Parent Resource List

Autism Spectrum Disorder:

ASPEN provides families and individuals whose lives are affected by Autism Spectrum Disorders (Asperger Syndrome, Pervasive Developmental Disorder-NOS, High Functioning Autism), and Nonverbal Learning Disabilities with: education, support and advocacy. [http://www.aspennj.org/](http://www.aspennj.org/)

Autism Association of America the nation’s leading grassroots autism organization, exists to improve the lives of all affected by autism through 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.
[www.autism-society.org](http://www.autism-society.org)

Autism Association of America-State of Florida Chapter a statewide organization that supports individuals with autism, their families, and caregivers [www.autismfl.com](http://www.autismfl.com)

Autism Resources Information and links regarding the developmental disabilities autism and asperger's syndrome. [www.vaporia.com/autism](http://www.vaporia.com/autism)

Autism Speaks is 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. [www.autismspeaks.org](http://www.autismspeaks.org)

Center for Autism and Related Disabilities (CARD) provides expert consulting, training and support, at no charge, for people with autism and related disabilities, their families and the professionals serving them. [www.coe.fau.edu/card/](http://www.coe.fau.edu/card/)

ESE Autism Web Site the School District of Palm Beach County is committed to excellence in education and preparation of all our students with Autism Spectrum Disorders. We provide a range of services at a variety of schools along with a continuum from Pre-K through High School. [www.palmbeachschools.org/ese/asd.asp](http://www.palmbeachschools.org/ese/asd.asp)
OASIS@MAAP is a nonprofit organization dedicated to providing information to families of individuals with Autism, Asperger syndrome, and Pervasive developmental disorder (PDD).  www.asperger.org

Cerebral Palsy:

United Cerebral Palsy (UCP) educates advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities.  www.ucp.org/

United Cerebral Palsy of South Florida (UCP) serves infants, children and adults with developmental disabilities at over 60 locations in Miami-Dade, Broward, and Palm Beach & Mid-Coast Counties.  www.ucpsouthflorida.org

National Institute of Neurological Disorders and Stroke (NINDS) Conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas.  www.ninds.nih.gov

CPParent web site supports the CPParent email list. CPParent is a group of parents, caregivers and others who work with children with cerebral palsy.  www.cpparent.org/

Cleft Lip/Palate:

Florida Cleft Palate-Craniofacial Association (FCPA) is a state-wide association of healthcare specialists and parents who welcome opportunities to help children with a facial difference.  www.floridacleft.org/

CleftAdvocate provides educational opportunities, on- and off-line support networks, social interaction, advocacy guidelines and financial issues of cleft repair and treatment.  www.cleftadvocate.org/

The University of Florida Craniofacial Center provides a broad spectrum of interdisciplinary services to patients and families pertaining to cleft lip and palate, facial disfigurement and other malformations of the head.  www.cleft.ufl.edu/mission.html

Florida Cleft and Craniofacial Network assists professionals and the families who care for children born with craniofacial differences; to educate and empower them with knowledge and understanding of the needs of children...
with cleft lip, cleft palate and other craniofacial conditions.
www.cleftnetwork.com

**Deaf/Blindness:**

The Florida School for the Deaf and the Blind is the state's center public school for eligible students who are deaf/hard of hearing and blind/low-vision pre-school through 12th grade. www.fsdb.k12.fl.us

The National Family Association for Deaf-Blind (NFADB) is a non-profit, national network of families focusing on issues surrounding deaf blindness. www.nfadb.org

Helen Keller National Center for Deaf-Blind Youths and Adults provides support services for youth and adults who are deaf-blind, their families and the professionals who serve them across the country. www.hknc.org

The National Consortium on Deaf-Blindness (NCDB) is a national technical assistance and dissemination center for children and youth who are deaf-blind. www.nationaldb.org

**Down Syndrome:**

National Down Syndrome Society is the national advocate for the value, acceptance and inclusion of people with Down syndrome. www.ndss.org

