CONNECTING THE DOTS...

A guide to finding services
for people with disabilities
in Delaware





First Steps

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Where to turn? What to do? The purpose of this booklet is to help anyone with a newly diagnosed disability to find supports and services. This guide is meant to help you identify the first steps to take to find the supports and services you and your family members may need.

Remember: You are not alone. There are people willing and able to help you. Help may be by way of informing you of services you are qualified for or by the support of another person who has gone through this before, providing emotional support and advice.

Hearing about your or a family member's disability time after time can be overwhelming. You may not know where to begin and yet so much needs to happen. This guide is meant to help you begin to navigate what may seem like a maze of services and supports. Being prepared and equipped with the right questions to ask and getting explanations about services can be your first steps toward positive results.

This booklet is divided into categories of services you may need including medical, financial, assistive technology, legal, education, caregiving, and advocacy resources. Also included is a glossary of terms and a list of abbreviations that will help familiarize you with commonly used terminology.



First: Educate Yourself

Get prepared. Begin by gaining a thorough knowledge of your or your family member's disability and how to work within the system of services. Knowing about the disability can help you gain some level of control over a situation that can often feel overwhelming and confusing. Knowledge is power, but be careful not to become weighed down by the avalanche of available information. Take your time to go through the information you find until you understand it. Do not be afraid or embarrassed to ask for help. This is a sign of strength and will help to ensure that you will locate the appropriate services.

Find out as much as you can about the disability. Search the Internet and contact national and local organizations and support groups. Ask your physician for information and if he/she can refer you to a specialist. Other families with experience with the same diagnosis/disability can give you additional insight and emotional support.

Caution: Always check out the information you receive with another source or person. As much as it is necessary to talk with other families in similar circumstances, do not make major decisions without thoroughly investigating first. For example: do not sell your home because someone said it is the only way to qualify for Medicaid.

Insurance

Find out what insurance coverage you have or are eligible for and the type of benefits it covers. Does it cover speech therapy, physical therapy, occupational therapy, home care, durable medical equipment, nursing visits, mental health services, and the types of supports your physicians, therapists, and specialists have said you or your family member will need?

The Doctor's Office

At the doctor's office come prepared with a list of written questions. Prioritize your concerns in case the doctor is unable to address all of them. Ask when he/she can discuss your concerns. Do not put on a brave face to your doctor. Doctors and their staff are the ones who complete paperwork when requesting medical equipment and/or services. They will inform insurance companies and agencies about any equipment, medical supplies, therapies, nursing visits, or other home care you may need. The necessary documentation when a prescription is needed is provided by the doctor's office. It is so important to communicate with your doctor so he/she can get a clear picture of what you need.

REMEMBER—You are the person responsible for communicating and explaining to your doctors what you need. Follow your instincts. No one knows 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 healthcare team. Demonstrating an objective view of your loved one's needs and abilities along with knowledge of the disability will help validate you as a valued member of the team. Then, when you make a request on behalf of your family member, doctors and other professionals will be more likely to hear your requests.

Getting Started

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





HINT—It is most important to remember that when you find the courage to express yourself in an honest and thoughtful manner you also do so as calmly and clearly as possible. It takes great stamina to share your concerns and to do so in a way that can be heard by others.

Following Up

Remember when making phone calls and/or talking with your healthcare professional:

- Do not make assumptions before you gather your facts. While you need to become knowledgeable about the disability, realize that much information on the Internet may have a slanted view depending on the source. Try to validate the information you find from at least one additional source.
- Write down your questions in a clear and succinct manner whenever you will be talking with a physician, therapist, or other service provider.
- Take notes. It is important to date the notes and document to whom you are speaking as well as the subject you discuss.
- Maintain a calm manner whenever possible. When strong emotions accompany your questions, sometimes physicians and other professionals hear only the emotion and not the content for which you are asking.
- 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 to inviting a mutually respectful relationship with healthcare and service professionals.

That First Call— Then All the Ones That Will Follow

In this booklet, you will find many of the agencies and programs in Delaware that are the logical first steps to contact as you search for information and services you may need. Here are some suggestions about how to make the most of your phone calls.

1: Prepare yourself to make the call:

- Make calls when you have time to talk, when you have paper and pen available, and when you are not rushed to meet some other demand.
- Always ask the name of the person with whom you are speaking.
- When calling an agency, tell your story as clearly and as succinctly as possible.
- Document all phone calls, information, and promises of services discussed.

- Ask the person you are talking with to tell you about the services and supports provided by the program or agency; avoid phrasing questions that can be answered with a "yes" or "no".
- Ask about eligibility for services and if your loved one might be eligible through more than one category or program.
- If an agency representative says he/she will call back, ask when; if he/she does not return your call, call again.
- Realize that sometimes it will take many calls to find out what you need.
- Ask for any brochures or written policies about the agency's services.
- Ask if there is a website address for the agency or services.
- Most of all—do not give up! If told "no," then ask where you can call to get what you need. Be persistent but not combative. You have the right to information and respectful service.

