

The Parent Training & Resource Center

RESOURCE

A Project of **The Advocacy Coalition for People with Disabilities**
in Partnership with **The Medical University of South Carolina**
supported by funding from **The US Department of Education**

The
Coalition
Newsletter

Annual
Disabilities
Conference

Free
Lending
Library

**The Family Resource Center
Parent Training and Resource Center**

PTRC
Website

**19 Hagood Avenue - MUSC
College of Health Professions, Research**

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Charleston, SC 29425

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mccartyb@musc.edu

Parent
To Parent
IEP Support

IDEA
Trainings

Meeting the Need for Disability Resources for Families and Professionals

Prepared for
South Carolina Autism Society
2001 Annual Conference
Perspectives in Autism
"Autism 101"
Friday, October 12, 8:00 — 9:00 AM



TELEPHONE NUMBERS TO NOTE:



FAMILY RESOURCE CENTER FOR DISABILITIES & SPECIAL NEEDS (The Parent Training & Resource Center)

E-mail
 Association for Retarded Citizens (The ARC)
 Attention Deficit Disorder Association (ADDA)
 Caring Connection (Charleston/Lowcountry)
 Carolina Children's Charity
 CASLS (Carolina Autism Supported Living Services)
Children's Rehabilitative Services (CRS)/BabyNet
 Continuum of Care (Emotionally Disturbed Children)
 Family Connections of South Carolina, Inc.
 Learning Disabilities Association of America
 Parents Anonymous of South Carolina
 ProParents
 Social Security Administration
 South Carolina Alliance for the Mentally Ill
SC AUTISM SOCIETY

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 843-763-2640
 843-573-1905
800-305-4173
 803-740-1570
 803-252-0914
 412-341-1515
 800-326-8621
 800-759-4776
 800-234-5772
 800-788-5131
800-438-4790

E-mail
 SCDDSN - Central Office (Columbia)
SCDDSN - AUTISM DIVISION

craig@scautism.org
 803-898-9609
803-898-9609

toll free
 SC Independent Living Council
 SC Protection and Advocacy for People with Disabilities
 SC Services Information System (SCSIS)
 Special Olympics
 Tourette Association of SC
 SC Disability Determination Division (Voc Rehab/Childhood Disability)

888-376-4636
 803-731-1439
 803-782-0639
 800-922-1107
 800-765-7276
 803-798-0990
 803-896-6410

SCHOOL DISTRICT NUMBERS

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GOVERNMENT NUMBERS

Governor James Hodges

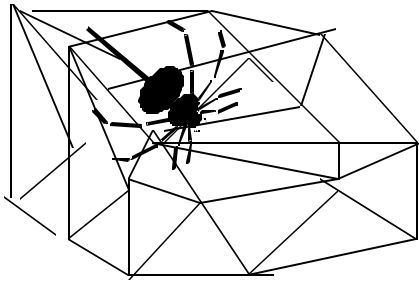
803-734-9818

Honorable Strom Thurmond (Senator/R)

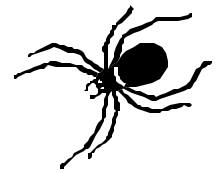
202-224-5972

Honorable Ernest F. Hollings (Senator/D)

202-224-6121



A Few CAPTIVATING INTERNET WEB SITES



South Carolina Autism Society: www.scautism.org

Autism Society of America: www.autism-society.org/

Parent Training & Resource Center: www.ptrc.org

Autism Research Institute: www.autism.com/ari/

Aspergers/Autism-On the Same Page: http://amug.org/~a203/table_contents.html

National Alliance for Autism Research (NAAR): www.naar.org

Autism National Committee: www.autcom.org Division Teach/UNC: www.teacch.com/teacch.htm

NCAS Book Store: http://appcomm.com/Merchant2/merchant.mv?Screen=SFNT&Store_Code=ASNC