The Gold Coast Down Syndrome Organization of Palm Beach County is a family support group advocating for improved outcomes for all people with Down syndrome. www.goldcoastdownsyndrome.org

**Emotional Behavior Disorders:**


Multiagency Network for Students with Severe Emotional/Behavioral Disabilities (SEDNET) creates and facilitates a network of key stakeholders committed to assisting in the provision of a quality system of care for students with or at-risk of emotional and/or behavioral challenges. http://www.sednetfl.info/Index.aspx
TA Center on Social Emotional Intervention takes the research that shows which practices improve the social-emotional outcomes for young children with, or at risk for, delays or disabilities and creates FREE products and resources to help decision-makers, caregivers, and service providers apply these best practices in the work they do every day.

www.challengingbehavior.org

The Association for Positive Behavior Support (APBS) is an international organization dedicated to promoting research-based strategies that combine applied behavior analysis and biomedical science with person-centered values and systems change to increase quality of life and decrease problem behaviors. www.apbs.org

**Fragile X Syndrome:**

The National Fragile X Foundation unites the Fragile X community to enrich lives through educational and emotional support, promote public and professional awareness, and Advance research toward improved treatments and a cure for Fragile X. www.fraxlex.org/

FRAXA supports families affected by Fragile X and raises awareness of this important but virtually unknown disease. www.fraxa.org

Fragile X Support Group on Yahoo is a forum for parents and families of children who have fragile X syndrome.
http://groups.yahoo.com/group/fragilex/

Hearing Impairments: ESE Department Palm Beach County School District, Deaf and Hard of Hearing Program
http://www.palmbeachschools.org/ese/dhh.asp

Florida Association of the Deaf, Inc. (FAD) is affiliated with the National Association of the Deaf (NAD) serving Deaf, Hard of Hearing, and Late Deafened citizens. www.fadcentral.org

Florida Coordinating Council for the Deaf and Hard-of-Hearing Governor-appointed council representing various stakeholders in the deaf community and professionals who work with individuals who are deaf, hard of hearing, late-deafened or deaf-blind. www.fccdhh.org

National Deaf Education Project (NDEP) Coalition of parents, consumers, professionals, and advocacy organizations involved in the education of
children who are deaf and hard of hearing, are working to develop an effective, communication and language-driven educational delivery system. www.ndepnow.org


Hand Speak American Sign Language on line dictionary. www.handspeak.com

**Fetal Alcohol Syndrome:**


**Heart Disorders:**

Congenital Heart Information Network (C.H.I.N.) is a national organization that provides information, support services, financial assistance and resources to families of children with congenital heart defects and acquired heart disease, adults with congenital heart defects, and the professionals who work with them. www.tchin.org

**Intellectual Disabilities/Developmental Disabilities:**

The National Association of Councils on Developmental Disabilities (NACDD) is a national membership organization with the purpose of promoting and enhancing the outcomes of our member councils in developing and sustaining inclusive communities and self directed services and supports for individuals with developmental disabilities. www.nacdd.org

Best Buddies Global volunteer movement that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities. www.bestbuddies.org

American Association on Intellectual and Developmental Disabilities (AAIDD) promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities. www.aamr.org
The National Association for the Dually Diagnosed (NADD) expert in providing professionals, educators, policy makers, and families with education, training, and information on mental health issues relating to persons with intellectual or developmental disabilities. [www.thenadd.org](http://www.thenadd.org)

The Florida Developmental Disabilities Council (FDDC) serves as an advocacy and planning body to influence the direction of programs and policies for individuals with developmental disabilities. [www.fddc.org](http://www.fddc.org)

**Prader-Willi Syndrome:**

Prader-Willi Syndrome Association (PWSA USA) Organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those affected by Prader-Willi syndrome. [www.pwsausa.org](http://www.pwsausa.org)