2: When contacting an agency, group your needs and concerns into clear categories:

- Who will pay for ...?
- How do I get transportation?
- How do I get the therapies needed?
- How can I get help in my home?
- How can I make my home more accessible?
- Are there waiting lists for specific services?
- How do I qualify for services? Is there a cost for services? While fees for some services are based on income eligibility, other services may be provided at no cost and some may always be at a cost. Asking about fees will help you plan.

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 your loved one's disability and needs so you can better answer 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?
- Know what financial resources and insurance options are available to you.
- Be prepared to answer questions the agency needs to assist you with the correct services:
 - How much care is needed?
 - Does your loved one require a nurse?
 - Is there a ventilator? Wheelchair? Etc.?
 - Does he/she need assistance with dressing or bathing?
- Whether he/she qualifies for long-term nursing care does not mean he/she has to go to a nursing home. If he/she meets the criteria for a nursing home then he/she meets the criteria for certain help at home.
- Keep records of doctors' names and numbers, names and doses of medications, the diagnoses, hospitalizations, and names of any agencies with which your family member has been registered.

HINT—Learn the terminology used by agencies. Do not be afraid or embarrassed to ask the meaning of terms unfamiliar to you. Asking for explanations or definitions demonstrates a desire for knowledge and encourages those you are speaking with to help you.

Finally: Redefining Normal

Life may feel like it has been turned upside down for you and your family. In time and after new routines are established and services and supports have been found that meet your loved ones needs, you will find that a new routine of normalcy returns to your household.

Caregiving

You may have just taken on one of the many roles of a caregiver. When providing care for someone else, the emotional and physical strain is significant. 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 yourself. Recognize your own strengths and limitations and ask for help when you need it.

Attitude: Some words of advice

Be prepared—don't make calls when you are rushed. Have paper and pen and a reasonable amount of time. Don't give up. You have the right to information and respectful service. Be persistent and patient. Realize that sometimes it will take many calls to find out what you want. No one person or organization has all the answers.

Document all phone calls, information, and promises received. Always ask the name of whom you are speaking with. Don't take "no" for an answer. Be persistent not combative. Try to remember you catch more flies with honey. If your level of frustration is high try making the call another day when you are refreshed and reenergized. When calling an agency tell your story as succinctly as possible. Think ahead of time what services you may need. Ask if there are waiting lists for specific services and how long it might be. Ask for an assessment to be done in person of your loved one to find out about qualifying for services. Is there a cost for their services? Income is sometimes irrelevant for receiving help; do not assume you will be denied services.

Learn the terminology. (See glossary on page 10.) Don't be afraid or embarrassed to ask the meaning of terms unfamiliar to you. When making calls, avoid phrasing questions that will elicit a "yes" or "no" answer. Ask if your loved one falls into more than one category as a way to tap into another source.

A good attitude impacts action. A positive attitude goes a long way, for yourself and your loved one. You will be more capable of proactive action on his/her behalf. Try not to put people on the spot; it makes them defensive. Try to enlist their support.

HINT—Do not be misled by agency names. The names of agencies 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 or your loved one's disability. They might surprise you with a "yes" or be able to provide you with other resource options. If told "no," then ask where you can call to get what vou need.



Agencies

Medical & Health Resources

Some state and federal agencies provide medical and health services for children and adults with disabilities in Delaware. The Department of Health and Social Services houses the Divisions of Developmental Disabilities Services, Medicaid & Medical Assistance, Public Health, Services for Aging and Adults with Physical Disabilities, Substance Abuse and Mental Health, and the Visually Impaired. The Department of Services for Children, Youth, and Families provides mental health and substance abuse services to children in Delaware. Your doctor may recommend additional services, including rehabilitation hospitals and home healthcare. These services are typically provided by private agencies; request a list of available options from your healthcare provider.



Division of Developmental Disabilities Services (DDDS)

Woodbrook Professional Center 1056 South Governor's Avenue Suite 101 Dover, DE 19904 (302) 744-9600 www.dhss.delaware.gov/dhss/ddds

What information do you ask for? Information about community-based services, case management, early intervention services, and community education and advocacy.

Why do you need this information? 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.

Division of Medicaid and Medical Assistance (DMMA)

The Lewis Building 1901 N. DuPont Highway, P.O. Box 906 New Castle, DE 19720 (302) 255-9500 (800) 996-9969 www.dhss.delaware.gov/dhss/dmma/

What information do you ask for? The following services are available through the Division of Medicaid & Medical Assistance: Medicaid Assistance Programs, Medicaid, Healthy Children (CHIP), Prescription Assistance (DPAP), Long Term Care, Home & Community Based Services, Cancer Coverage, Transportation, and Chronic Renal Disease.

Why do you need this information? Medicaid provides payment for healthcare to low-income families, aging, 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. Other medical services are also available for individuals.

Who do you need to make contact with? A health benefits manager.

