



Parent Guide 2006-2007

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Making a difference ... now!

Disclaimer

The information presented in this guide is general in nature and is intended to give parents a broad overview of available autism information resources in the area as well as nationwide. POAC of Oregon does not take responsibility for the use of this information by individuals, nor does POAC of Oregon advocate or take a position regarding the various options available. Parents should consult with a qualified professional for answers to specific questions and make decisions based on their individual needs.

Updates to this book

Updates to information in this guide can be found at:
<http://www.poac-or.org>

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What is POAC of Oregon?

Founded in 2005, Parents of Autistic Children (POAC) of Oregon was formed with a mission to provide scientifically based training to parents, teachers, and related personnel who provide direct services to children with autism and other developmental disabilities.

POAC seeks to utilize experts in the field to train teachers in the principles of applied behavioral analysis, direct instruction, and other teaching procedures based on research that have proven to be effective for teaching children with autism.

POAC's purpose is to involve parents, teachers and other "stakeholders" in the highest level of decision making regarding the education of children with autism.

POAC's board of directors consists only of parents, professionals and paraprofessionals who have demonstrated a deep commitment to providing quality intervention with children with autism and other developmental disabilities.

POAC's mission is to provide targeted and sustained training in the science of Applied Behavior Analysis (ABA) which emphasizes the teaching of Verbal Behavior. Pioneered by B.F. Skinner, ABA is the only research-based treatment recognized by the U.S. Surgeon General for children with autism in the 1999 report. The training places a heavy emphasis on the following important lines of ABA research:

- ◆ Functional Assessment - Classifying and selecting treatments based upon function of problem behavior
- ◆ Motivative Operations - Conceptual understanding and practical control of antecedent motivational variables
- ◆ Matching Theory - Practical manipulation of teaching variables to control learner response allocation to teacher instruction
- ◆ Skinner's Analysis of Verbal Behavior - How to teach verbal behavior to persons who do not acquire it typically

In addition, POAC will build capacity to provide training in Direct Instruction, an enriched, research-based curriculum that provides explicit instruction in Reading, Math, Language Comprehension, and more.

From an introduction to Verbal Behavior to courses in advanced classroom skills, POAC's teacher training is the cornerstone of the organization's mission. POAC is working towards preparing teachers to work with a child and/or adult with a developmental disability.

What is Autism?

Autism is a neurobiological disorder which severely impairs a child's communication and social interactions. Unable to learn from the natural environment as most children do, the child with autism shows little interest in the world or people around him. While all children with autism develop some normal and even advanced skills, they exhibit a wide range of behavioral deficiencies and excesses. Some behavioral symptoms of autism include:

- Speech and language are absent or delayed, while specific thinking capabilities may be present.
- Abnormal ways of relating to people, objects, and events.
- Abnormal responses to sensations, such as sight, hearing, touch, balance, smell, taste, reaction to pain, and the way a child holds his or her body.
- Ritualistic or perseverative behavior such as arranging objects into neat rows, gazing at spinning objects for extended periods of time, waving fingers in front of the eyes repeatedly, and insisting on particular routines.

Left untreated, autism inhibits a child's developmental growth to such a degree that most will require lifelong support. Estimates of occurrence range from 1:500 (CDC) to 1:250 (CA). To date, there are no known preventions or cures. Additionally, there is no proven cause or single gene. At this time, autism is thought to have several etiologies including genetics, environmental toxins such as lead, mercury, and waste products, vaccinations (MMR), and viruses (rubella in 1st trimester).

There is Hope...

For parents, autism is devastating. Imagine never hearing your child call your name, share a discovery, or look into your eyes. The panic and fear a parent experiences as his or her child rejects the people and world around him is heartbreaking. For children, autism severely limits the potential for an independent future. Though there is no cure for autism, there is hope — through **INTENSIVE EARLY BEHAVIORAL INTERVENTION**.

The Research...

Autism can be overcome! Lead by the promising work of Dr. O. Ivar Lovaas of UCLA's Clinic For The Behavioral Treatment of Children, Edward C. Fenske and colleagues of Princeton Child Development Center, and others, the research indicates that nearly half of young children with autism treated by an early intensive behavioral intervention program achieve normal or near normal intellectual and educational functioning by first grade. One follow-up study showed these children maintain normal functioning and as adults are leading normal lives, attending college and participating fully as members of their communities. Equally encouraging, the research suggests that most children benefit from such programs, enhancing communication, cognitive, social and self-help skills.

Intensive Early Behavioral Intervention

Similar to the method used by Annie Sullivan to teach Helen Keller, intensive behavioral intervention involves individually addressing a child's behavioral deficits and excesses. Breaking down deficit skills to small incremental tasks, a behavioral therapist works one-on-one with a child using repetition, feedback, and positive reinforcers to allow a child to master small tasks. Once mastered, basic skills are used to develop more complex abilities. Behavioral excesses, such as tantruming, aggression, and repetitive behaviors, are also addressed so that a child may learn how to more effectively and appropriately socially interact. Characteristic to an intensive behavioral treatment are:

- At least two years of therapy including 30 to 40 hours per week of one-on-one behavioral intervention.
- One-on-one teaching by trained therapists of specific cognitive, language, social and self-help skills.
- The use of positive reinforcers.

Though not a cure, early intensive behavioral intervention can make a significant difference in the life of a child with autism. Based on basic learning principles, its fundamental goal is not only to teach a child specific skills, but to ultimately develop a child's ability to learn how to learn.

The effects of an early intensive behavioral treatment program can be profound. For families, every step made towards more developmentally appropriate behaviors rekindles the optimism for a child's future once destroyed by an autism diagnosis. Furthermore, the benefits of gains made by children with autism are shared with their communities through the prospect of more productive, independent and normal lives.

POAC of Oregon FAQs:

Will POAC of Oregon provide treatment for my child?

No. At this time we have neither a location to provide training and treatment nor funding to hire qualified individuals to provide the training and treatment.

POAC of Oregon's immediate plans are to train others in effective behavioral and academic teaching procedures.

What can POAC of Oregon do for me?

POAC of Oregon is not a membership organization. The teacher training model ensures research-based, effective treatment for children and adults with autism.

TEACHERS: Learn how to use effective Direct Instruction curriculum and utilize ABA principles and teaching procedures that emphasize the teaching of verbal behavior.

ADMINISTRATORS: Learn how to save money, improve outcomes, and expand your in-house resources by training up local experts.

PARENTS: Learn how to become an integral part of the intervention.

What can I do for POAC of Oregon?

The Teacher Training model requires financial resources in order to train teachers, paraprofessionals, and parents in a model classroom setting. Grants and private donations mainly fulfill the financial needs.

POAC is looking for a building in Portland, Salem, or Albany to house trainings and a model classroom. Again, if you believe in this model, keep an eye out for a building that might be donated or purchased/leased at a low price.

Another way to help is to look at yourself or relatives for estate planning. There are ways of sheltering an estate from estate taxes by donating money or property to a nonprofit, thus bringing the estate value under the taxable amount. The family comes out ahead by not having to pay the estate tax and the nonprofit comes out with needed property/building or money.

Again, simply keep your eyes open for such opportunities. Are there relatives that might benefit from such estate planning and are sympathetic to the autism issues in Oregon? Ask your local estate planner/accountant who has experience in such matters.

Autism and ABA FAQs:

How do I know if my child has autism or PDD?

Through an educational evaluation from the Educational Service District (ESD) or a medical diagnosis by a knowledgeable physician or clinical psychologist who specializes in diagnosing autism found at CDRC or the Children's Program (See Appendix 2 for autism characteristics).

What is the difference between a Educational Evaluation of Autism and a Medical Diagnosis?

A medical diagnosis uses the *DSM IV*. The definition autism falls under the umbrella of Pervasive Developmental Delays (PDD) which includes Autism, Pervasive Developmental Delays Not Otherwise Specified (PDD-NOS), Asperger's Syndrome (AS), Rhett's Syndrome, Childhood Disintegrative Disorder. A diagnosis can be gained through CDRC, Children's Hospital, a medical doctor, psychologist, or psychiatrist.

An Educational Evaluation defines autism as including autism, PDD NOS, and Asperger's. The "handicapping condition" is the global term "Autism." Under this umbrella of "autism" falls the spectrum of disabilities from mild to severe. The level of severity is not explicitly determined during an educational evaluation/determination of eligibility. Under the education system, the child is evaluated by Early Intervention and/or ESD. A team, usually with a speech pathologist, autism specialist, and/or occupational therapist, looks for "significant characteristics" of autism in 4 areas: communication, social, and sensory and repetitive/ restrictive/ stereotypic interests and activities. The team determines "significance" together with the guidance of the specialists.

What are some educational programs used for children with autism?

Some competing educational programs include: Applied Behavior Analysis (ABA), Developmental methodology such as Structured Teaching and Stanley Greenspan's Floortime, and an eclectic approach which includes strategies from a behavioral and developmental approach. Please see the appendices for a comparison.

