14th Street
Wilmington, DE 19801

Nurses 'n Kids Pediatric Medical Program

What information do you ask for?

Ask for information about full or part-time care for your infant or toddler with acute or chronic medical needs, developmental delays or nutritional deficiencies. If you refer your child, Nurses 'n Kids will then contact your child's doctor to obtain a letter of medical necessity and to coordinate your child's care. Your child's doctors, clinicians or community coordinators may refer your child.

Why do you need this information?

Nurses 'n Kids provides physical, occupational and speech therapy for children as part of its Medical Day Care and Pediatric Outpatient Therapy programs.

Who do you need to make contact with?
There are two child care centers in Delaware. Contact the one in your area.

www.nursesnkids.com

New Castle County:
302-323-1118
904 Churchmans Road Extension
New Castle, DE 19702

Kent and Sussex Counties:
302-424-1770
705 North Street Extension
Milford, DE 19963

SKILLED HOME-BASED PEDIATRIC NURSING CARE

You may need help and support caring for a family member with a significant illness or disability. This section lists skilled home-based pediatric nursing care agencies in Delaware that will work with you and your child's doctor to develop a written plan of care and provide the nurses and other professionals needed to carry out the plan. Contact your pediatrician for a prescription and ask for a recommendation of an agency. Also check with your insurance company about coverage. You may refer your child or ask your doctor to contact the agency.

Bayada Nurses - Pediatrics

www.bayada.com/pediatric.shtml

Delaware Pediatrics (Medicare Certified):
32 Reads Way
New Castle, DE 19720
302-322-2300

Delaware Pediatrics South:
600 N.E. Front Street Extension
Milford, DE 19963
302-424-0654

Christiana Care VNA

www.christianacare.org/vna
888-862-0001 (24-hour assistance and appointment scheduling)

New Castle County:
302-327-5200
1 Reads Way, Suite 100
New Castle, DE 19720

Kent and Sussex Counties:
302-698-4300 (Kent)
302-855-9700 (Sussex)
2116 South Dupont Highway, Suite 2
Camden, DE 19934

Maxim Healthcare

www.maximhomecare.com

Wilmington Homecare:
302-478-3434
1409 Foulk Road, Suite 203
Wilmington, DE 19803

Dover Homecare:
302-734-9040
1012 State College Road, Suite 101
Dover, DE 19904

R P Homecare (formerly Ridgeway Philips of Delaware Inc.)

www.rphomecare.com

Main office:
866-323-1436
302-323-1436 ext. 13

Kids at Home:
302-323-1436 ext. 23
908 Churchmans Road Extension #B
New Castle, DE 19720-3109

Next Steps Resources

As time goes by, you will find that your needs and priorities are changing and you need additional resources. This section includes several categories of resources that will be of value to you as you take the next steps to find supports and services to meet your changing needs.

EMERGENCY PREPAREDNESS

Delaware Citizen Corps

What information do you ask for?

Ask how Delaware Citizen Corps can help you prepare for and respond to emergencies, or visit the websites hosted by this organization to access videos and brochures on disaster preparedness and preparedness for people with disabilities. There are also links to other emergency preparedness videos and brochures, and trainings on emergency preparedness and disaster readiness.

Why do you need this information?

The information and trainings will help you become prepared for a disaster so you can leave your home or stay in place in the safest way possible. You can learn how to create a plan, build an emergency kit and stay informed about the types of emergencies that could affect your area—the basics in becoming ready for any disaster.

Who do you need to make contact with?

Visit the Citizen Corps and PrepareDE websites to access the resources. Videos are generally available in English (no captions), English with English captions, and English with Spanish captions; some videos may be available with open captioning and American Sign Language. Call Delaware Citizen Corps if you do not have internet access.

302-659-2243
www.delawarecitizencorps.org
www.preparede.org

Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), Personal Emergency Response System

A Personal Emergency Response System is a device that allows a person who lives alone and is at high risk, because of a health problem or physical disability, to get immediate help in the event of an emergency. DSAAPD provides this service to this high-risk population.

See more DSAAPD information in State Agencies on page 12.

Emergency Preparedness Voluntary Registry

What information do you ask for?

The Delaware '911' emergency system and the Delaware Emergency Management Agency (DEMA) support the Emergency Preparedness Voluntary Registry for citizens who have non-typical functional needs such as people with disabilities, the Amish, those who do not speak English and children in care. Local and state emergency planners and first responders will use the information gathered from this site when responding to '911' calls and to plan for local and state emergencies.



Why do you need this information?

The information you enter about your particular needs will be shared with '911', fire, police and EMT personnel and will be used by emergency planners and first responders in times of crisis.

Who do you need to make contact with?

Visit the website to sign up for the registry. The form is available in English, Spanish and French.

www.de911assist.delaware.gov

Special Needs Alert Program (SNAP)

What information do you ask for?

The Special Needs Alert Program (SNAP) provides the county Emergency Medical Services (EMS) providers and local fire departments with information about children with special health care needs in their area prior to an emergency situation.

Why do you need this information?

When a child is registered in SNAP, EMS providers are alerted that the call is for a SNAP child. If medical information is available, providers will be able to give appropriate emergency care for the child and reduce the level of stress often experienced by the family during an emergency. Participation is free of charge and strictly on a voluntary basis.

Who do you need to make contact with?

Program staff.

302-223-1355

<http://dhss.delaware.gov/dph/ems/emscsnap.html>

EMPLOYMENT

The Arc of Delaware

See the Arc information in Education on page 20.