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

1901 N. DuPont Highway Main Building New Castle, DE 19720 (302) 255-9390 (800) 223-9074 (302) 453-3837; (302) 422-1415 www.dhss.delaware.gov/dhss/dsaapd

What information do you ask for? Services for adults with physical disabilities are listed in DSAAPD's Guide to Services for Persons with Disabilities in Delaware. This guide can be viewed in the publications section of this website. If you have trouble accessing this document, or if you would like to get copies, please contact DSAAPD and a staff person will assist you.

Why do you need this information? The Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) provides a broad range of programs and services in Delaware. Services and programs operated or funded by DSAAPD include: adult day services, adult foster care, Alzheimer's day treatment, assisted living, assistive devices, attendant services, case management, Delaware Passport to Independence, home modification, legal services, long-term care ombudsman program, Medicaid waiver for the elderly and disabled, medical transportation, personal care, and respite care.

Who do you need to make contact with? A case manager or social worker.

Division of Substance Abuse and Mental Health (DSAMH)

1901 N. Du Pont Highway New Castle, DE 19720 (302) 255-9399 Emergency Crisis: (800) 652-2929 www.dhss.delaware.gov/dhss/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? Call and ask for an intake coordinator in your local area.

Division for the Visually Impaired (DVI)

New Castle County: 1901 N. Du Pont Highway Biggs Building New Castle, DE 19720 (302) 255-9800

Kent and Sussex Counties: Milford State Service Center Annex 13 SW Front Street Milford, DE 19963 (302) 424-7240

www.dhss.delaware.gov/dhss/dvi/ index.html

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? To allow a person with a vision disability to achieve the highest level of independence that he/she wants to achieve.

Who do you need to make contact with? Call your local number and request to speak with an intake representative.

Birth to Three—Child Development Watch program

Division of Public Health New Castle County: 2055 Limestone Road Wilmington, DE 19808 (302) 995-8632 (800) 671-0500 Kent and Sussex Counties: 18 N. Walnut Street Milford, DE 19963 (302) 424-7300 (800) 752-9393

www.dhss.delaware.gov/dhss/dph/chs/ chscdw.html

What information do you ask for? Child Development Watch is the statewide early intervention program for children ages birth to 36 months. Child Development Watch helps you answer the question, "Is my child growing like other children?"

Why do you need this information? 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 an appointment or information, call or use the website to locate the clinic or service center nearest you.

Department of Services for Children, Youth, and Families (DSCYF)

Division of Child Mental Health Services (DCMHS) Department of Services for Children, Youth, and Families 1825 Faulkland Road Wilmington, DE 19805 (302) 633-2571 (800) 722-7710

Twenty-four hour crisis line: New Castle County (North of the C&D Canal): (302) 633-5128

New Castle County (South of the C&D Canal): (800) 969-HELP (4357)

Kent & Sussex Counties: (302) 424-HELP (4357)

www.state.de.us/kids/cmhs/cmhs.shtml

What information do you ask for? The Division of Children's Mental Health

Services (CMH) provides voluntary services to children up to age 18 and their families for children who have mental health or substance abuse problems. They respond to all child mental health emergencies.

Why do you need this information? CMH 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, there is a number of out patient facilities located in each county. Use the main number to make contact with your local office for information for outpatient service providers in your community. Use the crisis lines for emergency services.

Financial & Insurance Resources

The following federal and state agencies provide financial assistance to individuals with disabilities. Eligibility requirements and applications for the different programs vary. If you have private insurance, contact your insurance company and request to speak with a case manager about the benefits you have.

Social Security Administration

National: Office of Public Inquiries Windsor Park Building 6401 Security Boulevard Baltimore, MD 21235 (410) 965-2736

Local Offices: 920 W. Basin Road, Suite 200 New Castle, DE 19720 (302) 323-0304

500 W. Loockerman Street, Suite 100 Dover, DE 19904 (302) 674-5162

600 N. Dupont Highway Suite 202 Prof Park Georgetown, DE 19947 (302) 856-9620

Toll free numbers: (800) 772-1213 (800) 325-0778 TTY

www.ssa.gov/ or www.ssa.gov/phila/index.htm What information do you ask for? Social Security Disability Insurance (SSDI) provides benefits to people with disabilities who are "insured" by workers' contributions to the Social Security trust fund. An adult disabled before age 22 may be eligible for child's benefits if a parent is deceased or receiving retirement or disability benefits. The Supplemental Security Income (SSI) program makes cash assistance payments to people with disabilities, aged, and 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. For information about medical and financial eligibility requirements for SSI and SSDI, to apply for benefits, or ask any questions about services, contact your local office or the toll-free number.

Who do you need to make contact with? Your local Social Security Administration representative.

Division of Social Services (DSS)

The Lewis Building 1901 N. DuPont Highway, P.O. Box 906 New Castle, DE 19720 (302) 255-9500 (800) 372-2022 www.dhss.delaware.gov/dhss/dss/

What information do you ask for? The Division of Social Services (DSS) is directly responsible for administering Delaware's Temporary Assistance for Needy Families (TANF), Food Stamps, Subsidized Child Care, General Assistance, and Refugee Cash Assistance. The DSS website has a form that lets you see if your household is potentially eligible for Delaware's social service programs. You can then apply for these services online. ASSIST helps you submit an application and gives you additional information to complete the process.