What are some other therapies?

Some treatments that are used in conjunction with educational models include: sensory integration, Auditory Integration Therapy (AIT), occupational therapy, speech therapy, hippo therapy (horseback riding), craniosacral therapy, aqua therapy, art therapy, music therapy, facilitated communication, Grandin's hug machine, vision therapy, and dance therapy.

POAC of Oregon does not advocate or take a position regarding these

options. Since each child is an individual with his/her own special needs, you are advised to research the available treatment options, discuss these with your medical care provide, and make an informed decision based on your child's needs.

What are some medical treatments and where do I find a doctor to help me?

Biomedical treatments may include: vitamin therapy such as B6, Magnesium, vitamin A, epsom salt baths, melatonin, probiotics such as Culturelle and Primal Defense, and Essential Fatty Acids such as Cod Liver Oil (CLO).

Dietary interventions include the Gluten Free-Casein Free diet (GFCF), Specific Carbohydrate Diet (SCD), Feingold diet, and food allergy elimination. New and improved medical treatments are constantly added to the list. Some have scientific research, some do not.

Drug treatments may include: heavy metal detoxification or chelation, anti-yeast therapy, IVIG, secretin, Prozac, Zoloft, Tenex, Buspirone, Depakote, Risperdal, Secretin, Cloradine, anti-virals (Valtrex, Famvir), anti-fungals (Nizoral, Diflucan), Chelation, TTFD, Methylcobalamin, B12 shots, steroids, and anti-inflammatory drugs.

Doctors with experience in treating children with autism are often called Defeat Autism Now! doctors (DAN!) and can be found at: <http://oregonparentsunited.org/providers/providers3.htm>. DAN! doctors are growing in numbers.

DAN! doctors and the DAN! protocol date back to 1995 when the Autism Research Institution (ARI) convened group of physicians and scientists from the U.S. and Europe for the express purpose of sharing information and ideas toward defeating autism as quickly as possible. The participants continue to work together toward the goal of finding effective treatments.

There are special email lists for autism medical issues such as Phoenixkids, ORAutismSupport, and GFCFkids. See this booklet's section on Email Listserves on how to subscribe.

Why should I request a behavioral program for my child with autism?

ABA (Applied Behavioral Analysis) is the only treatment for autism that scientific research has proven to be effective for children with autism. (For more information see UCLA Program in Appendix 4). ABA has numerous research articles showing effectiveness in teaching children with autism and related disorders.

What is a behavioral program? Is it the same as a home program?

A behavioral program employs ABA techniques such as discrete trial

teaching, verbal behavior, precision teaching, incidental teaching and pivotal response training to change the behavior of your child with autism and to teach him or her the communication and social skills necessary to function in this world. For a program to be successful it must be intense: at least 30-40 hours a week of one-on-one teaching. Good programming and parental involvement are critical to the success of a program. An ABA program may occur in a school based setting but it should include a home program element. Because behavioral programs are often started when a child is very young, 2 to 4 years old, they are often done in the home because it is the “natural” environment. For more detailed information read the Glossary.

How do I pay for a behavioral program?

For the most part, parents often pay for the program themselves. A very few advocate enough to get Early Intervention or the School District to pay. Many rely on Developmental Disability Services, Disability Social Security, Insurance, Intensive In-Home Services, Respite Care, or private funds to directly or indirectly support some or all parts of a home/behavioral program.

My child has PDD, PDD/NOS, or has been diagnosed with “autistic-like” traits. Should we request a behavioral program?

Please consult with a professional. Several are listed in this book. However, scientific research suggests that ABA is appropriate and helpful for children with these diagnoses.

Why the need for advocacy?

Behavioral programs can be quite expensive and sometimes advocacy is required to convince your public service provider that a behavioral program is required to provide your child with a free and appropriate public education.

We have decided that an intensive behavioral program is best for our child. How do we get started?

In the section that follows there are steps to help you get started.

For Newly Diagnosed Parents

1. Obtain a computer, an email account, and an internet connection, if at all possible. There is no faster way of reaching out to other parents, gaining information, and getting your questions answered.
2. Get an intake evaluation from the designated Referral and Evaluation agency for your service area. Contact your Designated Referral and Evaluation Agencies by calling Office of Special Education at (503) 378-3700 x2337 or browse to <http://www.ode.state.or.us>
3. Join local and national listserves, support groups, and informational groups like:
 - POAC-OR list - <http://yahoogroups.com/group/poac-or/>
 - Oregon Parents United listserv - <http://oregonparentsunited.org>
 - Autism Society of Oregon - <http://www.autismoregon.com>
 - ORAutismSupport list - <http://yahoogroups.com/group/orautismsupport>
 - ARI - <http://www.autismresearchinstitute.com>
 - Autism-Oregon - <http://yahoogroups.com/group/autism-oregon>
4. Be wary of magic cure-alls and snake oil salesmen, <http://autism.com/ari/>
5. There are 2 main categories of treatment: MEDICAL and EDUCATIONAL. POAC of Oregon focuses on behavioral education.

EDUCATIONAL Therapies have 3 main approaches:

Behavioral - Applied Behavior Analysis (ABA), Pivotal Response Training (PRT), Discrete Trial (DTT), Lovaas, Precision Teaching

Developmental - Structured Teaching (TEACCH), Greenspan's Floortime, Social Stories

Eclectic - A combination of Behavioral and Developmental approaches along with various other complimentary treatments

MEDICAL Therapies have Biological and Drug approaches:

Biological: vitamins, minerals, and more

Drug: chelation, anti-yeast therapy, IVIG, secretin, Prozac, and more

6. Because there are many treatment options available, it is advisable to first consider those with scientific research. This is especially true of educational approaches.

Many of the medical treatments are non-standard and based on trial and error not double blind published peer reviewed scientific studies. Some doctors scoff at some of the diets and treatments because it's

often contrary to conventional medical wisdom. Sometimes you, the non-doctor parent, will have to educate the experienced professional. Strongly consider taking the time to locate and work with physicians who are experienced with your child's specific neurological disorder and who also network with other doctors in this field. <http://www.autism.com/ari/> see the: DAN! Physician Referral List

7. Do only one new treatment, supplement or drug, at a time and keep records (data) on what is causing changes. Then, be sure to give each approach plenty of time, several weeks, to work before passing judgment. It's OK to try things when you are sure they do no harm to your child and family physically, financially or emotionally.
8. Learn the law and your child's rights (see websites in back of book). Contact Developmental Disabilities Office, Oregon Parent Training Information (Oregon PTI) or a local advocate for help on IFSP/IEP goals and services.
9. Consider getting extra evaluation and services from private agencies for home programming, speech and occupational therapy. The state has to provide appropriate but not "all" or the "best" services.
10. Be completely involved in your home program in every aspect -- as much as it is possible for you. Detailed knowledge of your child can make a huge difference.
11. Your school district and professionals may not share your beliefs of educational and biological approaches. Try to work on win-win relationship with all people who interface with your child. Point out what teaching techniques work at home and offer any training that you and your team might be receiving in your home program.

If your child is on a special diet, ensure that the school is aware. Bring your own snacks and lunches and try to inform the teachers and school nurse (if one exists) of the specifics of the diet with an easy to read list of foods the child CAN eat and NOT eat. Volunteer with the PTA or in the classroom. Once they get to know you the return in favors and help for you child will be more than you put in.

12. Do not spend all your time and effort on the child with autism at the expense of your marriage, family and friends. The best treatment for your child is a happy, healthy, and loving family to support them. Your spouse, other children and YOU need love and support as well.
13. There is no single professional you can go to who will manage "all" your child's issues. You will have to become your child's expert and case manager.

