### **Contents:**

#### Autism 101

Milestone Checklist What is Autism Assistance for Your Child What is Early Intervention Glossary of Terms Related Therapy Wraparound Services Parent rights

#### **Family and Support Information**

Build and Develop Your Support Team Tips for Parents New to Autism Siblings Parents and Professionals Willing to Help Autism 101 Parents-Law Enforcement

#### Resources

Activities BHRS Camps Catalogs County/State Resources Haircuts Medical Supplies Physicians Shopping SSI Websites



#### K.A.R.E- Kommittee for Autism Research and Education

This resource book was created as a result of a grant from the Bureau of Autism Services. The goal is to help families of newly diagnosed children on the autism spectrum navigate through the vast amount of services and products that are currently available for individuals with autism. The inclusion of any particular agency or business does not imply an endorsement from The Bureau of Autism Services, K.A.R.E, or any agencies that link this guide to their website.

Many parents and professionals worked diligently to create this guide. The K.A.R.E group would like to thank everyone for the time and dedication they put into creating this guide. We would also like to thank the Bureau of Autism Services for the grant and for allowing us to incorporate some of their publications into the guide. We would also like to thank About.com for allowing us to use some of their autism publications.

The mission of the K.A.R.E group is the belief that through it's collaboration with families, educators, and community partners we will work together to enhance the lives of individuals with autism spectrum disorder. If you would like more information on the K.A.R.E group, please contact Lisa Hampe at 1-800-328-6481, ext. 272 or email <a href="https://www.hampel@iul.kl2.pa.us">https://www.hampel@iul.kl2.pa.us</a> or Renae Kotchman ext. 105 or email kotchmanr@iul.kl2.pa.us.

This Resource Guide can be viewed from the website listed below. Permission is given to copy this guide (with the exception of the Autism Bureau and About.com inserts) as long as credit is given to the K.A.R.E. group.

http://www.iu1.k12.pa.us

K.A.R.E Resource Guide



# Autism 101

## Important Milestones By The End Of 3 Months

Simply fill out your child's name, age and today's date and then check off the milestones your child has already achieved.

Child's Name	Child's Age	Today's Date
Social and Emotional	Hearing and Sp	eech
Begins to develop a social smile	Smiles at the sound of your voice	
Enjoys playing with other people and may cry	<ul> <li>Begins to babble</li> </ul>	
when playing stops	<ul> <li>Begins to imitate some sounds</li> </ul>	
Becomes more expressive and communicates more with face and body	Turns head toward direction of sound	
Imitates some movements and facial expressions		
Movement		
Raises head and chest when lying on stomach		
Supports upper body with arms when lying on stomach		
Stretches legs out and kicks when lying on stomach or back		
Opens and shuts hands		
Pushes down on legs when feet are placed on a		
firm surface		
Brings hand to mouth		
Takes swipes at dangling objects with hands		
Grasps and shakes hand toys		
Vision		
Watches faces intently		
Follows moving objects		
Recognizes familiar objects and people at a distance		

□ Starts using hands and eyes in coordination

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## Important Milestones By The End Of 7 Months

Simply fill out your child's name, age and today's date and then check off the milestones your child has already achieved.

Child's Name	Child's Age	Today's Date
Social and Emotional	Vision	
Enjoys social play	Develops full color v	rision
Interested in mirror images	Distance vision mature	
Responds to other people's expressions of emotion and appears joyful often	Ability to track movi	ng objects improves
Cognitive		
Finds partially hidden object		
Explores with hands and mouth		
Struggles to get objects that are out of reach		
Language		
Responds to own name		
Begins to respond to "no"		
Can tell emotions by tone of voice		
Responds to sound by making sounds		
Uses voice to express joy and displeasure		
Babbles chains of sounds		
Movement		
Rolls both ways (front to back, back to front)		
Sits with, and then without, support on hands		
Supports whole weight on legs		
Reaches with one hand		
Transfers object from hand to hand		
Uses hand to rake objects		
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## Important Milestones By The End Of 1 Year (12 Months)

Simply fill out your child's name, age and today's date and then check off the milestones your child has already achieved.

Child's Name	Child's Age	Today's Date
<ul> <li>Social and Emotional</li> <li>Shy or anxious with strangers</li> <li>Cries when mother or father leaves</li> <li>Enjoys imitating people in his play</li> <li>Shows specific preferences for certain people and toys</li> <li>Tests parental responses to his actions during feedings</li> <li>Tests parental responses to his behavior</li> <li>May be fearful in some situations</li> </ul>	<ul> <li>Language</li> <li>Pays increasing atter</li> <li>Responds to simple</li> <li>Responds to "no"</li> <li>Uses simple gesture for "no"</li> <li>Babbles with inflecti</li> <li>Says "dada" and "not uses exclamations,</li> <li>Tries to imitate word</li> </ul>	verbal requests s, such as shaking head on (changes in tone) mama" such as "Oh-oh!"
<ul> <li>Prefers mother and/or regular caregiver over all others</li> <li>Repeats sounds or gestures for attention</li> <li>Finger-feeds himself</li> <li>Extends arm or leg to help when being dressed</li> </ul>		
<ul> <li>Cognitive</li> <li>Explores objects in many different ways (shaking, banging, throwing, dropping)</li> <li>Finds hidden objects easily</li> <li>Looks at correct picture when the image is named</li> <li>Imitates gestures</li> <li>Begins to use objects correctly (drinking from cup, brushing hair, dialing phone, listening to receiver)</li> </ul>		

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## Important Milestones By The End Of 2 Years (24 Months)

Simply fill out your child's name, age and today's date and then check off the milestones your child has already achieved.

Child's Name	Child's Age	Today's Date	
Social and Emotional	Follows simple instru	ctions	
Imitates behavior of others, especially adults and older children	Repeats words overheard in conversation		
More aware of herself as separate from others	Movement		
More excited about company of other children	Walks alone		
	Pulls toys behind her while walking		
Emotional	Carries large toy or several toys while walking		
Demonstrates increasing independence	Begins to run		
Begins to show defiant behavior	Stands on tiptoe		
Separation anxiety increases toward midyear	Kicks a ball		
then fades	Climbs onto and down from furniture unassisted		
Cognitivo	Walks up and down	stairs holding on to support	
Cognitive Finds objects even when hidden under two or	Hand and Finae	or Skills	
three covers	Hand and Finger Skills Scribbles on his or her own		
Begins to sort by shapes and colors	<ul> <li>Turns over container to pour out contents</li> </ul>		
Begins make-believe play	<ul> <li>Builds tower of four blocks or more</li> </ul>		
		more often than the other	
Language			
Points to object or picture when it's named for him			

Learn the Signs. Act Early.

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Recognizes names of familiar people, objects, and

Says several single words (by 15 to 18 months)
 Uses simple phrases (by 18 to 24 months)

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Uses 2- to 4-word sentences

body parts





## Important Milestones By The End Of 3 Years (36 Months)

Simply fill out your child's name, age and today's date and then check off the milestones your child has already achieved.

Child's Name	Child's Age	Today's Date
Social and Emotional	Understands most sen	Itences
Imitates adults and playmates	<ul> <li>Understands placement in space</li> </ul>	
Spontaneously shows affection for familiar	("on," "in," "under")	
playmates	Uses 4- to 5-word sentences	
Can take turns in games	Can say name, age, and sex	
Understands concept of "mine" and "his/hers"	Uses pronouns (I, you, me, we, they) and some plurals (cars, dogs, cats)	
Emotional	Strangers can understand most of her words	
Expresses affection openly		
Expresses a wide range of emotions	Movement	
By 3, separates easily from parents	Climbs well	
Objects to major changes in routine	Walks up and down stairs, alternating feet	
	(one foot per stair step)	
Cognitive	Kicks ball	
Makes mechanical toys work	Runs easily	
Matches an object in her hand or room to a	Pedals tricycle	
picture in a book	Bends over easily without falling	
Plays make-believe with dolls, animals, and people	Hand and Eingo	r Skille
Sorts objects by shape and color	Hand and Finger Skills	
Completes puzzles with three or four pieces	Makes up-and-down, side-to-side, and circular	
Understands concept of "two"	lines with pencil or crayon	
Language	<ul> <li>Turns book pages one at a time</li> <li>Builds a tower of more than six blocks</li> </ul>	
Follows a two- or three-part command	<ul> <li>Holds a pencil in writing position</li> <li>Screws and unscrews jar lids, nuts, and bolts</li> </ul>	
<ul> <li>Recognizes and identifies almost all common objects and pictures</li> </ul>	<ul> <li>Turns rotating handles</li> </ul>	

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## Important Milestones By The End Of 4 Years (48 Months)

Simply fill out your child's name, age and today's date and then check off the milestones your child has already achieved.

Child's Name	Child's Age	Today's Date	
Social and Emotional <ul> <li>Interested in new experiences</li> </ul>	Understands the concepts of "same" and "different"		
<ul> <li>Cooperates with other children</li> <li>Plays "Mom" or "Dad"</li> </ul>	and "different" Engages in fantasy play		
Increasingly inventive in fantasy play	Language		
Dresses and undresses	Has mastered some	basic rules of grammar	
Negotiates solutions to conflicts	Speaks in sentences of five to six words		
More independent	Speaks clearly enough	gh for strangers to understand	
Free a Rana ad	Tells stories		
Emotional			
Imagines that many unfamiliar images may	Movement		
be "monsters"	Hops and stands on one foot up to five seconds		
Views self as a whole person involving body, mind, and factions.	Goes upstairs and downstairs without support		
mind, and feelings <ul> <li>Often cannot tell the difference between fantasy</li> </ul>	Kicks ball forward		
and reality			
	<ul> <li>Catches bounced ball most of the time</li> <li>Moves forward and backward with agility</li> </ul>		
Cognitive			
Correctly names some colors	Hand and Finger Skills		
Understands the concept of counting and may	Copies square shapes		
know a few numbers	<ul> <li>Draws a person with two to four body parts</li> </ul>		
Tries to solve problems from a single point	Uses scissors	, ,	
of view	<ul> <li>Draws circles and squares</li> </ul>		
Begins to have a clearer sense of time	Begins to copy some capital letters		
Follows three-part commands			
Recalls parts of a story			

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## Important Milestones By The End Of 5 Years (60 Months)

Simply fill out your child's name, age and today's date and then check off the milestones your child has already achieved.

Child's Name	Child's Age	Today's Date	
<ul> <li>Social and Emotional</li> <li>Wants to please friends</li> <li>Wants to be like her friends</li> <li>More likely to agree to rules</li> <li>Likes to sing, dance, and act</li> <li>Shows more independence and may even visit a next-door neighbor by herself</li> </ul>	<ul> <li>Tells longer stories</li> <li>Says name and address</li> <li>Movement</li> <li>Stands on one foot for 10 seconds or longer</li> <li>Hops, somersaults</li> <li>Swings, climbs</li> <li>May be able to skip</li> <li>Hand and Finger Skills</li> <li>Copies triangle and other shapes</li> <li>Draws person with body</li> <li>Prints some letters</li> </ul>		
<ul> <li>Emotional</li> <li>Aware of gender</li> <li>Able to distinguish fantasy from reality</li> <li>Sometimes demanding, sometimes eagerly cooperative</li> </ul>			
<ul> <li>Cognitive</li> <li>Can count 10 or more objects</li> <li>Correctly names at least four colors</li> <li>Better understands the concept of time</li> <li>Knows about things used every day in the home (money, food, appliances)</li> </ul>	<ul> <li>Dresses and undresses without help</li> <li>Uses fork, spoon, and (sometimes) a table knife</li> <li>Usually cares for own toilet needs</li> </ul>		
<ul> <li>Language</li> <li>Recalls part of a story</li> <li>Speaks sentences of more than five words</li> <li>Uses future tense</li> </ul>			

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#### What is Autism?

Autism is very complex, life-long disability that usually begins to appear in a child between 15 and 20 months of age. A 2007 study issued by the federal Centers for Disease Control and Prevention indicates that one in 150 children has some form of autism. Boys are four times more likely to have autism than girls. Recent research indicates autism has a genetic basis. Autism can affect social behavior, language skills and the way your child's body acts. Sometimes children and adults with autism behave in ways that seem strange or disturbing.

Children and adults with autism do not always show the same symptoms. Always consult your child's doctor to get a proper diagnosis. Autism is actually one of five disorders that are described commonly as "Autism Spectrum Disorders," which include:

- Autistic Disorder
- Asperger Syndrome
- Childhood Disintegrative Disorder
- Rett Syndrome
- Pervasive Developmental Disorders (Not Otherwise Specified)

•

This Web site uses the term "autism" or "ASD" to refer to all Autism Spectrum Disorders.

Symptoms of the way autism affects social behavior may include:

- Having less eye contact, even with family members
- Not responding when name is called
- Social awkwardness or lack of interest in others
- Being very attached to objects and using them in unusual ways
- Difficulty with transitions or change

Symptoms of the way autism affects language skills may involve:

- Delay in or failure to speak
- Absence of the use of gestures such as pointing or waving
- Impaired ability to have a conversation
- Repeating words or phrases but without meaning

Symptoms of the way autism affects the way your child's body acts may include: inflexibility and rigidity, high tolerance for pain, hand flapping or spinning.

Children and adults with autism sometimes have other disorders and disabilities, so it is very important to understand each individual child or adult in order to develop the most effective treatment plan. How each person with autism grows and develops depends on the interaction between his or her autism, family members and friends, teachers and other professionals, and types of treatment. For more detailed information and perspectives on the complicated nature of autism, visit these Web sites:

Autism Society of America National Institutes of Health Kennedy Krieger Institute Organization for Autism Research

Created by dpw communications office

Source: Commonwealth of Pennsylvania, Dept of Public Welfare, Bureau of Autism Services' website at <u>www.autisminpa.org</u>.

## How to Apply for Medical Assistance for Your Child with Autism

#### Building a support team around your child is the real first step

**Step 1: Apply for Social Security's Supplemental Security Income (SSI)** Why must you apply for SSI? Medical Assistance (MA) will pay for many of the services your child will need and in order too become eligible for Medical Assistance, you must first show proof that you applied for federal aid via SSI. "Proof" is in the form either of acceptance documents from SSI or a rejection letter.

You can apply for SSI online, by phone or in person. If you apply in person at your local Social Security office, you will need to bring your child's Social Security card, original birth certificate, and "medical evidence" of your child's diagnosis from a qualified physician (neurologist, psychiatrist, developmental pediatrician or PA certified psychologist). You will be asked for information on your family's assets. If your assets exceed allowable SSI limits (regardless of your child's diagnosis) you may be immediately "rejected." Ask the Social Security staff person to issue an official rejection letter immediately. If a letter cannot be issued while you wait, ask to have it mailed it to you. You will need the original rejection letter. Make a copy of the rejection letter for your own records.

Apply for SSI phone at: 1-800-772-1213 or <u>online</u>. If your child is found eligible for SSI, he or she is automatically eligible for Medical Assistance. See note on bottom of page for more information.