Autism Delaware, Productive Opportunities for Work and Recreation (POW&R)

What information do you ask for?

Ask for information about helping adults with autism spectrum disorders (ASD) be successful at employment, volunteer opportunities and recreation. POW&R is an Autism Delaware program dedicated to creating safe and sustainable networks that connect individuals to resources that support their choices of how they live, work and play in the community.

Why do you need this information?

POW&R uses a person-centered approach

to promote independence and supportive services for each individual's ability to live, learn, work and play. Services include vocational services, supported employment or self-employment, social and recreational opportunities, volunteerism, community activities and family support.

Who do you need to make contact with?

Contact Autism Delaware for more information about this program.

www.delautism.org/POW&R

New Castle County:

302-224-6020

924 Old Harmony Road, Suite 201

Newark, DE 19713

Kent County:

302-422-2255

P.O. Box 153

Milford, DE 19963

Center for Disabilities Studies at the University of Delaware (CDS)

The Transition, Education and Employment (TEEM) unit conducts programs to help people with disabilities determine employment interests and develop skills for employment.

See more CDS information in Advocacy on page 16.

Division of Vocational Rehabilitation (DVR)

See DVR information in State Agencies on page 14.

Division of Developmental Disabilities Services (DDDS)

DDDS works with the Department of Education and the Division of Vocational Rehabilitation to help students plan for employment upon leaving school. Ask about the supported employment program.

See more DDDS information in State Agencies on page 12.

MEDICAL AND DENTAL PREPARATION AND TREATMENT SERVICES

Practice Without Pressure (PWP)

What information do you ask for?

Ask about the medical, dental and personal care services (e.g. nail and hair grooming) that are provided to people with disabilities of all ages, with individual practice sessions if needed. PWP also offers women's health classes for teens and women with disabilities to prepare them for women's health exams and mammograms.

Why do you need this information?

Individual practice sessions help people with disabilities become familiar and comfortable with dental, medical and personal care procedures, especially if they are fearful of procedures or have traumatic experiences with procedures. Mentor sessions for family members and caregivers help sustain individual success following PWP practice sessions.

Who do you need to make contact with?

Classes and practices are held at PWP and off-site as needed.

302-832-2800
www.pwpde.com
2470 Sunset Lake Road
Newark, DE 19702

POSTSECONDARY EDUCATION

Center for Disabilities Studies at the University of Delaware (CDS)

CDS oversees a UD certificate program for students with intellectual disabilities.

See CDS information in Advocacy on page 16.

Department of Education (DOE), Transition

What information do you ask for?

Ask for information about transition planning to help your student move toward a successful future. The Transition page of the DOE website is a good source of information.

Why do you need this information?

Beginning at least by age 14 or eighth grade, transition planning is a part of every student's IEP process. The IEP team now includes the student as a part of the transition planning team. In addition, any agency representative who may provide and/or pay for transition services becomes a critical member of the planning

team. The areas of employment, post-secondary education or training, community participation and independent living are all to be considered in the transition planning and IEP process.

Who do you need to make contact with?

The transition coordinator in your school district. Visit the website below to view the Transition Staff Directory.

www.doe.k12.de.us/infosuites/students_family/specialized/transition/default.shtml

See more DOE information in State Agencies on page 12.

Colleges and Universities

Delaware's colleges and universities support the rights of students with disabilities to have equal access to education and make every reasonable effort to accommodate the needs of students with disabilities. Information is provided about the department to contact at each institution of higher learning.

Delaware College of Art and Design

Office of Student Services
302.622.8867 ext. 109
www.dcad.edu

Delaware State University

Office of Disabilities Services
302-857-6388
www.desu.edu/office-disabilities-services

Delaware Technical and Community College

Disability Support Services
www.dtcc.edu/disabilityservices

Each campus has an ADA contact to assist students in fulfilling the requirements to obtain reasonable and necessary academic adjustments.

302-571-5323 (Wilmington Campus)
302-855-1681 (Owens Campus, Georgetown)
302-857-1349 (Terry Campus, Dover)
302-454-3927 (Stanton Campus)

Goldey Beacom College

Office of the Dean of Students
302-225-6332
www.gbc.edu

University of Delaware

Office of Disability Support Services
302-831-4643
www.udel.edu/DSS

Wesley College

Disability Support
302-736-2491
www.wesley.edu

Widener Law

Office of Student Affairs
302-477-2173
http://law.widener.edu

Wilmington University

Office of Disability Services
302-356-4636
www.wilmu.edu/studentlife/disabilityservices

PROTECTIVE SERVICES

Child, Inc.

What information do you ask for?

Information about services for children who may be troubled, dependent, neglected and abused.

Why do you need this information?

To get help for children (and their parents) who are involved in domestic violence and other situations that cause children to be troubled and abused. Child, Inc. has programs that protect the victims and treat those responsible for acts of domestic violence. It operates the only children's shelter and runaway center in Delaware; offers parent education programs relating to separation, divorce and visitation; school programs for anger management and preventing dating violence; and family resource programs such as tutoring, literacy and other community-based programs.

Who do you need to make contact with?

Call the statewide hotline that relates to your concerns or the toll-free number for Kent and Sussex Counties.