Fragile X: www.FRAXA.org/

Learning Disabilities on line: www.ldonline.org/

The ARC (Assoc. of Retarded Citizens): TheArc.org/welcome.html

Pervasive Developmental Delay (PDD): www.voicenet.com/~cavalier/pddhome.htm

International Rett Syndrome Association: www2.paltech.com/irsa/irsa/htm

The Family Village: www.familyvillage.wisc.edu

National Association for Rare Diseases, Inc.: www.rarediseases.org

Listing of Specific Diseases & Disorders: www.mic.ki.se/Diseases/alphalist.html

Children & Adults with Attention Deficit Disorder (CHADD): www.chadd.org/

Special ed News: www.specialednews.com

IEP Information: www.shorelin.wednet.edu:/Intranet/IEP/iep.html

Disability is Natural: www.disabilityisnatural.com

South Carolina General Assembly: www.leginfo.state.sc.us/

Social Security Administration: www.ssa.gov

Axis Disability Rights Website: www1.us.nizkor.org/~axis/

Center on Human Policy: <http://soeweb.syr.edu/thechp/>

National Info. Ctr. for Child & Youth w/Disabilities (NICHCY): www.nichcy.org/

National Resource Center for Health & Safety in Child Care: <http://nrc.uchsc.edu/>

Research & Training Ctr. Family Support/Children's Mental Health: www.rtc.pdx.edu/

Bazelon Center for Mental Health Law: www.bazelon.org/

National Parent Network on Disabilities: www.npnd.org/

EDLAW-Special Education & the Law: www.access.digex.net/~edlawinc/

National Fathers Network: www.fathersnetwork.org/

Special Education Resources on the Internet: www.hood.edu/seri/serihome.html

Our Kids: wonder.mit.edu/ok/

Toys for Special Kids: www.Toys4SpecialKids.com/



W.I.T.W.D.A.T.L.M.?*

*What In The World Do All Those Letters Mean?

GLOSSARY OF COMMONLY USED ABBREVIATIONS

ABA	Applied Behavioral Analysis
ABC	Autism Behavior Checklist (diagnostic tool)
ADA	Americans with Disabilities Act of 1990
ADD	Attention Deficit Disorder
ADHD	Attention Deficit/Hyperactivity Disorder
ADL	Activities for Daily Living
ADOS	Autism Diagnostic Observation Scale (diagnostic tool)
AHA	American Hyperlexia Association
AIT	Auditory Integration Training
ANC	Austim National Committee (advocacy group) also: AUTCOM
APIB	Assessment of Pre-Term Infant Behavior
ARI	Autism Research Institute
AS	Asperger's Syndrome
ASA	Autism Society of America (National Advocacy/Support Group)
ASD	Autism Spectrum Disorder
ASL	American Sign Language
AT	Assistive Technology
BD	Behavior Disorder
BIP	Behavior Intervention Plan
CAN	Cure Autism Now (non-profit dedicated to research/cure)
CAPD	Central Auditory Processing Disorder
CARS	Childhood Autism Rating Scale (diagnostic tool)
CD	Communication Disorder
CEC	Council for Exceptional Children
CHAT	CHecklist for Autism in Toddlers (diagnostic tool)
CRS	Children's Rehabilitative Services
DAN	Defeat Autism Now conference/protocol of Autism Research Institute)
DD	Developmental Disability
DDSN	Department of Disabilities & Special Needs - State (SCDDSN)
D&E	Diagnosis & Evaluation
DSM-IV	Diagnostic Statistical Manual, 4th Revision
DSN	Department of Special Needs - Usually the County Department
DSS	Department of Social Services
ED/EH	Emotional Disorder/Emotional Handicap
EI	Early Intervention(ist)
EMD/EMH	Educable Mental Disability/Educable Mental Handicap
FAPE	Free Appropriate Public Education
FAS/FAE	Fetal Alcohol Syndrome/Fetal Alcohol Effects
FA	Functional Analysis (of Behavior) sometimes FAB or FBA
FC	Facilitated Communication
FEAT	Families for Early Autism Treatment (CA based advocacy group)
FTT	Failure to Thrive