**Step 2: Obtain the Correct Medical Assistance Application** You can apply for Medical Assistance online using <u>COMPASS</u>. You can also request a "General Benefits Application 600C" for Medical Assistance (PDF download): <u>Application for Health Care</u> <u>Coverage</u> You can also obtain this application from <u>your County Assistance Office</u> (CAO) or <u>your local elected official's office</u>.

**Step 3: Complete the Entire Application** Complete a printed version even if you apply online, as it will help you through the process. If you intend to mail your application, fill out the application completely, including income information. Fill out all sections, even portions you think may not apply to your child. Make a copy of your completed application. You will need this in case your application is lost, and it will be a useful reference when for the required annual renewal applications.

If you have questions about the application, call the Department of Public Welfare at 1-

800-692-7462 (1-800-451-5886 TDD for individuals with hearing impairments). You can also call <u>your County Assistance Office</u>. The <u>Pennsylvania Health Law Project</u> can help walk you through filling out the application.

On page 4 of the application, write YES next to your child's name in the column marked "Are you applying for this person?" Also write on page 4 at top: "MA FOR DISABLED CHILD HANDBOOK SECTION 355.4." This note flags your application as one for a child with autism.

**Step 4: Bring the Required Documents to <u>Your Local County Assistance Office</u> (CAO) for an Interview An interview can be done in person at your County Assistance Office or by phone. Some parents have found that applying in person, especially with all the proper documents, helps build a support team. You can also mail the application and documents – or <u>apply online using COMPASS</u> -- and follow up by phone to arrange an appointment. Some parents report that going to their local CAO without an appointment -- and simply waiting for the next available caseworker -- is faster. Bring all of these documents for the interview:** 

A completed MA Application
Your child's <u>original</u> birth certificate
Your child's Social Security card
The <u>original</u> SSI rejection letter (if you have received a rejection)
A document containing your child's diagnosis of autism from a physician qualified to diagnose autism
Recent pay stub (or most recent IRS Form 1040 if self-employed)
Your <u>Pennsylvania</u> driver's license
Evidence of your Pennsylvania residency (example: a utility bill containing your name and Pennsylvania address)

Your child is not required to attend any interview.

This interview and review of your documentation should result in your child being found eligible as a child with autism. The MA system in Pennsylvania evaluates your child based upon the same criteria as SSI, but without considering the family's financial situation. If your child is found eligible on a provisional basis, you will be issued a Medical Assistance Identification Number. Write this down, along with the name and phone number for your assigned caseworker. You should also request a temporary, or interim, <u>ACCESS card</u>, if it is not provided. This card can be used immediately with health care and behavioral health care providers. A permanent card will be mailed to you.

In some cases, persons may qualify for payment of medical services that were provided up to three months before the month in which you applied— this is called "retroactive" coverage. **Step 5: Prepare to Renew Your Application Every Year** You will need to complete a re-application once a year. A notice will be mailed to you by your CAO caseworker. You can reapply by mail or online using the Pennsylvania <u>COMPASS</u> system .

#### **Step 6: Once Your Child is Eligible for MA and Assigned an MA Identification Number, You Must Make Two Choices:**

<u>First</u>, using the online <u>Pennsylvania Medical Assistance Enrollment Service</u>, choose a **physical** health services provider in your county.

Once you have chosen a physical health services provider, you will receive a Member ID card. Bring this card and your ACCESS card to all medical appointments for your child. Also, bring these cards to your preferred pharmacy, so that they can put your child's information in their system.

Each plan provider has a Member Services unit, and a Special Needs unit. Write these numbers down with your other important numbers. Depending on your county of residence, other services, including transportation to medical appointments, may be available.

<u>Second</u>, find out which **behavioral** health care provider serves your county. You will not have choice to make: each county has a contract with behavioral health care provider. If you plan to obtain behavioral health services, you will need to contact a local direct-care wraparound agency and proceed with the intake process. These agencies are responsible to the care provider mentioned above contracted by your county.

#### Complaints

You should have a copy of the process for complaining in your county Health Care Plan Provider's "Member Handbook," mailed to you when you signed up for physical and behavioral health services

If you need a handbook, call your county Plan Provider to have them send you one. For Medical Assistance services, there is a grievance system to protect your rights. Each Plan Provider is required to have a formal process to help resolve client issues. In order to invoke those rights, you must use the complaint system.

#### Comments

The Department of Public Welfare welcomes constructive feedback about Medical Assistance services provided to families with autism. Use <u>the DPW Online Feedback</u> Page to give us your feedback.

#### Additional Independent Information About Your Child's Health Rights

For free legal advice and assistance call the <u>Pennsylvania Health Law Project</u> at (800)

274-3258 or (412) 434-5779.

\*\*\*

**About SSI** (from Step 1 at top of page)

SSI provides financial help to people who have limited income and assets and meet other rules (including disability). Based on the information you give about your child's (the "claimant") income, assets, citizenship status and disability and your income and assets, you may be eligible for SSI. Parent assets can be counted against a child's allowable \$2,000 resource limit. In most states, a child who gets SSI benefits can get Medicaid to help pay medical bills.

FYI: Children with autism fall under the category of "autistic disorder and other pervasive developmental disorders (112.10) in SSI's "<u>Disability Evaluation Under Social</u> <u>Security</u>," or "Bluebook."

\*\*\* Source: Commonwealth of Pennsylvania, Dept of Public Welfare, Bureau of Autism Services' website at <u>www.autisminpa.org</u>

Last modified on: June 30, 2008

#### What is Early Intervention?

**Early Intervention is the best treatment for children diagnosed with autism before the age of five.** There are two different types of Early Intervention Services for children. There are the birth to three services and the services for three to five years old.

#### **Early Intervention- Birth to three:**

The Early Intervention Program is designed to help families of infants and toddlers with, or at risk for, developmental delays to enhance the development of their children.

Entry into this program begins with a referral to Washington Communities MH/MR Center. A service coordinator will visit the family and complete a Family Assessment along with other required paper work and schedule evaluations to determine the child's eligibility for Early Intervention Services. Next, a Multidisciplinary Team Evaluation will determine eligibility. If the child is found eligible for services an Individual Family Service Plan (*IFSP*) will be developed. **\* IFSP will soon have a different name and become one document that continues through the Early Intervention process.** 

Services can include; Developmental Specialist,

Teachers of the Hearing-Impaired, Physical Therapist, Speech/Language Pathologist, Occupational Therapist, Teachers of the Visually-Impaired/Orientation and Mobility Specialist and other services.

These teachers and therapists assist parents, family members or other caregivers in learning ways to support their children within their daily routines and activities in their natural environment.

The staff can assist families to explore new ways to provide learning opportunities for their children throughout the day in any setting where they spend their time. They can also assist families in making accommodations (*as necessary*) to help each child participate more fully in family and community life.

Parents' participation in the development of each child's individual plan assures that all other team members know the goals and dreams families have for their children, and that they will work with them toward the accomplishment of these important outcomes.

Services for eligible children are provided year-round, and at no cost to families. The team decides the services and provider of service. For more information about Early Intervention Services or to make a referral call:

> Washington Communities MH/MR Center, Inc. 378 West Chestnut Street, Suite 205 Washington, PA 15301 724-229-2620 or 724-225-6940 or 866-765-2888 Vickie Amos, Early Intervention Coordinator 724-228-6832

#### **Early Intervention-Three to five:**

#### Intermediate Unit 1

Early Intervention preschool services are provided for children from three to five years old who exhibit a developmental delay or a physical or mental disability that requires specially designed instruction/special education services.

The term "developmental delay" includes delays of 25% or more in physical, cognitive, language and speech development or adaptive behavior or self help skills.

The Early Intervention Programs follow guidelines from the Department of Education, specifically Chapters 14 and 342 of the Pennsylvania School Code, which regulates special education services.

The Early Intervention services offered by Intermediate Unit 1's Child ALERT include: Speech and language therapy, Occupational Therapy, Physical Therapy, Vision Support, Hearing Support and Psychological Services.

These services are provided in a variety of settings, including: home based settings, private preschools, daycares, Head Start, and Child ALERT classrooms.

Developmentally Appropriate Practices (*DAP*) are used to address the physical, cognitive, communication, social/emotional and self-help developmental needs of children. Services are provided at no cost to families.

#### **Intermediate Unit 1**

One Intermediate Unit Drive Coal Center, PA 15423-9642 1-800-328-6481 or 724-938-3241, ext. 220 http://www.iu1.k12.pa.us/

**Barb Rothermel, Early Intervention Supervisor** 

#### **Early Head Start Program**

Community Action Southwest 150 West Beau Street, Suite 304 Washington, PA 15301-4425 724-225-9550 or 1-877-814-0788 www.caswg.org/

Community Action Southwest Early Head Start provides early, continuous, intensive, and comprehensive services for eligible pregnant women, infants and toddlers, and their families. The comprehensive services include child development, nutrition, health, mental health, disabilities and social services. Early Head Start provides services through both the Home-Based option and the Center-Based option, and encourages parent involvement in the program.

#### **Early Intervention Program**

Washington County Mental Health/Mental Retardation Program 100 West Beau Street, Suite 302 Washington, PA 15301 724-228-6832

#### Vickie Amos, Early Intervention Coordinator

To make a referral, call Mona Zahand at 724-229-2620 or 866-765-2888.

Early Intervention is programs that help children from birth to three who have at least a 25% developmental delay or a diagnosis that carries with it a risk of a developmental delay. Contracted programs are funded through the Washington County MH/MR Program. Entry into the program is through Washington Communities MH/MR Center.

#### SPHS MR Services Diversified Human Services, Inc.

301 Chamber Plaza Charleroi, PA 15022-1067 724-489-8096 ext. 4560 www.earlyinter@sphs.org

Supports and services for families/caregivers and infants and toddlers with developmental delays or at high risk of developmental delay. The professional staff may include: developmental specialist, physical therapist, occupational therapist, speech pathologist and teachers of the hearing impaired. Supports and services help children develop skills within their daily routines and activities. Services are available year-round and at no cost to families.

#### UCP of Southwestern Pennsylvania, Inc.

289 North Ave. Washington, PA 15301 724-223-7803 ext. 640 or 1-800-835-4140 www.ucpswpa.org

Supports and services for families/caregivers and infants and toddlers with developmental delays or at high risk of developmental delay. Professional staff may include: developmental specialists, physical therapists, occupational therapists, speech/language pathologists and teachers of the visually and hearing impaired. Supports and services help children develop skills within their daily routines and activities. Services are available year-round and at no cost to families. **Contact Monica Brooks**.

#### Zero to Three

www.zerotothree.org

A resource on the first three years of life. It is a national non-profit charitable organization whose aim is to strengthen and support families, practitioners and communities to promote the healthy development of babies and toddlers.

#### **Head Start Program**

Community Action Southwest Suite 304, Plaza Building 150 West Beau Street Washington, PA 15301 724-225-9550 or 1-877-814-0788 www.caswg.org/

The Community Action Southwest Head Start Program is designed to give children from low income-eligible families throughout Washington and Greene Counties an opportunity to receive a Pre-K education. CAS Head Start provides comprehensive services to children ages 3-5 yrs. and their families in the areas of education, health, nutrition, disabilities, mental health and social services.

#### **Intermediate Unit 1**

One Intermediate Unit Drive Coal Center, PA 15423-9642 1-800-328-6481 or 724-938-3241, ext. 220 http://www.iu1.k12.pa.us/

Early Intervention Preschool Programs for children 3-5 with developmental delays and special education needs. Contact the Intermediate Unit.

Questions about early intervention?

Call CONNECT 1-800-692-7288 (TTY Accessible)

# CONNECT puts families in touch with the people who can help.



Serving Children with Developmental Delays

Intervention

...helping families develop their child's potential.

#### What is Early Intervention?

Early intervention is a program that helps families develop their child's potential. All children grow and learn at different rates. Children who are developing more slowly than typical children are offered early intervention services. Support services are offered to families.

#### Who is eligible?

Infants, toddlers, and preschool children who have special needs due to developmental delays or disabilities are eligible to receive early intervention services.

#### What services are provided to meet the developmental needs of a child?

The services provided to children and their families differ based upon the individual needs of each child and the child's family. Services such as speech therapy, physical therapy, parent education/supports, and other family-centered services assist in child development and may be included in a family's early intervention program.

#### Where do families receive services?

Services may be provided in the child's home, child care center, nursery school, play group, and/or Head Start program. Services are provided at no cost to families.

## Who should parents contact to see if their child is eligible for early intervention services?

Parents who have questions about their child's development or disability may talk with their family physician or health care provider, school district, intermediate unit, or county early intervention program. The CONNECT Helpline, 1-800-692-7288, will also help answer questions about child development and specific disabilities. CONNECT staff may refer a family to the appropriate local agency to receive a developmental assessment. This assessment will determine if the child is eligible for early intervention services.

### **Glossary of Terms:**

This glossary is not a comprehensive list. It will expand with time. If there is a particular term or acronym you have encountered that you do not understand, please <u>contact us</u> so that we can add it to the list.

**ACCESS card**: The name of the <u>Medical Assistance</u> ID card indicating that your child is eligible for Medical Assistance. To apply for Medical Assistance, see How to Apply for Medical Assistance (MA) for Your Child with Autism in Pennsylvania (Age 21 or under).

**Age of Majority**: Once a child with autism or ASD turns 14, he or she may legally refuse treatment, including wraparound, unless parents have received a court order to make medical decisions on behalf of their son or daughter. For details, visit Child Behavioral Health Medical Necessity Criteria - EPSDT: Appendix T Part B2 - Child BH Medical Necessity Criteria - EPSDT

**Antipsychotics**: Antipsychotic medications act against symptoms of anti-social or self-destructive behavior. These medications cannot "cure," but they may lessen the severity of some symptoms. A fuller discussion of antipsychotic medications can be found at the <u>National Institute of Mental Health</u>.

Asperger Syndrome, Asperger Disorder or Asperger's: one of the conditions known as <u>Pervasive</u> <u>Developmental Disorders</u>. According to the National Institute of Neurological Disorders and Strokes, <u>Asperger's</u> is defined as a "developmental disorder that is characterized by limited interests or an unusual preoccupation with a particular subject to the exclusion of other activities." Asperger's is also characterized by average or above average IQ, and verbal ability.

Other symptoms include:

- Repetitive routines or rituals.
- Strange speech and language, such as speaking in an overly formal manner or in a monotone or taking figures of speech literally.
- Socially and emotionally inappropriate behavior and the inability to interact successfully with peers.
- Problems with non-verbal communication, including the restricted use of gestures, limited or inappropriate facial expressions or a peculiar, stiff gaze.
- Clumsy and uncoordinated motor movements.

Autism: Autism is defined differently in federal education law than in federal disability law.