**Rare Disorders:**

National Organization for Rare Disorders (NORD) provides information about diseases, referrals to patient organizations, research grants and fellowships, advocacy for the rare-disease community, and Medication Assistance Programs that help needy patients obtain certain drugs they could not otherwise afford. [www.rarediseases.org](http://www.rarediseases.org)

Medical Genetics University of Kansas Medical Center Information on genetic conditions /birth defects for professionals, educators, and individuals. [www.kumc.edu/gec/support/](http://www.kumc.edu/gec/support/)

**Rett Syndrome:**

International Rett Syndrome Association (IRSA) Emotional support, information and resources to families affected by Rett syndrome. [www.rettsyndrome.org](http://www.rettsyndrome.org)

**Seizure Disorder:**

The American Epilepsy Society promotes research and education, dedicated to the prevention, treatment and cure of epilepsy. [www.aesnet.org](http://www.aesnet.org)

The Epilepsy Foundation of America helps individuals and families affected by epilepsy and related neurological impairments by providing education, advocacy and services. [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)
Epilepsy Foundation Florida provides many valuable services to individuals and their families, regardless of their financial situation. www.epilepsyfla.org

**Speech and Language Impairments:**

Apraxia-Kids national nonprofit organization representing the needs and interests of children and families affected by apraxia. www.apraxia-kids.org/

ESE Department School District of Palm Beach County, Speech and Language Impaired Program helping students communicate through listening, speaking and literacy. http://www.palmbeachschools.org/ese/SpeechLanguage.asp

**Spina Bifida:**

The Spina Bifida Association (SBA) provides education, advocacy, research, and referral service. www.spinabifidaassociation.org

Spina Bifida of South Florida provides information and emotional support, as well as sponsoring social events, programs and educational conferences. www.sbofsf.org/

**Spinal Muscular Atrophy:**

Families of Spinal Muscular Atrophy (FSMA) Provides information, resources, research, information and links. www.fsma.org

**Traumatic Brain Injury:**

Brain Injury Association of America (BIAA) Provides information, education and support to assist the 3.17 million Americans currently living with traumatic brain injury and their families. www.biausa.org

**Visual Impairments:**

American Council of the Blind presents a wide array of media and other materials, including their official publication, “The Braille Forum”. www.acb.org

American Foundation for the Blind (AFB) connects families to knowledge and support. www.afb.org
National Federation of the Blind (NFB) provides advocacy, education, research, technology, and programs encouraging independence and self-confidence. www.nfb.org

Visual Impairment Guide contains information on many topics pertaining to parenting and teaching a child with visual impairments. www.viguide.com

**Williams Syndrome:**

Williams Syndrome Association provides resources, support and the latest medical information to help your child today and throughout his/her life. www.williams-syndrome.org

**Advocacy**

**National:**

The ADA National Network provides information, guidance and training on the Americans with Disabilities Act (ADA), tailored to meet the needs of business, government and individuals at local, regional and national levels. www.adata.org

Arc of the United States advocates for full participation of all children and adults with intellectual and developmental disabilities. www.thearc.org

Easter Seals -Easter Seals provides education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities. www.easterseals.com


National Disability Rights Network. is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States. www.napas.org

TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. www.tash.org

United Cerebral Palsy (UCP), educates, advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities. www.ucp.org

State:

Arc of Florida works with local, state, and national partners to advocate for local chapters, public policies, and high quality supports for people with developmental and other disabilities to be fully included in all aspects of their community. arcflorida.org/

Disability Rights Florida, a nonprofit organization providing protection and advocacy services in Florida. It works to promote quality of life, dignity, equality, self-determination, and freedom of choice for persons with disabilities through collaboration, education, advocacy, and legal and legislative strategies. disabilityrightsflorida.org/

Florida Commission on Human Rights - is the state agency charged with enforcing the state’s civil rights laws and serves as a resource on human relations for the people of Florida. fchr.state.fl.us/

Florida Developmental Disabilities Council works to promote innovative programs and practices designed to prevent developmental disabilities and improve the quality of life for individuals with such disabilities and their families.. www.fddc.org

