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# Wayne County



## Children and Youth with Special Health Care Needs Resource Guide

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## INTRODUCTION

This is a resource guide for Wayne County families who have Children and Youth with Special Health Care Needs (CYSHCN). The guide can help families find resources that their child may need. Taking advantage of these resources can be very beneficial for your family and your child's health. There are a range of diagnoses that might fall under the large umbrella of special health care needs. The Maternal and Child Health Bureau defines CYSHCN as "children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." Special health care needs can vary greatly and can include cerebral palsy, cystic fibrosis, sickle cell disease, asthma, diabetes, spina bifida, epilepsy, and developmental delays.

## INNOVATIVE APPROACHES

Innovative Approaches is a community-based and family-focused system of care for families of children and youth with special health care needs (CYSHCN). The goal of the Innovative Approaches initiative is to foster improvement for community-wide systems of care that will effectively meet the needs of families of CYSHCN, resulting in increased family satisfaction with services received and improved outcomes for CYSHCN.

To learn more about the Innovative Approaches Initiative in Wayne County please contact:

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## HOW TO USE THIS GUIDE

The resources listed in this resource guide are organized by type of service. Within each section the local resources are listed first followed by national resources. On pages 55-58 there is an alphabetical listing of all the agencies included in the guide. If you need a service you can look under the type of service to find it or if you know the name of the organization you can look in the alphabetical listing of resources on pages 55-58 to find the page number the organization is listed on. Listed resources include phone numbers and websites (if available) which can be used to contact the organization to find out more information.

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## ADVOCACY

The ARC of North Carolina – Provides advocacy and services to people with intellectual and developmental disabilities.

[www.arcnc.org](http://www.arcnc.org) .....1 (800) 662-8706

Disability Rights North Carolina- Provides protection and advocacy for persons with disabilities in North Carolina.

<http://www.disabilityrightsncc.org/>..... 1 (877) 235-4210

Guardian Ad Litem - A Guardian ad Litem (GAL) is a trained volunteer who is appointed by the court to advocate for the best interests of an abused or neglected child. In court, the GAL serves as an important voice for the child.

<http://www.nccourts.org/Citizens/GAL/> .....1 (919) 722-6300

Wrightslaw - Information about special education law, education law, and advocacy for children with disabilities.

<http://www.wrightslaw.com/> ..... NO AVAILABLE PHONE NUMBER

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## AT HOME SUPPORT (Respite/Personal Care/Resources)

A Caring Heart Case Management, Inc. - Provides targeted case management for individuals with Intellectual Disabilities and Developmental Disabilities (I/DD).

NO OFFICIAL WEBSITE ..... 1 (919) 587-0189

The Community Alternatives Program for Children (CAP/C) - Provides home and community based services to medically fragile children who, because of their medical needs are at risk for institutionalization in a nursing home.

<http://www.ncdhhs.gov/dma/medicaid/capchildren.htm> ..... 1 (888) 207-7828

The Community Alternatives Program for Disabled Adults (CAP/DA) - Provides a package of services to allow adults (age 18 and older) who qualify for nursing facility care to remain in their private residences.

<http://www.ncdhhs.gov/dma/cap/CAPContactList.pdf> ..... 1 (919) 429-473

The Community Alternatives Program for Persons with Intellectual Disabilities or Developmental Disabilities (CAP-ID/DD) - Provides community services for individuals who are mentally ill or developmentally delayed.

<http://www.eastpointe.net/> ..... 1 (800) 513-4002

Edwar Group, LLC – Provides services for the elderly and persons with disabilities.

NO OFFICIAL WEBSITE ..... 1 (919) 778-4723

Howell Support Services, LLC- Provides Adult Day Vocational Programs (ADVP), adult care homes, day activities program, community based CAP Services, CAP/DA, and case management.

<http://www.hssllc.com/index.htm> ..... 1 (919) 778-1506

Life Inc. – Provides Community Alternatives Program for persons with Intellectual Disabilities/ Developmental Disabilities (CAP-ID/DD), supported employment, day supports, personal care services, respite services, residential supports, home and community supports, and case management.

<http://www.lifeincorporated.com/> ..... 1 (919) 778-1900

NC START - North Carolina Systemic, Therapeutic Assessment, Respite and Treatment Program (NC START) serves adults (age 18 y/o and above) that have a primary diagnosis of Developmental Disability (DD) and challenging behaviors, often with a co-occurring mental illness. RHA Health Services Inc. provides NC START services in the Eastern region of the state.

<http://www.rhahealthservices.org/> ..... 1 (888) 962-3782

Skill Creations Inc. – Operates an Intermediate Care facility for the Mentally Retarded (ICF/MR) offering on-going training, treatment, and monitoring. Also provides community operations services including: Medicaid CAP IDD (Intellectual and Developmental Disabilities) waiver services, targeted case management, private pay respite, IDD/MI state funded services, IDD residential services, alternative family living situations, and diagnostic assessments.

<http://www.skillcreations.com/> ..... 1 (919) 734- 7398

A Small Miracle Inc. - A Small Miracle, Inc. is a CAP-ID/DD agency that provides comprehensive services to children and adults of all ages and with all types of disabilities.

<http://www.asmallmiracleinc.com> ..... 1 (800) 760-0665

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## CHILD CARE AND RESPITE

Child Care Resource and Referral (CCR&R) – A department of the Partnership for Children of Wayne County that addresses the need to build accessible, high quality child care in communities by working with families, providers, employers, trainers, funders, policy-makers and others.

<http://www.pfcw.org/crr/> ..... 1 (919) 735-3371

Head Start/ Early Head Start (WAGES) - Child-development program for children (0-5) of low-income families. Services are offered to meet the special needs of children with disabilities.

[http://www.wagesnc.org/headstart\\_earlyheadstart.htm](http://www.wagesnc.org/headstart_earlyheadstart.htm)..... 1 (919) 734-1178

North Carolina Pre-kindergarten Program - Provide high-quality educational experiences to enhance school readiness for at-risk eligible four-year-olds.

<http://www.pfcw.org/partnership-programs/early-care-education.html> ..... 1 (919) 735-3371

ARCH Resource Center for Respite and Crisis Care (NATIONAL) - The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community.

<http://archrespite.org/> ..... 1 (919) 490-5577, ext 222

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## CHILD DEVELOPMENT

Children’s Developmental Services Agency (CDSA) - Provides supports and services for families and their children, birth to three who have special needs.

[www.bearly.nc.gov](http://www.bearly.nc.gov) ..... 1 (252) 737-1177  
..... (Greenville) (919) 707- 5520

Community Care for Children (CC4C) – (Wayne County Health Department) Children birth to age three who are at risk for developmental delay or disability, long term illness and/or social, emotional disorders and children ages birth to five who have been diagnosed with developmental delay or disability, long term illness and/or social, emotional disorder may be eligible for the program.

[www.waynegov.com](http://www.waynegov.com)..... 1 (919) 731-1305

Pediatric Play Therapy – Provides play therapy for children, supportive counseling, and individual therapy.

<http://www.pediplaytherapy.com/> ..... 1 (919) 736- 8580

Thera-Peds - Serves children, birth to 21, in Occupational Therapy, Physical Therapy, Speech Language Therapy and Psychology.

<http://www.therapedsinc.com> ..... 1 (919) 739-0047

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## CIVIC INVOLVEMENT

Aktion Club (Sunrise Kiwanis) - Provides adults living with disabilities an opportunity to develop initiative, leadership skills and to serve their communities.

<http://www.sunrisekiwanisonline.org/>..... (919) 735 -1300

Mayor's Committee for Persons with Disabilities - Promotes equal opportunity for people with disabilities in all aspects of society including employment, housing, transportation, recreation, and education.

[http://www.ci.goldsboro.nc.us/comm\\_affairs\\_proj\\_prog.aspx#b](http://www.ci.goldsboro.nc.us/comm_affairs_proj_prog.aspx#b) ..... 1 (919) 580-4359



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## COUNSELING

Advance Empowerment Community Services, LLC - Provides individual, family and group therapy to children, adolescents and adults.

<http://advanceempowerment.com> ..... 1 (919) 734-0976

Eastpointe (Mental Health Services) - Management of comprehensive community services for mental health, developmental disabilities, and substance abuse.