Getting Started with a Behavioral Program

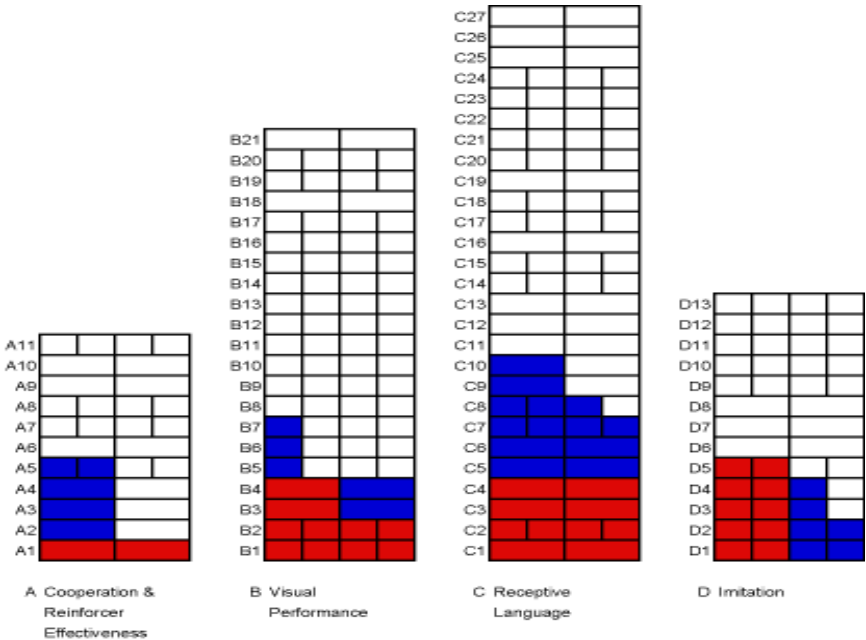
1. If the child hasn't already received an Autism Evaluation by the Education System, call Early Intervention or Referral and Evaluation Agency at 503-378-3600 x2337 or see <http://www.ode.state.or.us/sped/>
2. Obtain a computer, an email account, and an internet connection
3. Join local and national ABA listserves, support groups, and informational groups like:
 - Me-List listserv - (see Email List Serves)
 - DTT-NET list - <http://yahoogroups.com/group/dtt-net>
 - VerbalBehavior list - <http://yahoogroups.com/group/verbalbehavior>
4. Get a copy of ***Teaching Language to Children with Autism or Other Developmental Disabilities*** by Mark Sundberg and James Partington, ***Behavioral Intervention for Young Children with Autism*** by Catherine Maurice, and/or ***A Work in Progress*** by Ron Leaf and John McEachin. Some are available in your library.
5. Go observe a home program. By joining various email lists you can find local people that have sessions that you can view.
6. Begin learning about the special education law (see back of book). Contact Developmental Disabilities Office, COPE or a local advocate for help on IFSP/IEP goals and services.
7. Contact and interview ABA providers in order to determine which program is best suited for you and your child's needs.
8. Recruit, interview, and hire program therapists. Join the poac-or list at <http://yahoogroups.com/group/poac-or> to find potential therapists or referrals.
9. Be completely involved in your home program in every aspect -- as much as it is possible for you. Detailed knowledge of your child can make a huge difference.
10. Keep learning. Don't become over confident in your knowledge. Continue to attend conferences to remind yourself of the foundational principles of ABA.
11. Complete an assessment of your child's skills. The ***Assessment of Basic Language and Learning Skills*** (ABLLS) is highly recommended.

ABLLS - The Tool of Choice

The Assessment of Basic Language and Learning Skills (ABLLS) is a criterion-referenced assessment (not a norm-referenced assessment). This assessment helps design your home program and is an excellent tool for developing an IFSP or IEP.

It is best to complete the ABLLS as soon as possible so that you can get your home program started.

ABLLS is a set of over 400 questions designed to track your child's progress. There are 25 sections to the assessment. Each section contains 12-52 questions. Each question is rated with a score of 1, 2 or 4. The score correlates to a box in a chart. The chart helps you track skills and progress. Below is a small example of the chart.



As you can see, some of the boxes are filled with 2 different shades of gray. One shade might be red and the other blue.

The ABLLS is given every 3 to 6 months so the different shadings represent a different assessment period.

Once filled out (especially the first page), the ABLLS represents the skillset of a 5 year old child.

Whoa! How do I pay for this?

POAC of Oregon exists because the education system does not practice the principles of Applied Behavior Analysis. If schools were to **analyze** the progress of the children in their care, they would find that many, if not most, children do not make nearly the progress they could.

So if the education system doesn't pay, who does?

Well, you, the parent pays. Currently most insurance companies do not cover "behavioral" or educational treatments. Future insurance parity legislation might change that, but parents will need to speak up. A limited number of companies, like Microsoft, offer insurance coverage for ABA. At this time no company in Oregon openly covers ABA, although a few single instances do exist.

Some folks have found some pretty creative ways to raise funds:

1. Use volunteers from your church to run sessions. You'll need to train everyone, regularly supervise each therapist via video taping or sitting in on sessions, and ensure quality control through regular team meetings.
2. Hire students (\$8-\$15 per hour) from your local college, university, even high school. Again, you'll need to train everyone and ensure quality control.
3. Use funding from Children's Intensive In Home Services (CIIS) to pay for therapists. CIIS funding is limited to a small number of families across the entire state of Oregon and qualification is difficult. Ask your Developmental Disabilities Services casemanager for a CIIS Intake.
4. There is also limited funding via the Staley case (funding gained through the shutdown of Fairview State Hospital). Ask your DD Services casemanager.
5. Fundraise much as parents do with their child that needs expensive treatment or an operation.
6. Badger your insurance company and prove that ABA is medically necessary. Autism is a medical condition that requires treatment to become a productive part of society, just as stroke or mercury contamination. Search the internet on how this can be attempted.

How to Choose a Consultant

According to Association of Behavior Analysts, it is recommended that consultants meet certain minimum qualifications:

- A. A master's degree or better in psychology, special education or related field;
- B. At least two years of experience using ABA to treat autism in young children;
- C. Provide customized program design and monitoring;
- D. Provide training of line therapists. Expert consultation is essential to successful ABA programs.

Finding qualified professionals is frequently difficult. It is best to find a Certified Behavior Analyst or, in the minimum, a Certified Associate Behavior Analyst. However, because of the lack of certified professionals and the demand for ABA consultants often exceeds supply, some families may be forced to go out of state for ABA expertise. Another way to bring in experts is by banding together to bring an outside consultant for periodic visits and share the associated travel expenses. Various listserves are some ways families can get in touch with each other to hire a consultant.

Hiring a Home Therapist

Shown below is a sample therapist ad which families can modify and use to suite their own needs when looking for therapists. Many people also include a picture of their child in their ads. Some families use the term "therapists" while other families use the term "tutors" in describing those that work in home programs.

Sample Therapist Ad: Teaching Assistant Employment Opportunity

Teaching assistant positions available working with a team providing intensive early intervention for our 3-year-old autistic son, John. Our intensive home program is based on a structured, researched based approach using positive behavioral techniques to teach language, social skills, and play skills to children with autism. John is making progress in his current program indicating recovery is a real possibility.

Position requires dependable, energetic individuals who enjoy working with preschool-age children and have a strong desire to make a profound difference in a young child's life. Interest in psychology or special education is desirable. Knowledge of autism is helpful, but not required. Professional training and regular supervision will be provided.

Flexible hours; time commitment 6 to 10 hour a week provided in 2-3 hour time blocks.

Interview/Discussion Questions for Therapists

I. Information for Applicant

1. About child
2. Child's program - home / school / community
3. Time commitment per week and length of involvement
4. Regular therapy and progress reviews
5. How program may evolve and change over time

II. Personal Information

1. Own car
2. Educational background and GPA
3. CPR/First Aide training
4. Experiences with children
5. References

III. Questions for Applicant

1. Motivation for doing this kind of work
2. What do you do if the child bites or hits you?
3. How do you feel about being videotaped?
4. Have you changed a diaper?
5. How do you feel about bodily fluids?
6. Willing to train new therapists in the future?
7. Willing to attend training sessions, conferences etc.?
8. Willing to read recommended books, articles, etc.?
9. What do you think are primary responsibilities of a therapists are?
10. What type of activities would you do with a child of X age?
11. What would you do if a child wouldn't eat a meal?
12. What do you do in an emergency if you couldn't reach the parents?
13. What do you do when a child totally frustrates you?
14. How do you relax after a tough day?
15. How do you handle temper tantrum?
16. What are your favorite children's books?
17. What kind of relationship do you want with the family?
18. What kind of boss do you work best with?
19. What are the important traits you think a therapist should have?
20. How do you describe your temperament?
21. In what ways do you think you'll influence the child you work with?
22. How do you know it you are doing a good job?
23. How do you react to criticism from a supervisor?
24. What expectations do you have of the family?
25. If you had \$50 to spend on my child, how would you spend it?

IV. Applicants Personality Based On Interview Process

1. Patience, compassion, calm, dependable
2. Friendly - fun
3. Difficult - cranky
4. Too eager to commit without knowledge of involvement
5. Responsible, dedicated attitude toward work
6. Willingness to learn and follow directions
7. Willingness to work in challenging environment
8. Belief that change is possible
9. Clear voice and speech articulation
10. Intuition of child's needs and demeanor
11. How applicant interacts with the child
12. How applicant demonstrates simple task with a child as directed by parent

V. Scheduling, Pay and Other Issues

1. When are you available to work? How flexible?
2. Can you attend scheduled training session(s) and progress reviews?
3. Salary / taxes / insurance
4. Pay frequency
5. Do you bring meals or we supply them?
6. What would you like to know about our child?
7. How long would you like to be in this position? Long term plans?