302-762-6110 (Domestic Violence Hotline)
302-762-6373 (Runaway Youth Hotline)
1-800-874-2070 (Kent and Sussex Counties)
302-762-8989 (Administrative office)
www.childinc.com
507 Philadelphia Pike
Wilmington, DE 19809

Delaware Coalition Against Domestic Violence (DCADV)

What information do you ask for?

Information about domestic violence programs, victims assistance programs and issues relating to domestic violence.

Why do you need this information?

To assure your personal safety and the safety of members of your family. DCADV works to stop domestic violence and encourages victims of abuse to take control over their own lives. Activities include public education efforts, training initiatives and systems advocacy. DCADV works closely with the criminal justice, health care, education, advocacy and social service communities to facilitate the creation of effective policies and programs for battered women and their children.

Who do you need to make contact with?

Call the main number or visit the DCADV website to obtain more information.

302-658-2958

www.dcadv.org

100 W. 10th Street, Suite 903

Wilmington, DE 19801

Division of Family Services (DFS), Foster Care

See DFS, Foster Care in Stage Agencies on page 14.

Division of Family Services (DFS), Office of Children's Services

See DFS, Office of Children's Services in Stage Agencies on page 14.

Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), Adult Protective Services (APS)

What information do you ask for?

Information about services that are available for adults (18 years or over) with a physical or developmental disability who are living in the community and have experienced abuse, neglect or exploitation.

Why do you need this information?

If you are an adult with a physical or developmental disability who has experienced abuse, neglect or exploitation, or you suspect that an adult with a physical or developmental disability has been subject to abuse, neglect or exploitation, the Adult Protective Service Program will respond. A trained social worker will provide assistance to the person in need of protection.

Who do you need to make contact with?

Contact the Division of Services for Aging and Adults with Physical Disabilities during regular business hours (Monday through Friday, 8 a.m. to 4:30 p.m.). Call 911 for after-hours emergencies or at any time when someone is in immediate danger.

1-800-223-9074

See more DSAAPD information at State Agencies on page 12.

People's Place

What information do you ask for?

Ask for information about the SAFE program (Shelter Advocacy Freedom & Empowerment) if you are in a domestic violence situation in Kent or Sussex County. Or ask about other programs that will meet your social and mental health needs.

Why do you need this information?

If you are in a domestic violence situation, SAFE provides a safe environment, shelter and support for you and your children. In addition to providing shelter, family therapy, case management and transition services are provided, helping families to establish a new safe home environment on their own with improved skills and resources.

Who do you need to make contact with?

Call the administrative office for information about all services or one of the SAFE numbers for information about this program.

302- 422-8033 (Administrative office)

302-422-8058 (SAFE in Kent and Sussex Counties)

302-678-3886 (SAFE in Northern Kent County)

www.peoplesplace2.com

1129 Airport Road

Milford, DE 19963

RESIDENTIAL SKILLED NURSING, TRANSITIONAL AND PALLIATIVE CARE

Exceptional Care for Children

What information do you ask for?

Information about long-term skilled nursing care, transition from hospital to home care or palliative care and end-of-life comfort for technology-dependent children and their families. Every child admitted to Exceptional Care for Children must have a skilled nursing need such as a g-tube, tracheostomy, ventilator or central line.

Why do you need this information?

Your child may need temporary or long-term care in a skilled residential setting that provides care for children in a home-like environment.

Who do you need to make contact with?

To speak with someone about an admission, call the Social Services Department.

302-894-1001

www.exceptionalcare.org

11 Independence Way

Newark, DE 19713

SPECIAL NEEDS PLANNING AND GUARDIANSHIP

Families with children and other dependents with disabilities or special needs often need professional guidance on how best to prepare for the future well-being of these dependents. It is important to take steps to make financial plans and resolve guardianship issues when your child is young.

Delaware CarePlan, Inc.

302-633-4000

MetLife Center for Special Needs Planning

Patrick Bergmaier

1-877-638-3375 (MetLife National office)

610-458-8423 (Local office)

www.metlife.com/specialneeds

Nationwide

Diann Jones

302-449-5556

www.specialneedsplanning.org

TRANSITION

As an individual goes through different stages of life, assistance is often needed to assure that each transition is successful. The stages most often identified are birth through age three, three to five, school age (through age 18 or 21) and adulthood. The focus for young adults with disabilities and their parents is on navigating the transitions as they leave school and the pediatric health care system. Planning should begin early to ensure a smooth transition between service systems.

Birth to Three - Child Development Watch program

See *Birth to Three - Child Development Watch program in Early Intervention Resources* on page 19.

Center for Disabilities Studies at the University of Delaware (CDS)

See *CDS information in Advocacy* on page 16.

Delaware Family Voices/Family to Family Health Information Center (DE FV/F2F)

DE FV/F2F provides support and information about medical and insurance transitions.

See *DE FV/F2F information in Advocacy* on page 16.

Department of Education (DOE), Transition

See *Transition information in Postsecondary Education* on page 29.

See *more DOE information in State Agencies* on page 12.

Division of Transition of Care at Alfred I. duPont Hospital for Children

What information do you ask for?

Ask for help with the transition from pediatric health care into adult health care and request a consultation with the Division of Transition of Care. Your child's physicians can request the consultation or you can call on behalf of your adolescent child.

Why do you need this information?

Your child will need to find new adult physicians by the time he is 18 to 21 years of age. Preparation is key to a smooth transition. Your adolescent child can become more involved in his health care and work with Division of Transition of Care staff to develop an action plan.

Who do you need to make contact with?