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 criteria varies from program to program.

Who do you need to make contact with? Use the main number to connect with a local representative.

Assistive Technology/ Home Modifications

Assistive technology (AT) is broadly defined as any device that assists persons with disabilities. A variety of agencies provide AT services in Delaware, including the Delaware Assistive Technology Initiative, which can provide information and referral services for assistive technology and funding. Other agencies provide AT and home modifications as a component of their service delivery.

Delaware Assistive Technology Initiative (DATI)

University of Delaware/ Alfred I. DuPont Hospital for Children P.O. Box 269 1600 Rockland Road, Room 200 Wilmington, DE 19899 (302) 651-6790 (800) 870-3284 (302) 651-6794 TDD www.dati.org

What information do you ask for? Ask for information on funding, upcoming workshops, no-cost equipment loans, technical assistance regarding device selection, the Equipment Exchange Program, and quarterly newsletter.

Why do you need this information? To help connect you with tools needed to learn, work, play, and participate in community life safely and independently.

Who do you need to make contact with? Call or use the website to connect with an AT specialist in your area.

Department of Education (DOE)

Children with disabilities who need supports in order to participate in education services may be eligible for assistive technology (AT) devices and services. These AT services may be eligible to you or your family member through the Individuals with Disabilities Education Improvement Act (IDEA), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990. See DOE under Education for contact information on page 7.

Division for the Visually Impaired (DVI)

The Division for the Visually Impaired (DVI) provides various types of low-cost technology devices and training in the use of many other types of equipment to people of all ages with visual impairments.

See DVI under Medical & Health Resources for contact information on page 5.

Division of Vocational Rehabilitation (DVR)

4425 North Market Street P.O. Box 9969 Wilmington, DE 19809

Wilmington Office: (302) 761-8300 New Castle Office: (302) 326-8930 Newark Office: (302) 368-6980 Middletown Office: (302) 378-5779 Dover Office: (302) 739-5478 Georgetown Office: (302) 856-5730 www.delawareworks.com/dvr/ welcome.shtml

What information do you ask for? DVR services include goods or services that are required to assist an individual with a disability to obtain or retain employment. This includes assessment, counseling and guidance, information and referral, physical/mental restoration services, rehabilitation technology, skill training, job placement assistance, interpreter services, supported employment services, and other services. State vocational rehabilitation agencies are often a major funding source of AT for workingage individuals with disabilities.

Why do you need this information? DVR services help people with physical and mental disabilities obtain or retain employment. DVR provides disability determination services for SSI and SSDI. An Independent Living Program also helps people with disabilities

function in the community.

Who do you need to make contact with? An agency representative from your local area.

Division of Services for Aging and Adults with Physical Disabilities

Home Modification Program

The Home Modification Program pays for 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. An example of a home modification is the installation of a wheelchair ramp. Modifications are made to permanent residences only.

See DSAAPD under Medical & Health Resources for contact information on page 4.

Legal Services

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

Disabilities Law Program (DLP) Community Legal Aid Society

Community Service Building 100 W. 10th Street, Suite 801 Wilmington, DE 19801 (302) 575-0690 (800) 773-0606 (302) 575-0696

Kent County: 840 Walker Road Dover, DE 19904 (302) 674-8500 (800) 537-8383 (302) 575-0696

Sussex County: 144 E. Market Street Georgetown, DE 19947 (302) 856-3742 (800) 773-0606 (302) 575-0696

www.declasi.org/dis.html

What information do you ask for? Advocacy services for Delaware residents with physical or mental disabilities. Qualifications for each program are described in detail on the web page. 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.

Adult Protective Services

Division of Services for Aging and Adults with Physical Disabilities

The Adult Protective Service (APS) Program responds to cases of suspected abuse, neglect, or exploitation of adults with disabilities and impairments. The program serves persons who are 18 years old or older, who have a physical or mental disability, and who are not living in a long-term care facility.

See DSAAPD under Medical & Health Resources for contact information on page 4.

Education

All children in Delaware are entitled to a free and 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. Other agencies provide assistance in navigating the education system.

Department of Education: Special Education

Exceptional Children and Early Childhood Group 401 Federal Street, Suite 2 Dover, DE 19901 (302) 735-4210

www.doe.state.de.us/programs/specialed/

What information do you ask for? Special Education Services for children ages three through 21.

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



Who do you need to make contact with? First contact your local school district's Special Education Director. If the local school district does not have the needed information, contact the Director of Exceptional Children, Early Childhood Education at the number listed.

Parent Information Center of Delaware (PIC)

5570 Kirkwood Highway Orchard Commons Business Center Wilmington, DE 19808 (302) 999-7394

City of Wilmington Office: 3707 N. Market Street (PAL Center) Wilmington, DE 19802 (302) 764-3252

Georgetown: 109 N. Bedford Street Georgetown, DE 19947 (302) 856-9880

Toll-free number: (888) 547-4412

www.picofdel.org

What information do you ask for? The Parent Information Center provides information 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.