Therapist Contract

When you decide on a therapist, have a contract ready for her to examine and sign. This makes everything clear between both parties and will save you future anxiety. It is recommended that you cover these things:

1. A description of services
2. Procedure for missing a session
3. The number of hours per week will be working
4. The length of time (months) of commit
5. Where the services will take place
6. The pay scale and the varying rates for therapy, meetings, and training if applicable
7. Performance review periods and pay raises
8. Travel expenses—will they be covered and how much?
9. Taxes. Will they be responsible for their own federal, state and Social Security taxes? Since the therapist is working for your family as an independent contractor, you'll need to provide her with a 1099 each year covering all payments.
10. Confidentiality about therapy and your child

ABA Myths and Misconceptions

Applied Behavioral Analysis has gained international attention and significant acceptance as a scientifically proven effective method for teaching individuals with autism. Despite this, ABA theory and methodology remain a mystery to many parents and teachers.

As with any unfamiliar concept, myths and misconceptions exist. Assumptions and decisions are made based on inaccurate and incomplete information. The following is a list of common misconceptions and rebuttals.

1. ABA is experimental - ABA is research-based. It is the culmination of procedures which have been validated through a long history of empirical research. Case studies and replication studies are ongoing.
2. ABA utilizes punishment - ABA utilizes child-oriented positive experiences to reinforce target skills.. The goal of ABA is to prevent the escalation of situations to an aversive level through the reinforcement of alternative behaviors - Current practices do not include aversives (e.g., physical punishment).
3. ABA is mechanistic - ABA is systematic. At the entry level, many children with autism learn best through repeated practice to acquire target behaviors. However, there is always a balance between discrete trial teaching and opportunities to "go play". As the program continues, children become increasingly more capable of incidental and observational learning in natural contexts. That is the goal of all ABA programs.
4. ABA produces robotic children who do not generalize - In the acquisition phase of a skill, it is normal for behavior to appear somewhat less fluent and somewhat more deliberate (Recall the first time you rode a bike). However, in the generalization and maintenance phases of acquisition, skills become fluent and natural. Effective therapists do not interact with children in a robotic manner. They establish strong positive bonds with the children, and their interactions typically include many varied forms of reinforcement.
5. One-on-One instruction isolates children - The acquisition of skills through one-on-one therapy enables children to benefit from interactions with peers. Intensive and successful one-on-one adult instruction is a precursor to group and peer interaction. Intensive ABA separates a child from his family ABA invites family participation, and this leads to a feeling of empowerment. Participation in therapy establishes positive and interactive relationships.

6. ABA is too demanding - Children with autism thrive on structure, and structure is a key feature of any good program. Progress depends on intensity as measured by the frequency of learning opportunities. Studies have shown that parents of children in ABA perceive themselves as less stressed.
7. ABA teaches splinter skills - The goal of ABA is to teach children how to learn from the natural environment. The curriculum represents a pyramid of individual target skills which are eventually combined to form more complex skills.
8. ABA robs children of their childhood - The opportunity to have fun and to play are key features of ABA programs. The goal of ABA is to enable the child to experience the greatest degree of participation in the natural environment.
9. ABA only benefits high functioning children whose parents aim for recovery - ABA has proven to be highly effective for children with autism at all levels of severity. The critical measure of success is improvement.
10. ABA is delivered by inexperienced personnel - Para-professionals who serve as therapists participate in an intensive workshop at the beginning of their employment. They then participate in periodic team meetings which include continuing training and are supervised by the professional consultant(s).
11. Any professional who understands behavior modification can serve as a program consultant - It takes specific training (e.g., ABA, communication development, characteristics of children with autism) and supervised experience to run a home program competently. Serious errors can be made if the consultant is not trained properly. There is formal certification in ABA through the Behavior Analyst Certification Board (BACB). Parents seeking professional support should: (a) become informed about the content and form of ABA, (b) talk with other parents whose children are involved in ABA, and (c) ask potential consultants for a resume including the possibility of references from families with whom they have worked previously.
12. ABA is the same as Lovaas and Discrete Trial (DTT) - No, ABA is a broad field of study and application with a wide breadth.
13. ABA does not work past age 6 - ABA is used in everyday life with all walks of people and animals. Many older children and adults have made huge gains with the application of ABA.

ABA Basics

Applied Behavior Analysis (ABA) is a science that studies functional relationships between behavior and environmental variables. ABA uses principles of behavior to create behavior change of significance to the client (i.e. teaching adaptive behaviors and reducing maladaptive behaviors).

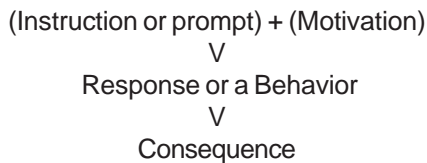
Decades of research exists in the behavioral sciences. ABA is based on individual studies which can be found in journals such as the ***Journal of Applied Behavior Analysis*** (JABA)

The basics of Applied Behavior Analysis (ABA) are extensive, to say the least. Professionals dedicate years to obtaining advanced degrees in the field of ABA.

The following pages represent a brief overview. It is best to attend workshops, join email lists, and hire a consultant to understand ABA terminology and put in practice the science of behaviorism within the context of a behavioral curriculum.

Behavioral Principals

Basic Principles of Behavior include 4 part formula:



Where:

Instruction can include "Touch your nose".

Prompting can include wet hands when washing causing you to dry your hands.

Motivation can include the satiation (too much of something) or the deprivation (not enough of something) that can cause a behavior to occur more often or less often. For instance, giving salty foods will increase the behavior of requesting juice.

Behavior can include saying something or doing something such as answering a question, screaming, or kicking.

Consequences can include positive reinforcement, negative reinforcement, positive punishment, and negative punishment.

Types of Reinforcement

Positive Reinforcement: the method mostly used - something reinforcing is presented after a response, and as a result, the future frequency of the behavior increases (e.g., child receives candy after saying "cup.")

Negative Reinforcement: very seldom used - something aversive is removed after a response, and as a result, the future frequency of the behavior increases (e.g., child leaves work table after saying "cup.")

Reinforcer Examples

- √ Swinging
- √ Trampoline
- √ Edibles (candies, chips, carrots)
- √ Tickles
- √ Toys
- √ Video
- √ Computer
- √ "Nice work putting away your clothes"

Types of Punishment

Positive Punishment: an aversive stimulus is presented after a behavior which therefore decreases the frequency of a behavior(e.g., child must do tasks whenever he/she hand flaps.)

Negative Punishment: a reinforcing stimulus is removed after a behavior which therefore decreases the frequency of a response class. (e.g., candy is taken away whenever child hand flaps.)

ABA and Behavior Change

Applied Behavior Analysis uses the principles of behavior already outlined to create behavior change of benefit to children with autism. The consequences of behaviors can be manipulated to strengthen some behaviors and weaken others. In addition to reinforcement, punishment, and manipulation of motivation, there are a number of behavior change procedures that can be implemented.

Behavior Change Procedures

Extinction: Previously reinforced behavior is no longer reinforced, resulting in a decrease in the frequency of the behavior. May produce an extinction burst, a brief increase in the frequency, duration, and intensity of the behavior and/or novel behaviors. An example is to ignore screaming behavior in a store because the child wants candy.

Differential Reinforcement: Desired behaviors are reinforced while undesirable behaviors are placed on extinction. An example might be to teach a child to tap someone on the shoulder to interrupt and ask a question.

Compliance Teaching Procedure: A teaching session set up in advance to ensure the child follows through with a request or demand. The instruction is given without any emotion until the child complies. This can be a time consuming procedure and will likely cause an extinction burst. It is important to not quit before the child complies as an inappropriate behavior might be reinforced.

Shaping: Reinforcing successive approximations to a target behavior. For instance, when teaching a new sign language item, the approximation of a sign would slowly become closer to the actual sign by reinforcing an approximation. Then when the initial approximation is consistent, put that approximation on extinction and then only reinforcing a closer approximation. Continue until the sign is an appropriate approximation.

Prompting: Prompts increased the likelihood that a behavior will occur. Prompts include verbal, gestural, modeling, and physical guidance. It is important to fade prompts so that they are no longer needed. Reduce errors by using errorless teaching or errorless prompting which insures a high level of correct responses. Errorless teaching involves use of prompts before the child responds.

Chaining (forward & backward): Chaining requires a task analysis, which involves breaking a task (such as shoe tying) into its individual small parts (such as tying a knot, making one loop, then crossing the other string over and making the second loop, and finally pulling tight). You can teach one step at a time where the beginning steps are completed by the instructor and the final steps are completed by the student or in reverse order where the first steps are completed by the student and the rest are completed by the instructor. After each step is completed correctly, add another step one at a time until the student can do all steps of the task.

Generalization: Generalization occurs when a behavior that has been taught transfers to the natural environment across different people and places, when training of one behavior leads to the development of a similar behavior not specifically taught, and when behaviors taught are maintained in the natural environment over time.