[www.eastpointe.net](http://www.eastpointe.net)..... 1 (800) 513-4002

Family Works Psychological Center - Family oriented mental health and substance abuse clinic with specialists in the evaluation and treatment of depression, anxiety/panic disorders, chronic mental health issues, childhood disorders (ADHD and disruptive behaviors), autism spectrum, Asperger's, and other developmental conditions, substance abuse, and family related counseling.

<http://www.familyworkscenter.com/Goldsboro.html> ..... 1 (919) 778-8551

Goldsboro Counseling Center - Provides Individual, Couple & Family Counseling for Children, Adolescents and Adults.

<http://goldsborocounseling.com> ..... 1 (919) 778 -5594

National Alliance on Mental Illness (NAMI) North Carolina – Provides information to persons affected by mental illness and their families and serves as their advocate on a state and national level.

<http://naminc.org/> ..... 1 (800) 451-9682

NOVA Behavioral Health Care - Operates Intermediate Care Facilities for the Mentally Retarded (IMC/MR). Also provides Community Behavioral Health Services treats children and adults with a primary diagnosis of mental illness, emotional disturbance, intellectual disability, or substance-related disorders.

<http://www.novabehavioralhealthcare.com> ..... 1 (866) 945-8704

One-to-One with Youth Inc. – Provides community/behavioral mental health services.

NO OFFICIAL WEB SITE..... 1 (919) 731-2119

Triangle Comprehensive Health Services - Provides services which assist an individual in gaining access to needed medical, social, educational, and/or other services.

NO OFFICIAL WEB SITE..... 1 (919) 751-0277

Waynesboro Family Clinic- Community mental health center which provides a range of mental health services for children, adolescents, adults, family, and marriage therapy, substance abuse services, DWI services and Community Support services and Intensive In-Home Services (Family Preservation).

<http://www.waynesborofamilyclinic.com/>..... 1 (919) 734-6676

\*\*\* Also listed in HEALTH RESOURCES section

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## FAMILY SUPPORT

Autism Society of North Carolina - Works to directly improve the lives of individuals and families affected by autism by focusing on advocacy, education, and providing direct services.

<http://www.autismsociety-nc.org/>..... 1 (800) 442-2762

Autism Society of Wayne County – Local chapter of the Autism Society of North Carolina.

<http://home.earthlink.net/~asncwayne/> ..... 1 (919) 222-4539

Easter Seals UCP North Carolina - Assists people managing disabilities and mental health challenges. Services are centered around each person's individual needs to live, learn and participate fully in his or her community.

<http://nc.eastersealsucp.com/>..... 1 (800) 662-7119

Exceptional Children's Assistance Center (ECAC) - Provides information, education, outreach, and support to and for families with children across the state of North Carolina.

<http://www.ecac-parentcenter.org> ..... 1 (800) 962-6817

Exceptional Family Member Program (EFMP) Seymour Johnson Air Force Base - The A&FRC can discuss and recommend appropriate local, state and national resources.

<http://www.seymourjohnson.af.mil/> ..... 1 (919) 722-1918

Family Support Network of Eastern North Carolina- Provides emotional support and resource information for families who have a child with a disability, chronic illness, premature birth and for families who have experienced the death of a child.

<http://www.fsnenc.org/>..... 1 (252) 847-5120

Innovative Approaches Parent Advisory Council – (Wayne County Health Department) A group of parents and providers in Wayne County who have and/or work with Children and Youth with Special Health Care Needs (CYSHCN). The council works on projects such as promoting awareness of services for CYSHCN, providing training in the community to families and providers; and having representatives on community agencies and boards.

<http://www.waynegov.com> ..... 1 (919) 731-1236

Local Interagency Coordinating Council (LICC) - A group of parents and professionals dedicated to assisting families of children with special needs in accessing the services they need.

<http://www.bearly.nc.gov/index.php/icc/licc>..... 1 (919) 705- 2709 (English, 1 (919) 580- 3608 (Spanish)

North Carolina Cooperative Extension Service - Provides educational programming, publications, and events on a wide array of topics.

<http://wayne.ces.ncsu.edu/>..... 1 (919) 731-1521

Partnership for Children of Wayne County - The Partnership for Children provides or connects families with early care & education, health, and family support services needed for young children.

<http://www.pfcw.org/> .....1 (919) 735-3371

Smart Start & The North Carolina Partnership for Children –North Carolina initiative to ensure that every child reaches his or her potential and is prepared to succeed in a global community. Smart Start helps working parents pay for child care, improves the quality of child care and provides health and family support services in every North Carolina county.

<http://www.smartstart.org/>..... 1 (919) 821-7999

Treatment and Education of Autistic and Communication related handicapped Children (TEACCH) - TEACCH provides clinical services such as diagnostic evaluations, parent training and parent support groups, social play and recreation groups, individual counseling for higher-functioning clients, and supported employment.

<http://teacch.com/>..... 1 (252) 830-3300

Parents as Teachers - Early childhood parent education program, which supports parents in their role as their child's first and most influential teacher and provides home visits, play groups, and links to community resources.

<http://wayne.ces.ncsu.edu/content/PAT> ..... 1 (919) 731-1520

Young Mom's Connect - A program that connects young women age 13-24 who are pregnant and/or parenting with a range of services in Wayne County.

<http://www.pfcw.org/parents-guardians/> ..... 1 (919) 735-3371, ext 230

The Center for Children with Special Needs (NATIONAL) - The Center for Children with Special Needs provides information to families and professionals focusing on children who have chronic physical, developmental, behavioral or emotional conditions such as asthma, cancer, autism, or cerebral palsy.

<http://cshcn.org/resources-contacts/resources-directory/> ..... NO AVAILABLE PHONE NUMBER

\*\*\* Also listed in INFORMATION/INTERPRETERS/SUPPORT ADVOCACY section

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## HEALTH INSURANCE/FINANCIAL ASSISTANCE

Medicaid (Department of Social Services) - Health program for low-income adults, their children, and people with certain disabilities.

<http://www.waynegov.com> ..... (919) 580 -4034

Insure Kids Now (NATIONAL) - Your child or teen may qualify for no-cost or low-cost health insurance coverage through Medicaid and the Children's Health Insurance Program (CHIP).

<http://www.insurekidsnow.gov/> ..... 1(877) 543-7669

Supplemental Security Income (SSI) (NATIONAL) - Program designed to help aged, blind, and disabled people, who have little or no income; and it provides cash to meet basic needs for food, clothing, and shelter.

<http://www.ssa.gov/ssi/> ..... 1 (800) 772-1213 or 1 (800) 325-0778 (TTY)

\*\*\* Also listed in SOCIAL SERVICES section

TriCare (Military Insurance) (NATIONAL) - Health insurance for the military population.

<http://www.humana-military.com/> ..... 1(800)444-5445

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## HEALTH RESOURCES

The Center for Children with Complex and Chronic Conditions (C5 Program) – Focuses on providing medical care and care coordination for children with chronic and degenerative conditions including severe cognitive, developmental or motor delays and requiring coordination of multiple specialists, therapies and/or medical technology.

<http://www.vidanthealth.com/medicalcenter/servicesDetail.aspx?id=8700>..... 1 (252) 847- 2923

Diabetes Management Solutions - Diabetes Management Solutions maintains The Diabetes Bus Initiative, a mobile diabetes education program which provides free diabetes self-management classes to several rural North Carolina communities via primary physician offices and hospitals.

<http://www.thediabetesbus.org/> ..... 1 (877) 781-6664

Goldsboro Pediatrics - Provides comprehensive care for children. As a leader in pediatric care, Goldsboro Pediatrics is involved in national and statewide projects which help to improve the healthcare of all children.

[www.goldsboropediatrics.com](http://www.goldsboropediatrics.com)..... 1 (919) 734-4736

Goshen Medical Center - Provides comprehensive primary health care services.

<http://www.goshenmedical.org/> ..... 1 (919) 739-8680

Mt. Olive Medical Clinic - Mount Olive Family Medicine Center, Inc. is dedicated to the health and well-being of the residents of Wayne County and the surrounding areas.