- Under the federal **education** law, the Individuals with Disabilities Education Act (<u>IDEA</u>) §300.8 (c)(1)(i), autism is defined as "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences."
- Federal **disability** law recognizes the <u>DSM-IV definition of autism</u>, which focuses on behavior for diagnosis by a qualified medical professional. This definition is considered the "medical" diagnosis.
- The difference between the two definitions can be confusing. All behavioral health services include an evaluation to determine needs, just like public education. However, to be eligible for Medical Assistance your child must have (among other things) a medical diagnosis within the Autism Spectrum Disorder.

• School districts, however, are required to evaluate any child suspected of having a disability under the federal education law, <u>IDEA</u>. They are not required to use the DSM-IV medical definition for identifying a child with autism (and some educational professionals may not be qualified to make this diagnosis). School districts must use the language of special education law to find a child eligible for special education services.

Autistic: A person with autism. Most families tend to prefer the phrase, "a person with autism," which focuses on the person rather than the label.

Autism Spectrum Disorder or ASD: The <u>Centers for Disease Control and Prevention</u> (CDC) defines ASD as "a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls." ASD includes the diagnoses of <u>autistic disorder</u>, <u>PDD-NOS</u>, <u>Asperger Syndrome</u>, <u>Rett Syndrome</u> and <u>Childhood Disintegrative Disorder</u>.

**Behavior Treatment Plan** (or Behavior Care Plan): A written plan describing goals and objectives and behavioral treatments proposed to address the client's behavioral health issues. This includes what responsibilities the client, family and wraparound providers have to meet the goals to demonstrate clinical progress. The treatment plan is developed by wraparound staff with input from parents. It is then reviewed and agreed to in an Interagency Service Planning Team (ISPT) meeting, which can include county MH/MR staff, BH-MCO staff and the provider (but this team may vary by county). The ISPT must include school staff if the child is in a public school.

**Behavioral Health Managed Care Organization** (BH-MCO or "Bimco"): An organization contracted to manage countywide behavioral health services. BH-MCO's are "indirect" providers, meaning that they manage the "direct" providers: wraparound agencies that actually provide service to your family.

**Behavioral Health Services**: These services are defined as the staff, type of support and service intensity necessary to address a person's behavioral health needs. Wraparound agencies directly provide these services to clients in their home and/or school. Behavioral health does not include physical services such as occupational therapy, physical therapy or speech therapy. However, behavioral goals may overlap physical therapy goals. For example, if the desired outcome of a behavioral goal is to have a child "verbally refuse" instead of biting, then speech is how this goal will be met (and measured). More information at <u>Behavioral Health Choices</u>.

**Behavioral Specialist Consultant** (BSC): The professional who manages and coordinates services by the wraparound agency with a family. Though not required, BSC's may have experience with people with autism, have autism-specific training, and/or be Board Certified Behavior Analysts.

**Board Certified Behavior Analyst** (BCBA): A professional who has passed a standardized curriculum and tests indicating they have certain competencies in the field of Applied Behavior Analysis. For details about Pennsylvania's program, visit <u>www.bacb.com</u>.

**CARS** (Childhood Autism Rating Scale): According to WPS Publishing, "this 15-item behavior rating scale allows clinicians and educators to recognize and classify autistic children...on a scale from mild to severe autism." It does not offer recommendations for treatment or intervention.

**Case Management**: Support coordination of long-term services for persons with autism. A professional provides links to other professionals and referrals to appropriate services, and helps the family gain access to necessary supports. Case managers monitor established services, advocate and respond to crises.

**Children's Health Insurance Program** (<u>CHIP</u>): A program designed to provide insurance coverage to children whose families earn too much to qualify for Medical Assistance, do not have insurance offered through an employer and cannot afford to purchase private insurance.

**Companion Attendant:** A trained adult who assists a higher functioning person during college classes (taking notes, test taking, negotiating with instructor), and/or learning these skills.

**COMPASS** (<u>COM</u>monwealth of <u>Pennsylvania Application for <u>Social Services</u>): <u>COMPASS</u> is Pennsylvania's online application for social-service programs that allows an individual to apply for social programs from a computer with Internet access at any time. It serves as a single access point for a variety of programs, including health care coverage, food stamps, cash assistance benefits, long term care and home energy assistance.</u>

**Consent to Treatment:** According to Medical Assistance regulations, a child must consent to treatment after he or she turns 14. Many people with autism are incapable of giving informed consent; therefore, some parents must declare their child incompetent in court, or get power of attorney (POA).

**Day Habilitation**: Learning adaptive behavior skills to participate in ordinary community activities such as grocery shopping, banking, clothes shopping, taking a walk, going to the library or religious services.

**Developmental Delay:** This term is used to describe children (birth to 24 months) who may not be meeting developmental milestones related to their speech, language, physical, social and other skills typical for their age. It is also a specific legal term to describe children between the ages of three and five who are found eligible by the public education system to be eligible for early intervention services. This term has meaning and significance in <u>PA education law</u>. For more information on development milestones, visit the <u>Mayo</u> <u>Clinic</u> or <u>First Signs</u>.

**DSM-IV**: The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, American Psychiatric Association, 2000). DSM uses the absence or delay of anticipated behaviors that are developmental milestones to clinically diagnose a person.

**DPW**: <u>Pennsylvania Department of Public Welfare</u>. See also <u>Office of Medical Assistance Programs</u> (OMAP) or <u>Office of Mental Health and Substance Abuse Services</u> (OMHSAS).

**EPSDT** or **Early and Periodic Screening, Diagnosis and Treatment**: The federal Medical Assistance program that funds medical and behavioral health services for children from birth to age 21. The keys to EPSDT are identifying problems early, starting at birth; checking children's health at periodic, age-appropriate intervals; doing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems; performing diagnostic tests to follow up when a risk is identified; and treating the problems found.

**Early Intervention** (EI): Public services designed to address early learning and physical issues of children from birth to age five, provided at no cost to eligible children and their families. Direct services are provided through county providers, and local Intermediate Units. Administered through the Office of Child Development and Early Learning.

FAPE: Popular acronym for Free Appropriate Public Education.

**FERPA** (Family Educational Rights and Privacy Act): The federal law requiring that your child's special education status and information remain confidential. See also HIPAA below.

**HIPAA** (<u>Health Insurance Portability and Accountability Act</u>): The federal law that protects your confidential personally identifiable medical information from ordinary disclosure, and requires health care providers to have in place -- and publicly distribute -- a policy for protecting your personal information.

**HealthChoices**: Pennsylvania's mandatory <u>Medicaid managed care program</u>. The purpose of the program is to provide medical, behavioral, and substance abuse services to Medical Assistance recipients.

**IDEA** (<u>Individuals with Disabilities Education Act</u>): Reauthorized in 2004, this law forms the basis for a disabled student's right to a free, appropriate, public education, or <u>FAPE</u>.

**IEP** (Individual Education Plan): This is a signed agreement of an IEP team outlining the what, where, when and often how a special education student will be provided a meaningful education specific to their needs. The IEP team can consist of the student (if appropriate), parents, regular and/or special education teachers, a school or school system representative, Therapeutic Support Staff (TSS) and Behavioral Specialist Consultant (BSC). For more information, visit the <u>Pennsylvania Department of Education</u>.

**Loophole**: The "loophole" eliminates family income as a factor in determining if a child is eligible for Medical Assistance for persons with Autism Spectrum Disorder.

**Managed Care Organization** (MCO): Nearly all of Pennsylvania's Medical Assistance Services are provided through <u>Managed Care Organizations</u> (MCO).

MA: Medical Assistance, also known as ACCESS and Medicaid.

Medicaid: The same as Medical Assistance.

**Medical Necessity**: This represents a group of criteria used to find a person eligible for services. A person may have a condition, but must meet medical necessity criteria to be eligible for services, for instance wrap-around services under Medical Assistance.

**MH/MR** (Mental Health/Mental Retardation): The Mental Health and Mental Retardation Act of 1966 requires your <u>county MH/MR office</u> to provide <u>community mental health services</u>, including: short-term inpatient treatment, partial hospitalization, outpatient care, emergency services, specialized rehabilitation training, vocational rehabilitation, and residential arrangements.

**Need**: "Need" for services must be determined in both medical and educational law. If your child has autism, evaluations will confirm the diagnosis and identify any areas of need, whether they are educational, medical, or behavioral. Parent input is mandatory.

**OBRA Waiver**: A waiver is a federal funding stream that allows states to be exempt from (or "waive") certain requirements. The <u>OBRA waiver</u> is a funding stream regulated by federal law, generally designed for persons with developmental disabilities that substantially limit major life functions.

**ODP** (Office of Developmental Programs): Creating the new Office of Developmental Programs within DPW in 2007 was one of the core recommendations of the Pennsylvania Autism Task Force. In its initial stages, Office of Developmental Programs will house a Bureau of Mental Retardation Services and a Bureau for Autism Services, as well as necessary support bureaus.

**OMAP** (<u>Office of Medical Assistance Programs</u>): A program office located within the Pennsylvania Department of Public Welfare. For the purposes of people with autism, OMAP administers the joint state/federal Medical Assistance program that purchases health care for over 10,000 "loophole" children.

**OMHSAS** (Office of Mental Health and Substance Abuse Services): A program office located within the Pennsylvania Department of Public Welfare responsible for behavioral health services ranging from community to hospital programs with emphasis on helping children, adolescents and adults to remain in their communities.

**OVR** (<u>Office of Vocational Rehabilitation</u>): Located within the Pennsylvania Department of Labor & Industry. This office administers job/vocational training and coaching to persons with disabilities based on a model of temporary need.

**PCP** (Primary Care Provider): A specific medical services provider (doctor) responsible for providing primary care services and locating, coordinating, and monitoring other medical care and rehabilitative services (in addition to behavioral health services) on behalf of a Medical Assistance recipient.

PDE: Pennsylvania Department of Education.

Privacy: See also HIPAA (health records privacy) and FERPA (school records privacy).

**Residential Habilitation**: Learning behavior skills that may be ordinary household tasks or self-help. Selfhelp, also called personal care, refers to activities such as showering, shaving, toileting and dressing. Residential habilitation also includes learning to do household tasks, making meals and other activities you would do when you return home from work or other daytime activities.

**Respite**: Services provided to the family or caregiver of a person with autism so that they may have time to attend to sibling's or other family member's needs, to have time to go out to dinner, attend to personal appointments or simply relax. These may be in or out of home services.

**Special Needs Trust:** A legal financial entity established by parents of children with disabilities to provide for supplemental needs not covered by public assistance funds that cover basic needs. The fund is created because assets owned by a person with autism would prevent their eligibility for publicly funded services until the funds were gone. The trustee distributes funds from the trust to the person with autism for non-basic supplies. For more information, visit the <u>Autism Society of America</u>.

**TSS** (Therapeutic Support Staff): This person has a certain level of experience, education and training to support a person with autism one-on-one in settings found to require their support. This could include school, social functions and community.

**Waiver**: A waiver is a <u>funding program</u> where the state is allowed to "waive" certain requirements, usually of a federal law or program. In Pennsylvania, two waivers are most likely to serve a person with autism; the <u>Consolitated Waiver</u>, and the <u>OBRA Waiver</u>.

**Wraparound**: Wraparound or "wrap" refers to behavioral health services, such as Therapeutic Support Staff (TSS) and Behavioral Specialist Consultant (BSC) support, that "wrap" around other supportive services. Wraparound may include trained workers who support and intervene on behalf of a client to implement the client's Behavioral Treatment Plan.

#### Last modified on: October 9, 2007

Source: Commonwealth of Pennsylvania, Dept of Public Welfare, Bureau of Autism Services' website at <u>www.autisminpa.org</u>



#### **Related Therapy/Services**

Children with autism may be evaluated for, or need a variety of services, including, but not limited to, speech, occupational, and physical therapy. You or your service provider may notice difficulties in any of these areas and request an evaluation.

Speech Therapy will address communication needs for the individual with autism. Depending on the needs, individuals will learn how to communicate, interpret and express verbally and non-verbally, and engage in socialization or play skills.

Occupational Therapy (OT) can address fine and/or gross motor skill deficits that are needed for daily living or academics. An occupational therapist may also help to address sensory difficulties. Sensory integration is the way the body takes in and processes environmental stimuli. Often children with autism have difficulties with how they process incoming sensory information. You may see sensitivities to noises, smells, foods or clothing. Your child may want to swing or spin incessantly. We all have sensory issues. Individuals with autism have them much more intensively.

Physical Therapy (PT) is used to address significant delays with gross motor, and sometimes fine motor skills. Children may have low muscle tone, which could create difficulty with walking, sitting, or performing academic functions.

Individuals with autism may receive more than one of these therapies depending on his or her needs. Some parents receive services through their educational program and take their child to additional outside therapies. It is important to remember that your child will only qualify for these services in the school setting if their needs are educationally based (ex: trouble with getting on/off the bus, interacting or performing daily functions in the school setting, etc.) Any therapies or services that are a part of your child's IEP at school will not be charged to you or your insurance.

### Wraparound or BHRS Services

#### What are "wraparound" services?

"Wraparound" is a nickname for Behavioral Health Rehabilitation Services (BHRS), which "wrap" around existing services. BHRS is a Medicaid-funded program providing trained professional support for children under age 21 to reduce or replace problem behavior with positive, socially appropriate behavior. Wraparound services are family and child-centered, and they can take place in variety of settings, not just one place. Services are defined by the Behavior Treatment Plan, or Behavior Care Plan. Progress is monitored with data, updated regularly and reevaluated every three months. Also, wraparound services are often very personal. Some families may need to adjust to new persons actively joining their daily activities.

#### How are services decided?

The Behavior Treatment Plan is the plan developed by a team representing several support agencies. This team includes parents, any lead teacher, a Behavior Specialist Consultant (BSC), any services coordinator, any therapist or counselor, and any person(s) the family wishes, including an advocate. If appropriate, your child is included. The plan includes goals, objectives, and treatments. Goals may target safety, functional, communication, social and classroom behavior and each member of the team is assigned responsibility to help meet the goals. Goals are individual to the needs of your child and family, and are updated as often as every three months.

#### Who provides services?

Wraparound services are usually provided directly to clients by Therapeutic Staff Support (TSS), Therapeutic Staff Support Assistants (TSSA), a Behavior Specialist Consultant (BSC) and a Mobile Therapist (MT), who work for a local agency. Your community may have several agencies, but not all of them may serve children with autism of your child's age.

#### When and where do services occur?

The Behavior Treatment Plan includes the prescription for "level of care," or the treatment hours assigned each week to TSS, MT and BSC, and in which setting. Settings often include school, camp and/or home.

#### What do services look like?

TSS and TSSA provide one-on-one service. For instance, your child's therapist may instruct a child on how take turns using cards, a worksheet, games, checklists, scripts and other strategies. The TSS and TSSA may then prompt the child to practice that skill in natural settings such as circle-time, recess or during a play date. This instruction may occur at your home and be practiced there, and at some point with other children. The TSS or TSSA take data and record treatment notes to measure the client's progress toward independent use of the skill. The BSC regularly reviews these notes to adjust treatment and goals as needed.