Functional Behavior Assessment (FBA): A functional behavior assessment involves procedures used to identify the causes of maladaptive behaviors and then creating a plan to address the behaviors. It is important to take data before the plan is implemented then after implementation to ensure the plan is effective.

When a Problem Behavior May Occur

- √ When working on a demanding task
- √ When access to items or activities is denied
- √ When adult attention is not focused on the child
- √ When the environment is unstructured or under enriched
- √ When the child is bored and doesn't know what to do with self

Steps in a Functional Analysis

1. Functional Interview
2. Direct Observation
3. Formulation of a Hypothesis
4. Experimental Analysis
5. Functional Analysis Summary
6. Behavioral Plan (interventions based on the function of the behavior)

If the problem behavior is a function of attention or items:

1. Enrich the environment (e.g. give non-contingent attention frequently)
2. Withdraw attention for problem behavior (unless self-injurious)
3. Teach the child an appropriate way to ask for attention or tangible items

If the problem behavior is a function of escape from demands:

1. Use effective teaching practices (e.g. pair with reinforcement) to reduce the motivation for escape
2. Never allow the child to escape demands again (require the child to complete the task, even if this means physical guidance) – “Compliance Training”
3. Teach the child an appropriate way to ask for a break

If the problem behavior is a function of self-stimulatory sensation:

1. Provide an enriched environment
2. Block the stim
3. Teach more appropriate/less harmful forms of self-stimulation

Effective Teaching Practices

- √ Pair teaching environment with fun
- √ Keep the demands low at first – fade into more demands slowly
- √ Reduce learner errors
- √ Teach the child to communicate the need for assistance
- √ Teach the child to communicate the need for a break
- √ Reduce task complexity when you notice the child is losing attention
- √ Provide consistent breaks
- √ Provide a choice of task activities
- √ Provide a choice of reinforcing activities

- √ Ensure maintenance of mastered tasks while presenting new tasks (intermix easy and difficult demands)
- √ Pace instruction properly
- √ Mix and vary instructional demands
- √ Teach to fluency (skills are demonstrated correctly and quickly)

Pairing in an ABA Program

Pairing ensures the child runs to the teacher, not away from the teacher. Pairing is important because the child sees you as fun and rewarding, and knows that “work” can be “fun.”

Pairing involves:

- Active interaction between therapist and child
- Where the teacher is critical for the activity
- Controlling access to reinforcers (deliverable in small amounts, which go away by themselves)
- Presenting the teacher and words followed by a reinforcer
- Therapist seen as “Giver” that improves the child’s experience
- Narrating (versus instructing)
- Use of natural language in the child’s natural environment
- Waiting for interaction before reinforcement
- Use of reinforcers (such as high 5’s and treats) and freebies
- Following the child’s motivation
- Being patient – don’t rush the pairing process just to get to “teaching stuff”
- Wide variety of play activities that are sometimes child directed and sometimes contrived by therapist
- Child looking at therapist for reinforcement, child moving toward therapist for reinforcement and interaction
- Improving set of conditions for the child (child is happier while interacting with therapist than alone)
- Little to no demands are placed on child (very easy demands may be faded in over time)
- Expectations that child only begin to view therapist as reinforcing person, someone who they look forward to seeing
- Fun / Talking, Cheering, Laughing, Giggling (wide variety of activities to choose from with lots of materials, etc)
- Emphasis on establishing reinforcing relationship between child and therapist so that new skills can be taught at a later time

Pairing is not:

- A lot of demands (questions, commands, etc.)
- Turning the reinforcing activity into a task
- Silence, passive, or playing next to the child without engaging the child
- Work, where the situation becomes a worsening set of conditions for the child (child would happier alone, stimming, etc)
- Totally child directed
- A high frequency of escape and/or avoidance behaviors on part of the child
- Where the therapist is seen as “Taker”
- Demands placed on child

Pair the Teaching Environments with Reinforcement: Initially, correlate the teaching environment (such as table & chair) with highly valuable reinforcers.

Pair the Teacher/Therapist with Reinforcement: "Pairing" refers to associating yourself with the delivery of reinforcing items and events. Through pairing you establish yourself as a reinforcer. Avoid the use of escape (“Go Play”) as the reinforcer for responding during Intensive Teaching Sessions. Therapists can also use non contingent reinforcers or “freebies.”

"Just because you covered the material doesn't mean the children learned the material. That tells about what you did. It doesn't tell about what you taught. If you want to know what you taught, you have to look at what the children learned." - Siegfried Engelmann

Direct Instruction K-12

Direct Instruction (big “D”, big “I”) is a system of teaching which includes a set of teaching principles and specifically developed curriculum. Many use the DI curriculum developed through SRA (sra4kids.com). Curriculum includes *Reading Mastery*, *Connecting Math Concepts*, *Spelling Mastery*, *Reasoning and Writing*, *Language for Learning*, *Language for Thinking*, *Corrective Reading* and much more. Each curriculum set is expensive (\$250-\$600) but can be had for far less on ebay, internet book resellers, and lists such as the DI list (see section on email listserves).

Direct Instruction is based on Zig Engelmann's theory that children can learn at an accelerated rate if educators deliver instructions that are clear, are able to predict likely misinterpretations and therefore reduce confusion, and assist in forming generalizations.

It is a highly structured, intensive teaching program that aims to absolutely prepare the educator in such a way that all children learn to 100% mastery of the subject.

Every Direct Instruction program has undergone testing, retesting, and multiple revisions in an attempt to convey with absolute accuracy the intended information while remaining as efficient as possible.

Direct Instruction programs have also been statistically proven to be incredibly effective systems of teaching. Project Follow Through (FT), the largest education experiment in history, showed DI to be the only educational system proven effective in educating children in all areas of application.

Direct Instruction programs are designed around not only a teaching method, but a complete system of strategies that have been proven to communicate and educate the learner with the most efficiency and effectiveness.

These methods include:

- Scripted Lesson Plans
- Rapid-Paced Interaction with Students
- Correcting Mistakes Immediately
- Achievement-Based Grouping
- Frequent Assessments

Direct Instruction is primarily for grades K-6 in areas of spelling, reading, language arts, math, expressive writing, and science. There are also remedial programs for special education and adult education in corrective reading and corrective math.

Oregon/SW Washington Providers of Behavioral Therapy

The following list of Providers of Behavioral Therapy was compiled as a service to Oregon parents. This list is not exhaustive; there may be other qualified ABA providers whose names do not appear in this guide. If you know of any other ABA providers that you feel should be added to this list, please contact POAC of Oregon. **POAC of Oregon does not endorse, recommend, or guarantee results with any of the consultants listed. POAC of Oregon strongly recommends that parents ascertain and verify credentials of consultants in order to make a fully informed decision.**

Behavior Analysis Treatment and Training (BATT)

Stacey Enfield, M.A. Psychology
14845 SW Murray Scholls Dr. Suite 110 Box #129
Beaverton, OR 97007
503-590-9120
FAX: 503-590-9120 stasia99@aol.com
<http://www.sbatt.com>

Behavioral Consulting Group, Inc.

Robbin J. Sobotka-Soles, Director
7210 North Oatman Avenue
Portland, OR 97217
503-516-9085

Building Bridges

Elizabeth Steege, BCBA
924 SE 13th Ave.
Portland, OR 97214
503-525-0632 steege@aol.com
<http://www.bridgespdx.com>

The Child Development Center of Oregon (CDCO)

Executive Director Therese Steward, M.A.
P.O. Box 1603
Hillsboro, OR 97123
503-645-9975
FAX: 503-648-6042 CDSOautism@netscape.net

Cynthia Hurtt

Behavioral Program Manager, Certified Therapeutic Recreational Specialist
18819 SE 12th Way
Vancouver, WA 98683
360-944-9987 cahurtt@msn.com

Maria Foundation

Eugene, Oregon
Laurine Guido
541-345-4356 office

Northwest Young Autism Project

Shawn Horne
15685 SW 116th Ave.
PMB #240
King City, OR 97224
503-620-9952
Fax: 503-620-4008 nyapshawn@comcast.net
<http://www.freewebs.com/nyap>

Shonnet Brand, MA, BCBA & Tiffany Schwander, MA

P.O. Box 80514
Portland, OR 97280
503-547-0546 tiffanys@srbtcs.com, shonnet@srbtcs.com
<http://www.srbtcs.com>

Washington Providers of Behavioral Therapy

(Thanks to FEAT of Washington for providing this list)

Autism Horizons

16924 SE 325th Place
Auburn, WA 98092
253-735-2482 Girvinbradley@worldnet.att.net

Christa Graves, M.Ed.

Seattle, WA
206-378-1280 crewaepi@hotmail.com

Dana Demaso, Ph.D.