<http://www.mofmc.com/> ..... 1 (919) 658-4954

North Carolina Assistive Technology Program– Maintains lending library of assistive technology devices; provides training and consultation.

<http://www.ncatp.org/> ..... 1 (919) 233-7075

North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse- Provides a wide variety of community-based support services, including sheltered employment and residential services to adults with developmental disabilities to enable them to live and work in the least restrictive setting possible.

<http://www.ncdhhs.gov/mhddsas> ..... 1 (800) 662-7030

North Carolina Library for the Blind and Physically Handicapped - Special public library that circulates books and magazines especially made for persons who cannot use regular printed material because of a visual or physical disability. The library is located in Raleigh, but mails materials throughout the state.

<http://statelibrary.ncdcr.gov/lbph/>..... 1 (888) 388-2460

ReNu Life - Offers a residence facility and a day program for traumatic brain injury survivors.

<http://www.renulife.org/> ..... 1 (919) 734-0266

School Health Services - School Nurses serve all of Wayne County's Public Schools and are responsible for developing care plans for students requiring special health care procedures, monitoring immunizations for compliance with state law, and performing certain screenings and follow up.

<http://www.waynecountyschools.org/domain/122> ..... 1 (919) 731-6310

Sickle Cell Disease Association of America Inc., Eastern NC- Provides services to persons with sickle cell disease. Focuses on early detection and treatment and offers education and genetic counseling for the general public.

<http://www.sicklecelleasternnc.org/> .....(910) 346-2510 or 1(866)- NC- SCELL

W.A.T.C.H. (Wayne Action Teams for Community Health) Mobile Medical Unit - Mobile Medical Unit travels to 20 predetermined locations each month. All medical visits, including necessary lab work, are provided free of charge to uninsured persons residing in Wayne County.

<http://www.getwatch.org/> ..... 1 (919) 222-4450 for appointment  
..... 1 (919) 731- 6933 for patient assistance program

Wayne County Health Department- Provides a variety of preventative health programs and services for children and youth with special health care needs including: Child Health, Immunizations, Orthopedic Clinic, and Woman, Infants, and Children (WIC) program

[www.waynegov.com](http://www.waynegov.com)..... 1 (919) 731-1000

Wayne County Health Department Orthopedic Clinic - Provides services to children birth to 21 years of age with suspected or diagnosed problems of the bones, muscles or joints including physical therapy evaluations, equipment assessments and needs, casting, and bracing.

<http://www.waynegov.com> ..... 1 (919) 731-1005

Waynesboro Family Clinic - Community mental health center which provides a range of mental health services for children, adolescents, adults, family, and marriage therapy, substance abuse services, DWI services and Community Support services and Intensive In-Home Services (Family Preservation).

<http://www.waynesborofamilyclinic.com/>..... 1 (919) 734-6676

\*\*\* Also listed in COUNSELING section

Wayne Initiative for School Health (WISH) - Wayne County Public Schools program providing affordable, accessible physical and mental health services to adolescents.

<http://www.waynecountyschools.org/domain/2228> ..... 1 (919) 739-8266

Women Be Healthy - Curriculum developed to enable women with mental retardation and other developmental disabilities to become more active participants in their health care. The North Carolina Office on Disability and Health (NCODH) provides free training to service providers to teach them how to implement the curriculum.

<http://www.fpg.unc.edu/~ncodh/WomensHealth/week2.cfm> ..... 1 (919) 966-0871

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## HEARING AND VISION

Eastern North Carolina School for the Deaf - The Eastern North Carolina School for the Deaf (ENCSD), is a day/residential facility for the education of children who are deaf and hard of hearing.

<http://www.encsd.net/> ..... 1 (252) 237-2450

\*\*\* Also listed in SCHOOLING/EDUCATION section

Wilson Regional Center: Division Services for the Deaf and the Hard of Hearing - Advocacy, information, counseling, skills development and tools for Deaf, Hard of Hearing, Deaf-Blind and Speech-Impaired individuals and their families.

<http://www.ncdhhs.gov/dsdhh/rrc/wilson/wilson.htm> ..... 1 (800) 999-6828

North Carolina Early Intervention Program for Children who are Deaf or Hard of Hearing – The Early Intervention Program for Children who are Deaf or Hard of Hearing provides services to children who are deaf, hard of hearing, or deaf/blind, age’s birth to three, and their families. Concentrating on language and communication skill development, itinerant professionals provide family-centered intervention in home and daycare settings.

<http://www.ncoes.net/preschools.shtml> ..... 1 (828) 432-5352

Health Services Team (Wayne County Health Department) - The Health Service Team works with child care providers and parents that have children ages 0-5 years of age. The team focuses on preventive health education, consultation, health assessments, health screenings (hearing, vision, dental, and development) and provides referral and follow up for appropriate services.

<http://www.waynegov.com/165810410142431703/cwp/view.asp?A=3&Q=277161&C=54822>.....

..... 1 (919) 580-4041

Lions Club International (NATIONAL) - Lions Clubs provide resources for the blind and hearing impaired worldwide. Local Lions club in or near your community may sponsor a program that provides assistance for the purchase of eyeglasses, hearing aids, health-related services, scholarships or educational needs.

<http://www.lionsclubs.org> ..... 1 (630) 571-5466



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## INFORMATION ASSISTANCE AND REFERRAL

Americans with Disabilities Act (ADA) - The Americans with Disabilities Act of 1990 prohibits private employers, state and local governments, employment agencies and labor unions from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms, conditions, and privileges of employment.

<http://www.ada.gov> ..... 1 (800) 514-0301

CARE-LINE - The CARE-LINE is the North Carolina Department of Health and Human Services' (NCDHHS) toll-free Information and Referral telephone service. Information and Referral Specialists provide information and referrals regarding human services in government and non-profit agencies. If you have a questions about services that are available to you through the NCDHHS, CARE-LINE staff can guide you to the appropriate source.

<http://qa.dhhs.state.nc.us/ocs/careline.htm> ..... 1 (800) 662-7030

Employment Security Commission (ESC) - The Employment Security Commission is the host agency for Wayne County JobLink Career Center which is comprised of organizations that provide employment and training-related services. The Center's services include labor market information, vocational counseling, clerical testing, job information and referral, unemployment insurance information, specialized services for military veterans, on-the-job training, work experience and institutional training.

<https://www.ncesc.com> ..... 1 (919) 731-7950

Legal Aide of North Carolina- Non-profit agency providing legal representation to low-income people in order to ensure equal access to justice and to remove legal barriers to economic opportunity.

<http://www.legalaidnc.org/> ..... 1 (866) 219-5262

North Carolina Children with Special Health Care Needs Help Line- A toll-free line for those living with, caring for or concerned about a child with special health care needs.

<http://www.ncdhhs.gov/dph/wch/families/helplines.htm> ..... 1 (800) 737-3028

North Carolina Client Assistance Program (CAP) – Assists individuals with disabilities in understanding and accessing rehabilitation services.

<http://cap.state.nc.us/>..... 1 (800) 215-7227

North Carolina Division of Vocational Rehabilitation - Provides counseling, training, education, transportation, job placement, assistive technology and other support services to people with physical, psychiatric or intellectual disabilities. Services provided to assist individuals with living independently and with finding a job and staying on the job.

<http://www.ncdhhs.gov/dvrs/>..... 1 (919) 778- 3795

North Carolina Statewide Independent Living Council - Provides programs and services for people with all types of disabilities and their families.

<http://www.ncsilc.org/>..... 1 (888) 762-7452

Wayne County Services on Aging - Provides services to enhance the lives of older adults through programs, services, and activities which encourage independence, involvement, and advocacy within the community.

<http://www.waynegov.com/165810410153641807/site/> ..... 1 (919) 731-1591

Wayne Opportunity Center /Wayne Opportunity Center HOPE Program - A community based rehabilitation facility offering Vocational Evaluation, Work Adjustment Training, Job Placement, Job Coaching, Adult Developmental Vocational Programs (ADVP), CAP – ID/DD Services, Supported Employment CORE Training, CORE Plus Training, and Adult Basic Education.