Division of the Visually Impaired (DVI)

The DVI Education Unit provides statewide educational services to children, ages birth through high school graduation, who have a visual impairment.

See DVI under Medical & Health Resources for contact information on page 5.

Caregiving/Respite

Organizations that provide respite services and personal attendant services are listed below. Caregivers can also look to the health and medical resources for assistance in providing caregiving to their loved ones through home health care aides, personal care attendants, and personal assistants.

Department of Education (DOE)

Children with autism in Delaware are eligible to receive respite services through their school district in Delaware. Contact your local school district Special Education Director or DOE for information on eligibilty for respite services.

See DOE under Education for contact information on page 7.

Division of Developmental Disabilities Services (DDDS)

See DDDS under Medical & Health Resources for contact information on page 4.

Division of Services for Aging and Adults with Physical Disabilities

The Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) funds several types of respite services. Based on eligibility for specific respite programs, care can be provided in the home; through temporary placement in a long-term care facility or adult foster care; or in various community settings. DSAAPD also provides personal attendant services for individuals with disabilities with activities of daily living to live independently.

See DSAAPD under Medical & Health Resources for contact information on page 4.

Advocacy

The following agencies and organizations can assist you with information and resources to help you educate yourself about services for people with disabilities in Delaware. These organizations can provide you with information, resources, and training and can help you advocate for yourself or your family member. Training programs, such as *Partners in Policymaking* offered by the Developmental Disabilities Council, provide education to people with disabilities and their family members about local, state, and national issues that impact people with disabilities.

Developmental Disabilities Council (DDC)

Margaret M. O'Neill Building 410 Federal Street Dover, DE 19901 (302) 739-2232 www.state.de.us/ddc/default.shtml

What information do you ask for? Questions 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 oversees the *Partners in Policymaking* advocacy training program, 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 group's activities and how you or your child can help advocate for improved systems change.

Disabilities Law Programs (DLP)

See DLP under Legal Services for contact information on page 7.

Child Development Watch

See Child Development Watch under Medical & Health Resources for contact information on page 5.

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

461 Wyoming Road University of Delaware Newark, DE 19711 (302) 831-6974 (302) 831-4689 TDD www.udel.edu/cds

What information do you ask for?

The mission of the Center for Disabilities Studies (CDS) is to expand and improve services available to Delawareans with disabilities and their families, including: university education, community education, model programs, technical assistance, program evaluation, and research and dissemination of disability-related information. Why do you need this information? Increase your knowledge about programs, services, and research related to disabilities.

Who do you need to make contact with? An agency staff member.

Freedom Center For Independent Living

400 N. Broad Street Middletown, DE 19709 (302) 376-4399 (302) 376-4397 TTY (866) OUR-FCIL www.fcilde.org

What information do you ask for?

Freedom Center is a nonprofit organization created by and for people with disabilities. A resource and advocacy organization, Freedom Center promotes independent living and equal access for people with all types of disabilities of any age.

Why do you need this information? The Freedom Center for Independent Living 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.

Governor's Advisory Council for Exceptional Citizens (GACEC)

George V. Massey Station 516 W. Loockerman Street Dover, DE 19904 (302) 739-4553 www.state.de.us/gacec/index.htm

What information do you ask for? GACEC is a volunteer council with formal appointments by the Governor. The Council holds scheduled meetings to review regulations, policy, and laws that affect children and adults with disabilities. Its 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? An agency staff member.

Independent Resources, Inc. (IRI)

Two Fox Point Centre 6 Denny Road, Suite 101 Wilmington, DE 19809 (302) 765-0191

32 W. Loockerman Street, Suite 104 Dover, DE 19904 (302) 735-4599

410 S. Bedford Street, #37 Georgetown, DE 19947 (302) 854-9330

(800) 232-5460 TT/TTY (800) 232-5470 Voice

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? Independent Resources, Inc. (IRI) provides services in independent living, advocacy, information and referral, outreach, and community education.

Who do you need to make contact with? An agency staff member in your local area.

State Council for Persons with Disabilities (SCPD)

410 Federal Street Dover, DE 19901 (302) 739-3120 (800) 232-5470 TDD www2.state.de.us/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. 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.

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 below includes information on both DART services.

DART First State

119 Lower Beech Street Wilmington, DE 19805 1-800-553-3278 1-800-252-1600 TTY www.dartfirststate.com

What information do you ask for? Information on schedules, routes, and accessibility of the fixed route system. Eligibility information and process for Paratransit services.

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. DART Paratransit Eligibility, in accordance with the Americans With Disabilities Act, is determined based upon a review of the individual's ability to independently navigate the fixed route system, as well as the accessibility of routes and stops to meet that individual's transportation needs.

Who do you need to make contact with? A customer service representative.

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Glossary of Terms

Acquired brain injury (ABI)

Occurring after birth, an injury to the brain which is not hereditary, congenital or degenerative. They include aneurysms, infections of the brain, stroke, and in addition, accidents (which 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, he or she takes action to promote the foundation, 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 possessed by a person prior to receiving services or instruction.