Division of Transition of Care staff

302-651-5502
1600 Rockland Road
Wilmington, DE 19803

Division of Vocational Rehabilitation

DVR should be contacted by the time a child is 16 years old.

See *DVR information in State Agencies* on page 14.

Parent Information Center (PIC)

PIC provides support to families as they prepare to transition out of the school system.

See *PIC information in Education* on page 21.

TRANSPORTATION

Transportation services in Delaware are provided through public and private agencies. DART provides public transportation services through accessible fixed route and Paratransit buses. The listing in this section includes information on both of these DART services.

DART First State: Delaware Transit Corporation

What information do you ask for?

Information about schedules, routes and accessibility of the fixed route system. Eligibility information and process for Paratransit services, which are provided door-to-door, and the Senior Citizens Affordable Taxi (SCAT) program, which provides a 50% discount on taxi fares for senior citizens and persons with disabilities.

Why do you need this information?

Many fixed route buses now have features to make riding easier for people with disabilities, including wheelchair lifts, kneeling features, large designation signage, low floor buses and bus stop voice announcements. In accordance with the Americans with Disabilities Act, DART Paratransit eligibility is determined based upon a review of an individual's ability to independently navigate the fixed route system and the accessibility of routes and stops to meet the person's transportation needs. SCAT services require you to meet eligibility, which can be determined through an application process.



Who do you need to make contact with?

A customer service representative.

1-800-652-DART (1-800-652-3278)
1-800-252-1600 (TTY)
www.dartfirststate.com

Glossary of Terms

Acquired brain injury (ABI): Occurring after birth, an injury to the brain that is not hereditary, congenital or degenerative. Included are aneurysms, infections of the brain, stroke and accidents that result in traumatic brain injury, or TBI.

Activities of daily living (ADL): Activities include eating, dressing, bathing, using the toilet, getting in and out of bed and getting around inside the house. Assessments are often used to determine an individual's ability to perform such tasks without assistance.

Adaptive behavior: An individual's ability to take care of his or her personal needs and act appropriately in social situations.



Adaptive physical education: Teaching and recreation strategies to help support students with disabilities, allowing them to participate in physical education classes and activities.

Advocate: A person who supports the interests of people with disabilities and speaks on their behalf. To ensure equality for people with disabilities, an advocate takes action to promote the creation, modification or enforcement of laws, policies and procedures.

Age appropriate: Activities, events and materials to which a person is typically exposed at a certain age (e.g., co-ed dances in middle school).

Age norm: The age at which a person typically acquires a certain skill or behavior (e.g., walking or reading).

Americans with Disabilities Act (ADA): Passed in 1990, the primary civil rights law protecting individuals with disabilities. Designed to prevent discrimination in the workplace, improve access to services, and increase participation in local, state and federal governments.

Assessment, testing and evaluation: A process used to collect information and make decisions about a person's development. The information can be used, for example, to determine eligibility for specific programs or services.

Assistive technology: Tools designed to help people with disabilities function more independently and complete everyday tasks (e.g., kitchen utensils with large grips, shower seats or specialized computers).

At risk: Children and adults affected by specific characteristics, behaviors or situations that may cause developmental delays (e.g., poverty).

Attendant services: Programs that provide personal care and support services to people with disabilities, allowing them to live in their own homes and interact with their communities.

Audiology: The study of hearing and hearing disorders.

Baseline: The level of skills demonstrated by a person prior to receiving services or instruction.

Care coordinator: This professional makes it easier for children with special health care needs and their families to connect with appropriate services and resources by coordinating this effort for them. In their important role of providing a medical home for all children, primary care physicians have a vital role in the process of care coordination, in concert with the family.

Case manager: A professional who works at a hospital or for a service delivery provider and has the following responsibilities: assesses a patient's or client's situation and needs; works with a patient or client and the family to develop an appropriate plan of care; and provides ongoing coordination to ensure a patient's or client's needs are met.

Chronic: A condition that is continuous or persistent over an extended period of time.

Cognitive: Pertaining to the mental processes of perception, memory, judgment and reasoning.

Customized employment: Employment that is individually tailored for job seekers who have complex needs and require more individual assistance to achieve their employment goals. The job seeker is the primary source of information and drives the process.

Decubitus: A skin sore caused by unrelieved pressure (also known as ulcer, pressure sore or bedsore).

Developmental disability: The federal definition of a developmental disability covers persons whose disability occurs before age 22 and includes a mental or physical impairment or a combination of both. There must be a substantial limitation in three or more of these major life areas: self-care, expressive or receptive language, learning, mobility, capacity for independent living, economic self-sufficiency or self-direction.

Developmental screening: A procedure designed to identify children who should receive more intensive assessment for potential developmental delays. Screening can allow for earlier detection of delays and improve health and well-being for the children who are identified.

Developmentally delayed: A child who develops cognitive, language, social, physical or sensory skills significantly later than his/her peers.

Durable medical equipment: Includes devices, controls or appliances that enable people to increase their ability to perform activities of daily living.

Early intervention services: Identifying potential developmental delays for children and treating these delays before the age of three.

Early and Periodic Screening, Diagnosis and Treatment (EPSDT): This federal mandate entitles children enrolled in Medicaid to the following services: *early* identification of problems, starting at birth; *periodic* checking of health at age-appropriate intervals; *screening* tests for physical, mental, developmental, dental, hearing, vision, etc.; *diagnostic* tests to follow up when a risk is identified; and *treatment* of the problems found for as long as is medically necessary to correct the condition or prevent worsening of symptoms/ functioning.