#### How can my child get services?

Contact your county MH/MR office <u>HCSIS Services and Supports Directory</u> and request wraparound services. Your child must be found eligible for wraparound services by a local agency. Families should contact agencies and determine which may have the best experience and staff for their child's needs.

#### What wraparound is not

Wraparound services are medically necessary services. Wraparound is not a substitute or supplement for speech and language, occupational or physical therapies. Wraparound is not a substitute for academic instruction by a teacher.

For details Visit our glossary for the definitions of acronyms and words used in this section. In addition, your Behavior Health Managed Care Organization (BHMCO) likely has printed materials and a Web site designed to help you understand their wraparound services and complaint process.

#### Why does my child need wraparound services when I already have education

**services?** There are similarities between wraparound services and education services. However there are important differences because the long-term goals of these two systems are different. School services are designed to meet the goals of <u>IDEA</u>, a federal education law that focuses on functional and academic skills that prepare a student for independent living, a job or further education. Wraparound services focus on community integration and skill development to increase the independence of individuals and their families. See our page on wraparound or Behavioral Health Rehabilitation Services (BHRS) for details.

If you have suggestions about how to improve the information contained here, please contact DPW Communications Office: <u>DPW-Communications@state.pa.us</u>.

Source: Commonwealth of Pennsylvania, Dept of Public Welfare, Bureau of Autism Services' website at <u>www.autisminpa.org</u>.

Last modified on: October 9, 2007



#### **Parents Right's**

Parents are valuable members in their child's educational process. State and Federal laws are put into place to protect individuals with special needs. Parents have certain rights when it comes to their child's education. Schools will provide you with rights in the form of Procedural Safeguards. Make sure you read these rights. A copy of these rights can be obtained online @ http://www.parent.pattan.net under the opportunities for resolving disagreements link. If you need help understanding these rights you may ask to have them explained to you. An excellent source for understanding the special education process is the Pennsylvania Parent Guide to Special Education for School Age Children. This document can be ordered through the Pennsylvania Training and Technical Assistance Network (PATTAN) @ 610-265-7321. There is no charge for this document. For questions regarding educational law or issues you may call Pennsylvania's Department of Education @ 717-783-3750. For more information concerning IEP meetings and development of IEP visit WrightsLaw to view,

"8 Steps to Better IEP Meetings : Play Hearts, Not Poker." @ http://www.wrightslaw.com/advoc/articles/iep.bollero.hearts.htm



# Family & Support Information

## **Build and Develop Your Support Team**

#### **Build and Develop Your Support Team: Guidance for Parents of Children Recently Diagnosed with Autism**

You are not alone in facing the challenges of raising and caring for a person with autism. Addressing the needs of a person with autism requires a team effort. Dedicated and experience professionals throughout Pennsylvania can help. Your support team can also expand in several directions, depending on your own family and social networks and the type of contact your child has with others outside the home.

As a parent you are the best person to develop and manage the support team on behalf of your child, to help him or her reach their maximum human potential. Your support team may include people who have the most direct contact with your son or daughter with autism:

- Your son or daughter with autism is part of the team
- Both parents: you and your spouse and/or partner
- Your child's brothers and/or sisters
- Your child's doctor
- Your child's other medical specialists
- Your child's psychiatrist or psychologist (who evaluates developmental, academic and functional skills over time)
- Your Support Coordinator(s) (assigned by county MH/MR and other programs)
- Your child's teachers, both general education and special education
- Your child's therapists, whether private or provided by your school
- Other family members
- Your child's behavior specialist and Therapeutic Staff Support (TSS) person (if your child is receiving wraparound care)
- Any privately paid behavior specialists

Your support team may include also people who may have casual or indirect contact with your son or daughter with autism:

- Your child's school principal
- Your child's bus driver(s)
- An advocate
- Assigned Managed Care (MCO) Special Needs Unit caseworker
- Medical Assistance caseworker
- Your child's dentist and oral surgeon
- Other medical service providers
- Community members (librarian, chief of police, fire chief)
- Your family attorney

- Your neighbors
- Camp directors
- Your local pharmacist
- Sitters and Respite Care workers

Some parents have found it helpful to begin building the team by obtaining contact information for each person in one notebook or folder, perhaps by taping their business cards to the cover. When you obtain new documents that report on or recommend changes to your child's services or needs, consider making copies and sharing the document with others on the team. To keep the team making informed recommendations, arm them with other's knowledge. For instance, when your child goes to the pediatrician, consider bringing a copy of the latest psychological evaluation and discuss it with the doctor. In an emergency, members of your support team will already have crucial documents in their file.

You may wish to keep one folder of all important originals and add to it as necessary. Consider the following as your child's important documents:

- Birth Certificate
- Social Security Card
- Proof of citizenship, if necessary
- Dental records (most recent checkup and last completed school exam form)
- Vision and hearing records and evaluations, copy of recent prescription
- Vaccination records
- Documentation of diagnosis
- Behavioral Health Treatment Plan
- Educational and psychological evaluations
- Reports from medical specialists
- Copy of your insurance cards
- Copy of your child's Medical Assistance Card and any other cards
- Recent photo
- Most recent Individualized Education Plan (IEP) or IFSP
- Any disciplinary records
- High school transcript
- Diploma or Certificate of Attendance
- Most recent prescriptions, if any
- Any special tests (EEG, GI, etc)
- List of any special dietary or biomedical interventions
- Back up copy of instructions for any AAC device

Special Notes: Support Coordinators have specific roles in assisting your son or

daughter, roles defined by the Medical Assistance program. They can be very helpful, if you are aware of what they can do and ask. Support coordinators can:

- Help you make informed decisions by explaining benefits and detailed information that is confusing.
- Help you manage services by working with your son or daughter to identify, facilitate, monitor and coordinate services to maximize benefits for your child.
- Help you gain access to other benefits that may be available through state, federal or local sources. These include medical, social, educational, assistive technology, respite and other services.
- Be your advocate by ensuring your child has maximum input and benefit in obtaining local resources, they can make calls and attend meetings with you or your child.
- Help you begin and coordinate any required re-evaluation in a timely, efficient manner.
- Ensure that your child's Individual Service Plan (ISP) is comprehensive and meets your son or daughter's needs.

Your child's doctor may also be his or her Primary Care Provider, chosen through your Managed Care Services of Medical Assistance. Your doctor should be kept informed of all changes in medical or educational condition or services. Your doctor is required to prescribe any occupational speech or physical therapy evaluation and treatment services.

If you have suggestions about how to improve the information contained here, please contact DPW Communications Office: <u>DPW-Communications@state.pa.us</u>.

Source: Commonwealth of Pennsylvania, Dept of Public Welfare, Bureau of Autism Services' website at <u>www.autisminpa.org</u>.

Last modified on: October 9, 2007

# About.com

# Author: Lisa Jo Rudy

Now that you know your child is autistic, you may be feeling isolated, scared, or just plain baffled. If so, you're not alone -- other parents have "been there and done that." Here are just a few hints and tips for managing these first few weeks and months, from parent readers of the Autism.About.Com site.

# Learn About Autism

Educate! Educate yourself, your relatives, and anyone who is around your child. Look at both sides of the story. The first thing I found was an overwhelming assortment of stories detailing the horrors of autism. There are just as many positive stories out there. Look for them and focus on the positive. Read about and listen to people on the autism spectrum. They know more about what it's like to be autistic than we do. There are numerous websites and forums for autistic individuals. I've gotten lots of great advice from them.

# Learn About Therapies for Autism While Maintaining a Balanced Life

Learn about different therapies. Know what is being done to your child! Keep in mind that a certain therapy may not work for your child. That is okay, just try something new. Also, don't make everything therapeutic. If you turn play into work, it will remove the joy from it. Try not to overwhelm you child (and your family, and yourself) with therapies. While therapy may be important, keep in mind that juggling numerous therapy schedules and home life is tedious at best. It cannot rule your life.

# Find Help and Advice, and Select What Works for You

When your child is of school age, work with your classroom teachers and your school district special needs representative. A good relationship will go a long way. There is a ton of assistance out there. Most states have chapters of the Autism Society of America, and you can usually get an autism advocate to assist you with decision-making. Also, find out if you have a Disabilities and Special Needs Board. You can get a representative for your child and yourself. Our representative has been a lifesaver when we are overwhelmed or when we have needed an advocate. Just like when you were pregnant, you will be given lots of advice from many different sources. You don't have to take all the advice. Consider it and follow what you feel is right.

# **Respect, Love and Learn From Your Child**

Respect your child's boundaries. For example, if your child hates the way fleece feels, don't force it on them. Put it aside and try again later. Same goes for food and play. Make sure your child knows that you love him or her. Don't be embarrassed if your child plays differently than the children around her. It is how it is. If a curious parent or child asks, tell them. Autism is nothing to be embarrassed about.

# **Read Helpful, Inspirational Poems and Books**

<u>"Welcome to Holland</u>" by Emily Perl Kingsley sums things up quite nicely and it was a turning point for me after my son's diagnosis.

One of the best books I read when I was going through the same tough times that you may be right now is called Overcoming Autism by Lynn Koegel and Claire Lazebnik. It is such a practical book and always leaves me feeling encouraged. You don't have to read it all in one sitting. You can pick out the chapter that applies to your current challenge and take it from there. I can't tell you how much this book helped me in those first days.

# **Be Patient; Be Positive**

Many kids seem severely autistic at a young age, and then become very high functioning when they grow older. So keep a positive attitude and remember, it takes time. Be patient.

Learn to appreciate and love your child in her quirkiness. It's like learning a different language, a different culture. You have to respect her as a different human being, and not see everything she does in a negative light.

Don't underestimate what she is capable of doing or understanding. There are several cases of severely autistic people who learned to express their feelings through typing, and blew everyone away with their intelligence.

Be patient and gear up for this long journey. You may be surprised about the good things that will come your way.

# Help Your Child Build On Her Strengths and Interests - Not Yours

Ask yourself why it bothers you that she doesn't want to kiss her doll or prefers to collect toys rather than play with them. Many great researchers started with the same behaviors. Maybe one day she'll make new discoveries that will wow the world because rather than hanging out with her friends at the mall, or she'll prefer to collect and classify specimens she finds in the yard playing on her own. You have a great independent mind in her. And so you will help her develop that.

# Hire the Best Therapists

You should know that often times the therapist Early Intervention sends over aren't always the best, but the ones who are available. I'd keep a close eye on their effectiveness, and consider hiring your own.

# **Consider Changing Your Child's Diet**

Food sensitivities can make a tremendous difference in a child's life... physically, emotionally AND cognitively. Try the GFCF (gluten-free casein-free) diet. Also, many parents who did not experience success with the GFCF diet now swear by SCD (Specific Carbohydrate Diet).

### Give Yourself the Time and Space You Need

Give yourself permission to grieve! You have lost the child you thought you'd have, as surely as if she was here and then died. She didn't physically die, but your idea of her did. So grieve -- feel bad. It's OK. At the same time, though, get to know this wonderful new person you received in your "ideal" child's place. Slowly, over time, your memories of that "other" perfect child you thought you were getting will become more distant and less significant, to be replaced with the wonderful memories you will make. Give yourself permission to take a break from everything on a regular basis. Having someone babysit for you once in awhile so you can do something that's all you will help decrease your stress.

# Love Your Child As He Is

The one most important thing I have learned is to love your child as they are. You must fully accept them the way they are. That feeling of complete acceptance they will receive from you will help them more than anything. Our son has done all the therapies but his progress did not go speeding ahead until I fully accepted him as he was. Then, with a feeling of full acceptance and love, his progress took off. I also was much more **at** peace.

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# Siblings

Siblings are valuable friends and playmates for your child with autism. The decision of what to tell siblings and how much is a personal decision each family must make. Of course, part of this decision is based on age of the siblings. Children (as well as adults) are often afraid of what they do not understand. Parents will serve as important teachers to open the doors for future patience, understanding, and acceptance. There are resources to help families and siblings. Below are a few suggestions:

- Siblings of Children with Autism: A Guide for Families-Sandra Harris & Beth Glasberg
- Sibling Stories: Reflections on Life with a brother or Sister on the Autism Spectrum-Feiges, Weiss, Harris
- Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism- Fiona Bleach
- 4. Me, My Brother and Autism-A. Phalon

If you have an older sibling there are sibling support groups available for them in the area. Support groups such as ABOARD, Autism Link, FBR, and the Wesley Institute will be able to provide more information on these groups. Contact information for these organizations can be found in this resource guide.



# Parents and Professionals Willing to Provide Support

**Denise Angelo** –Parent and Professional dmlangelo@zoominternet.net

Tricia Baum-Parent baumbuilders@comcast.net

Tammi Bogan-Parent tbogan@fairpoint.net

Frank and Debbie Danko-Parents 724-839-7191

Melissa Deal-Parent mldeal@atlanticbb.net

Lesley Ezzi myaces@atlanticbb.net

**Perri Greco-**Professional grecop@co.washington.pa.us

Sharon Guerra-Parent 724-489-0539

Lisa Hampe-Professional hampel@iu1.k12.pa.us

Sandy Kadash-parent KSanda4@aol.com

**Paul Keteles** 724-880-3419

**Renae Kotchman-**Professional 724-938-3421, ext. 105 kotchmanr@iu1.k12.pa.us

Marlene Kubina-Professional 1-800-328-6481, ext. 115 kubinam@iu1.k12.pa.us

Maria and Dan Piatt-parent Dwp8@earthlink.net

MaryAnn Rocco-Professional roccom@iu1.k12.pa.us

Christine Schreiner-Parent cebarrett2@aol.com

Jennifer Suppo-Parent delsuppo@yahoo.com

# Law Enforcement and Autism: a 101 course for Parents

#### • Police Officers are in the business of helping people.

The majority of them went into this field because they wanted to make a difference and help others. When the civilians and Police Officers work together they can solve problems and make their communities better for everyone.

#### • Get to know your local Police Officers.

Call and ask them to stop by when they have time to get to know your family and your child. They will be happy to do that. Getting to know who is in their community is important part of a police officers job. Introduce yourself and your child to them at local public events. Work with your school and police department to start the "Utilizing Police in the Schools" Program that can be found at <u>www.papremisealert.com</u> It is free and easy to start. It is the most effective, least expensive training program you will ever see.

#### • Teach your children that Police Officers can help them.

Individuals with autism are very concrete thinkers. They are going to need to know that if they are ever in trouble to go to a person in uniform and ask for help. Do not threaten your child with arrest or jail if they don't do their homework, refuse to clean their room or decide not to go to school. Those are issues to work through with your IEP team or Behavior Specialist. The police are the people they are going to need to feel safe approaching when they are in the community.

#### • Teach your child to provide identifying information to Officers

Start teaching your children to give their name, address and phone number as soon as they are able. If they are nonverbal, teach them to show an ID card or American Sign Language. Even if the Officer cannot Sign, he/she will understand that there is a special need.