88411/2 Interlake Ave. N.
Seattle, WA 98107
206-916-7182 ddemas@chmc.org, ddmaso@juno.com

Derek Lucky, M.S., Consulting Behavior Analyst

Ellensburg, WA

509-306-9534

luckyderek@hotmail.com

Autism Center on Human Development and Disabilities , Univ. of WA

Box 357920

University of Washington

Seattle, WA 98195

206-221-6806

<http://depts.washington.edu/uwautism>

Education, Behavior and Disabilities Consulting, NW Institute

Ross Greek, M.A.

PO Box 97

Castle Rock, WA 98611

360-274-9162 Rhgreek@cport.com

Educational Consultant for Special Needs

Linda Mason, M.Ed.

1720 NE 105th St.

Seattle, WA 98125

206-527-2496 Ccampus@accessone.com

Fabrizio/Moors Consulting

Michael A. Fabrizio, M.A./RBA

Alison L. Moors

1745 12th Ave. S Apt. 2

Seattle, WA 98144

206-324-3805

Northwest Behavioral Associates (NBA)

Stacy Shook, Ph.D., Program Director

12506 128th Lane NE

Kirkland, WA 98304

425-823-6442 nba@nba-autism.com

<http://www.nba-autism.com>

Talk, Learn and Communicate

Nola Marriner, Ph.D.

17535 15th Ave. NE

Seattle, WA 98155

206-440-9708 Info@talklc.com

<http://www.talklc.com>

National Providers of Behavioral Therapy

Autism Partnership

Ronald Leaf, Ph.D. & John McEachin, Ph.D., Directors
3346 Olive Avenue
Signal Hill, CA 90807
310-424-9293
<http://autismpartnership.com>

Center for Autism and Related Disorders (CARD)

Doreen Granpeesheh, Ph.D., Director
Los Angeles, CA
818-995-4673

Lovaas Institute of Early Intervention (LIFE)

11500 West Olympic Blvd, Suite 46
Los Angeles, CA 90064
310-914-5433 info@lovaas.com
<http://www.lovaas.com>

The RACE School

<http://theraceschool.org/>

Resources in Autism Education

4455 Torrance Blvd., #801
Torrance, CA 90503-4335
310-791-2062 serviceinfo@autismed.com
<http://www.autismed.com>

Young Autism Project at UCLA

UCLA Department of Psychology
405 Hilgard Avenue
Los Angeles, CA 90024
310-825-2319

Oregon Resources & Information Providers:

Autism Society of Oregon

P.O. Box 13384
Salem, OR 97309
503-234-5729 / 1-888-AUTISM-1
<http://www.autismoregon.com>

Autism Training and Support, Inc.

P.O. Box 41995
Eugene, OR 97404
541-689-2327 info@autismtraining.com
<http://autismtraining.com>

Autistic Children's Activity Program (ACAP)

P.O. Box 4606
Portland, OR 97208
503-978-3989 ACAP_office@netzero.net
<http://www.autism.com/acap/>

Bridgeway House

Eugene, OR
541-345-4734 info@bridgewayhouse.org
<http://bridgewayhouse.org>

Developmental Disabilities Office (State)

2575 Bittern St. NE.
Salem, OR 97309
(888) 390-5437 dhrinfo@state.or.us
<http://oddsweb.mhd.hr.state.or.us/>
A county based resource that can provide respite care and be a potential sources of funding.

FEAT of Oregon

<http://www.feator.org>

Hearing & Speech Institute

1675 SW Marlow Avenue, Suite 200
Portland, OR 97225-5104
Tel: 503-228-6479 amandac@hearingandspeech.org
Toll Free: 877-702-2828
<http://www.hearingandspeech.org/children/autism.asp>

Kindtree

Eugene, Oregon
<http://www.kindtree.org/>

Northwest Autism Foundation

519 15th Street
Oregon City, OR 97045
nwautism@uswest.net
<http://autismnwaf.com/>

Oregon Technical Assistance Corporation (OTAC)

886 Beverly Avenue NE, Suite I-21
Salem, Oregon 97305-1373
503-364-9943 maseaton@otac.org
<http://www.otac.org/autism>

Parents of Autistic Children (POAC or Oregon)

poac@poac-or.org
<http://poac-or.org>

Project PACE

2360 SW 170th Ave.
Beaverton, OR 97006
Director Kathi Calouri, Ph.D.
503-356-8334 contact@projectpace.com
<http://www.projectpace.biz>

Threshold

Sharone Lee, Executive Director
PO BOX 12302
Salem, OR 97309
503-375-9462 sharone@understandingautism.org
<http://www.understandingautism.org/>
An excellent resource for newly diagnosed parents.

National Resources & Information Providers:

* Please see <http://www.feator.org> for a listing of attorneys and advocates

Association for Science in Autism Treatment (ASAT)

175 Great Neck Road, Suite 406
Great Neck, New York 11021
516-466-4400 asat@autism-treatment.org
<http://www.asatonline.org/>

Autism Research Institute

4182 Adams Ave.
San Diego, CA 92116
619-281-7165
<http://www.autismresearchinstitute.com>

Autism Society of America

7910 Woodmont Ave. Suite 650
Bethesda, MD 20814-3015
301-657-0881 or (800) 3-AUTISM
<http://www.autism-society.org/>

Cure Autism Now Foundation (CAN)

5225 Wilshire Blvd, Suite 226
Los Angeles, CA 90036
323-529-0500

Defeat Autism Now! (DAN!)

<http://www.autism.com/ari/>
DAN! Practitioners: <http://www.autism.com/ari/danlist.html>

National Alliance for Autism Research (NAAR)

414 Wall Street
Research Park, Princeton, NJ 08540
609-430-9160

Unlocking Autism

Unlocking Autism Headquarters
P.O. Box 1086
Baton Rouge, LA · 70821-1086
225-926-3252
<http://www.unlockingautism.org/>

Useful Web Sites-Applied Behavior Analysis

Parents of Autistic Children (POAC) of Oregon

<http://www.poac-or.org>

Verbal Behavior Network

<http://verbalbehaviornetwork.com/>

An excellent website with much information and videos.

ABA Connection

<http://www.abaconnections.com>

Association for Direct Instruction

<http://www.adihome.org>

Association for Science in Autism Treatment (ASAT)

<http://www.asatonline.org/>

ASAT is committed to science as the most objective, time-tested and reliable approach to discerning between safe, effective autism treatments, and those that are harmful or ineffective.

Behavior Analyst Certification Board

<http://www.bacb.com/>

Cambridge Center for Behavioral Studies

<http://www.behavior.org/>

Kathy and Calvin's Home Page

<http://kathyandcalvin.com>

Journal of Applied Behavior Analysis

<http://www.envmed.rochester.edu/wwwrap/behavior/jaba/jabahome.htm>

Parents of Autistic Children (POAC)

<http://www.poac.net> & <http://verbalbehaviornetwork.com>

An excellent site for parents and teachers dedicated to training in VB

Precision Teaching/Celeration

<http://www.celeration.org/>

Pages of Interest at Oregon Dept of Education

Oregon Department of Education

<http://www.ode.state.or.us/admin/>

A variety of information about education in Oregon including the administrative rules and regulations for special education and how funds to school districts are allocated.

Oregon Office of Special Education (SPED)

<http://www.ode.state.or.us/sped/>

Update on Complaints, Due Process Hearing and Litigation

<http://www.ode.state.or.us/sped/spedlegal/index.htm>

Special Education Law & Advocacy

Oregon Parents United

<http://oregonparentsunited.org>

Advocacy, Information Source for Parent/Student, an online Parent Support Group, and an Oregon Information and Referral Source

Oregon Advocacy Center

310 SW Fourth Ave.

Portland, OR 97204

(503) 243-2081 welcome@oradvocacy.org

(800) 452-1694

<http://www.oradvocacy.org/>

The Council of Parent Attorneys and Advocates (COPAA)

<http://www.copaa.net/>

EdLaw - <http://www.edlaw.net>

Gary Mayerson - <http://mayerslaw.com>

IDEA Practices - <http://www.ideapractices.org>

Individual's with Disabilities Act - <http://www.ed.gov/IDEA>

Reed Martin - <http://www.reedmartin.com>

Oregon Parent Training Information (Or PTI) - <http://open.org/orpti>

U.S. Department of Education (ED) Home Page - <http://www.ed.gov/>

Wrights Law - <http://www.wrightslaw.com>

IEP 4 U - <http://www.iep4u.com/>

Web Sites on Autism and Related Disorders

American Hyperlexia Association (AHA!)

<http://www.hyperlexia.org/>

The Autism Research Institute

<http://www.autism.com/ari/>

The Autism Society of America

<http://www.autism-society.org/>

The Autism Society of Oregon

<http://autismoregon.com>

Center for the Study of Autism

<http://www.autism.com/>

An excellent resource guide for information about autism. It contains many links to other autism sites.