Florida Family Care Council - Florida Statutes, created this all-volunteer organization to give self-advocates and families a voice in the policies and decisions affecting their lives. The FCCF's purpose is to advise the Agency for Persons with Disabilities www.fccflorida.org

Florida Law Help is a guide to free legal information and legal services in Florida, administered by Florida Legal Services, Inc. It provides access to dozens of organizations offering information about the courts, community resources and free and low-cost legal aid programs. www.floridalawhelp.org
Florida’s Voice on Developmental Disabilities is a statewide independent advocacy and networking non-profit organization comprised of families and friends of persons with developmental disabilities. www.floridasvoice.org

Floridians for the Future of the Developmentally Disabled - is committed to assist families, advocates and professionals by giving them the information and tools to advocate collectively and effectively on behalf of their loved ones with developmentally disabilities. www.ffddnews.com

Florida Youth Council offers many opportunities for interested youth and emerging leaders o participate, including an Annual Youth Summit, a program Newsletter in both electronic and print formats, and a comprehensive online outreach program that takes advantage of the power of social networking. www.floridayouthcouncil.com

Local:

CILO - Coalition for Independent Living Options - CILO provides the four core services: Advocacy; Information & Referral; Independent Living Skills; and Peer Support, as well as a wide variety of other services including after-School and Summer programs for teens, emergency financial assistance, and disability sensitivity seminars. Most services are completely free of charge. www.cilo.org

Palm Healthcare Foundation Inc. the leading public healthcare foundation in Palm Beach County, bringing the community together to identify common goals and implement transformative healthcare solutions. www.palmhealthcare.org

United Cerebral Palsy of South Florida, serves infants, children and adults with developmental disabilities at over 60 locations in Miami-Dade, Broward, Palm Beach & Mid-Coast Counties. http://www.ucpsouthflorida.org

Education/ Individual Education Plans (IEPs)

National:

Office of Special Education Programs (OSEP), an office within the U.S. Department of Education, is dedicated to improving results for infants, toddlers, children, and youth with disabilities—including communication disorders—from birth through age 21. Professional and consumer publications are available. www.ed.gov
Center on the Social and Emotional Foundation for Early Learning is a national resource center funded by the Office of Head Start and Child Care Bureau for disseminating research and evidence-based practices to early childhood programs across the country.  www.vanderbilt.edu/csefel

TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates.  www.tash.org

State:


Florida Department of Education Bureau of Exceptional Education and Student Services (BEESS) administers programs for students with disabilities.  www.fldoe.org/ese/

Florida Department of Education, BEESS Resource and Information Center (BRIC) provides parents, educators, and other Floridians with access to information about exceptional student education, student services, juvenile justice education, early intervention, parent and professional partnerships, and many other topics. Most items produced are available electronically. One complimentary copy of parent materials and other selected items can be ordered free of charge.  www.fldoe.org/ese/clerhome.asp

Florida Department of Education/Division of Vocational Rehabilitation provides services for eligible persons with physical or mental impairments. These services are designed to enable the consumer to prepare for, secure, retain or regain employment.  www.rehabworks.org/

Florida Diagnostic and Learning Resources System (FDLRS) provides diagnostic, instructional, and technology support services to district exceptional education programs and families of students with disabilities. Service centers include 19 centers that directly serve school districts in the areas of Child Find, Human Resource Development (HRD), Parent Services, and Technology.  www.fdlrs.org/

Florida Diagnostic and Learning Resources System (FDLRS) Palm Beach County www.palmbeachschools.org/ese/fdlrsps.asp

Florida Virtual Schools (FLVS) is a public school online, you can access more than 120 courses, from Geometry to AP Art History and everything in between. Public, private and homeschooled students, from kindergarten-12th grade, can take virtual courses whether they live in Florida or not. [www.flvs.net/Pages/default.aspx](http://www.flvs.net/Pages/default.aspx)

Getting Ready For Your Child’s IEP (Brochure)  