#### • Teach your child how to safely approach a Police Officer.

When a child is young, say up to 6 years of age, a police officer will easily be able to recognize the excitement of a child around his/her uniform or car but as the child ages the behaviors will appear to be menacing. It is important to teach children to walk up to an officer, not run at them. Also teach them to keep their hands out of their pockets and not reach for the officer's badge, gun, or flashlight.

• **Provide information before a crisis**. Check out this website <u>www.papremisealert.com</u> Download a form, fill it out, and take it to your local Police Department. You can print out directions for Police Departments as well and ask them to help you out.

#### • Always disclose your condition to an Officer.

You and your child should disclose the diagnosis as soon as possible. Teach your child to carry an ID card or Medic-Alert Bracelet so that in the event of a crisis and the child or adult is unable to speak or give his or her information the police will be able to know that there is a diagnosis to be considered.

#### • Families of children with autism are not immune from abuse

If an Officer or hospital worker takes time to investigate the possibility that your child has been abused due to bruises or scars from self-injurious behaviors, try not to be offended. They are working to protect your child. They don't know you or your family they have to go off of what they are seeing. It is good that they care enough to look twice. Provide a copy Autism 101 for Mandated Reporters to your local police, it can be found on our website.

#### • When you call the Police, they will come

I know that sounds pretty basic but realize that when you call the police they will come and do what they need to do to contain the situation. Parents need to understand what that means. When the Police have trouble they have no one to call, except for more police. Most times and most interactions end well with the situation being resolved without physical contact or further action, but your child may be arrested, may be handcuffed or tasered if necessary. Your child may be subject to an involuntary psychiatric commitment that will last no less than 3 days.

#### • Learn the number for your County Crisis Intervention Team.

They work under the department of Mental Health and they are a resource that may be helpful to you and your child in the event of a behavioral or mental health crisis. Work to make sure they have the training and expertise to help during a crisis. Call your local Department of Mental Health to get the phone number, add it to your cell phone director and emergency numbers for care providers. In Pennsylvania check our website to find the number for every counties Crisis Intervention Hot Line.

#### • Police Officers are not doctors, psychologists, or Behavior Specialists.

We are truly fortunate in Pennsylvania that by the end of 2008 every police officer in the state will have received autism training. That does not mean they can diagnose, recognize it on the street, or use perfect de-escalation techniques. Their training will give them a thumbnail sketch of the disability and some suggestions to improve interactions. An Officers job is far more complicated and involved than dealing only with individuals with autism. The training is to provide some insight and techniques that should improve understanding and interactions. For more information on the autism specific training contact Dennis Debbaudt at www.**autismriskmanagement**.com

#### • Autism is NOT a get out of jail free card.

People with autism can form intent and commit crimes; many cannot and so need to be treated in a different manner. If someone who cannot form intent repeatedly causes harm or damage in the community it may be in their best interest for them to be placed in a setting that will allow them appropriate freedoms and supervision to remain safe and keep the public safe as well. It is critically important to access all available resources for assistance such as a county or state agency that provides support services, community advocacy groups and support groups to find information on how to best protect your child or adult child.

Susan F. Rzucidlo compiled this information from families and police officers across the nation. All copyrights are maintained by SPEAK Unlimited Inc. More information for first responders can be found at www.papremisealert.com PERMISSION: You are permitted and encouraged to reproduce and distribute this material in any format provided that you do NOT alter the wording in any way, you do not charge a fee beyond the cost of reproduction and you leave this notice on all reproductions. © 2003-08



# Resources



# **Leisure Activities**

#### **Beacon Lodge Camp**

114 SR 103 South Mt. Union, Pa 17066-9601 Phone: 814-542-2511 www.beaconlodge.com

#### **Challenger Baseball**

Fayette County-open to any county Hopwood, Pa Contact: Wilma King Email: <u>wilmakin@verizon.net</u> Phone: 724-677-0479

### CubScouts

Greater Pittsburgh Council Flag Plaza Pittsburgh, PA 15219-3699 Phone: (412) 471-2927 Web site: **http://www.gpc-bsa.org** This site will help you find the pack closest to you

#### Falcon Gymnastics- Special Needs

220 Nazareth Drive Belle Vernon, Pa Phone: 724-684-6260

# Fallowfield Stables Inc. (Therapeutic Horseback Riding)

155 Yankosky Road Charleroi, Pa 15022 Phone: 724- 239-3329

# 4-H Program

Penn state Cooperative Extension 724-438-0111

#### **Girl Scouts**

1-800-248-3355 Call to find the nearest troop http://www.girlscouts-wpa.org/



# **BHRS/Respite/Case Management**

#### Fayette

ACS Psychological Associates 136 E. Fayette Street Uniontown, Pa 15401

Alliance Health 2 W Main Street Suite 712 Uniontown, PA 15401 Phone: 724-430-0988

ARC, Fayette 80 Old New Salem Road Uniontown, Pa 15401 Phone: 724-438-8416

Chestnut Ridge Counseling Services 724-437-1554

Connellsville Counseling & Psychological Services 416 S. Pittsburgh St. Connellsville, Pa 15425 Phone: 724-626-8420

Family Behavioral Resources (FBR) 253 S. MT. Vernon Avenue Uniontown, PA 15401 Phone: 724-438-4960

The Stern Center For Developmental & Behavioral Health 110 South Arch Street Connellsville, Pa 15425

WJS Psychological Services 99 S. Pennsylvania Avenue Uniontown, Pa 15401

#### Washington

ARC Human Services Foxpointe Centre, Suite 200 201 S. Johnson Road, Bldg. 1 Houston, Pa 15342-1300 Phone: 724-745-3010, ext. 108

Behavioral Dynamics, INC. 382 West Chestnut Street Suite 106, Chestnut Place Washington, PA 15301 Phone: 724-222-2265

Centerville Clinics Case Management Department 1152 Wood Street California Pa 15419 Phone: 724-938-2099

Community Action Southwest (California) 1263 Zulu Street California, Pa 15419 Phone: 724-938-2249

Community Action Southwest (Canonsburg) 203 Valleyview Terrace Canonsburg, Pa 15317 Phone: 724-743-2143

Community Action Southwest (Washington) 150 West Beau Street Washington, Pa 15301 Phone: 724-225-4156

Community Action Southwest (Washington) 801 E. Wheeling St. Washington, Pa 15301 Phone: 724-228-2402

Community Alternatives 53 East Wheeling Street Washington, Pa 15301 Phone: 1-800-332-1208 Community Psychiatric Center 435 Donner Avenue, Suite 320 Monessen. Pa 15062

Family Behavioral Resources Milcraft Center 90 W.Chestnut Street, Suite 915 Washington, Pa 15301 Phone: 724-229-0311

Northwestern Human Services 1075 Waterdam Plaza McMurray, PA 15317 Phone: 724-942-4677

Pressley Ridge Family Based 2055 Jefferson Avenue Washington, PA 15301

#### SPHS

568 Galiffa Drive Donora, Pa 15033 Phone: 724-379-1420

SPHS Behavioral Health 301 E. Donner Avenue Suite 102 Monessen, Pa 15062 Phone: 724-684-9000, ext. 4523

#### TRIPIL

69 East Beau Street Washington, Pa 15301 Phone: 724-223-5115

Washington Communities MH/MR 378 West Chestnut St. Suite 205 Washington, Pa 15301 Phone: 724-225-6940

Wesley Spectrum 11 Mayview Road Canonsburg, PA 15317

#### Greene

Centerville Clinics 1070 Old National Pike Road Fredricktown, Pa 15333 Phone: 724-632-5828, ext. 2151

Community Psychiatric Center 434 West George Street Carmichaels, Pa 15320 Phone: 724-966-7733

Pressley Ridge Family Based 95 E. High Street Waynesburg, Pa 15370

The Stern Center for Developmental and Behavior 203 West George St. Carmichaels, Pa 15320 Phone: 1-877-626-9941

#### Gym Dandy's

345 Meadowlands Blvd. Washington, Pa 15301 Phone: 724-745- 5558 gymdandys@verizon.net Gymnastics for children with special needs. Contact Karen.

#### Hoofbeats

Therapeutic Riding Program 724-438-0709

# **In Stride Therapeutic Riding** 465 Springdale Rd.

Eighty-Four, PA 15330 412-302-5393 www.instridetherapeuticride.org

#### Kennywood

West Mifflin, Pa Phone: 412-461-0500

#### **Kids and Company**

135 North 3 Street Connellsville, Pa 15425 Phone: 724-628-2422

#### L'il Wild Things

150 Malone Ridge RoadWashington, PA 15301724-250-9150Baseball program for children with special needs. Contact Sue Hazlett

#### Pittsburgh Zoo

One Wild Place Pittsburgh, Pa 15206-1178 412-665-3639 http://zoo.pgh.pa.us/

#### **Recreation Station**

289 North Avenue Washington, Pa 15301 724-223-7805 www.recstation.org

#### **Reiki: Circles for Children with Special Needs**

Reiki enhances traditional medical and therapeutic treatments and promotes a sense of peace and well-being. Cost: Offering from your heart 412-920-2911 the-place-for-reiki@earthlink.net

#### Seth's Place

A farm like setting to encourage and promote a sense of acceptance, stability, and self worth by nurturing a bond between animals and children. 232 Stimmel Rd. Fredericktown, Pa 15333 Owners: Bill and Tammi Bogan (parents of a child with autism) 724-267-4494 tbogan@fairpoint.net

#### **Special Olympics PA**

Washington County 136 Cummins Ave. Houston, PA. 15342 724-745-9434 www.specialolympicspa.org Organized games for people with disabilities. Ages 8 and up.

#### **Top Soccer**

82 Look-Out DriveMonongahela, PA 15063724-379-5386Soccer for children with special needs ages 4 and up. Contact Peggy Neason.

#### YMCA

Taylor Run Road Charleroi, Pa 15022 Phone: 724-483-8077

#### **Special Needs Passes and Accommodations:**

These recommendations are from parents of children with autism.

#### Disney, Kenneywood, and Idewild Park

Check guest relations for a special pass to avoid the long waits in line. Please bring documentation of your child's disability and/or a letter from the child's doctor in order to receive the special pass.

We have also heard if you are at Disney and your child "runs from you", inform the nearest Disney employee and they will close all the gates and exits until your child is found.



#### Camps:

#### **ARC Mon Valley Summer Day Camp**

Address: Mon Valley YMCA Taylor Run Road, Charleroi, PA Ages: 8 - 21 years of age Dates: 6 weeks during June and July - Monday thru Friday Contact person: Jacky Stark (724) 872-8422

General Information: An approved program that includes functional academics, socialization skills, weekly themes, field trips, community awareness, swimming, sports, crafts, and on-site programs/visitors.

#### **Camp Laughalot-Greene County**

Address: Waynesburg Central High School Ages: 6-18 years of age Contact person: Darrrilyn McCrerey (724) 745-3010

General Information: Camp LaughAlot is dedicated to providing a typical summer day camp experience for children with physical and mental disabilities and autism in Greene County. They provide opportunities for campers to grow socially and personally with a supportive environment. Camp activities include field trips, special visitors, swimming, and arts and crafts.

#### **Camp Laughalot- Washington County**

Arc Human Services, Inc. Address: Foxpointe Center, Suite 200 201 South Johnson Road Houston, PA 15342 Contact person: Darrilyn McCrerey (site locations: Canon MacMillan Middle School and Canonsburg Town Park)

#### FBR

Phone: 724-438-4960 or 724-229-0311

#### NHS Human Services Stepping Stones Program

Contact person: Autumn Grimes (724) 942-4677 washss@nhsonline.org

This is a site and community-based therapeutic program for children with an autism spectrum diagnosis. The camp runs sessions for ages 3-7, and 8-14 from June to August.



# **Catalogs/Magazines**

#### AAPC: Autism Asperger Publishing Company

AAPC offers a range of books that offer practical solutions related to Autism Spectrum Disorders. PO Box 23173 Shawnee Mission, KS 66283-0173 Phone: 1-877-277-8254 Website: <u>www.asperger.net</u>

#### Ablenet, Inc.

Ablenet offers a wide range of assistive technology devices and products. 2808 Fairview Avenue North Roseville, MN 55113 Phone: 1-800-322-0956 Website: www.ablenetinc.com

#### Abilitations

Offers multi-sensory materials with a wide range of products that can be used in a classroom, home, or therapy session. PO Box 922668 Norcross, GA 30010-2668 Phone: 1-800-850-8602 Website: <u>www.integrationscatalog.com</u>

#### ACCI (Augmentative Communication Consultants, Inc. )

This company offers resources dealing with assistive technology. PO Box 731 Moon Township, PA 15108 Phone: 1-800-982-2248 Website: <u>www.acciinc.com</u>

#### **Achievement Products**

This company offers products for assessment, sensory stimulation and integration, seating equipment, gross and fine motor materials, and products to aid in perceptual development. PO Box 9033 Canton, Ohio 44711 Phone: 1-800-373-4699 Website: www.specialkidszone.com

#### Advocate

The *Autism Advocate* is published five times each year. It offers a diverse collection of the latest issues in autism, chapter highlights, first-person accounts of families living with and growing with autism, and tips from parents and professionals.