<http://www.wayneopportunitycenter.org/> ..... 1 (919) 735-5363

Work Source East - Provides vocational counseling, comprehensive vocational evaluation, employee development services and skills training for individuals with disabilities.

<http://www.ncdhhs.gov/dvrs/pwd/ervrf/ervrf.htm> ..... 1 (919) 731-7956

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## INFORMATION/INTERPRETERS/SUPPORT ADVOCACY

United Healthcare Children's Foundation (NATIONAL) - The Foundation embraces and supports the concept of facilitating access to health-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully covered by the available commercial health benefit plan. The Foundation provides financial assistance toward the family's share of the cost of medical services.

<http://www.uhccf.org/> ..... 1 (952) 992-4459

Attention Deficit Disorder Association (NATIONAL) - The Attention Deficit Disorder Association provides information, resources and networking opportunities to help adults with Attention Deficit Hyperactivity Disorder lead better lives.

<http://www.add.org/> ..... 1 (800) 939-1019

Autism Society of America (NATIONAL) - The Autism Society exists to improve the lives of all affected by autism by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy.

<http://www.autism-society.org/> ..... 1 (800) 328-8476

Autism Speaks (NATIONAL) - Autism Speaks is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

<http://www.autismspeaks.org> ..... 1 (866) 362-6227

Center for Children with Special Needs (NATIONAL) - The Center for Children with Special Needs provides information to families and professionals focusing on children who have chronic physical, developmental, behavioral or emotional conditions such as asthma, cancer, autism, or cerebral palsy.

<http://cshcn.org/> ..... 1 (206) 884-5735

\*\*\* Also listed in FAMILY SUPPORT section

Children with Attention Deficit Disorder (CHADD) (NATIONAL) - CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) is the nation's leading non-profit organization serving individuals with AD/HD and their families.

<http://www.chadd.org/> ..... 1 (800) 233-4050

Complex Child (Free Online e-Magazine) (NATIONAL) - Complex Child is a monthly online magazine written by parents of children with special healthcare needs and disabilities. It is intended to provide medical information, along with personal experiences, in simple language that other parents can understand.

<http://www.complexchild.com/> ..... NO AVAILABLE PHONE NUMBER

Disease or Condition-Based Agencies and Clinics (NATIONAL) -

<http://www.healthfinder.gov/> ..... NO AVAILABLE PHONE NUMBER

Family Village (NATIONAL) - A global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support.

<http://www.familyvillage.wisc.edu/> ..... NO AVAILABLE PHONE NUMBER

Family Voices (NATIONAL) - Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

<http://www.familyvoices.org/> ..... 1 (888) 835-5669

Food Allergy Initiative (NATIONAL) - Our goal is to fund research that seeks a cure; to improve diagnosis and treatment; to increase federal funding of food allergy research and create safer environments through advocacy; and to raise awareness through education.

<http://www.faiusa.org/> ..... 1 (855) 324-9604

Make a Wish Foundation (NATIONAL) - The Make-A-Wish Foundation® has enriched the lives of children with life-threatening medical conditions through its wish-granting work.

<http://www.wish.org/> ..... 1 (800) 722-9474

March of Dimes (NATIONAL) - We help moms have full-term pregnancies and research the problems that threaten the health of babies.

<http://www.marchofdimes.com/> ..... 1 (206) 624-1373

Medline Plus (NATIONAL) - MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, it brings you information about diseases, conditions, and wellness issues in language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, and for free.

<http://www.nlm.nih.gov/medlineplus/> ..... NO AVAILABLE PHONE NUMBER

National Down Syndrome Society (NATIONAL) - The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

<http://www.ndss.org/> ..... 1 (800) 221-4602

National Information Center for Children and Youth with Disabilities (NATIONAL) - NICHCY serves the nation as a central source of information on disabilities in infants, toddlers, children, and youth providing information on IDEA, the law authorizing early intervention services and special education. State Resource Sheets will help you connect with the disability agencies and organizations in your state.

<http://nichcy.org/> ..... 1 (800) 695-0285 (Voice/TTY)

National Organization for Rare Disorders (NORD) (NATIONAL) - The National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

<http://www.rarediseases.org/> ..... 1 (800) 999-6673 (VM only)

.....1 (203) 797-9590 (TDD)

Pacer Center's Kids Against Bullying (NATIONAL) - PACER Center is a parent center for families of children and young adults with all disabilities—physical, mental, learning, and emotional. The mission is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents.

<http://www.pacerkidsagainstbullying.org/> ..... 1 (888) 248-0822

Starlight Children's Foundation (NATIONAL) - Starlight Children's Foundation has been dedicated to improving the quality of life for children around the globe with chronic and life-threatening illnesses and life-altering injuries by providing entertainment, education and family activities that help them cope with the pain, fear and isolation of prolonged illness.

<http://www.starlight.org/> ..... 1 (800) 950-9474

United Cerebral Palsy (NATIONAL) - United Cerebral Palsy educates advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities. UCP works to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network that has helped millions.

<http://www.ucp.org/> ..... 1 (800) 872-5827

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## MEDICAL/DENTAL/BEHAVIORAL

Center for Mental Health Services (NATIONAL) - CMHS leads Federal efforts to treat mental illnesses by promoting mental health and by preventing the development or worsening of mental illness when possible.

<http://www.samhsa.gov/about/cmhs.aspx> ..... 1 (877) SAMHSA-7/(1-877-726-4727)

..... 1 (800) 487-4889 (TTY)

Muscular Dystrophy Clinics (NATIONAL) - Through more than 200 hospital-affiliated clinics, MDA offers quality medical care from doctors, nurses and therapists experienced in dealing with neuromuscular diseases. These clinics also serve as sites for clinical trials of the latest experimental therapies and drugs. MDA also offers some 240 support groups for those with neuromuscular diseases and their families. In addition, each year more than 4000 youngsters attend weeklong MDA summer camps.

<http://www.mda.org> ..... 1 (800) 572-1717

Shriner's Hospital for Children (NATIONAL) - Shriners Hospitals for Children® is changing lives every day through innovative pediatric specialty care, world-class research and outstanding medical education. The 22 hospitals in the United States, Canada and Mexico provide advanced care for children with orthopedic conditions, burns, spinal cord injuries, and cleft lip and palate.

<http://www.shrinershospitalsforchildren.org/> ..... 1 (800) 237-5055

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## MEDICAL SUPPLIES/EQUIPMENT

NC Mobility - Provides specialized products and services to meet the needs of the physically challenged.

<http://ncmobility.com/> ..... 1(866) 422-4247

Medical Device Portal (NATIONAL) - Comprehensive resource of medical company, product and service information.

<http://www.zapconnect.com> ..... NO AVAILABLE PHONE NUMBER

OptionCare, Inc./Walgreens Home Care (NATIONAL) - Complimentary support services for many chronic and complex conditions providing: Specialized medications and condition-specific care and expertise; Convenient medication delivery; Confidential follow-up, including refill reminders by phone; Help with insurance verification; Easy online refills and prescription recordkeeping.

<http://www.walgreenshealth.com/> ..... 1 (866) 924-9377

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## NUTRITION

NC Division of Public Health: Nutrition Services Branch - This section assists parents or guardians with children who have special dietary needs. If your child has been identified as having a disability and has special dietary needs, changes can be made to your child's school breakfast and/or lunch at no extra charge with the proper written medical statement from your physician.

[http://www.nutritionnc.com/special/special\\_diet.htm](http://www.nutritionnc.com/special/special_diet.htm) ..... 1 (919) 707-5799

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## RECREATION

The City of Goldsboro Parks and Recreation Department - Inclusion support and accommodations are available for persons with specialized needs or disabilities in order to actively participate in educational as well as recreational programs.

<http://www.goldsboroparksandrec.com/>..... 1 (919) 739-7489

Kidz Dayz - A day camp setting serving children ages 3-16 years old with a diagnosis of Autism and/or Developmental Delay.

<http://www.kidzdayz.org> ..... 1 (919) 735-1171

Special Olympics Wayne County - Sports organization for children and adults with intellectual disabilities.

<http://www.sonc.net/wayne>..... 1 (919) 734-7023

Stepping Stones Stables – Offers therapeutic riding for people with special needs including behavioral issues, physical disabilities, developmental disabilities, and brain injuries.