GLOSSARY OF COMMONLY USED ABBREVIATIONS

GDD	Global Developmental Delay
HCBS	Home and Community Based Services
HFA	High Functioning Autism
HMO	Health Maintenance Organization
IDEA	Individuals with Disabilities Education Act of 1990
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
IHP	Individualized Habilitation Program
IPP	Individual Program Plan
I&R	Information and Referral
IRWE	Impairment-Related Work Expense
LBW	Low Birth Weight
LD	Learning Disability
LEA	Local Education Agency
LFA	Low Functioning Autism
LRE	Least Restrictive Environment
MH	Mental Health (DMH-Department of Mental Health)
MMR	Mild Mental Retardation
MR	Mental Retardation
NBD	Neurobiological Disorders
NICU	Neonatal Intensive Care Unit
NIH	National Institute of Health
NOS	Not Otherwise Specified
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiant Disorder
OHI	Other Health Impaired
OSEP	Office of Special Education Programs (Federal)
OSERS	Office of Special Education & Rehabilitative Services (Federal)
OT	Occupational Therapy
P&A	Protection & Advocacy Agency (SCP&A-South Carolina's P&A)
PCA	Personal Care Assistant
PDD	Pervasive Developmental Disorder
PDDNOS	Pervasive Developmental Disorder Not Otherwise Specified
PECS	Picture Exchange Communication System
PMD	Profoundly Mentally Disabled
PT	Physical Therapy
PTRC	Parent Training and Resource Center
SPD	Semantic Pragmatic Disorder
SI	Sensory Integration
SIB	Self-Injurious Behavior
SLP	Speech Language Pathologist
SSA	Social Security Administration
SSI	Supplemental Security Income
SSDI	Social Security Disability Insurance
TEACCH	Treatment & Education of Autistic & Related Communication Handicapped Children
TEFRA	Tax Equity and Fiscal Responsibility Act (Katie Beckett)
TMD/TMH	Trainable Mentally Disabled/Handicapped
UAP	University Affiliated Program
WIC	Women, Infants, & Children Program



MILESTONES OF GROWTH & DEVELOPMENT

I'M JUST A KID, WHAT SHOULD I DO?

I'M 9 MONTHS OLD! I ...

- Copy sounds or gestures
- Reach for crumbs or other small things with my thumb & fingers
- Move toys from one hand to the other
- Support myself with my straightened arms when I'm on my stomach
- Understand the word "No"

I'M 12 MONTHS OLD! I ...

- Respond to my name
- May be scared of strangers
- Look for an object if you hide it from me, even if I can't see it
- Crawl on my hands and knees
- Pull myself to a standing position
- Walk by holding onto furniture
- Can drink from a cup with your help
- Enjoy playing games, like peek-a-boo or patty cake
- Say 1 to 2 words

I'M 15 MONTHS OLD! I ...

- Use gestures
- Like to look at pictures in a book
- Can hold a crayon in a fist
- Hand toys to you when you ask me
- Can point to pictures you name, if things in the picture are familiar
- Walk alone without help

I'M 18 MONTHS OLD! I ...

- Like to pull & push things
- Follow simple directions
- Pull off shoes & socks
- Feed myself sometimes
- Step off low objects & keep my balance
- Turn 2 to 3 pages of a book at a time
- Can point to one body part
- Can name one object
- Like to copy your words or actions

I'M 21 MONTHS OLD! I ...

- Can name 2 objects
- Like to pretend-play
- Can put together a simple picture puzzle if it has only 2 or 3 large pieces
- Like to throw balls
- Like to play alone with toys for a short time
- Say "No" a lot

I'M 24 MONTHS OLD! I ...

- Use 2 to 3 words together, like "No, Mommy" or "More cookies"
- Say names of toys and people
- Feed myself with a spoon
- Turn one page at a time
- Point to hair, eyes, and nose when someone asks me
- Show affection to family members and pets
- Run short distances without falling

MORE MILESTONES

I'M 3 YEARS OLD! I ...

- Answer simple questions
- Walk up steps, alternating feet
- Put my clothes on by myself
- Open simple containers
- Like to play with other children
- Repeat simple rhymes & songs
- Use 3 to 5 word sentences
- Name at least one color correctly
- Jump in place