Website: http://www.autism-society.org/site/PageServer?pagename=AutismAdvocate

#### **Attainment Company**

Attainment Company offers educational materials, computer software, and adaptive devices to teach individuals with autism and other disorders daily living skills such as: money management, telling time, conversation skills, social networking, and more. PO Box 930160 Verona, Wisconsin 53593-0160 Phone: 1-800-327-4269 Website: www.AttainmentCompany.com

#### **Autism Asperger's Digest**

This is a bi-monthly publication focusing on autism spectrum disorders Phone: 1-800-489-0727 Website: www.autismdigest.com

#### Autism Resource Network, Inc.

Nonprofit organization featuring books and educational items 904 Mainstreet, # 100 Hopkins, MN 55343 Phone: 952-988-0088 Website: <u>www.autismshop.com</u>

#### **Don Johnston**

This is a company that offers products for student who learn differently. 26799 West Commerce Drive Volo, Il 60073 Phone: 1-800-999-4660 Website: www.donjohnston.com

#### **Flag House Special Populations**

Flag House is a supplier of physical education equipment and products, in addition to sensory and therapy items. Po Box 109 Hasbrouck Heights, NJ 07604-3116 Phone: 1-800-793-7922 Website: www.flaghouse.com

#### **Fun and Function**

Fun and Function offers creative, therapeutic, and educational toys, equipment, and resources. This is a Pennsylvania company. PO Box 11 Merion Station, PA 19066 Phone: 1-800-231-6329 Website: www.funandfunction.com

#### **Future Horizons**

Publications on Autism/Asperger's Syndrome 720 N. Fielder Road Arlington, TX 76012 Phone: 800-489-0727 Website: www.futurehorizons-autism.com

#### Handwriting without Tears

Handwriting Without Tears is a developmentally based and engaging writing program. 8001 MacArthur Blvd. Cabin John, MD 20818 Phone: 301-263-2700 Fax: 301-263-2707 Website: www.hwtears.com

#### Laureate Learning Systems, Inc.

Special Needs Software 110 E. Spring St. Winooski, VT 05404-1898 Phone: 800-562-6801 Website: www.laureatelearning.com

#### LinguiSystems

Therapeutic materials for speech therapists, parents, and educators. 3100 4th Ave. East Moline, IL 61244 Phone: 800-776-4332 Website: <u>www.linguisystems.com</u>

#### **Mayer-Johnson**

Assistive communication products PO Box 1579 Solana Beach, CA 92075-7579 Phone: 800-588-4548 Website: <u>www.mayer-johnson.com</u>

#### **PCI Educational Publishing**

PCI provides resource books, teaching materials, and software. 4560 Lockhill Selma Rd., Ste. 100 San Antonio, TX 78249-2075 Phone: 1-800-594-4263 Website: www.pcicatalog.com

#### **Pocket Full of Therapy (PFOT)**

PFOT offers unique materials needed to provide appropriate, motivating, and fun pediatric therapy and learning. PO Box 174 Morganville, NJ 07751 Phone: 732-441-0404 Fax: 732-441-1422 Website: <u>www.pfot.com</u>

#### **PRC-Pretke Romich Company**

PRC provides quality language and assistive technology products to people with disabilities, their families and professionals. 1022 Heyl Road Wooster, Ohio 44691 Phone: 800-262-1984 Website: <u>www.prentrom.com</u>

#### Proed, Inc.

Proed is the leading publisher of standardized tests, books, curricular and therapy materials, and professional journals. 8700 Shoal Creek Blvd. Autsin, TX 78757-6897 Phone: 800-897-3202 Website: <u>www.proedinc.com</u>

#### **Rifton Equipment**

Rifton is a catalog that offers adaptive equipment for individuals who have physical limitations. Examples of the equipment are in the areas of mobility, standing, sitting, and personal care. 359 Gibson Hill Road Chester, NY 10918-2321 Phone: 1-800-571-8198 Website: www.rifton.com

Slater

Slater offers software to aid in picture assisted reading and writing programs (ex. Pix Writer) 351 Badger Circle Guffey, CO 80820 Phone: 719-479-2255 Website: www.slatersoftware.com

#### **Super Duper Publications**

Therapy products and games P O Box 24997 Greenville, SC 29616 Phone: 1-800-277-8737 Website: <u>www.superduperinc.com</u>

#### TFHUSA

TFSH produces and sells a line of adapted toys ad products for children and adults with special needs. 4537 Gibsonia Road Gibsonia, PA 15044 Phone: 1-800-467-6222 Website: <u>www.tfhusa.com</u>

#### Silver Lining Multimedia

Silver Lining MM provides software and related products for visual learners. Po Box 544 Peterborough, NH 03458 Phone: 1-888-777-0876 Website: <u>www.silverliningmm.com</u>

#### **Therapy Shoppe**

The Therapy Shoppe is a specialty shop for school and pediatric therapists, teachers, and parents. PO Box 8875 Grand Rapids, MI 49518 Phone: 1-800-261-5590 Website: <u>www.Therapyshoppe.com</u>

#### FAYETTE

Support groups/support for parents whose children have any kind of behavioral challenges, developmental, social or emotional concerns or addictions

ADVOCATE Debbie Hudak 411 Morris BuncieRoad Smithfield Pa 15478 724-725-9269

ADVOCATE Barb Keefer Parents Involved Network PIN 31 Connellsville Street Uniontown Pa 15401 724-438-7551 bkeefer@mhainfayettecounty.org

Local Interagency Coordinating Council Fayette and Greene (Early Intervention-0-5 years) Contact: Lynne Clingan (724) 430-1370 Cathy Densmore 1-800- 328-6481 Call for location, date, and time.

Arc, Fayette Contact: Nancy Davis (724) 438-8416 Local advocacy organization for persons with developmental disabilities.

PARENTS SUPPORT GROUP PARENT MENTOR The ARC of Fayette County Nancy Pohaski Nancy Davis 80 Old New Salem Road Uniontown Pa 15401 724-38-8416

#### NAMI

Support group for parents/loved ones of those dealing with mental health issues Carmella Hardy 6 Bluff St Dunbar Pa 15431 724-277-8173

PENNSYLVANIA FAMILY SUPPORT ALLIANCE Support and education group Jacquie Fritts Crime Victims Center 63 N Beeson Avenue Uniontown Pa 15401 724-438-1470

PARENTS OF AUTISTIC KIDS SUPPORT GROUP PAK- Aboard sponsored Lorine Sproul 241 Duff Road McClellandtown Pa 15458 724-430-9824

#### PARENTS OF AUTISTIC KIDS

(PAK) Aboard sponsoredMarty Swartz520 New Salem RoadUniontown Pa 15401724-438-5761

LOVE OUR CHILDREN SUPPORT GROUP, ADVOCATE and Aboard sponsored support group for parents who have children with autism spectrum disorder Lisa Rizza 1081 Valley View Drive Scottdale, Pa 15683 724-887-7742

#### FAYETTE AUTISM NETWORK (F.A.N.)

F.A.N. meets the 2<sup>nd</sup> Tuesday Of every month at 7 pm. F.A.N is for parents, family members and professionals that are interested in education, training, and biomedical interventions. 215 Jacob Murphy Lane Uniontown Pa 15401 www.FANsupport.org 724-434-5018

#### K.A.R.E. KOMMITTEE FOR AUTISM RESEARCH AND EDUCATION Group of parents, educators, and providers working together to meet needs of individuals with autism. We serve Washington, Greene, and Fayette conties. Please contact Renae Kotchman 724-222-1040 x 105 kotchmanr@iu1.k12.pa.us

#### FAYETTE COUNTY

COLLABORATIVE BOARD INTEGRATED CHILDREN'S SERVICE PLAN - contact Carol Over 100 New Salem Road Suite 118 Uniontown Pa 15401 724-425-2432 This group works to improve lives of children and families, community, parents welcomed.

PARENT MENTOR/ADVOCATE Gayla Lafferty PO Box 404 Hopwood Pa 15445 724-439-9407 Early Head Start 724-434-5250

#### SUPPORT GROUP FOR THE CUSTODIAL PARENT Community Action Family Center Casey Ramage Tami Knouse 140 North Beeson Ave Uniontown Pa 15401 724-437-6050 x213

#### SUPPORT GROUP FOR NONCUSTODIAL PARENT Community Action Family Center Casey Ramage Tami Knouse 140 North Beeson Ave Uniontown Pa 15401 724-437-6050 x213

#### SOUTHWEST PA LOCAL TASK FORCE FOR EDUCATION Encompasses Fayette, Greene and Washington counties For info on becoming part of this group please call Anita Walters at 724-437-3237

724-437-9595

Office of Vocational Rehabilitation (OVR) 724-439-7465

Goodwill Industries 724-437-9878

Parents Involved Network(PIN) 724-438-7551

Private Industries Council (PIC) Education Services, Job Search, On the Job Training 724-437-2590 VALUE Vision and Leadership Uniting Education Ellen Mancuso Pennsylvania Protection and Advocacy <u>emancuso@ppainc.org</u> Coalition of Pa advocacy groups for children with special needs

ELKS HOME NURSE PROGRAM Patricia O'Connor Director 814-781-7860 pato@ncentral.com Margie Wood Ass Director 724-225-1395 <u>mwood15301@comcast.net</u>

#### ONLINE CHAT SUPPORT GROUP

Group is for parents who are raising children with special needs. <u>www.myadlcenter.org</u> <u>dsoucy@myadlcenter.org</u>

#### SELECTIVE MUTISM SITES

Several sites below with info on selective mutism. <u>http://www.healthline.com/search?q1=se</u> <u>lective+mutism&utm\_source=no\_health\_ channel&utm\_medium=google&utm\_c ampaign=serp&utm\_term=selective%20 mutism</u>

http://www.selectivemutismfoundation.o

http://www.selectivemutism.org/

Dads Matter 724-437-2590 email: dadsmatter@privateindustrycouncil.com

Intermediate Unit 1 Task Force Contact: Lynn Wiltrout or Toni Lozar Meetings held the first Thursday of each month (times varies). 1-800-328-6481, ext. 205

Parent Involved Network (PIN) Meetings held the second Monday of each month 10:00 am- 12:00 pm Oak House Drop-In Center 31C Connellsville Street, Uniontown, Pa Contact: Barb Keefer 724-437-7551

Head Start of Fayette 724-430-4818

Pressley Ridge Family Preservation Program 724-430-6000

Easter Seals of Western PA 724-437-4047

Mental Health /Mental Retardation(MHMR) 724-430-1370

Fayette County Commissioners Office 724-437-4525

Fayette County Community Action Information and Referral 724-437-6050 1-800-427-4636

#### GREENE

Support groups/support for parents whose children have any kind of behavioral challenges, developmental, social or emotional concerns or addictions

PA FAMILIES INC STATEWIDE FAMILY NETWORK 1-800-947-4941 pafamilies@alltel.net CALL OR EMAIL FOR CURRENT LIST

NAMI WASHINGTON/GREENE Thomas Shade 115 Christman Ave Washington Pa 15301 724-228-9847

LOCAL INTERAGENCY COORDINATING COUNSEL LICC Parents and professionals that meet to improve/educate in area of early intervention Lauren Chambers Greene County Human Services 3<sup>rd</sup> floor Fort Jackson Building 19 S Washington St Waynesburg Pa 15370 724-852-5276 EARLY CARE AND SCHOOL SUCCESS COMMUNITY TEAM Amy Switalski Greene County Human Services 3<sup>rd</sup> floor Fort Jackson Building 19 S Washington St Waynesburg Pa 15370 724-852-5276 The Team promotes high quality early care and education for all families in Greene County to ensure readiness to learn through partnerships with parents and community collaborations.

FBR/ABOARD WAYNESBURG FAMILY SUPPORT AND SOCIAL SKILL/PLAY GROUP Faciitators- Kim Forrester-Green/ Greg Sawyer Last Wed. of month, 6-8pm 1470 E. High Street Waynesburg Pa 15370 724-627-0290 FBRAutism@aol.com

ONLINE SUPPORT GROUP FOR AUTISM http://groups.yahoo.com/group/children\_ with\_autism/

K.A.R.E. KOMMITTEE FOR AUTISM RESEARCH AND EDUCATION Group of parents, educators, and providers working together to meet the needs of individuals with autism. Serving Washington, Greene, and Fayette counties. Please contact Renae Kotchman 724-222-1040 x 105 kotchmanr@iu1.k12.pa.us

#### WASHINGTON

Support groups/support for parents whose children have any kind of behavioral challenges, developmental, social or emotional concerns or addictions

#### PA FAMILIES INC STATEWIDE FAMILY NETWORK 1-800-947-4941 pafamilies@comcast.net PLEASE CALL FOR UPDATED LIST OR EMAIL.

TOURETTE SUPPORT GROUP Jay Goodman 3468 Ivy Hill Lane Finleyville Pa 15332 724-348-0358

#### WASHINGTON COUNTY ABOARD (AUTISM) SUPPORT GROUP

Meets the last Thursday of each month Lynne Oleary 339 North Jefferson Ave Canonsburg Pa 15317 724-743-0445

#### ONLINE SUPPORT GROUP FOR AUTISM

http://groups.yahoo.com/group/children\_ with\_autism/

#### FBR/ABOARD WASHINGTON FAMILY SUPPORT AND SOCIAL SKILL/PLAY GROUP

Last Monday of month, 6-8pm Facilitator- Lisa Baxter 75 E. Maiden Street Suite 103 Washington Pa 15301 724-229-0311 FBRAutism@aol.com

#### AUTISM PARENT SUPPORT GROUP

Northwestern Human Services 1075 Waterdam Plaza McMurray Pa 15317 724-942-4677

# LOCAL INTERAGENCY COORDINATING COUNSEL

LICC parent Committee of parents and professionals meet to improve services etc for early intervention Lois Chisholm 1732 Ridgewood Drive Washington Pa 15301 724-228-6977

#### **REAL FAMILY SUPPORT GROUP**

Support for parents of children with special needs Barb Hughes PO Box 1228 365 Jefferson Ave Washington Pa 15301 1-800-245-4453 724-225-0510 x353

#### **RELATIVES AS PARENTS**

Support group (and reimbursable services) for those age 60 or older residing in Fayette, Greene or Washington County who are caring for relative children aged 18 and under in their homes. Bill Garrow FCSP Supervisor 305 Chamber Plaza Charleroi Pa 15022-1607 1-888-300-2704 x4418 bgarrow@swpa-aaa.org

#### LEARNING SUPPORT GROUP FOR PARENTS OF SPECIAL NEEDS CHILDREN

Sue Schmidt 224 Thomasville Road McMurray Pa 15317 724-942-0209

#### ELKS HOME SERVICE PROGRAM

724-229-9050



# State Agencies and Organizations

#### **ABC Education Advocacy**

www.ABCadvocacy.net

Step-by-Step Parent Advocacy and Resources for families of children with special needs in Pa public Schools Contact is Pam Cook 412-851-0252

ABOARD (Advisory Board on Autism and Related Disorders) Elliot Frank, Chair Marie Mambuca, Family Support Coordinator 35 Wilson Street, Suite 100 Pittsburgh, PA 15223 (412) 781-4116; (800) 827-9385 E-mail: <u>info@aboard.org</u> Web: <u>www.aboard.org</u>

# ACHIEVA

711 Bingham St
Pittsburgh Pa 15203
<u>contact@achieva.info</u>
412-995-5000
1-888-272-7229
A member of The Partnership
Organization that helps people with disabilities and their families, offers support, services etc.