Case manager

A professional who works at a hospital or for a service delivery provider to: assess a patient or client's situation and needs; work with a patient or client and the family to develop an appropriate plan of care; and provide ongoing coordination to ensure a patient 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.

Decubitus

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

Developmental disability

A chronic disability present in an individual at least five years of age that: is attributable to a mental or physical impairment (or a combination of both); manifests before the age of 22; and results in substantial functional limitations in three or more major areas of life activity.

Developmentally delayed

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

Durable medical equipment

Includes devices, controls, or appliances that enable a person to increase his/her ability to perform activities of daily living.

Early intervention services

Identifying potential problems for children and treating those problems before the age of three.

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 three and 21.

Home care

Provided when an individual needs assistance with daily personal routines and household chores in order to stay at home.

Home health aide

An individual who has received a certain number of hours of training on how to provide personal care (dressing, bathing, feeding, etc.). He or she 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 plan (IEP)

An individually 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 himself or herself. The IEP, which can be amended at any point, designates specific goals for the student and the supports necessary to meet those goals.

Individualized family service plan (IFSP)

A unique plan—designed for a child under three years of age and his or 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)

Most recently amended in 2005, the act guarantees services and supports to students with disabilities between the ages of three and 21.

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

A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an atypical ability to listen, think, speak, read, write, spell or do mathematical calculations. 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 designates the frequency and intensity of services necessary for a person with a disability to meet his or her goals.

Long-term care

Occurs when an individual needs assistance with personal care (bathing, dressing, feeding, etc.) and is provided in a person's home, a nursing home, an institution, or a combination of the three.

Mainstreaming

In a school or community center setting, the time a person with a disability spends participating in activities alongside children or adults without disabilities.

Mental age

Based on an assessment by a psychologist or educational diagnostician, it represents the level of thinking and reasoning an individual exhibits. However, 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 three years" is rarely accurate).

Mental retardation

See intellectual disability.

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.

Paratransit

Performed by the local transit authorities for those who are unable to use the regular fixed route service safely, or when the environment is not accessible.

People first language

People first language puts the person before the disability and describes what a person has, not what a person is.

Physical therapy

Therapy services that help a person develop control over large muscle groups and improve movement (such as walking or sitting) around his or her environment.



Placement

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

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 families' homes or outside programs.

Self-advocate

A person with a disability who takes responsibility for his or her life. Selfadvocates know their rights and stand up for those rights, helping to change unjust policies and procedures while bringing about positive change for themselves and others.

Self-determination

The philosophy that a person with a disability should choose his or her own life goals, the people who will support them in those goals, and the way in which those goals will be accomplished.

Service companion

A person who assists an individual with social and recreational activities as well as assisting with the individual's safety. According to current state regulations, the companion cannot provide personal care.

Service coordinator

A professional whose job is to assist families in finding, securing and monitoring the services necessary to support family members with disabilities.

Skilled level of nursing

Medical procedures that can only be performed by a licensed nurse. The amount of this type of service determines the level of care and support a person with a disability receives.

Special education services

The supports needed to ensure that the goals and objectives of a student's IEP are met.

Speech therapy

A specialty focusing on the diagnosis and treatment of speech and communication disorders.

Support services

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

Supported employment

Due to an individual's disability, he or she may need extra supports at a job site to be successful, including a job coach who provides one-on-one training or an attendant who assists with personal and behavioral needs.

Universal design

Products, homes, apartments and services that are designed so that every person, including those with all types of disabilities, can use them.

Vocational rehabilitation

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

Waiver

States have the option of implementing a waiver program in order to use federal Medicaid funds to provide home and community services instead of placing individuals in institutions.

Acronyms

DSEA

DTC

DVI

State Agencies, Divisions, and Programs

Programs			
APS	Adult Protective Services (Division of Services for Aging and Adults with Physical	DVR DYRS	Di Re Di Re
	Disabilities)	ECAP	Ea
DART	Delaware Authority Rapid Transit (formerly DAST)	ECT	As Ex
DCMHS	Division of Child		Tea
Dewins	Mental Health Services (often referred to as CMH)	EIC	Ed Im Co
DCPS	Division of Child Protective Services (often referred to as	EPPC	Ed and Co
	CPS)	FCRB	Fo
DDDS	Division of Developmental Disabilities Services	ICCF	Bo Int for
DFS	Division of Family Services		Fai
DHSS	Department of Health and Social Services	ICT	Int Co Tro
DLTCRP	Division of Long Term Care Residents Protection	IRMC	(Ui Int Ma
DOE	Department of Education		Co
DPC	Delaware Psychiatric Center	Delaware Ad Organization	
DPH	Division of Public Health	AAB	Ar Ac
DSAAPD	Division of Services for Aging and Adults with	ASD	Au De
DOLLAR	Physical Disabilities	CCCD	Co
DSAMH	Division of Substance Abuse and Mental Health	CODHHE	for Dis
DSBA	Delaware School Boards Association	CODITIE	Co Ha Eq
DSCYF	Department of Services for Children, Youth,	CQSE	Ce Sp
	and Families (often referred to as the Kid's Department)	DADB	De for