[http://3illy.com/images/web/stepping\\_stone\\_site/WebPage.html](http://3illy.com/images/web/stepping_stone_site/WebPage.html) ..... 1 (919) 394- 6269

Victory Junction Gang Camp – Provides life-changing camping experiences to children with chronic medical conditions or serious illnesses in a safe and medically sound environment.

<http://www.victoryjunction.org/> ..... 1 (877) VJG-CAMP

Accessible Trails (for wheelers and slow walkers) (NATIONAL) - Learn about accessible trail and greenway design, new projects, training opportunities, legal issues, and proposed federal guidelines.

<http://www.americantrails.org/> ..... 1 (530) 547-2060

Professional Association of Therapeutic Horsemanship International (NATIONAL) - The Professional Association of Therapeutic Horsemanship International (PATH Intl.) changes and enriches lives by promoting excellence in equine-assisted activities and therapies.

<http://www.pathintl.org/> ..... 1 (800) 369-7433



Special Olympics (NATIONAL) - The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.

<http://www.specialolympics.org/>..... 1 (800) 700-8585

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## SCHOOLING/EDUCATION

The Asperger Connection School - Private school serving children with High Functioning Autism/Asperger's.

<http://www.theaspergerconnectionschool.org/> ..... 1 (919) 920-5799

Eastern North Carolina School for the Deaf - The Eastern North Carolina School for the Deaf (ENCSD) is a day/residential facility for the education of children who are deaf and hard of hearing.

<http://www.encsd.net> ..... 1 (252) 237-2450

\*\*\* Also listed in HEARING AND VISION section

Exceptional Children's Division – Public Schools of North Carolina - Information on public education for children with special needs.

<http://www.dpi.state.nc.us/ec> ..... 1 (919) 807-3969

Governor Morehead School for the Blind - School and resource center that provides resources for all North Carolina students with visual impairment, their families, and the professionals who serve them.

<http://www.governormorehead.net> ..... 1 (919) 733-6192

\*\*\* Also listed in HEARING AND VISION section

Lenoir Community College – Disability Services provides a counselor to assist students and faculty with any reasonable accommodations that need to be made to provide equal access to the college's programs.

[http://www.lenoircc.edu/Student\\_Services/dis\\_servindex.htm](http://www.lenoircc.edu/Student_Services/dis_servindex.htm) ..... 1 (252) 527-6223, ext 331

Louisburg College - Office of Learning Support and Disability Services (OLSDS) provides, arranges and coordinates accommodations and services for individuals with disabilities.

<http://www.louisburg.edu/academics/support/disabilityservices.html> ..... 1 (919) 497- 3236

Project STEPP - Supporting Transition and Education through Planning and Partnerships (STEPP) is a collaborative program that partners a variety of East Carolina University's colleges and campus resources with area high schools and community opportunities. The program offers comprehensive academic, social, and life-skills support to a select number of students with identified Specific Learning Disabilities who have shown the potential to succeed in college.

<http://www.ecu.edu/cs-educ/stepp/> ..... 1 (252) 328-4260

St. Andrews University – Disability Services works to provide student who are academically qualified but have physical, learning or psychiatric disabilities with equal access to higher education.

<http://www.sapc.edu/access/index.php> ..... 1 (800) 763-0198

UNC-Pembroke - Disability Support Services strives to provide individuals with the tools by which they can better accomplish their educational goals.

<http://www.uncp.edu/dss/> ..... 1 (910) 521- 6695

Wayne County Schools Exceptional Children Program- Assists students with disabilities to develop mentally, physically, emotionally, and vocationally through the provision of an appropriate individualized education in the least restrictive environment..

[www.waynecountyschools.org](http://www.waynecountyschools.org)..... 1 (919) 705-6027

Wayne Community College – Disability Services assists with integrating students with disabilities into the college to help them achieve equal opportunity and to be able to participate in and benefit from the programs and activities enjoyed by all students.

<http://www.waynecc.edu/counseling/disability-services/> ..... 1 (919) 735-5151, ext 6729

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## SOCIAL SERVICES

Supplemental Security Income (SSI) - Supplemental Security Income (SSI) is a Federal income supplement program designed to help aged, blind, and disabled people, who have little or no income; and it provides cash to meet basic needs for food, clothing, and shelter.

<http://www.ssa.gov/ssi/> ..... 1 (800) 772-1213 or 1 (800) 325-0778 (TTY)

\*\*\* Also listed in HEALTH INSURANCE/FINANCIAL ASSISTANCE section

Services For The Blind - (Department of Social Services) Provides services to the blind (including children and adults) and visually impaired citizens of Wayne County. Services such as instruction in independent living as well as specialized equipment are available.

[www.waynegov.com](http://www.waynegov.com) ..... 1 (919) 731-1102

Wayne County Department of Social Services - Provides a variety of services to empower individuals to improve their quality of life including economic services, children and family services, and adult services.

<http://www.waynegov.com> ..... 1 (919) 580-4034

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## TRANSPORTATION

Goldsboro – Wayne Transportation Authority (GATEWAY) – ADA Transportation is available to qualified disabled residents of Goldsboro that live within 3/4 mile of fixed bus routes and are going to a destination that is also within 3/4 mile of the routes. This service is available to those individuals whose disability prevents them from independently boarding an accessible fixed route bus (with the driver operating the lift) and/or prevents them from getting to or from a boarding location.

[www.waynegov.com](http://www.waynegov.com) ..... 1 (919) 736-1374

National Patient Air Transportation Helpline (NATIONAL) - The National Patient Travel HELPLINE provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available in the national charitable medical air transportation network

<http://www.patienttravel.org/> ..... 1 (800) 296-1217

## GLOSSARY

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### 504 Plan

A plan for students with special health care needs that lists accommodations related to a child's disability and required by the child so that he or she may participate in the general classroom setting and educational programs. A 504 Plan is supported by the federal law, Section 504 of the Rehabilitation Act of 1973. See Section 504.

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### Accessible

Easy to enter, use, or communicate with. Examples include buildings that are wheelchair accessible or programs with TTY/TDD lines for people who are deaf or hard of hearing.

### Accommodation

Service, provision, or adaptation to meet a specific need. In special education, accommodation refers to the types of services offered to a child so that he or she can fully participate in school.

### Activities of Daily Living (ADLs)

Basic everyday tasks, such as bathing, dressing, toileting, eating and moving around.

### Acute

In medicine, "acute" refers to a symptom or illness that appears suddenly.

### Acute Care Hospital

A hospital that provides a full range of medical care, usually over the short-term, for sickness or injury.

### Advocacy

Speaking up or taking action for a person, a group, or a belief. An advocate may help a family resolve problems with a school system or a health insurance plan.

### Affiliation

Membership in a group or plan. Your primary care provider (PCP) may be affiliated with a hospital and a health insurance plan.

#### Americans with Disabilities Act (ADA)

A federal law that protects the rights of people with disabilities from discrimination in any public program, service, or building.

#### Apgar Score

This is a score to rate the health and strength of a baby right after birth.. It measures heart rate, breathing, color, muscle tone, and reflexes on a scale from 1 to 10.

#### Appeal

To formally ask or request that a decision be reviewed.

#### Appropriate

Right, correct, or well matched to the needs of a child or family.

#### Assessment

The formal process used by expert professionals to learn about a person's strengths and needs. An assessment can also be called an evaluation. Assessment results are used to recommend treatments or develop care plans. Sometimes an assessment or evaluation is used to determine whether a person is eligible for a service or benefit.

#### Assistive Technology (AT)

Any kind of tool or piece of equipment that helps a person live more independently. AT can be high-tech or low-tech.

#### Attending Physician

The main doctor who is responsible for the care of your child. Also, the experienced doctor who supervises the medical team involved in your child's care.

#### Audiologist

An expert in the non-medical management of the auditory and balance systems; specializes in the study of normal and impaired hearing, hearing loss prevention, the identification and assessment of hearing and balance problems, and the rehabilitation of persons with hearing and balance disorders.