Free and appropriate public education (FAPE): The guarantee (included in the Individuals with Disabilities Education Act) that all children with disabilities will receive cost-free, individually designed education between the ages of 3 and 21.

Home care: Provided when an individual needs assistance with daily personal routines and household chores in order to stay in his/her home.

Home health aide: An individual who has received the required number of hours of training about how to provide personal care (dressing, bathing, feeding, etc.). The aide provides the support in the home and is typically, but not always, employed by a home health agency.

Inclusion: The philosophy that people with disabilities should receive all their services and supports in the same settings and locations where people without disabilities live, work, worship, play or go to school.

Individualized Education Program (IEP): A customized written plan for a student with a disability, developed and agreed upon by the student's family, teacher(s), school administrators, therapist(s), other specialists, and whenever possible, the student as well. The IEP, which can be amended at any time, designates specific goals for the student and the supports necessary to meet these goals.

Individualized Family Service Plan (IFSP): A unique plan—designed for a child under 3 years of age and his/her family—that emphasizes positive outcomes and the actions needed to reach them. The plan is developed by the family, early childhood educators and specialists.

Individuals with Disabilities Education Act (IDEA): IDEA was originally enacted by Congress in 1975 to ensure that children with disabilities have the opportunity to receive a free appropriate public education, just like other children. The law has been revised many times over the years. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities. It mandates that eligible children with disabilities between the ages of 3 through 21 receive a free appropriate public education.

Intellectual disability: A disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18.

Learning disability (LD): A learning disability is more than a difference or difficulty with learning—it is a neurological disorder that affects the brain's ability to receive, process, store and respond to information. It can make it difficult to acquire certain academic and social skills. It does not include learning problems that are primarily the result of visual, hearing or motor disabilities.

Least restrictive environment (LRE): An educational setting for a student with a disability that mirrors, as closely as possible, a general educational setting while providing the supports necessary to meet the student's goals and objectives.

Level of Care (LOC): Typically one of three levels (low, moderate or high) of support that determines the frequency and intensity of services necessary for a person with a disability to meet his or her goals.

Long-term care: This term is used to describe various home and community-based services for people who need help taking care of themselves. Long-term care can be provided in a variety of settings, including the home, a day program, assisted living facility, etc.

Mainstreaming: The time a person with a disability spends participating in activities alongside children or adults without disabilities in a school or community center setting.

Managed Care Organization (MCO): Managed care is an organized way to ensure that people receive the quality medical care they need in the most cost-effective manner. A managed care organization is a public or private organization that makes health care services available to enrolled participants. In Delaware, Medicaid benefits are provided mainly through a managed care organization. The Division of Medicaid and Medical Assistance offers a choice of MCOs to allow people to select the plan that is best suited to their needs

Medical home: In a family-centered medical home, the pediatric care team works in partnership with the child and his/her family to assure that all of the medical and non-medical needs of the patient are met. Care in a medical home is accessible, continuous, comprehensive, patient- and family-centered, coordinated, compassionate and culturally effective.

Mental age: It represents the level of thinking and reasoning an individual exhibits based on an assessment by a psychologist or educational diagnostician. Since mental ability is derived from more than just measures of age, the term should be used cautiously (e.g., the phrase “she has a mental age of 3 years” is rarely accurate).

Mental health disorder: The absence of emotional and psychological well-being; an individual has difficulty using cognitive and emotional capabilities, functioning in society, and/or meeting the ordinary demands of everyday life.

Motor development: The skills needed to effectively move around one's environment (gross motor skills) and to pick up, release and use objects (fine motor skills).

Occupational therapy: Therapy services that help a person to develop daily living and fine motor skills, such as writing, dressing and using utensils.

Ombudsman: An impartial person who advocates on behalf of a consumer and will investigate complaints and provide representation, education, information and other assistance for the individual.

Paratransit: Transportation provided by the local transit authorities for those who are unable to use the regular fixed-route service safely. The Americans with Disabilities Act includes guidelines about who is eligible to utilize paratransit.

Patient- and/or family-centered care: A trusting, collaborative, working partnership with families, respecting their diversity and recognizing that they are the constant in a child's life.

People-first language: People-first language puts the person before the disability and describes what a person has, not what a person is. (e.g. a person with autism, not an autistic person).

Physical therapy: Therapy services that help a person develop control over large muscle groups and improve movement (such as walking or sitting).

Placement: In the realm of education, the classroom or setting where a student receives schooling or IEP services.

Prescribed Pediatric Extended Care (PPEC): Out-patient health care service prescribed by a physician for children who are medically and/or technologically dependent. Included are services focused on meeting the physiological as well as developmental, physical, nutritional and social needs of the children served.

Respite care: A service for families that provides short-term (a few hours) or longer-term (a week or more) relief from caring for a person with a disability. These services may take place in the family's home or in outside programs.

Self-advocate: A person with a disability who takes responsibility for his/her life. Self-advocates know their rights and stand up for these rights, helping to change unjust policies and procedures while bringing about positive change for themselves and others.

Self-determination: This practice supports people with disabilities in choosing their own life goals, the people who will provide support in achieving these goals, and the way in which the goals will be accomplished.

Service companion: A person who assists an individual with social and recreational activities and safety. According to current state regulations, the companion cannot provide personal care.

Service coordinator: A professional who assists families in finding, securing and monitoring the services necessary to support family members with disabilities.