# AUTISMLINK

Support, information etc Online support groups and discussion boards 376 Wagon Wheel Trail Wexford Pa 15090 412-377-8778 info@autismlink.com www.autismlink.com

#### **Autism Society of America**

7910 Woodmont Avenue, Suite 300 Bethesda, MD 20814 (301) 657-0881; (800) 3-AUTISM Web: <u>www.autism-society.org</u>

#### **Coordinator for Transition Services**

James Palmiero, Managing Director Pennsylvania Training and Technical Assistance Network (PATTAN) 3190 William Pitt Way Pittsburgh, PA 15238 (412) 826-6850; (800) 446-5607 E-mail: jpalmiero@pattan.net Web: www.pattan.net

#### **Community Parent Resource Center**

(Serving American Street Empowerment Zone and providing intense training sessions to parents of children with disabilities in Philadelphia)
Luz Hernandez, Program Director
Hispanos Unidos para Ninos Excepcionales
(Philadelphia HUNE, Inc.)
202 W. Cecil B. Moore Avenue
Philadelphia, PA 19122
(215) 425-6203
E-mail: <u>huneinc@aol.com</u>
Web: <u>http://huneinc.org</u>

(Serving rural Northwest Pennsylvania) Gail Walker, Director The Mentor Parent Program, Inc. P.O. Box 47 Pittsfield, PA 16340 (814) 563-3470; (888) 447-1431 (in PA) E-mail: <u>gwmpp@verizon.net</u> E-mail: <u>mentorparentprogram@verizon.net</u> Web: www.mentorparent.org

#### **Disability Rights Network**

Disability Rights Network of Pennsylvania (DRN) is a statewide, non–profit corporation designated as the federally–mandated organization to advance and protect the civil rights of all adults and children with disabilities. DRN works with people with disabilities and their families to ensure their rights to live in their communities with the services they need, to receive a full and inclusive education, to live free of discrimination, abuse and neglect, and to have control and self–determination over their services. General information /questions can be emailed to intake@drnpa.org where intake

workers who are advocates and attorneys.

www.drnpa.org

#### Pittsburgh Office

429 4th Avenue, Suite 1901 Pittsburgh, PA 15219-1505 (412) 391-5225 [Voice] (412) 467-8940 [TDD] (412) 391-4496 [Fax] drnpa-pgh@drnpa.org [Email]

Wexford Office

8500 Brooktree Road Suite 100 Wexford, PA 15090 800-276-0928 [Voice] 724-934-1344 [Fax]

#### **Education Law Center**

Non-profit legal advocacy and educational organization dedicated to ensuring that all of Pennsylvania's children have access to a quality public education.

aaviles@elc-pa.org PITTSBURGH CONTACTS 412-391-4496 TTY- 412-467-8940 sbaur@dlp-pa.org WEBSITE- www.elc-pa.org

#### Governor

Honorable Edward G. Rendell 225 Main Capitol Building Harrisburg, PA 17120 (717) 787-2500 E-mail Web Form: <u>http://sites.state.pa.us/PA\_Exec/Governor/govmail.html</u> Web: <u>www.governor.state.pa.us/</u>

#### **Official State Web Site**

Web: www.state.pa.us/

#### **Governor's Commission For Children and Families**

List of Health and Human Services List of Advocacy Resources Parent Guides <u>www.pachildren.state.pa.us</u> A website with information for parents and families.

#### **United States Senators**

Honorable Arlen Specter (R) 711 Hart Senate Office Building Washington, DC 20510 (202) 224-4254 (202) 228-1229 (Fax) E-mail Web Form: <u>http://specter.senate.gov/public/index.cfm?FuseAction=Contact.ContactForm</u> Web: <u>http://specter.senate.gov/</u>

# Honorable Robert P. Casey, Jr. (D) 383 Russell Senate Office Building Washington, DC 20510 (202) 224-6324 (202) 228-0604 (Fax)

E-mail Web Form: <u>http://casey.senate.gov/contact.cfm</u> Web: <u>http://casey.senate.gov/</u>

#### Job Accommodation Network

JAN helps you hire, retain, promote qualified employees/applicants with disabilities, provide accommodation options, etc jan@jan.wvu.edu www.jan.wvu.edu

#### Joey Online Support Group

Just Open Everybody's Eyes Support for parents who have children with behavioral issues gramaro@aol.com

#### **Kids Together**

Volunteer non-profit that provides information on inclusive communities, schools, includes an inclusive education listserve, email, newsletter, website info. PO Box 45 Quakertown Pa 18951 staff@kidstogether.org www.kidstogether.org

Mental Health Association in Pennsylvania MHAPA works on behalf of mental health through advocacy, education and public policy. Wendy Luckenbill, Family/Child Policy Coordinator 1-800-692-7443 Wluckenbill@mhapa.org www.mhapa.org

#### **Mentors for Self Determination**

Group of self advocates, family members and caregivers whose mission is to provide current and accurate information to people regarding the MR system in Pa. We offer statewide mentoring so people have a better understanding of the system, promote self determination by sharing life experiences and networking with others. This is done in one session or group session called Family Connections.

Debbie Leasure 814.547.1577 <u>dleasure@mentors4sd.org</u> <u>www.mentors4sd.org</u>

# Office of State Liaison of Career and Technical Education for Students with Disabilities

Lee Burket, Director Bureau of Career and Technical Education Division of Field Support Department of Education 333 Market Street, 11th Floor Harrisburg, PA 17126-0333 (717) 787-5530 E-mail: <u>lburket@state.pa.us</u> Web: <u>www.pde.state.pa.us</u>

# **Office of Vocational Rehabilitation**

OVR provides services to eligible persons with disabilities with the goal of getting or keeping competitive employment. You will be eligible for OVR services if: You have a disability that is physical, mental, or emotional impairment which results in a substantial impediment to employment, and you can benefit in terms of an employment outcome from services provided, and ,

Vocational Rehabilitation services are required for you to prepare for, enter, engage in or retain gainful employment. A Vocational Rehabilitation Counselor will determine eligibility.

OVR provides a wide range of services to eligible applicants. The individual being served and the vocational rehabilitation counselor develop an Individualized Employment Plan jointly. The services you receive will be arranged to meet your individual needs. Not everyone will need every service. OVR services include: diagnostic services, vocational evaluation, counseling, training, restoration services, placement assistance, assistive technology, and support services. There is no charge for diagnostic services, counseling and job placement. However, a customer maybe required sharing the cost of other services after a financial needs assessment is completed.

Additional information, including local OVR office locations can be found on <u>www.dli.state.pa.us</u>, click on disability services. Also find OVR offices across the state. 1-800-442-6367

#### PA Education for All Coalition

Diane Perry The Partnership Institute on Disabilities Temple University 1301 Cecil B Moore Ave Room 423 Ritter Annex Philadelphia Pa 19122 215-204-3031 610-522-0698 Chapter meetings, on-line community, Parent Consultant Network

#### Pa Families Inc.

Statewide Network 1-800-947-4941 pafamilies@comcast.net

#### **Parent to Parent**

Linking families of children or adults with disabilities or special needs. Network created by families for families of children and adults with special needs. We connect families in similar situations with one another so that they may share experiences, offer practical information and/or support. 1-888-727-2706 www.parenttoparent.org

#### PA Tourette Syndrome Association

Sherrie Sponseller , Administrator 132 West Midlle Street Gettysburg Pa 17325 Advocates will do IEP for any child diagnosed with tourettes in any county in Pa 1-800-990-3300 717-337-1134 www.patsainc.org

#### **PEAL Center**

Pennsylvania's Parents Training and Information Center serving Western and Central Pa. Organization provides disability info, info about special education process and parent's rights, Parent Advisors are available to provide info and resources to assist the family with problem-solving strategies and direct them to other community resources ,trainings in Understanding IEP's, IDEA'04, Building Continuity, etc For information contact: Parent Education and Advocacy Leadership Center 1119 Penn Avenue Suite 400 Pittsburgh Pa 15222 412-422-1040 1-866-950-1040 cduch@pealcenter.org

#### Pennsylvania Health Law Project

Provides free legal services and advocacy to Pennsylvanians having trouble accessing publicly funded health care coverage or service. CALL- 1-800-274-3258 1-866-236-6310 TTY EMAIL - <u>staff@phlp.org</u> <u>www.phlp.org</u> 1-888-890-5665 1-888-572-7368 717-561-0098

#### Pennsylvania Human Rights Commission

Mission is to administer and enforce the PHR Act and the PFEOA of Pa for the identification and elimination of discrimination and providing of equal opportunity for all persons. PITTSBURGH OFFICE 412-565-5395 www.phrc.state.pa.us

#### Pennsylvania Parents and Caregivers Resource Network

Statewide cross-disability group supports parents and caregivers, helps to form local groups and network with other parents PO Box 4336 Harrisburg Pa 17111 info@ppcrn.org 1-888-890-5665 1-888-572-7368 717-561-0098

#### **PRADER-WILL SYNDROME** Association of Pennslyvania

Debbie Fabio 104 Persimmon Place Cranberry Township Pa 16066 724-779-4415

www.pwsausa.org

#### **Special Kids Network**

Helps parents of special needs children find resources in Pa and provides technical assistance to help groups develop, expand and maintain programs and support systems that serve children with special needs. 1-800-986-4550

## **Special Kids Network Coordinators**

Regional system of care coordinators can assist at the community level to help families and organizations work on projects to improve life in their communities for kids with special needs/disabilities.

Toll free: 1-877-986-4550 Western- Sharon Gretz sgretz@gotoskn.org WEBSITE www.health.state.pa.us/skn

## Starfish Advocacy Association

This is an Internet community for families of children with neurological disorders such as ADHD, bipolar disorder, Asperger's, PDD, SID, learning disabilities, OCD, tourette syndrome, etc. Services include forum boards, interactive chat room, moderated chats, informational resources, online classes in educational advocacy, education consultations. 216-283-2377

www.starfishadvocacy.org starfish@starfishadvocacy.org

Starfish Advocacy Assoc 3341 Warrensville Center Road Suite 203 Shaker Heights, Ohio 44122

# State Department of Education: Special Education

John J. Tommasini, Director Bureau of Special Education Department of Education 333 Market Street, 7th Floor Harrisburg, PA 17126-0333 (717) 783-6913 Special Education Consultline: (800) 879-2301(V/TTY) Web: <u>www.pde.state.pa.us</u>

## **State Vocational Rehabilitation Agency**

William A. Gannon, Executive Director
Office of Vocational Rehabilitation
Department of Labor and Industry
1521 N. 6th Street
Harrisburg, PA 17102
(717) 787-7312
E-mail: wgannon@state.pa.us
Web: www.dli.state.pa.us/landi/cwp/view.asp?a=128&Q=168255&dsftns=4490

## **United States Representatives**

To find the contact information for your representative in the House of the U.S. Congress, visit the House's Web site at: www.house.gov, or call: (202) 225-3121; (202) 225-1904 (TTY).

## University Centers for Excellence in Developmental Disabilities

Diane Nelson Bryen, Executive Director Institute on Disabilities at Temple University - UCEDD University Services Building, Suite 610 1601 N. Broad Street Philadelphia, PA 19122 (215) 204-1356 (V/TTY) E-mail: <u>dianeb@temple.edu</u> Web: <u>http://disabilities.temple.edu</u>

Nathan Blum, M.D., Director Leadership Education in Neurodevelopmental Disabilities (LEND) Children's Seashore House of the Children's Hospital of Philadelphia 3405 Civic Center Boulevard, Room 210 Philadelphia, PA 19104-4388 (215) 590-7466 E-mail: blum@email.chop.edu

Value

Vision and leadership uniting education Ellen Mancuso <u>emancuso@ppainc.org</u> Pennsylvania Protection and Advocacy Coalition of Pa advocacy groups for children with special needs Suite 100 Pittsburgh Pa 15223 1-800-827-9385



# HAIRCUTS

Carrie's Curls 1008 Lewis Street Brownsville, Pa 15417 Phone: 724-785-0332 Monday-Saturday by appointment

Dawn's Styling Salon 1375 Allison Avenue Washington, Pa 15301 Phone: 724-225-5718 Thursday, Friday, Saturday

Hair & There 980 Chartiers Street Washington, Pa 15301 Phone: 724-229-1936

Regis Crowne Center Mall Washington, Pa 15301 Phone: 724-222-8330

Stalnaker Shear Symme 56 South Beeson Avenue Uniontown, Pa 15401 Phone: 724-439-5655



# **Medical Supplies**

Free Diapers, wipes, pull-ups **Punxy Medical Supplies** Child has to be 3 years old, with a prescription from a doctor saying "incontinence supplies". Provide Huggies diapers, pull-ups, and wipes. Phone: 1-877-229-2940

Free Diaper/Pull up Program **Tri-Med Inc.** Phone: 1-800-541-0734

# **Partnerships for Prescription Assistance**

Hotline Resource for families who do not have prescription coverage receive free or reduced brand name medicines.

# 1-888-4PPa-NOW

# WIC

150 West Beau Street Washington, Pa 15301 Phone: 1-877-814-0788



# **PHYSICIANS AND PRACTITIONERS:**

## **DAN! Doctors:**

Dennis J. Courtney, M.D. 533 Washington Avenue Bridgeville, Pa 15017 Phone: 412-221-5562 Fax: 412-221-5237 Specialties: Integrative medicine, mercury, amalgam, detoxification

Franne R. Berez, M.D, N.D. 5801 Beacon St. Pittsburgh, Pa 15217 Phone: 412-422-5433 Fax: 412-422-1935 Specialties: Homeopathic medicine, family practice

Heidi Weinhold, N.D. The Enhancement Center 3075 Washington Road McMurray, Pa 15317 Phone: 724-969-6906 Fax: 724-969-4170 Specialties: Naturopathic medicine, homeopathic and herbal remedies, dietary and lifestyle changes

# **Diagnosis:**

Children's Hospital of Pittsburgh Child Development Unit (CDU) Children's on Fifth 3420 Fifth avenue Pittsburgh, PA Phone: 412-692-5589 Provides diagnostic developmental evaluations and follow-up recommendations for children. The Watson Institute 412-749-2889 301 Camp Meeting Road Sewickley, PA 15143 www.thewatsoninstitute.org

# PEDIATRICS, PSYCHIATRISTS, & CHILD DEVELOPMENT:

The Autism Center of Pittsburgh 135 Cumberland Rd. Suite 105 Pittsburgh, PA 15237 Phone: 412-364-1886

Dr. Faber Children's Institute Child Development 1405 Shady Avenue Pittsburgh, Pa 15217-1350 Phone: 412-692-5540 email: <u>sfa@the\_institute.com</u> \*\*\* Dr. Faber has a very long waiting list. To get in sooner, if you are available on short notice you can asked to be called if there is a cancellation.