### Baseline

A starting point used to compare observations or data. Baseline physical findings are the results from your child's first physical exam. Baseline vital signs are your child's regular heart rate (pulse), blood pressure, respiratory rate (breathing rate), and body temperature. Baseline neurological status is an assessment of your child's development, cognition, motor skills, and mental health. Baseline ancillary findings are any other important issues about your child.

### Benefit

A service or type of support, usually provided through a government program or health insurance plan.

### Birth To Three (Same as CDSA)

A program of services for children between birth and 3 who currently have a developmental delay.

### Block Nursing

See Continuous Nursing Services.

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### Care Coordinator

A professional who works with the family and the primary care physician and helps to coordinate care among different service providers. This work may also be called case management. A Care Coordinator also helps to arrange needed benefits and services. A Care Coordinator may also be called a Case Manager, Service Coordinator, or Care Manager.

### Case Management

A service to help plan and coordinate health care. Case management is often provided by a Care Coordinator or Case Manager.

### Child Life Specialist

A professional who works in a hospital and plays with children in a way to help them understand the hospital environment. A Child Life Specialist also provides fun activities and entertainment to keep children busy.

### Children's Developmental Services Agency (CDSA)

A program of services for children between birth and 3 who currently have a developmental delay.

### Children and Youth with Special Health Care Needs (CYSHCN)

Children and Youth with Special Health Care Needs (CSHCN) are those from birth to 21 years old who have, or are at increased risk for, chronic physical, developmental, behavioral or emotional conditions. Generally these children also need more health and related services than most children.

### Chronic

In medicine, the term refers to a long-term or recurring (comes back again and again) condition or illness.

### Cognition

The mental process of knowing, including awareness, perception, reasoning, and judgment. The adjective is cognitive.

### Community-Based Care

Services delivered locally, or as close to the child's home as possible. This type of care helps a child participate fully in all aspects of family and community life.

### Congenital

Present at, or existing from, the time of birth.

### Continuous Nursing Services

Skilled one-to-one nursing provided by a licensed or registered nurse for more than 2 hours per day. Sometimes called block nursing, private duty nursing, or shift nursing.

### Copayment

Also called co-pay or co-insurance.. A set amount of money a person pays towards a covered medical expense. A co-pay is usually paid during an office visit or for a prescription.

### Conservatorship

Conservatorship is a court process and legally binding. It makes an adult (or adults) legally responsible for the financial decisions of a person who is unable to make financial decisions for himself or herself.

### Coverage

The services or items provided or paid for, usually by a health insurance plan.

### Developmental Delay

This term refers to when a child does not reach developmental milestones (such as walking or talking) within the same time range as most other children. Developmental delays may be generalized (all milestones), or they may show up in just one or two milestones. Developmental disability usually refers to a general delay, and to chronic conditions appearing in childhood which result from mental or physical impairment. Often this means major and life-long limitations in everyday functioning. See Impairment.

### Diagnosis

The naming of a specific disease or condition according to a standard system (such as ICD-9 or DSM-4).

### Dietary Supplements

Extra calories, vitamins, minerals, proteins, or other nutrients. Usually taken in the form of pills, powders, or drinks. Also called dietary additives.

### Discharge Plan

A plan created by a hospital team of providers for your child before it's time to leave the hospital. The discharge plan lists the supports your child will need at the time of discharge from the hospital (such as appointments to see health care providers, plans for home health nursing, assessment for durable medical equipment).

### Due Process

Due process is an important element of the state and federal legal systems. It gives you the legal right to be notified and to be heard if certain benefits or services are denied to you or your child. For example, there are regulations that make sure that parents can challenge the State's decisions about their children's eligibility for Early Intervention or special education services.

### Durable Medical Equipment (DME)

Supplies or equipment that last a long time and help meet particular medical needs.



### Elective Procedure

A medical test, procedure, or surgery that is not an emergency. Usually a person and doctor decide and plan the procedure together in advance.

### Eligible

Meeting certain requirements for getting services or benefits.

### Emergency Information Form for Children with Special Needs

The form is filled out by your child's primary care provider (PCP) and gives emergency providers the information they need to properly care for your child.

### Emergency Response Plan

An emergency plan created by you and your child's primary care provider. An Emergency Response Plan includes: medical information about your child, the name(s) of your child's PCP and other important providers, where your child should be taken in an emergency, and treatment that should be provided to your child in certain situations.

### Enrollment

The process of joining a health insurance plan. People enroll in health plans through their employers, through professional associations or clubs, through public benefits programs, or as individuals.

### Entitlement

A service or benefit that an eligible person has a right to receive.

### Evaluation

In medicine, an evaluation is a checkup, a study, or a series of tests used to determine the current status of a patient or a particular condition. An evaluation may also refer to the process used to determine whether or not a child is eligible for a service or benefit See Assessment.

### Family-Centered Care

Care that recognizes the family as the most central and important influence in the child's life.

In family-centered care, the provider makes sure that the family participates in all health care decisions about the child. Family-centered care is one of the key elements of Medical Home.

### Family Support Services

Services to meet the needs of family members. Examples include: respite care, parent networks, equipment exchanges, advocacy services, support groups, information and training, and any other assistance that enhances family life and participation in the community. See also Family-Centered Care.

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### Genetic

A trait that is hereditary, "runs in the family," passed down, or affected by genes. Genetic counseling is when a trained genetic counselor educates and counsels families about inherited genetic disorders.

### Gestation

The time that a baby is carried in the uterus during pregnancy. Babies are expected to be born after 10 months or 40 weeks gestation. A premature baby is born before 37 weeks gestation. See Premature.

### Grievance

A complaint about or dissatisfaction with a service or benefit.

### Guardianship

Guardianship is a court process and legally binding. It makes an adult (or adults) legally responsible for the personal and financial decisions of a person who is unable to make these decisions alone. A guardian may or may not be a relative. Parental rights may or may not be terminated. Guardianship can be temporary or permanent, partial or complete.

#### Head Circumference

The measurement of length around your child's head. It helps to assess growth and development.

#### Health Care Proxy

Someone legally designated to make medical decisions in the event that a person cannot make them for him or herself.

#### Health Care Provider

Any professional who provides a health care service (such as a doctor, nurse, or therapist).

#### Health Insurance

A type of insurance that pays for covered health care costs. Primary health insurance is the main plan that covers most health care costs. Secondary health insurance is the additional insurance that covers costs not paid for by the primary health insurance plan.

#### Home Health Aide

A professional who provides home care services, including: personal care services; simple dressing changes or help with medications that do not require the skills of a nurse; help with special activities and therapies; and routine care of prosthetic and orthotic devices.

#### Hospice Care

The special kind of health care focused on life-limiting illness. It can be provided in the home and outside of the home in hospitals or hospice centers. Hospice care may include any of the home health services, but also usually includes both counseling services and palliative care nursing. Palliative care is focused on preserving patient comfort and dignity in the face of terminal disease.

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#### Immunization

A substance (usually given in the form of a shot) that protects a person from viruses and bacteria. Also called a vaccine.

#### Impairment

An injury, deficit, or disability.

### Inclusion

In the schools, inclusion or inclusive education means that all children learn together in the same schools and classrooms. Services and supports for children with special needs are built into regular school and classroom activities. See Mainstreaming.

### Individualized Education Program (IEP)

A special education service plan for a child's school program. It is required by law for all children receiving special education services. An IEP describes an individual child's educational goals, and any services or help the child needs to meet those goals.

### Individualized Family Service Plan (IFSP)

A care plan required by law for every child enrolled in Birth to Three.

### Individualized Health Care Plan (IHCP)

A care plan designed to manage the medical care of a child with special health care needs in school.

### Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act is the federal special education law.

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### Least Restrictive Environment (LRE)

The IEP team must consider educating a child with a disability in an environment that is appropriate for that child. Some children are educated in a more restrictive environment than others due to the significance of their needs.

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### Mainstreaming

Programs and policies to include people with disabilities in regular programs and services, such as education. See Inclusion.

### Mandate

Something that is required by law. For example, free public education is a mandate.

#### Medical Emergency

A serious medical condition that results from injury, sickness or mental illness, which is sudden and severe and requires immediate treatment.

#### Medical Fellow

A doctor who has finished medical school and residency, and is spending 3 or more years learning to be a specialty doctor.