Service provider: This term generally refers to agencies and individuals certified and selected to provide day and residential services for people with intellectual and developmental disabilities.

Skilled level of nursing: Skilled nursing services are services ordered by a doctor that require the skills of a licensed nurse and must be provided directly by or under the general supervision of the nurse to assure the safety of the patient and to achieve the medically desired result. The skilled need, physician's recommendations and insurance coverage are all considered when deciding on the level of care and support an individual may receive.

Social and emotional wellness: The social and emotional wellness of a child is shaped by secure relationships with his/her primary caregivers in nurturing environments. Social and emotional wellness in a child from birth to 5 years is reflected through healthy attachments and the ability to confidently explore, regulate and express emotions in natural settings.

Special education services: In accordance with IDEA requirements, special education is in place to provide additional services, supports, programs and specialized placements or environments to ensure that the educational needs of all students are met. Special education services are provided to qualifying students at no cost to the parents. The range of special

Natalye Madric & Tayla Robeson



Understanding the medical terms used by doctors and therapists and the complexity of the social service system can be overwhelming. Learning about the complex needs of a child with a disability or special health care needs can be compared to learning a new language. After the premature birth of her daughter, Tayla, Natalye Madric learned everything she could about Tayla's needs and the services available to her. Natalye now works to teach other families what she has learned.

Born 16 weeks early, Tayla Robeson weighed only 1 pound 4 ounces. She was

diagnosed with hydrocephalus and was placed in the neonatal intensive care unit at Christiana Hospital. She later transferred to Nemours/Alfred I. duPont Hospital for Children where she underwent brain surgery. When she was discharged after a month, Tayla left the hospital on a ventilator and required nursing care and therapies at home.

Tayla had several brain surgeries and an eye muscle surgery throughout the first few years of her life; she was also diagnosed with cerebral palsy. She received services and therapies through Delaware's Early Intervention System

Child Development Watch (CDW), a program that helps improve the development of infants and toddlers with disabilities or developmental delays and provides supports to families to help their children develop to their fullest potential. Tayla then transitioned from CDW to preschool at the Early Learning Center (ELC) at the University of Delaware, where she was in an inclusive classroom and received occupational, physical and speech therapy. She then enrolled in kindergarten at a public school.

Natalye stresses that perseverance is critical in navigating services. "You don't know unless you ask," she says, "Don't be embarrassed to ask questions. If you don't understand a word used, ask for clarification. This will help you find the best supports for your family." One of the resources she found that answered many of her questions is the Disabilities Law Program of the Community Legal Aid Society, Inc. Natalye also found that searching the Internet for information was helpful, especially when she needed to find updated contact information for service providers. Keeping detailed documentation is important as well, and Natalye keeps binders of information related to Tayla's medical and educational needs.

Natalye began working as a teacher at the Early Learning Center in May 2010 and enjoys spending time with young children. Earlier, she had put her career and education on hold to take care of Tayla until she turned three. Inspired by everything she has done to help her daughter, Natalye plans to return to school for a degree in nursing and a masters degree in special education. She also has taken the knowledge she has gained to help other families. She is doing this through involvement with March of Dimes and the Parent Information Center (PIC), where she completed an internship with the PIC of Delaware's Family Leadership Academy. She hopes that sharing her story will help other families understand the resources that are available and the best way to advocate for their children.

education support varies based on need and educational jurisdictions, but must meet the goals and objectives of an eligible student's IEP. Eligibility is determined through educational testing that must be requested in writing by the parent or guardian.

Speech-language therapy: Therapy services that focus on the diagnosis and treatment of speech and communication disorders.

Support services: In educational settings, services (such as transportation, therapies and medical services) that allow a student with a disability to participate in school.

Supported employment: Supported employment helps individuals with the most severe disabilities, for whom competitive employment has not traditionally occurred, to engage in competitive work in an integrated work setting (a community setting that employs individuals with and without disabilities). Ongoing support services, such as job coaches, transportation, assistive technology, specialized job training and individually tailored supervision, allow these individuals to perform their jobs.

Universal design: Products, building and services that are designed so that all people, including those with any type of disability, can use them.

Vocational rehabilitation: The Division of Vocational Rehabilitation (DVR) is the state's public program that helps people with physical and mental disabilities obtain or retain employment.

Waiver: States can use a waiver to request that the federal government remove certain federal restrictions on how Medicaid dollars are spent. For example, a waiver can allow the state to use Medicaid funding in a more flexible way to pay for home-based services for a specific population as an alternative to institutionalized care.

Acronyms

Delaware Agencies and Programs

AAR	Adult Abuse Registry
ADRC	Aging and Disability Resource Center
APS	Adult Protective Services
CHIP	Children's Health Insurance Program
CLIMB	Consortium Leadership and Independence through Managing Benefits
DART	Delaware Authority for Regional Transit
DDC	Developmental Disabilities Council
DDDS	Division of Developmental Disabilities Services
DEMA	Delaware Emergency Management Agency
DFS	Division of Family Services
DHSS	Department of Health and Social Services
DLTC	Division of Long Term Care
DMMA	Division of Medicaid and Medical Assistance
DODHH	Delaware Office for the Deaf and Hard of Hearing
DOE	Department of Education
DOL	Department of Labor
DPAP	Delaware Prescription Assistance Program
DPBHS	Division of Prevention and Behavioral Health Services
DPC	Delaware Psychiatric Center