Delaware State Education Association	
Delaware Transit Corporation	
Division for the Visually Impaired	
Division of Vocational Rehabilitation	
Division of Youth Rehabilitative Services	
Early Childhood Assistance Program	2.0
Exceptional Children Team	
Education Improvement Commission	
Educational Planning and Placement Committee	
Foster Care Review Board	
Interagency Council for Children and Families (state and county)	DDC DE CEC
Interagency Collaborative Treatment Team	DelARF
(Unique Alternatives) Interagency Resource Management	DSA
Committee	DSPAC
dvocacy ons	FACT
Architectural Accessibility Board	GACEC
Autism Society of Delaware	
Coordinating Council for Children with Disabilities	HLADE
Disabilities	DOOD

Council on Deaf and Hard of Hearing

Center for Quality Special Education

for Deaf/Blind

Delaware Association

Equality



DDC	Developmental Disabilities Council
DE CEC	Council for Exceptional Children
DelARF	Delaware Association of Rehabilitation Facilities
DSA	Down Syndrome Association of Delaware
DSPAC	Delaware State Parent Advisory Committee
FACT	Families and Communities Together
GACEC	Governor's Advisory Council for Exceptional Citizens
HLADE	Hearing Loss Association of Delaware
PCCD	Partners Council for Children with Disabilities
PIC	Parent Information Center of Delaware, Inc.
SCPD	State Council for Persons with Disabilities



Service Delivery Organizations

AI DuPont	A.I. DuPont Children's Hospital
The Arc	The Arc of Delaware
CAP	Client Assistance Program
CDS	Center for Disabilities Studies
CERTS	Collaborative Efforts to Reinforce Transition Success
CLASI	Community Legal Aid Society, Inc.
DAAP	Delaware Alternate Assessment Program
DAPA	Delaware Alternate Portfolio Assessment
DATI	Delaware Assistive Technology Initiative
DLP	Disabilities Law Program

Early CHOICES	Children Having Opportunities in the Continuum of Educational Services in early intervention	ICAN
IRI	programs Independent Resources, Inc.	ICAP
MEANS	Making Employment a New Success for Delawareans	ICAS
NAMI-DE	National Alliance on Mental Illness DE Chapter	IDEA
PAC	Parent Advisory Committee (districts)	IDEALR
PAT	Parents as Teachers	
PEEC	Parent Early Education Center	IEP
UCP	United Cerebral Palsy	IFSP
Laws and Po	IIP	
AAR	Adult Abuse Registry	
ABA	Architectural Barriers Act of 1968	ILC
ADA	Americans with Disabilities Act	PASS
ADAAG	Americans with Disabilities Act Accessibility Guidelines	Section 5
CFR	Code of Federal Regulations	SEEDS
DSTP	Delaware Student Testing Program	SES
ELL	English Language Learners	SIG
ELP	Essential Lifestyle Plan	SIP
ESL	English as a Second Language	Sped
ESY	Extended School Year for Special Education Services (may be required under an IEP)	SSDI
FAPE	Free Appropriate Public Education	SSI
FERPA	Family Educational Rights and Privacy Act	STEPS

	Heath Insurance Portability and Accountability Act
	Increasing Capabilities Access Network
	Inventory for Client and Agency Planning
	Inclusive Comprehensive Assessment System
	Individuals with Disabilities Education Act (successor to P.L. 94-142)
	Individuals with Disabilities Education Act Law Review
	Individualized Educational Plan
	Individualized Family Service Plan
	Individual Improvement Plan
	Intensive Learning Center
	Plan to Achieve Self-Sufficiency
04	Section 504 of the Rehabilitation Act of 1973
	Special Education Effectiveness Development System
	Special Education Services
	State Improvement Grant
	State Improvement Plan
	Special Education (sometimes written as "Special Ed" or "Spec. Ed.")
	Social Security Disability Insurance
	Supplemental Security Income
	Sequenced Transition to Education in the Public Schools