SPEECH & LANGUAGE MILESTONES

<u>AGE</u>	<u>HEARING & UNDERSTANDING</u>	<u>EXPRESSIVE LANGUAGE</u>
3-6 Mos.	Responds to sounds & voices by looking toward sound source.	Babbles. Practices sounds. Vocalizes back.
6-12 Mos.	Responds to requests like "Come Here" Looks at pictures. Understands gestures.	Babbling sounds like real speech. Plays simple games like pat-a-cake. Vocalizes to get attention
1-2 Years	Obeys simple commands like "Put the truck in the box." Can point to body parts. Recognizes pictures of objects. Listens to rhymes & songs.	Says first words & names objects. Repeats phrases like "all gone." Begins to use 2 words sentences.
2-3 Years	Identifies objects by function (ie: "Which one do you play with?") Understands prepositions/adjectives.	Uses 2-4 word sentences. Vocabulary builds to about 900 words. Uses adjectives/pronouns.
3-4 Years	Listens to stories. Follows 2-part commands. Can match & sort objects. Remembers recent events.	Asks lots of questions. Speech is understandable. Tells stories, shares ideas. Vocabulary builds to 1500 words. Counts to three.
4-5 Years	Comprehends 2500 words. Understands common opposites (hot/cold). Follows 3-part commands. Likes books, tries to "read" them.	Uses complete sentences. Uses how & where questions. Talks about imaginary things. Counts to ten.
5-6 Years	Understands time concepts. Begins to differentiate between fact & fantasy. Understands humor, plot, surprise. Can sequence 4 pictures to make story.	Tells several things about an object. Tells sequence of events. Likes to pretend & act out stories. Uses complex sentences.
6-8 Years	Understands riddles. Anticipates story endings Wonders about abstract concepts.	Gives short oral reports. Uses details in description. Names days, months, numbers in order.

These milestones are guidelines. Children will vary. It may be useful to understand the progression of developmental milestones in typically developing children when writing IEP goals and objectives. This information is helpful as you watch for pre-emerging/emerging skills.

Special Education 101

A List of Disabling Conditions/Special Education Programs

A diagnosis of Autism is specifically named as a disabling condition which results in eligibility for special education services under the Individuals with Disabilities Education Act (IDEA). Other eligibility categories it may be helpful to understand include:

Learning Disabled (LD): Must have *at least* low average abilities and a significant discrepancy between measured intellectual skills and achievement in one of the following academic areas: basic reading skill (reading decoding), reading comprehension, written expression, math computation, or math applications.

Speech or Language Impairment: Refers to a communication disorder such as stuttering, impaired articulation or language impairment that adversely affects a student's educational performance. (This category is most often reserved for students with an articulation disorder, but physicians can also advocate for special education placement under this category for those students who are language impaired.)

Emotionally Disabled (ED): (sometimes referred to as Seriously Emotionally Disturbed-SED): Must be found to evidence significant emotional, motivational or social disturbances, requiring special classes and educational instruction.

Educably Mentally Disabled (EMD): (Mild MR): IQ, achievement and adaptive skills must be between 48 and 70.

Trainably Mentally Disabled (TMD): (Moderate MR): IQ and adaptive skills must be between 25 and 48.

Profoundly Mentally Disabled (PMD): (Severe MR): IQ and adaptive skills must be between 0 and 25.

Models of Service Delivery Within School Settings

Regular Class with Consultation to the Teacher: In this placement option the student spends the entire school day in the regular classroom & receives no direct special education services. An instructional specialist or other staff member provides assistance to the teacher in relating to the individual needs within the classroom

Itinerant Services: A special education teacher provides direct services *less than 50 minutes daily*. Such a model can provide flexibility to students who have less severe disabilities or who are being transitioned out of special education.

Resource Services: A special education teacher provides *at least 50 minutes of daily services* directly to the student.

Self Contained Services: The student attends a special education program taught by a special education teacher who is certified in the child's specific disabling condition. The child should be mainstreamed in the subjects/areas which are strengths.

Homebound Services: Such services are deemed necessary for those students exhibiting severe problems such as significant emotional problems, those who are posing a danger to themselves or others or those who may have significant medical problems that prohibit attending school.

Special Day School: Some districts have contractual arrangements with agencies to provide treatment for those students who cannot benefit from inclusion in a regular school.

Eligibility Criteria Note for Related Services: In order for a student to receive additional services such as OT, PT or speech services, a determination has to be made that the services are educationally relevant.

Support Personnel

Audiologist: The audiologist provides diagnostic audiological testing for children who fail the hearing screening evaluation. Maintenance of hearing aids and other equipment is provided.

Brailist: The brailist is responsible for converting regular classroom texts and other material into braille for students with visual impairments.

Guidance Counselors: All students, K-12, including those with disabilities, receive assistance and services from the guidance counselors in the areas of personal, social, educational and career development.