Online Asperger Syndrome Information & Support (OASIS)

<http://www.udel.edu/bkirby/asperger/>

The Sibling Support Project

<http://www.chmc.org/departmt/sibsupp>

Society for Auditory Integration Training

<http://www.up-to-date.com/saitwebsite/table.html>

Yale Child Study Center Autism/PDD Clinic

<http://info.med.yale.edu/chldstdy/autism>

Meta Sites with lots of links

Autism and PDD Resources

<http://www.autism-pdd.net/links/oregon.html>

Autism Resources

<http://www.autism-resources.com/>

Comprehensive list of autism resources on the internet.

jypsy's links- HUNDREDS of Autism, Aspergers, PDD, etc

<http://www.isn.net/~jypsy/autilink.htm>

Autism/ABA/Support Email Listserves

ABA Parents List

<http://yahoogroups.com/group/abaparents>

Autism-Oregon List

<http://yahoogroups.com/group/autism-oregon>

Direct Instruction List

<http://yahoogroups.com/group/DTT-NET>

DTT-NET List

<http://yahoogroups.com/group/DTT-NET>

FEAT of Oregon List

http://yahoogroups.com/group/feator_news

POAC of Oregon List

<http://yahoogroups.com/group/poac-or>

Ruth Allen's Me-List

To join, email: listserv@iupui.edu. In the body of your message type:
sub me-list YourFirstName YourLastName

Schafer Autism News - Electronic Newsletter

<http://home.doitnow.com/~subs/>

Verbal Behavior List

<http://yahoogroups.com/group/VerbalBehavior>

Medical Email Listserves

GFCFKids List

<http://yahoogroups.com/group/GFCFKids/>

ORAutismSupport List

<http://yahoogroups.com/group/orautismsupport>

Phoenixkids List

To join, email: phoenixkids-owner@yahoogroups.com

Recovered Kids List

<http://groups.yahoo.com/group/recoveredkids/>

Useful Books

Behavioral Intervention / Special Education

Behavioral Intervention for Young Children With Autism : A Manual for Parents and Professionals by Catherine Maurice (Editor), Gina Green (Editor), Stephen C. Luce (Editor)

This book provides an overview of successful behavior intervention programs. A must have for effective behavior treatment of autism.

A Work In Progress by Ron Leaf and John McEachin

Explains how to run an ABA program do discrete trials complete with prompting and reinforcement.

Teaching Language to Children with Autism or Other Developmental Disabilities by Mark Sundberg and James Partington

Focuses on the different aspects of language such as mands, tacts, intraverbals per Skinner's 1957 book, Verbal Behavior. It provides a unique perspective on learning language that goes beyond just labeling nouns.

When Everybody Cares: Case Studies of ABA with People with Autism by Bobby Newman

Highlights a series of 20 case studies that explain and elaborate principles in Applied Behavior Analysis. This is done in an engaging format, easily understood by layperson and professional alike.

Words From Those Who Care: Further Case Studies of ABA with People with Autism by Bobby Newman (Editor), Dana Reinecke (Editor), Leo Newman (Editor)

Full of examples of behavior analysis used to help the children. The book is full of enough technical details to give parents and workers some ideas about how to solve problems, yet those details are presented in a way parents and paraprofessionals can understand them, even with humor.

Right from the Start : Behavioral Intervention for Young Children With Autism : A Guide for Parents and Professionals by Sandra L.

Harris, Mary Jane Weiss, Mary Jane Gill-Weiss

A brief introductory book that is easy to read and provides useful information about behavioral intervention and applied behavioral analysis.

Activity Schedules for Children with Autism: Teaching Independent Behavior by Lynn E. McClannahan and Patricia J Krantz

Activity schedules enable children with autism to accomplish activities with greatly reduced adult supervision.

Speech and Language

Teach Me Language: A Language Manual for children with autism, Asperger's syndrome and related developmental disorders by Sabrina K. Freeman, Lorelei Dake, Isaac Tamir

A comprehensive language program for children who have mastered communicative intent and have gained a small vocabulary and the skills to use language to communicate.

Success Stories

Let Me Hear Your Voice : A Family's Triumph over Autism by Catherine Maurice

This is a story of a family with two children with autism who have recovered from Autism by following an ABA program.

Autism: From Tragedy to Triumph by Carol Johnson and Julia Crowder

IEP/IFSP Development & Special Ed Law

ABLLS - The Assessment of Basic Language and Learning Skills by Partington & Sundberg

A wonderful way parents, teachers, aides can assess your child every 6 months to a year. Shows a graphical chart of progress. Great for ideas on IFSP goals & evaluation criteria. For beginner, younger children with few beginning skills (so they don't fall off the scale).

Wrightslaw: Special Education Law by Pamela Darr Wright and Peter W.D. Wright

Includes a CD-ROM with the latest information on the IDEA and other relevant special education laws. This book covers commonly asked questions, with answers on the laws surrounding autism and related disorders. It also includes the entire IDEA.

What Do I Do When. . . The Answer Book on Special Education Law - 2nd Ed by Susan Gorn <http://www.lrp.com>

Better IEPs : How to Develop Legally Correct and Educationally Useful Programs by Barbara D. Bateman and Mary Anne Linden

This is the definitive guide to understanding and writing Individualized Education Programs (IEPs). It presents a powerful, three-step process that focuses on the individual student and avoids the all too common routinized approach to program development.

General Autism / Asperger's

Autism Treatment Guide by Elizabeth K. Gerlach

This comprehensive guide outlines basic facts, research information and effective treatment options for autism. Objectively written, it contains extensive resource listings and suggested readings.

Educating Children with Autism published by National Academy Press
Guide can be purchased or viewed on-line at <http://www.nap.edu/books/0309072697/html/>

Siblings of Children with Autism by Sandra L. Harris

An invaluable guide to understanding sibling relationships, how autism affects these relationships, and what families can do to support their other children.

Targeting Autism: What We Know, Don't Know, and Can Do to Help Young Children With Autism and Related Disorders by Shirley Cohen

This book gives overview information about life cycles in autism, intervention options, recovery from autism. This is a light read that provides a general overview.

Medical

Biological Treatments for Autism and PDD by William Shaw, Bernard Rimland, Bruce Semon, Lisa Lewis

A book about biological basis for autistic behaviors. Covers antifungal and antibacterial therapies, gluten and casein restriction, homeopathy, vitamin therapy, gamma globulin treatment, transfer factor therapies, treatment of food allergies, and alternatives to antibiotic therapy.

Special Diets for Special Kids by Lisa Lewis

A mother who developed and implemented a successful diet program that aided in the recovery of her child who had allergies that caused autistic symptoms.

What Your Doctor May Not Tell You About Children's Vaccinations

by Stephanie Cave, Deborah Mitchell

A look at the history of childhood immunizations and offers an alternative schedule for those who wish to be careful about the administration of vaccines to their children.

Applied Behavioral Analysis (advanced reading)

Applied Behavior Analysis by Cooper, Heron, Heward

Behavior Modification: What it is and how to do it by Martin and Pear

Behavior Modification: Principles and Procedures by Raymond G. Miltenberger

Functional Assessment and Program Development for Problem Behavior: A Practical Handbook by O'Neill, Horn

Newsletters and Publications

Autism Research Review International: Published by ARI

Journal of Applied Behavior Analysis (JABA):

<http://www.envm.ed.rochester.edu/wwwrap/behavior/jaba/>

Journal of Experimental Analysis of Behavior (JEAB):

<http://www.envm.ed.rochester.edu/wwwrap/behavior/jaba/>

Naarrative: Published by NAAR

The Advocate: Published by Autism Society of America

The Analysis of Verbal Behavior: The Association for Behavior Analysis

The Behavior Analyst: Western Michigan University

<http://www.behavior-analyst-online.org>

Useful Articles

Lovaas, O.I. "Behavioral treatment and normal educational and intellectual functioning in young autistic children," *Journal of Consulting and Clinical Psychology*, Vol. 55, No. 1, p. 3-9, 1987.

<http://www.ctfeat.org/Lovaas87.htm>

This publication summarizes Lovaas's ground breaking study in which 9 of 19 children receiving intensive behavioral treatment achieved normal functioning.

Lovaas, O.I., Smith, T, & McEachin, J.J. "Clarifying comments on the Young Autism study: Reply to Schopler, Short, and Mesibov," *Journal of Consulting and Clinical Psychology*, Vol. 57, p. 165-167, 1989.

A number of criticisms have been leveled at Lovaas's two studies, some of which are distortions of the truth. In this publication, Lovaas and his colleagues respond to these criticisms.

McEachin, J.J., Smith, T. & Lovaas, O.I., "Long-term outcome for children with autism who received early intensive behavioral treatment," *American Journal on Mental Retardation*, Vol 97, No.4, p.

359-372, 1993. <http://www.cfbeat.org/Lovaas93.htm>

The follow-up to Lovaas's 1987 article, it takes a critical look at the children that achieved normal functioning 6 years later.