#### Medical Home

Medical Home is an idea that promotes a coordinated system of care that is accessible, continuous, comprehensive, family centered, compassionate, and culturally effective. The primary care provider shares responsibility to ensure that the child receives this kind of care.

#### Medical Necessity

Standards of medical practice that health plans use to make decisions about the coverage of special services or equipment.

#### Medical Resident

A doctor who has finished medical school and is spending 3 years learning clinical medicine. A resident is supervised by an attending doctor.

#### Medical Student

A student in medical school who has not yet received his or her degree. A medical student is supervised by an attending doctor.

#### Member Service Representative

A health insurance plan employee who can help you with questions about covered services and benefits.

#### Mental Health Counselor

A provider, usually with an advanced university degree in counseling or psychology, who can counsel you and your child on mental health – mood, behavior, and family issues.

#### Nurse

A nurse provides and coordinates the hands-on treatment and care of your child. A nurse also assesses symptoms and alerts the doctor to any changes in status by either writing in the medical chart or notifying the doctor immediately.

#### Nurse Practitioner (NP)

A nurse practitioner is a registered nurse with advanced academic and clinical training that provides primary and specialty medical care. A NP diagnoses and manages most common and many chronic illnesses, either independently or as part of a health care team.

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#### Occupational Therapy

Treatment to help a person develop mental or physical skills for daily living, especially fine motor skills. Examples include dressing, bathing, writing, and using a fork or spoon. Occupational therapy often involves identifying and learning to use equipment that helps people with these activities.

#### Orthosis

A support or brace for weak joints or muscles.

#### Over-the-Counter (OTC) Medicine

Medication that is available without a prescription.

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#### Palliative Care

Care that is provided not to cure, but to keep a patient comfortable. Examples include providing warmth, pain control measures, and appropriate nutrition and medications. See Hospice Care.

#### Parent-to-Parent Support

Parents of children with disabilities providing information and one-on-one support to each other.

#### Personal Care Attendant (PCA)

An independent caregiver who helps with the activities of daily living.

### Physical Therapy

Treatment to relieve pain and to improve or restore movement skills and muscle function. Examples of methods of physical therapy include exercise, stretching, massage, heat, cold, water or electrical stimulation therapy.

### Physician's Assistant (PA)

A health care provider specially trained to provide medical care under the supervision of a doctor. A PA can conduct physical exams, diagnose and treat illnesses, order and interpret tests, counsel on preventive health care, assist in surgery, and can often write prescriptions.

### Prescription Drug

Medication that is available only with a written order from a medical provider who is licensed to prescribe medications.

### Premature

Happening or arriving before the expected or usual time. A premature baby is usually defined as a baby born at least 3 weeks early, after a gestation period of less than 37 weeks. Sometimes, prematurity means a birth weight of less than 2500 grams (about 5 1/2 pounds), regardless of gestational age. See Gestation.

### Primary Care

The routine (regular) health care your child gets from a primary care provider (PCP).

### Prior Authorization

Also called prior approval. Getting permission for special services or equipment in advance by the health plan, usually based on medical necessity.

### Private Duty Nursing

See Continuous Nursing Services.

### Prosthesis

An artificial device to replace a missing part of the body.

### Primary Care Provider (PCP)

The term for any professional who provides primary care. A primary care provider (PCP) may be a pediatrician, family physician, specialty physician, nurse practitioner, or physician's assistant.

### Provider Network

A group of doctors, hospitals, and other health care providers who work together with a health insurance plan to provide health care services.

### Psychiatrist

A medical doctor who can counsel you and your child about mental health – mood, behavior, and family issues. If needed, a psychiatrist prescribes medications that help with mood or behavior.

### Psychologist

A provider, usually with a doctorate in psychology, who can counsel you and your child about mental health – mood, behavior, and family issues. A psychologist also does special testing to understand how your child learns, thinks, and feels.

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### Referral

An authorization by a health provider or health insurance plan for a person to receive care (often specialty care) from another provider. Each health plan has its own rules about referrals. Most plans have their own networks of specialists.

### Rehabilitation

The process of helping a person reach the highest level of function, independence, and quality of life possible.

### Respite Care

A service that provides temporary care to a child by any trained caregiver. For example, a respite care worker could be another family member, friend, or a professional caregiver. Respite care can take place in out-of-home and in-home settings for any length of time, depending on the needs of the family and available resources.

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### Screening

The use of basic, standardized procedures to test health, hearing, vision, developmental, behavior, and other factors to identify children with, or at risk of, disabilities or special health care needs.



### Second Opinion

An evaluation by a second provider, other than your child's regular providers. You may want your child to get a second opinion if a health provider gives you a new diagnosis or tells you that your child needs a certain treatment or surgery. You may want to know if another provider agrees with the decision. Most health plans will pay for you to get a second opinion.

### Section 504

A federal law that protects the rights of people with disabilities from discrimination in programs or activities that receive federal funds. See 504 Plan.

### Service Date

A term used by health insurance plans for the date of an appointment, treatment, or test.

### Self Contained

Located within a regular education school, a full day or mostly full day class or program for children with disabilities, who cannot be educated in a regular classroom with appropriate accommodations ; characterized by highly individualized, closely supervised specialized instruction.

### Skilled Nursing

Care and treatments by a Registered Nurse (RN) or a Licensed Practical Nurse (LPN). A nurse can provide teaching and support, perform a skilled procedure, or provide a specific therapy.

### Special Education

Special education is specially designed instruction and related services that meet the unique needs of an eligible student with a disability or a specific service need that is necessary to allow the student with a disability to access the general curriculum. The purpose of special education is to allow the student to successfully develop his or her individual educational potential. Special education is free through the public school system.

### Specialist

A doctor or other health care provider with "special" training in a certain area of medical care.

### Specialty Care

Care from a doctor or health other provider who has special training and experience in treating certain body systems or conditions.

### Syndrome

A group of symptoms or characteristics that occur together, but have not yet been classified as a disease.

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### Tertiary Care Center

A hospital that provides specialized inpatient and outpatient care.

### TTY (Text Telephone)

A TTY, also called TDD (Telecommunications Device for the Deaf), is a special device that lets people who are deaf, hard of hearing, or speech-impaired use the telephone to communicate, by allowing them to type messages back and forth to one another instead of talking and listening. A TTY is required at both ends of the conversation in order to communicate.

### Transition

The process of moving from one stage of life or type of service to another. For children with special health care needs, transition usually refers to process of growing older and becoming more independent in areas of health care, employment, living, and recreation. Children in Early Intervention (EI) also experience transition when they leave EI and move to school services.

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### Urgent Care

Care given in situations that require immediate treatment but are usually not life-threatening, such as an ear infection, sprained ankle, or flu-like symptoms.

### Utilization Management

A process where health care professionals review planned hospital admissions, surgery, and other procedures to make sure they are necessary and appropriate.

### Vendor

A provider, supplier, or seller. For example, a durable medical equipment (DME) vendor is the company that provides your child with equipment.