Dr. Linda Gourash-Intercare 180 Ft. Couch Road, Suite 304 Pittsburgh, Pa 15241 Phone: 412-831-0355 ext. 1

Dr. Nguyen 169 South Mount Vernon Avenue Uniontown, Pa 15401 Phone: 724-438-3524

Dr. R. Chandra-Gastroenterology 2840 Liberty Avenue Pittsburgh, Pa 15222 Phone: 412-281-1999

Dr. Douglas Corwin 400 Locust Avenue Washington, Pa 15301 Phone: 222-9300 Dr. Robert Lowenstein Monessen, Pa 15062 Phone: 724-684-4710

#### Psychologists/Psychiatrists/Evaluators

Dr. Auria Mon Valley Health Center Monessen, Pa 15062 Phone: 724-684-9000

Stacey Kuhn, MS, BCBA 9 South Pennsylvania Avenue Uniontown, Pa 15401 Phone: 724-430-0555, 1-800-686-0767 Fax: 724-430-0966 wjs@atlanticbb.net

Dr. Jalangeer & Carol Stern 110 S. Arch St. #2a Connellsville, Pa 15425 Phone: 724-9941

Walter J. Sigut, Licensed Psychologist 613 Main Street Bentleyville, Pa 15314 Phone: 724-239-3077 & 1-800-686-0767 Fax: 724-430-3077 wjs@atlanticbb.net

Walter J. Sigut, Licensed Psychologist 99 South Pennsylvania Avenue Uniontown, Pa 15401 Phone: 724-430-0555 & 1-800-686-0767 Fax: 724-430-0966 wjs@atlanticbb.net

Dr. Thuppal - Cornerstone Care 35 Southwest Street Waynesburg, PA 15370 724-627-0782 Fax: 724-627-0726

# **DENTISTS:**

Dr. Geeshay-Pediatric Dental Specialist 634 Pittsburgh Road Uniontown, Pa 15401 Phone: 724-439-1576 ww.geshaydental.com

PH Dental School 3501 Terrace Street Pittsburgh, Pa 15217 Phone: 412-684-8405

Sapon & Sapon, DDS 160 Kruger St. Wheeling, WV 26003 Phone: 304-242-2400

Pediatric Dentistry South 1580 McLaughlin Run Rd Upper St. Clair, PA 15241 412 257 1150 Has three locations. Contact: Dr. Richard C. Ruffalo

# **VISION:**

Dr. Walker 30 Trinity Point Drive Washington, PA 15301 Phone: 724-229-7769

Dr. Perry Christopher 355 Wal-Mart Drive Uniontown, Pa 15401 Phone: 724-438-7550



# Shopping

Herbalicious.....Everything Nutritious 617 West Main Street Mount Pleasant, Pa 15666 Phone: 724-542-9745 M-F 10-6, Sat. 10-4

Nature's Pickins 464 Connellsville Street Uniontown, Pa 15401 Phone: 724-438-4211

Nature's Way Market 796 Highland Avenue Greensburg, Pa 15601 Phone: 724-836-3524 Closed Sundays

Sunny Bridge Natural Foods 130 Gallery Drive McMurray, Pa 15317 Phone: 724-942-5800 Toll Free: 1-877-942-5801 Website: <u>www.sunnybridgenaturalfoods.com</u> M-Th: 10-8, Fri. 10-6, Sat. 9-5, Sun. 11-4

Yarecks Health Foods 2 McKean Avenue Charleroi, Pa 15022 Phone: 724-489-9261

Lori Bakes-Gluten Free 100 S. McDonald St. McDonald, Pa 15057 Phone: 724-926-3658 Website: <u>www.loribakes.com</u> Email: <u>lori@loribakes.com</u> M-F 9-3, Sat. 8-1, Sun.-Closed



# **Medical Assistance**

# COMPASS-Commonwealth of Pennsylvania Access to Social Services

Qualification information for children with a disability to qualify for medical assistance through the "loophole". Phone: 724-223-4342 Website: <u>https://www.humanservices.state.pa.us/compass/CMHOM.aspx</u>

## **Health Law Project**

In Pennsylvania there is the possibility of receiving Medical Assistance under Category PH 95, aka "loophole" for your child with autism. Through PH 95, parent income is not a factor. To view a complete document explaining why you may want to consider Medical Assistance, Qualifications, and the Application Process, please visit the website below or call the Health Law Project at 1-800-274-3258

http://www.phlp.org/Website/MA%20Loophole/Loophole%20guide%20updated%2002. 2008.pdf



There is a wealth of valuable information on the internet. Please be aware that unfortunately, there are also those who may take advantage of families that have members with autism. The purpose of our website listings is to provide reliable sites recommended by parents and professionals, so that families can obtain information and find support that is needed. All of the websites are current at the time of press. These sites are not intended to serve as endorsements, only to provide places to retrieve needed information. If you do not have a computer or internet access at home many local libraries provide both services free of charge. If you have a laptop many coffee shops, restaurants, and even McDonald's provide free or low cost internet access.



# WEBSITES

<u>www.aap.org</u> American Academy of Pediatrics (AAP)

The American Academy of Pediatrics is dedicated to the health of all children. This side has information specific to autism for parents and professionals.

www.autism-society.org Autism Society of America

ASA is the nation's leading grassroots autism organization dedicated to improve the lives of all affected by autism. They provide public awareness, advocate for appropriate services, and provide up to date information regarding treatment, education, research, and advocacy. The website helps to answer frequently asked questions and provides tips of the day.

www.abcteach.com ABC Teach

ABC Teach provides teaching activities and flashcards for parents or teachers to use. This website has a variety of activities and printables, many are free.

www.aboard.org

ABOARD: Advisory Board on Autism and related Disorders

ABOARD's mission is to impact the lives of Pennsylvania children, adolescents, and adults with autism through intervention, support, and education. This website provides information on autism, legislation, services, support groups, and trainings.

www.assistivetech.com Tobbii

Tobii ATI is a developer of hardware and software solutions for people with physical, cognitive, and speech disabilities. This website will help you to learn more about augmentative communication devices, speech generating devices, and services. They have a monthly newsletter as well as free webinars.

www.autism.com/ari Autism Research Institute (ARI)

Autism Research Institute is a worldwide network of parents and professionals concerned with the effects of autism. This website is built around the premise that autism is treatable. It also supports information on Defeat Autism Now(DAN).

www.autismlink.com

Autism Link

Autism Link's mission is to provide opportunities for inclusion, information, and support; to keep affected parties up to date on news and information and to help them find support. This website provides general autism information, research, a mailing list, resources, and chat rooms.

#### www.autisminpa.org Bureau of Autism Services

The Bureau of Autism services was formed in 2006 as a direct result of the Autism Task Force and the needs expressed in these meetings for services needed for individuals with autism and their families. This website provides information on autism, services, new initiatives, and research being done in the field of autism. A must see for all parents.

## www.autismresearchnetwork.org

The National Institute of Health(NIH) Autism Research Network

The NIH supports two major research networks dedicated to understanding and treating autism. This website provides a single source of information about these networks and the research they conduct. Work from Dr. Nancy Minshew and the University of Pittsburgh is featured.

#### www.autismspeaks.org Autism Speaks

Autism Speaks focuses on raising the public's awareness of autism. It strives to advance studies in autism, increase advocacy for families, and conduct fundraising to support its goals. This website has a video glossary of autism and first signs with a side by side comparisons of children with autism and those without. This website also contains a 100 day kit that leads families through the 100 days after diagnosis.

www.autismteachingtools.com Autism Teaching Tools

Autism Teaching Tools was created by a parent as a resource to help parents and professionals find specific teaching tools and tips for working with learners with autistic spectrum disorders. This site provides information on child safety, behavior, curriculum, play, and social relationships.

#### www.cafemom.com

Café Mom

Café Mom is a website for a mom's to connect, share stories, or just vent.

## www.centerforautism.com

CARD: The Center for Autism and Related Disorders

CARD is among the world's largest and most experienced organizations effectively treating children with autism and related disorders. This organization follows the principles of Applied Behavior Analysis (ABA). The site embodies ABA and assessment information, special education laws, and intervention strategies.

#### www.cec.sped.org Council for Exceptional Children

CEC is the largest international professional organization dedicated to improving policies, setting professional standards and educational outcomes, and providing resources for parents and professionals.

www.childswork.com Childswork-Childsplay

Childs Work is a resource for counseling games and books for children.

#### www.cindysautisticsupport.com Cindy's Autistic Support

Cindy's Autistic Support is a Pittsburgh based autistic support classroom that provides a support website for parents and educators of children with autism. The site includes link to other sites and examples of supports.

www.cpcwecare.com Community Psychiatric Center (CPC)

CPC is a privately run mental health program that specializes in helping children reach their full potential. This website contains information and resources for autism spectrum disorders.

#### www.difflearn.com

Different Roads to Learning

Different Roads to Learning was created by a parent of a child with autism to provide a complete resource for Applied Behavior Analysis materials. Parents and professionals are able to purchase books, flashcards, dvds, and software.

## www.do2learn.com

Do 2 Learn

Do 2 Learn is a site dedicated to those individuals who may see the world in ways we do not yet understand. This website provides pre-created activities, schedules, songs, picture cards, and more. This is a great resource for parents and professionals.

www.dynavoxtech.com

DynaVox

DynaVox is the world's leading provider of augmenative and alternative (AAC) solutions for individuals with speech, language, and learning challenges. This website provides communication tips, page sharing, a parent guide, and helpful links.

www.familyvillage.wisc.edu Family Village

Family Village is a global community that integrates information, resources, and communication opportunities. This website provides informational resources, opportunities to connect with others, adaptive activities and materials, legal issues, and family resources.

www.fathersnetwork.org National Fathers Network (NFN)

National Fathers Network advocates for and provides resources and support to all men who have children with disabilities.

<u>www.gfcfdiet.com</u> Gluten Free-Casin free diet

This website offers information on the various diets, as well as, links and recipes.

<u>www.gfmall.com</u> Gluten Free Mall This is a gluten free food vendor directory.

www.grasp.org

GRASP: Global and Regional Asperger Syndrome Partnership

GRASP is an educational and advocacy organization serving individuals on the autism spectrum. This website offers information for individuals on the spectrum, parents, and professionals. The site provides free support networks ad elists, research, and advocacy information.

#### www.kylestreehouse.org

Kyle's Treehouse

Kyle's Treehouse is a website that provides information for families and professionals on resources, different treatments, and myths. There is also a section for discussion boards.

<u>www.ianproject.org</u> Interactive Autism Community (IAN)

IAN is an online project designed to accelerate the pace of autism research by linking researchers with families. Families can also provide feedback, interact with other families, and help form collaborations. A web project of the Kennedy Krieger Institute.

www.iidc.indiana.edu/ Indiana Resource Center for Autism (IRCA)

Indiana Institute on Disability and Community

Indiana Resource Center for Autism is a website run by the university and hosts some of the research they do. There are is also information from Dr. Temple Grandin and other helpful articles and links.

www.kidshealth.org Kids Health

Kids Health gives information for parents, children and teens related to autism and other topics. It is a user friendly site with easy to understand information.

K.A.R.E. Resource Guide

# www.loribakes.com/

Lori Karavolis "Lori Bakes Gluten Free" website offers sample recipes, upcoming events, her own experience with the gluten free diet and features her own cookbooks.

#### www.maapservices.org

MAAP: More Advanced Individuals with Autism/Asperger Syndrome and Pervasive Developmental Disorder

MAAP Services for Autism and Asperger Syndrome is a non-profit organization dedicated to providing information and advise to families. Through its quarterly newsletter, The MAAP, the organization provides networking opportunities for parents and professionals.

#### www.mayer-johnson.com

Mayer Johnson offers AAC educational products, interactive products, and boardmaker software. This website has a special section called "Sharing" which allows families to get ideas for boards, shows sample demos and activities. There is also a section for web classes.

## www.hanen.org

The Hanen Center

The Hanen Center is a Canadian charitable organization committed to helping young children communicate effectively by supporting those that have relationships with the child. This website provides resources for developing language.

## www.nichcy.org

National Dissemination Center for Children with Disabilities

NICHCY provided research based information on effective educational practices, state resources, laws and regulations, new publications and a special section called Zigawhat. This section provides opportunities for kids to connect with others, play games, and tell their stories.

## www.nickjr.com

Nick Jr.

Nick Jr. provides a fun, safe website for children to explore and learn some basic school readiness skills. This site is also a resource for parents who have children with interests in certain characters or videos.

#### www.researchautism.org

#### OAR: Organization for Autism Research

OAR is an organization led by parents and grandparent of children and adults on the autism spectrum. It's mission is to apply research to the challenges of autism that parents, professional, and caregivers face daily. The website contains monthly newsletters, conference information, practical research, and resources.

#### www.aspergersyndrome.org/ or www.udel.edu/bkirby/asperger

## OASIS: Online Asperger Syndrome Information and Support

OASIS was created by parents of children with Asperger Syndrome. This user friendly web site offers links to information on Asperger Syndrome, social skills, support groups, and research.

#### www.pattan.k12.pa.us

#### Pattan: Pennsylvania Training and Technical Assistance Network

Pattan is an initiative of the Pennsylvania Department of Education working in partnership with families and local education agencies to support programs and services to improve student learning and achievement. This website provides free online courses, resources, training information for an array of subjects and disabilities. This site also provides two special features: the lending library and training materials. Although Pattan has continuous opportunities for free trainings, parents cannot always attend. Pattan records many of these trainings. Parents can view them online or request that a DVD be sent to them. In addition, Pattan provides a lending library. Parents can work with their LEA to borrow resources from this library for free. These resources include books, videos, and other materials.

www.pealcenter.org Parent Education & Advocacy Leaders (PEAL)

The PEAL center serves families of children with disabilities and special health care needs. They provide information and training in our area for parents, families, and professionals.

#### www.schwablearning.org

#### Schwab Learning

Schwab Learning provides information on managing your child in his home and school, offers a parent message board, and provides information on IEP's.

#### www.symbolworld.org

## Symbol World

Symbol World is a resource website for parents and educators. This website provides step by step picture instructions for self-help skills, computer skills, and an array of educational subjects. All links provide the pictures and symbols for the materials that go with the lessons.

#### www.tacanow.com

TACA: Talk About Curing autism Now

TACA provides information, resources, and support to families affected by autism. For families that have just received the autism diagnosis, TACA aims to speed up the cycle time from diagnosis to effective treatments.

www.teacch.com or www.unc.edu/depts/teacch

TEACCH: Treatment and Education of autistic and Communication Handicapped Children

TEACCH is an evidence based service, training, and research program for individuals of all ages and skill levels with autism spectrum disorders. This website provides information on autism, education and communication approaches, and TEACCH materials and services.

#### www.thearc.org

The Arc

The Arc is devoted to promoting and improving supports and services for all people with intellectual and developmental disabilities. The Arc provides an online resource guide for families specific to Pennsylvania, links for national organizations, special education, and assistive technology.

#### www.thewatsoninstitute.org

#### The Watson Institute

The Watson Institute today is an educational organization, specializing in educating children with special needs, as well as those professionals and pre-professionals who serve children with special needs. On this site there is information for parents and professionals.

www.tonyattwood.com.au

Tony Attwood

Tony Attwood is a Dr. of Psychology. He is well known for sharing his knowledge of Asperger's Syndrome. This website is a guide for parents, professional, and people with Asperger's Syndrome

www.trainland.tripod.com

**Beyond Autism** 

Beyond Autism is a website by a parent of a child with autism. This website has over 2,700 working links to other resources and is a comprehensive source of information for parents just starting their journey with autism.

#### www.ussaac.org

USSAAC: United States Society for Augmentative and Alternative Communication

USSAAC is dedicated to providing information and support on the issues, technology, tools, and advancements within the world of AAC.

www.voiceforliving.com

Voice for Living

Voice for Living is an information resource and exchange site for people worldwide challenged by speech disabilities. This website is a place for you to discover how an array of tools and techniques can open a world of possibilities for those who cannot speak.

www.words-plus.com

Words+, Inc.

Words+, Inc. is dedicated to "unlocking the person" by improving the quality of life for people with disabilities. Words+, Inc. provides communication and computer access products.

#### www.wrightslaw.com

#### Wrightslaw

This website provides accurate and reliable information about special education, education law, and advocacy for children with disabilities