McKay Scholarship Program, students with disabilities may be eligible to participate in the McKay Scholarship Program. The program was created to provide educational options to parents of students with disabilities. [http://www.palmbeachschools.org/ese/McKay.asp](http://www.palmbeachschools.org/ese/McKay.asp)

Mediation in Exceptional Student Education (Brochure)  

Parent’s Introduction to Exceptional Student Education in Florida, this book explains the ESE process and key ideas in the state and federal laws about ESE. It provides basic information only. It does not cover every situation for every child and it is not meant to provide legal advice. [www.fldoe.org/ese/pdf/ESEParent.pdf](http://www.fldoe.org/ese/pdf/ESEParent.pdf)

Project 10 - Transition Education Network is Florida’s statewide discretionary project supporting the secondary transition of youth with disabilities. [www.project10.info/](http://www.project10.info/)


¿Qué es la educación de estudiantes excepcionales para niños(as) superdotados(as)? (Spanish) [www.fldoe.org/ese/pdf/spangift.pdf](http://www.fldoe.org/ese/pdf/spangift.pdf)

**Local:**
KIND Foundation is a non-profit educational organization assisting parents, teachers and professionals to help developmentally delayed and learning disabled children. www.kindfoundation.org

Prekindergarten ESE Site If you suspect your child has developmental delays. http://www.palmbeachschools.org/ese/prekese.asp

ESE Secondary Transition Web Site Planning the transition from school to adult life begins, at the latest, in high school. In fact, transition planning is required by law to begin once a student reaches the age of 14. http://www.palmbeachschools.org/ese/TransitionServices.asp

**Assistive Technology**

Alliance for Technology Access (ATA) offers a range of information, training, and resources on the subject of assistive technology. http://www.ataccess.org/

Bookshare, an accessible online library for people with print disabilities http://www.bookshare.org

Florida Alliance for Assistive Services and Technology (FAAST) is a non-profit organization that provides Floridians with disabilities of all ages with access to assistive technology. http://www.faast.org

National Instructional Materials Accessibility Standards (NIMAS) serves as a resource to educators, parents, publishers, conversion houses, accessible media producers, and others interested in learning more about and implementing Instructional Materials Accessibility Standards. http://www.nimas.cast.org

Neighborhood Legal Services, operates the National Assistive Technology Advocacy Project to assist persons with disabilities and the advocates and agencies that serve them. http://www.nls.org

**Government Agencies**

**Federal:**
Office of Special Education Programs (OSEP) an office within the U.S. Department of Education, is dedicated to improving results for infants, toddlers, children, and youth with disabilities—including communication disorders—from birth through age 21. Professional and consumer publications are available. www.ed.gov

State:

Agency for Health Care Administration is the chief health policy and planning entity for the state. The Agency is primarily responsible for the state's $21.9 billion Medicaid program that serves more than 3.1 million Floridians, the licensure of approximately 41,000 health care facilities and the sharing of health care data through the Florida Center for Health Information and Policy Analysis. www.ahca.myflorida.com

Agency for Persons with Disabilities, state program that assists people who have developmental disabilities and their families. It also provides assistance to identify the needs of people with developmental disabilities and funding to purchase supports and services. www.apd.myflorida.com

Children's Medical Services (CMS), program provides children with special health care needs with a family centered, managed system of care. Children with special health care needs are those children under age 21 whose serious or chronic physical or developmental conditions require extensive preventive and maintenance care beyond that required by typically healthy children. www.cms-kids.com

Florida Disability Disaster Plan- Disaster can strike without warning. It is important for citizens with disabilities to plan ahead for an emergency situation and know what to do in the event of an emergency. www.floridadisaster.org/disability

DISABILITY.GOV - The official federal government site connecting the Disability Community to Information and Opportunities. www.disability.gov