## ACRONYMS

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### A Acronyms

AAC | Alternative Augmentative Communication

ABA | Applied Behavioral Analysis

ABC | Antecedent, Behavior, Consequence

ADA | Americans with Disabilities Act

ADD/ADHD | Attention Deficit/Attention Deficit Hyperactivity Disorder

ADLs | Activities of Daily Living

ADR | Alternative Dispute Resolution

AIG | Academically/Intellectually Gifted

AIM | Accessible Instructional Materials

APE | Adaptive Physical Education

APR | Annual Performance Report

ARD | Admission, Review, and Dismissal Committee

ARRA | American Recovery and Reinvestment Act of 2009

ASD | Autism Spectrum Disorders

ASL | American Sign Language

AT | Assistive Technology

AU | Autism Spectrum Disorder

AYP | Adequate Yearly Progress

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## B Acronyms

BIE | Bureau of Indian Education

BIP | Behavioral Intervention Plan

BOE | Board of Education

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## C Acronyms

CAP | Corrective Action Plan

CAPD | Central Auditory Processing Disorder

CAP/C | Community Alternatives Program for Children

CAP/DA | Community Alternatives Program for Disabled Adults

CAP ID/DD | Community Alternatives Program Intellectual Disabilities/Developmental Disabilities

CAPTA | Child Abuse Prevention and Treatment Act

CBA | Curriculum Based Assessment

CC | Closed Captioning

CDA | Child Development Associate

CDSA | Children's Developmental Services Agency

CDC | Centers for Disease Control and Prevention

CEC | Council for Exceptional Children

CF | Cystic Fibrosis

CFR | Code of Federal Regulations

CIFMS | Continuous Improvement and Focused Monitoring System

COP | Community of Practice

CP | Cerebral Palsy

CYSHCN | Children and Youth with Special Health Care Needs

CSPD | Comprehensive System of Personnel Development

CST | Child Study Team

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## D Acronyms

DB | Deaf-Blind

DD | Developmental Delay

DD Act | Developmental Disabilities Assistance and Bill of Rights Act

DF | Deafness

DIBELS | Dynamic Indicators of Basic Early Literacy

DoDDS | Department of Defense Dependent Schools

DS | Down Syndrome

DSM | Diagnostic and Statistical Manual of Mental Disorders by the American Psychiatric Association

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## E Acronyms

EC | Exceptional Children

ECE | Early Childhood Education

ECSE | Early Childhood Special Education

ED or SED | Serious Emotional Disability

ED | U.S. Department of Education

EDGAR | Education Department General Administrative Regulations

EHA | Education of the Handicapped Act (now IDEA)

EHDI | Early Hearing Detection and Intervention

EI | Early Intervention

EIS | Early Intervening Services

ELL | English Language Learner

EPSDT | Early Periodic Screening, Diagnosis and Treatment

ERIC | Educational Resources Information Center

ESD | Extended School Day

ESEA | Elementary and Secondary Education Act

ESL | English as a Second Language

ESY or EYS | Extended School Year or Extended Year Services

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## F Acronyms

FAPE | Free Appropriate Public Education

FAS | Fetal Alcohol Syndrome

FBA | Functional Behavioral Assessment

FC | Facilitated Communication

FEOG | Full Educational Opportunity Goal

FERPA | Family Educational Rights and Privacy Act

FOIA | Freedom of Information Act

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## G and H Acronyms

GE | General Education

GPRA | Government Performance and Results Act

HI | Hearing Impaired

HO | Hearing Officer

HoH | Hard of Hearing

HOUSSE | High Objective Uniform State Standards of Evaluation

HQT | Highly Qualified Teacher

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## I Acronyms

IA | Instructional Assistant

IAES | Interim Alternative Educational Setting

ID | Intellectual Disabilities

IDEA | Individuals with Disabilities Education Act

IEE | Individualized Educational Evaluation

IEP | Individualized Education Program

IES | Institute of Education Sciences

IFSP | Individualized Family Service Plan

IHE | Institution of Higher Education

ITCA | Infants and Toddlers Coordinators Association

ITP | Individualized Transition Plan

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## L, M, and N Acronyms

LD | Learning Disability

LEA | Local Education Agency

LEP | Limited English Proficiency



LRE | Least Restrictive Environment

MD | Muscular Dystrophy

MDR | Manifestation Determination Review

MOU | Memorandum of Understanding

MU | Multiple Disabilities

NASDSE | National Association of State Directors of Special Education

NCLB | No Child Left Behind Act (Elementary and Secondary Education Act)

NIH | National Institutes of Health

NIMAS | National Instructional Materials Accessibility Standard

NIMH | National Institute of Mental Health

NPRM | Notice of Proposed Rule Making

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## O Acronyms

OCD | Obsessive-Compulsive Disorder

OCR | Office of Civil Rights

ODD | Oppositional Defiant Disorder

OHI | Other Health Impairment

OI | Orthopedic Impairment

O & M | Orientation and Mobility

OSEP | Office of Special Education Programs

OT | Occupational Therapy

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## P and R Acronyms

P&A | Protection & Advocacy

PALS | Peer-Assisted Learning System

PASS | Plan for Achieving Self-Support

PBS | Positive Behavioral Supports

PCA | Personal Care Attendant

PD | Physical Disability

PDD | Pervasive Developmental Disorder

PEI | Spanish acronym for the Individualized Education Program (Plan Educativo Individualizado)

Perkins Act | Carl Perkins Vocational and Applied Technology Education Act

PLAAFP | Present Level of Academic Achievement and Functional Performance

PP | Paraprofessional

PS | Preschool

PT | Physical Therapy

PTI | Parent Training and Information Center

RFP | Request for proposals

RS | Related Services

RTI | Response to Intervention

RttT | Race to the Top Fund

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## S Acronyms

§ | This symbol means “Section” as in “§ 300.7 Child with a disability” in the IDEA regulations

SAS | Supplementary Aids and Services

SB | Spina Bifida

SCHIP | State Children’s Health Insurance Program

SE | Special Education

SEA | State Education Agency

SEAC | Special Education Advisory Committee

Section 504 | Section 504 of the Rehabilitation Act

SED or ED | Serious Emotional Disability

SI | Sensory Integration

SIG | State Improvement Grant

SIP | State Implementation Plan

SLD | Specific Learning Disability

SLI or SI | Speech/Language Impairment

SLP | Speech/Language Pathologist

SPOA | Specific Power of Attorney

SPP | State Performance Plan

SSDI | Social Security Disability Income

SSI | Supplemental Security Income

SST | Student Study Team

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## T to Z Acronyms

TA&D | Technical Assistance and Dissemination Network funded by the Office of Special Education Programs (OSEP)

TANF | Temporary Assistance to Needy Families

TBI | Traumatic Brain Injury

TDD | Telecommunication Devices for the Deaf

TS | Tourette Syndrome

T-TA | Training and Technical Assistance

TTY | Teletypewriter (phone system for the deaf)

TWWIIA | Ticket to Work and Work Incentives Improvement Act

VI | Visual Impairment

Voc Ed | Vocational Education

VR | Vocational Rehabilitation

WIC | Women, Infants and Children (Special Supplemental Food Program)

WWC | What Works Clearinghouse

## QUICK LINKS

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American Society for Deaf Children .....	<a href="http://www.deafchildren.org">www.deafchildren.org</a>
American Foundation for the Blind .....	<a href="http://www.afb.org">www.afb.org</a>
Assistive Technology (AT) Network .....	<a href="http://www.atnet.org">www.atnet.org</a>
Autism Society of America .....	<a href="http://www.autism-society.org">www.autism-society.org</a>
Balance 4 Kids .....	<a href="http://www.balance4kids.org">www.balance4kids.org</a>
Children's Disabilities Information .....	<a href="http://www.childrensdisabilities.info">www.childrensdisabilities.info</a>
The Center for Children with Special Needs ...	<a href="http://cshcn.org/resources-contacts/resources-directory/">http://cshcn.org/resources-contacts/resources-directory/</a>
Families for Early Autism Treatment.....	<a href="http://www.feat.org">www.feat.org</a>
Genetic and Rare Conditions. Univ. of Kansas Medical Center....	<a href="http://www.kumc.edu/gec/support/">http://www.kumc.edu/gec/support/</a>
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National Dissemination Center for Children with Disabilities.....	<a href="http://nichcy.org/">http://nichcy.org/</a>
National Fathers Network .....	<a href="http://www.fathersnetwork.org">www.fathersnetwork.org</a>
North Carolina Department of Health and Human Services .....	<a href="http://www.ncdhhs.gov/">http://www.ncdhhs.gov/</a>
North Carolina Department of Public Instruction Exceptional Children Division .....	<a href="http://www.ncpublicschools.org/ec/">http://www.ncpublicschools.org/ec/</a>

Parenting Special Needs.....[www.specialchildren.about.com](http://www.specialchildren.about.com)

Parents Helping Parents.....[www.php.com](http://www.php.com)

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### FOR CHANGES OR TO REPRODUCE THIS GUIDE:

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Information in this guide is maintained by Innovative Approaches of Wayne County based at the Wayne County Health Department. If you have any changes, please contact Dr. Heidi E. Austin at (919) 731-1236 or [heidi.austin@waynegov.com](mailto:heidi.austin@waynegov.com)

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