DPH	Division of Public Health
DSAAPD	Division of Services for Aging and Adults with Physical Disabilities
DSAMH	Division of Substance Abuse and Mental Health
DSBA	Delaware School Boards Association
DSCYF	Department of Services for Children, Youth, and Families (The Delaware Children's Department)
DSEA	Delaware State Education Association
DVI	Division for the Visually Impaired
DVR	Division of Vocational Rehabilitation, also known as VR
DYRS	Division of Youth Rehabilitative Services
ECAP	Early Childhood Assistance Program
ECT	Exceptional Children Team
EDTAC	Elderly and Disabled Transit Advisory Committee
EIC	Education Improvement Commission
EPPC	Educational Planning and Placement Committee
FCRB	Foster Care Review Board
GACEC	Governor's Advisory Council for Exceptional Citizens
ICC	Interagency Coordinating Council (for Infants and Toddlers)
ICCF	Interagency Council for Children and Families
ICT	Interagency Collaborative Team

ISI	Inclusive Schools Initiative
SCPD	State Council for Persons with Disabilities
SNAP	Special Needs Alert Program
STEPS	Sequenced Transition to Education in the Public Schools

Delaware Disability-related Organizations

AAB	Architectural Accessibility Board
AD	Autism Delaware
The Arc	The Arc of Delaware
CAP	Client Assistance Program
CDS	Center for Disabilities Studies
CERTS	Collaborative Efforts to Reinforce Transition Success
CFF	Children and Families First
CCCD	Coordinating Council for Children with DisAbilities
CLASI	Community Legal Aid Society, Inc.
CODHHE	Council on Deaf and Hard of Hearing Equality
CQSE	Center for Quality Special Education
DADB	Delaware Association for Deaf/Blind
DAP	Delaware Autism Program
DATI	Delaware Assistive Technology Initiative
DE CEC	Delaware Council for Exceptional Children
DE FV/F2F	Delaware Family Voices/ Family to Family Health Information Center

DeIARF	Delaware Association of Rehabilitation Facilities
DFRC	Delaware Foundation Reaching Citizens with Intellectual Disabilities
DLP	Disabilities Law Program
DSA	Down Syndrome Association of Delaware
DSPAC	Delaware State Parent Advisory Committee
Early CHOICES	Children Having Options in the Continuum of Educational Services
F2F	Delaware Family to Family Health Information Center
Family SHADE	Family Support and Healthcare Alliance Delaware
FCIL	Freedom Center for Independent Living
HLAA	Hearing Loss Association of America
HLADE	Hearing Loss Association of Delaware
IRI	Independent Resources, Inc.
PIC	Parent Information Center of Delaware
MHA	Mental Health Association of Delaware
NAMI-DE	National Alliance on Mental Illness, Delaware Chapter
PAC	Parent Advisory Committee
PAT	Parents as Teachers
PEEC	Parent Early Education Center
UCP	United Cerebral Palsy

Disability-related Terms

AAC	Augmentative and Alternative Communication
ACA	Patient Protection and Affordable Care Act
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
AMD	Adaptive Mobility Device
ASL	American Sign Language
AT	Assistive Technology
BIP	Behavior Intervention Plan
CAP	Corrective Action Plan
CART	Communication Access Realtime Translation
CAS	Comprehensive Assessment System
CASA	Court Appointed Special Advocate
CFR	Code of Federal Regulations
CM	Case Manager
CNA	Certified Nursing Assistant
COPM	Coordinator of Planning and Monitoring
CSHCN	Children with Special Health Care Needs
CSPD	Comprehensive System of Personnel Development
CST	Child Study Team
CSW	Clinical Social Worker
CYSHCN	Children and Youth with Special Health Care Needs
DCAS	Delaware Comprehensive Assessment System
DCAS-Alt1	Delaware Comprehensive Assessment System Alternate Assessment



DME	Durable Medical Equipment
DSP	Direct Support Professional
ED	Educational Diagnostician
EI	Early Intervention
ELL	English Language Learners
ELP	Essential Lifestyle Plan
EMS	Emergency Medical Services
EMT	Emergency Medical Technician
EPSDT	Early Periodic Screening, Diagnosis and Treatment
ESL	English as a Second Language
ESY	Extended School Year for Special Education Services
FAPE	Free Appropriate Public Education
FBA	Functional Behavior Assessment
FERPA	Family Educational Rights and Privacy Act