The Division of Disability Determinations makes decisions on the medical eligibility of Florida citizens applying for state and federal disability benefits. www.doh.state.fl.us/DD/DDdescription.html
Florida Early Steps Program, Florida's early intervention system that offers services to eligible infants and toddlers (birth to thirty-six months) with significant delays or a condition likely to result in a developmental delay.  
www.cms-kids.com/families/early_steps/early_steps.html

Florida Medicaid -  www.mymedicaid-florida.com

Florida Department of Education Bureau of Exceptional Education and Student Services (BEESS), administers programs for students with disabilities.  www.fldoe.org/ese/

Florida Department of Education, BEESS Resource and Information Center (BRIC) provides parents, educators, and other Floridians with access to information about exceptional student education, student services, juvenile justice education, early intervention, parent and professional partnerships, and many other topics. Most items produced are available electronically. One complimentary copy of parent materials and other selected items can be ordered free of charge.  http://www.fldoe.org/ese/cherhome.asp

Florida Virtual Schools (FLVS) is a public school online, you can access more than 120 courses, from Geometry to AP Art History and everything in between. Public, private and homeschooled students, from kindergarten-12th grade, can take virtual courses whether they live in Florida or not.  http://www.flvs.net/Pages/default.aspx

Governor's Commission on Disabilities- The official state clearinghouse for programs and information for the disabled.  dms.myflorida.com/other_programs/governor_s_commission_on_disabilities

**Other Agencies and Resources**

Arc of Palm Beach County provides services, education and advocacy for children and adults who have developmental disabilities, and their families.  http://www.arcpbc.org

Best Buddies International is dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated
employment and leadership development for people with intellectual and developmental disabilities. www.bestbuddies.org

Center for Autism and Related Disorders (CARD) provides expert consulting, training and support, at no charge, for people with autism and related disabilities, their families and the professionals serving them. www.coe.fau.edu/centersandprograms/card/default.aspx

Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving the educational success of individuals with disabilities and/or gifts and talents. www.cec.sped.org

Central Florida Parent Center (Parent Training and Information Center of Central and Northeast Florida). http://www.cflparents.org

Disability Scoop the Premier Source for Developmental Disability News www.disabilityscoop.com


Florida Disabled Outdoors Association- enriches lives through accessible inclusive recreation and active leisure for all. www.fdoa.org/

Family Network on Disabilities family-driven support, education, information, resources, and advocacy. www.FNDFL.org

JCC of Boca Raton provides programs designed to enhance the lives of children, teens and adults with disabilities www.levisjcc.org

JCC of The Palm Beaches provides programs designed to enhance the lives of children, teens and adults with disabilities. www.jcconline.com

Jewish Association for Residential Care (JARC) provider of community-based Jewish residential services, serving nearly 150 adults in its group homes and various supported living arrangements. www.jarc.org

National Alliance on Mental Illness of Palm Beach County (NAMI) is dedicated to the welfare and support of persons with serious mental illness and their families, educating the public through courses, meetings and publications that encourage understanding and tolerance. www.namipbc.org
National Council on Disability is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities. www.ncd.gov

National Disability Rights Network Protection and Advocacy for Individuals with Disabilities is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and the Client Assistance Programs (CAP) for individuals with disabilities. www.napas.org

National Federation of the Blind Florida is the state affiliate of the National Federation of the Blind. www.nfbflorida.org

National Information Center for Children and Youth with Disabilities (NICHCY) offers information and connections to the full spectrum of disabilities in children, including developmental delays and rare disorders. www.nichcy.org/


Parent to Parent of Miami is a community parent resource center for families of children and adults with all disabilities. http://ptopmiami.org/

Wright's Law, information about special education law, education law, and advocacy for children with disabilities. www.wrightslaw.com

Social Security Disability Resource Center provides information on the US federal government's two disability benefit programs, title II social security disability benefits and title 16 SSI disability benefits. www.ssdrc.com

Genetic Alliance a network that includes more than 1,000 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. www.geneticalliance.org

National Organization for Rare Disorders (NORD) provides information about rare diseases through its publications, website, and other educational offerings. www.rarediseases.org
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