Interpreters: These individuals assist students with hearing impairments by providing interpreting services in classrooms, at school functions and for extracurricular activities.

Job Coaches/Transition Specialists: Students are introduced to the work force through the intervention of a job counselor. Placement and supervision of the students improve the transition from school to the adult world or from school to post secondary programs.

Nurses: All students are served by the nursing staff. Some students may require written Health Management Plans which are developed and monitored by the nursing staff.

Occupational Therapists: Skills and work experiences are provided for students with physical disabilities in order to prepare them for functional participation in the community at large. Therapy is provided in order for the students to benefit from their special education instruction.

Orientation/Mobility Specialists: Students with visual impairments are assisted in their development of mobility skills within the school & community.

Physical Therapists: Children who need physical therapy for improving or maintaining their mobility are aided by the therapists. Program goals are directed by attending physicians and provided in order for the students to profit from their special education instruction.

Psychologists: These professionals provide consultation, counseling, and diagnostic testing for both regular and special education students. They participate with school-based testing teams to formulate intervention strategies.

Instruction Specialists (may have a different title district by district): These master's level teachers provide consultation and intervention in all special classrooms. Assistance is provided to the teacher in adapting the curriculum to meet the students' education needs.

Speech Clinicians: Students with speech/language problems receive services in individual or small group therapy sessions on a weekly basis by these professionals.

Social Worker: Coordinating interagency efforts to support students in the least restrictive environment, the social worker is the liaison between the home, school and community.

SPECIAL EDUCATION 201 — THE IEP AND BEYOND

Understanding the special education process and its components is challenging. It is important to know your rights and responsibilities as a parent and how the IDEA provides for your participation in developing an individual education program for your child. There may be several relevant areas to learn about: the evaluation, the IEP team, the functional assessment, a positive behavior intervention plan. The good news is there are agencies who can help you understand the process. Please contact the SCAS and inquire about receiving help through the Parent School Partnership or contact PRO-PARENTS (800-759-4776). If you live in Berkeley, Dorchester or Charleston County you may contact the Parent Training and Resource Center for assistance (843-792-3025).

RESOURCE DIRECTORY

The Parent Training and Resource Center

OCTOBER 2001

ADVOCACY 101

When I saw this in a "Dear Abby" column I immediately grabbed my scissors and cleared off a spot on my refrigerator door. For me, this list serves as a reminder as I plan my IEP strategies, ready myself for advocacy meetings, or try to make sense to my teenagers. I hope you find these suggestions as valuable as I do. Peter S. Chantilis, Attorney-Mediator, from Dallas, Texas compiled this list of suggestions. His forty years of practicing law and mediation brought him these conclusions:

- 1 Learn to disagree without being disagreeable. It's all right to be assertive, but not aggressive, abusive, or abrasive.
- 2 When someone says something with which you disagree, try not to be judgmental.
- 3 Maintain eye contact when greeting people, and shake their hands. (Touching is important.)
- 4 Be kind and courteous to everyone.
- 5 Remember that civility is a sign of strength, not weakness.
- 6 Speak softly. (People tune out loud, angry voices.)
- 7 Saving face is important. Give your opponent the opportunity to withdraw.
- 8 Your attitude is more important than your aptitude.
- 9 Mutual respect is the key to avoiding conflict.
- 10 Give the other person a chance to be heard without interrupting.
- 11 The shortest distance between two people is a smile.

The Parent Training and Resource Center (PTRC), is the result of a partnership between The Advocacy Coalition for People with Disabilities and the Medical University of South Carolina, College of Health Professions, Research Office. The Parent Training and Resource Center is made possible through a grant from the U.S. Department of Education, by funds allocated by the Individuals with Disabilities Education Act (IDEA). Program services include a free, comprehensive lending library, a quarterly newsletter (The Coalition), an annual disabilities conference held at The Citadel in Charleston, a website and the Peer-Parent Mentor Program for Special Education Support. To find out more information about any of these services please contact The Family Resource Center.

**For more information about
The Advocacy Coalition for People with Disabilities
please contact;
Paula Byers, Program Coordinator: (843) 795-5316
David Conway, ACPD Board President: (843) 876-1525**

Every effort is made to keep the information contained in this Resource Directory current. If you are aware of changes that should be made to the contents of this Directory please contact the Family Resource Center (843) 792-3025.