FQHC	Federally Qualified Health Centers	LMN	Letter of Medical Necessity	PPEC	Prescribed Pediatric Extended Care
FTE	Full Time Equivalent	LOF	Letter of Finding	PT	Physical Therapist/Therapy
GCS	Glasgow Coma Score	LOP	Local Operational Plan	PWD	Person with a Disability
HHA	Home Health Aide	LRE	Least Restrictive Environment	RTC	Residential Treatment Center
HIPAA	Health Insurance Portability and Accountability Act	MBI	Medicaid Buy-in	SEA	State Educational Agency
ICAN	Increasing Capabilities Access Network	MCO	Managed Care Organization	Section 504	Section 504 of the Rehabilitation Act of 1973 (the section that concerns non-discrimination)
ICAP	Inventory for Client and Agency Planning	MDT	Multi-Disciplinary Team	SEEDS	Special Education Effectiveness Development System
ICAS	Inclusive Comprehensive Assessment System	MFP	Money Follows the Person	SES	Special Education Services
IDEA	Individuals with Disabilities Education Act	MOA	Memorandum of Agreement	SIG	State Improvement Grant
IDEALR	Individuals with Disabilities Education Act Law Review	MOE	Maintenance of Effort	SLP	Speech-Language Pathologist
IEE	Independent Educational Evaluation	MOU	Memorandum of Understanding	SIP	State Improvement Plan
IEP	Individualized Educational Program	MOVE	Mobility Opportunities Via Education/Experience Curriculum	Sped	Special Education (sometimes written as "Special Ed." or "Spec. Ed.")
IFSP	Individualized Family Service Plan	MSW	Masters in Social Work	TDD	Telecommunications Device for the Deaf
IIP	Individual Improvement Plan	NPA	Nurse Practices Act	TPR	Termination of Parental Rights
ILC	Intensive Learning Center	OT	Occupational Therapy/Therapist	TTY	Text Telephone (for the hearing impaired)
IPRD	Identification, Placement, Review, Dismissal	Part B	Public law that authorizes assistance for the education of all children	UDL	Universal Design for Learning
IQ	Intelligence Quotient	Part C	Public law that authorizes early intervention programs for infants and toddlers with disabilities (formerly Part H)	Vo-Tech	Vocational-Technical School or Program
ISIS	Integrated Services Information System	P&A	Protection and Advocacy	WISC	Wechsler Intelligence Scale for Children
IST	Instructional Support Team	PAS	Personal Assistance Services		
JPIP	Junior Partners in Policymaking	PASS	Plan to Achieve Self-Sufficiency		
LCCE	Life Centered Career Education	PBS	Positive Behavior Support		
LEA	Local Educational Agency	PCA	Personal Care Attendant		
LEP	Limited English Proficiency	PCIP	Pre-existing Condition Insurance Plan		
		PIP	Partners in Policymaking		
		POC	Purchase of Care		

Disabilities and Special Health Care Needs

ABI	Acquired Brain Injury
ADD/ ADHD	Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder
AIDS	Acquired Immune Deficiency Syndrome
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
AU	Autism
CF	Cystic Fibrosis
CP	Cerebral Palsy
DB	Deaf/Blind
DD	Developmental Disability or Developmentally Delayed
DS	Down Syndrome
FASD	Fetal Alcohol Spectrum Disorder (includes FAS - fetal alcohol syndrome, ARND - alcohol related neurodevelopment disorder and ARBD - Alcohol-Related Birth Defects)
HI	Hearing Impaired
ID	Intellectual Disability
LD	Learning Disability
MH	Mental Health
MI	Mental Illness
MS	Multiple Sclerosis
NTD	Neural Tube Defect
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiant Disorder
OI	Osteogenesis Imperfecta

PDD	Pervasive Developmental Disorder
SB	Spina Bifida
SCI	Spinal Cord Injury
SED	Severely Emotionally Disturbed
SEM	Social/Emotional Disability
SLD	Specific Learning Disability
SLI	Speech and Language Impaired
TBI	Traumatic Brain Injury
VI	Visually Impaired

National Organizations

AAIDD	American Association on Intellectual and Developmental Disabilities (formerly AAMR—American Association on Mental Retardation)
ACB	American Council for the Blind
ASDC	American Society for Deaf Children
AUCD	Association of University Centers on Disabilities
BIA	Brain Injury Association
CCD	Consortium for Citizens with Disabilities
CEC	Council for Exceptional Children
CHADD	Children with Attention Deficit Disorder
NACDD	National Association of Councils on Developmental Disabilities
NAMI	National Alliance on Mental Illness



NASDSE	National Association of State Directors of Special Education
NASDTEC	National Association of State Directors of Teacher Education and Certification
NCATE	National Council for Accreditation of Teacher Education
NCD	National Council on Disability
NCIL	National Council on Independent Living
NDCCD	National Dissemination Center for Children with Disabilities
NFCA	National Family Caregivers Association
NFV	National Family Voices
NICHCY	National Dissemination Center for Children with Disabilities
NORD	National Organization for Rare Disorders

STOMP Specialized Training of Military Parents

UCPA United Cerebral Palsy Associations

Federal Agencies and Programs

ACF Administration on Children and Families

ADD Administration on Developmental Disabilities

ATBCB Architecture and Transportation Barriers Compliance Board

CDC Centers for Disease Control and Prevention

CMS Centers for Medicare and Medicaid Services

HHS United States Department of Health and Human Services

DOJ United States Department of Justice

DOL United States Department of Labor

ED United States Department of Education

EEOC Equal Employment Opportunity Commission

HUD Department of Housing and Urban Development

JAN Job Accommodation Network

MC&FP Military Community and Family Policy

MCHB Maternal and Child Health Bureau

NCSET National Center on Secondary Education and Transition

NIDRR National Institute on Disability and Rehabilitation Research

OCR Office of Civil Rights

OSEP Office of Special Education Programs

OSERS Office of Special Education and Rehabilitation Services

PCEPD President's Committee on Employment of People with Disabilities

PCPID President's Committee on People with Intellectual Disabilities

RSA Rehabilitation Services Administration

SSA Social Security Administration

SSDI Social Security Disability Insurance

SSI Supplemental Security Income

TANF Temporary Assistance for Needy Families (formerly AFDC)

TEFRA Tax Equity Fiscal Responsibility Act

TWIIA Ticket to Work Incentive and Improvements Act

VAMC Veterans Administration Medical Center

WIC Women, Infants and Children



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My Notes



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