TANF	Temporary Assistance for Needy Families	IEE	Independent Educational Evaluation	TDD	Telecommunications Device for the Deaf
TEFRA	(formerly AFDC) Tax Equity Fiscal	IPRD	Identification, Placement, Review,	TPR	Termination of Parental Rights
TWIIA	Responsibility Act Ticket to Work	IQ	Dismissal Intelligence Quotient	TTY	Teletype or Teletypewriter
	Incentive and Improvements Act	ISD	Intermediate School District	UDL	Universal Design for Learning
Vo-Tech	Vocational-Technical School or Program	ISIS	Integrated Services Information System	WISC	Wechsler Intelligence Scale for Children
VR	Vocational Rehabilitation	IST	Instructional Support Team	Disability Na	
WIC	Women, Infants and	LCCE	Life Centered Career Education	ABI	Acquired Brain Injury
	Children			ADD/ADHD	Attention Deficit
Other Impo	rtant Acronyms	LEA	Local Educational	MDD/MDHD	Disorder/Attention
ADL	Activities of Daily		Agency		Deficit Hyperactivity Disorder
	Living	LEP	Limited English	AIDS	Acquired Immune
AMD	Adaptive Mobility	LOD	Proficiency	AIDS	Deficiency Syndrome
	Device	LOF	Letter of Finding	AS	Asperger Syndrome
AT	Assistive Technology	LOP	Local Operational Plan	ASD	Autism Spectrum
CAP	Corrective Action Plan	LRE	Least Restrictive Environment		Disorder
CAS	Comprehensive Assessment System	MDT	Multi-Disciplinary	AU	Autism
CASA	Court Appointed		Team	CF	Cystic Fibrosis
CHSH	Special Advocate	MOA	Memorandum of	СР	Cerebral Palsy
CNA	Certified Nursing		Agreement	DB	Deaf/Blind
	Assistant	MOU	Memorandum of Understanding	DD	Developmental
COPM	Coordinator of	MSW	Masters in Social Work		Disability or Developmentally
	Planning and Monitoring	OT	Occupational Therapy/		Delayed
CSPD	Comprehensive System		Therapist	DS	Down Syndrome
	of Personnel	P&A	Protection and	FAS/FAE	Fetal Alcohol
CET	Development		Advocacy		Syndrome/Fetal Alcohol Effects
CST	Child Study Team	PAS	Personal Assistance Services	HI	Hearing Impaired
CSW	Clinical Social Worker	PBS	Positive Behavioral	ID	Intellectual Disability
DME	Durable Medical Equipment	100	Supports		
ED	Educational	PIP	Partners in	LD	Learning Disability
	Diagnostician		Policymaking	MH	Mental Health
5	Early Periodic	РТ	Physical Therapist/ Therapy	MI	Mental Illness
	Screening, Diagnosis and Treatment	PWD	Person with a Disablity	MR	Mental Retardation
FTE	Full Time Equivalent	RTC	Residential Treatment	MS	Multiple Sclerosis
GCS	Glasgow Coma Score	NI U	Center	NTD	Neural Tube Defect
HHA	Home Health Aide	SEA	State Educational	PDD	Pervasive Developmental
ICF/MR	Intermediate Care		Agency		Disorder
	Facility for the Mentally Retarded	SLP	Speech Language Pathologist	SB	Spina Bifida

SCI SED	Spinal Cord Injury Severely Emotionally	NCATE	National Council for Accreditation of	OSEP	Office of Special Education Programs
	Disturbed	NCD	Teacher Education National Council on		(under the Department of Education)
SEM	Social/Emotional Disability	INCL	Disability	OSERS	Office of Special Education and
SLD	Specific Learning Disability	NCIL	National Council on Independent Living		Rehabilitation Services (under the Department
SLI	Speech and Language Impaired	NDCCD	National Dissemination Center for Children with	PCEPD	of Education) President's Committee on Employment of
TBI	Traumatic Brain Injury	NFCA	Disabilities National Family		People with Disabilities
VI	Visually Impaired	INFCA	Caregivers Association	PCPID	President's Committee on People with
National Or		NICHCY	National Information Center for Children &		Intellectual Disabilities
AAIDD	American Association on Intellectual and		Youth with Disabilities	RSA	Rehabilitation Services Administration
	Developmental Disabilities (formerly AAMR—American	NORD	National Organization for Rare Disorders	SSA	Social Security Administration
	Association on Mental Retardation)	NPF	National Parkinson Foundation	U.S. DHHS	United States Department of Health
ACB	American Council for the Blind	UCPA	United Cerebral Palsy Associations	U.S. DOE	and Human Services United States
ASDC	American Society for Deaf Children	Federal Agencies			Department of Education
AUCD	Association of	ACF	Administration on	U.S. DOJ	United States
University Centers on Disabilities	ADD	Children and Families Administration on	U.S. DOL	Department of Justice United States	
BIA	Brain Injury Association		Developmental Disabilities		Department of Labor
CCD	Consortium for Citizens with Disabilities	АТВСВ	Architecture and Transportation Barriers Compliance Board	VA	Veterans Administration
CEC	Council for Exceptional Children	CMS	Center for Medicare and Medicaid Services		
CHADD	Children with Attention Deficit Disorder (national, county groups in DE)	EEOC	Equal Employment Opportunity Commission	1 AS	5 8 B
NACDD	National Association of Councils on Developmental	HUD	Department of Housing and Urban Development		
	Disabilities	JAN	Job Accommodation Network		
NAMI	National Alliance on Mental Illness	NCSET	National Center on Secondary Education		
NASDSE	National Association of State Directors of	NIDRR	and Transition National Institute on	This project was partially funded by the Administration on Developmental Disabilities	
NASDTEC	Special Education National Association of State Directors of Tascher Education and	NIDKK	National Institute on Disability and Rehabilitation Research	of the Administra	tion for Children and S. Department of Health and
	Teacher Education and Certification	OCR	Office of Civil Rights		



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To order copies of Connecting the Dots, please contact the Center for Disabilities Studies.