Birnbrauer, J.S. & Leach, D.J. "The Murdoch early intervention program after 2 years," *Behaviour Change*, Vol. 10, p. 63-74, 1993.

This article describes the most comprehensive attempt, to date, at replication of the original Lovaas study.

Perry, R., Cohen, I., & DeCarlo, R. "Case study: deterioration, autism, and recovery in two siblings," *Journal of the American Academy of Child and Adolescent Psychiatry*, Vol. 34, p. 232-237, 1995.

This publication is a case study following two siblings from initial diagnosis to recovery from autism due to intensive behavioral treatment.

Fenske, E.C., Zalenski, S., Kranz, P.J. & McClannahan, L.E. "Age at intervention and treatment outcome for autistic children in a comprehensive intervention program," *Analysis and Intervention in Developmental Disabilities*, Vol. 5, p. 49-58, 1985.

This article demonstrates the need for behavioral intervention to be implemented early to be most effective. A difficult article to find in Connecticut, it will have to be obtained through interlibrary loan.

"Can Autism Be Detected at 18 Months? The Needle, the Haystack, and the CHAT." *British Journal of Psychiatry*, Vol. 161, p. 839-843, 1992.

"Long-Term Follow-Up: Early Intervention Effects Lasting." *Autism Research Review International*, Vol., 7, No. 1, 1&6, 1993. (Reference to CHAT-Checklist for Autism in Toddlers).

"Replicating Lovass' Treatment and Findings: Preliminary Results" by Glen O. Sallows and Tamlyn D. Graupner.

<http://www.wiautism.com/prelimin.htm>

Smith, T., Groen A.D., Wynn, J.W. "Randomized trial of intensive early intervention for children with pervasive developmental disorder," *Am J Ment Retard*, Vol. 105, No. 4, p. 269-85, 2000.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10934569&dopt=Abstract

(be careful, no spaces in the above URL)

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. "Intensive Behavioral Treatment at School for 4- to 7-Year-Old Children With Autism: A 1-Year Comparison Controlled Study," *Behavior Modification*, Vol. 26 No. 1, p. 49-68, 2002.

State and Federal Reports

National Academy Press

<http://www.nap.edu/books/0309072697/html/R1.html>

The US Government has issued **Mental Health: A Report by the Surgeon General** (<http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html#autism>), validating the research supporting ABA as the leading treatment for autism. The report concludes “thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”

Oregon Autism Task Force Report, July 1, 2000

(<http://www.ode.state.or.us/sped/spedareas/autism/finalrec1.pdf>)

The New York State Department of Health has issued **Clinical Practice Guidelines, Report of the Recommendations on Autism / PDD** (<http://www.health.state.ny.us/nysdoh/eip/menu.htm>). The report recommends “a **minimum** of approximately twenty hours per week of individualized behavioral intervention using ABA techniques.”

Maine Administrators of Services for Children with Disabilities

(MADSEC) has issued a Report of the Autism Task Force concluding that ABA is the only intervention “substantiated as effective by the scope and quality of the research.”

California has issued a **Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders**

(<http://www.feet.org/docs/cabestpr.pdf>). This is an especially good source for learning about commonly used diagnostic and assessment tools.

Useful Educational Materials and Catalogs (toys, books, software, flashcards, etc)

- 1. Autism Academy**
Available from Different Roads to Learning: <http://www.difflern.com>
A Discrete Trial learning system in CD ROM format.
- 2. Autism Teaching Tools**
<http://www.autismteachingtools.com>
- 3. Autism and Developmental Disabilities Resource Catalog**
800-501-0139 <http://www.frs-inc.com>
- 4. Cognitive Concepts Inc.** 847-328-8099
<http://www.cogcon.com> This company provides a program titled earobics.
- 5. Constructive Play Things** 800-448-4115
<http://constplay.com>
- 6. Critical Thinking Books and Software** 800-458-4849
<http://www.criticalthinking.com/>
- 7. Different Roads to Learning** 800-853-1057
<http://www.difflern.com>
- 8. Edmark** 800-362-2890
<http://www.edmark.com>
Interactive learning for PreK-12 and Special Needs Students.
- 9. Frank Schaffer** 800-421-5565
<http://www.frankschaffer.com>
- 10. Hooked on Phonics** 800-532-3607
<http://www.hop.com>
- 11. Imaginart Communication Products** 800-828-1376
- 12. Intellitools** 800-899-6687
<http://www.intellitools.com> This company provides a variety of software. These programs allow you to adapt existing software to the capabilities of the user and to create custom programs for children.
- 13. Kaplan School Supply** 800-334-2014
<http://www.kaplanco.com>
- 14. Lakeshore Learning Materials** 800-421-5354
<http://www.lakeshorelearning.com>

15. **Laureate Learning Systems** 800-562-6801
http://www.laureatelearning.com. This company provides research based computer software designed to build language skills.
16. **Lindamood-Bell** 800-233-1819
http://www.lblp.com
17. **LinguiSystems Inc.** 800-776-4332
http://www.linguisystems.com Speech & language products
18. **LocuTour Multimedia Cognitive Rehabilitation** 800-777-3166
http://www.LocuTour.com This company sells several software products including: Train Time; Look! Listen! & Learn!; Phonology; Articulation; It's a Safari; It's a Series: Everyday objects, Food & More.
19. **LRP Publications** 800-341-7874 ext. 275
http://www.lrp.com Legal publications
20. **Mayer-Johnson Co.** 609-550-0084
(Assistive Technology) *http://www.mayer-johnson.com* This company provides Picture Communication System symbols, Boardmaker, and Speaking Dynamically.
21. **Paul Brookes Publishing Co.** 800-638-3775
http://www.brookespublishing.com Books about autism
22. **Pro-Ed Publishing Company** 800-897-3202
http://www.proedinc.com Books and manuals
23. **Science Research Associates (SRA)**
http://sra4kids.com
Where you can purchase DISTAR Direct Instruction curriculum like *Reading Mastery*, *Language for Learning*, and *Connecting Math*.
24. **Super Duper School Company** 800-277-8737
http://www.superduperinc.com
25. **Ultra Phonics Tutor** 888-765-3942
http://www.prolexia.com This Orton-Gillingham tutoring product is for students with reading disabilities or delays.
26. **VB Teaching Tools** 888-765-3942
http://www.VBteachingtools.com This site contains COMPLETE testing and teaching kits that correspond to the ABLLS protocol.

Appendix 1

History of POAC of Oregon

Some parents and local teachers attended Dr. Carbone's Introduction to Verbal Behavior three day workshop and saw the benefits of this approach. They were convinced this current line of research would yield the best results for their children. Unfortunately, there was a lengthy waiting list to work with any of Dr. Carbone's associates.

The group further found that there were no available trained professionals using this current line of research; the demand was too great. There were not enough trained professionals offering this service or recognizing the need. They found many consultants to evaluate programs, but found few that could demonstrate clinical expertise and even fewer that were willing to train the children's teachers.

The lack of trained professionals was further aggravated by the fact that even though there has been a dramatic increase in Autistic Spectrum Disorder, there has been no corresponding increase in educational literature or journal articles. In fact, very few colleges offer specialty courses on working with children with developmental disabilities using research-based approaches such as Applied Behavior Analysis and Verbal Behavior.

In addition to ABA, Direct Instruction curriculum (sra4kids.com) is another under-utilized method of helping children with autism. DI curriculum involves scripted teaching to ensure the children receive consistent instruction and error correction procedures.

The lack of trained professionals and absence of research based curriculum led the founders to decide that their resources would best be spent on training professionals and parents, a component not often seen.

Appendix 2

DSM-IV Criteria for Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3):

1. Qualitative impairments in reciprocal social interaction, as manifested by at least two of the following:
 - a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - b. Failure to develop peer relationships appropriate to developmental level.
 - c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. Lack of social or emotional reciprocity.
2. Qualitative impairments in communication as manifested by at least one of the following:
 - a. Delay in, or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
 - b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
 - c. Stereotyped and repetitive use of language or idiosyncratic language.
 - d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.
3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
 - a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest, abnormal either in intensity or focus.
 - b. Apparently inflexible adherence to specific, nonfunctional routines or rituals.
 - c. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping, or twisting, or complex whole body movements).
 - d. Persistent preoccupation with parts of objects.

B. Delays or abnormal functioning in at least one of the following areas with onset prior to age 3 years: (1) social interaction, (2) language as

used in social communication, or (3) symbolic or imaginative play.

- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

DSM-IV Criteria for Pervasive Developmental Disorder Not Otherwise Specified PDD- NOS (including atypical autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" - presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or sub-threshold symptomatology, or all of these.

Source: The Diagnostic and Statistical Manual, 4th Edition, American Psychiatric Association, 1994.

Appendix 3

Asperger's Syndrome

Written by Stephen M Edelson, Ph.D.

Center for the Study of Autism, Salem, Oregon

Asperger's syndrome was first described by a German doctor, Hans Asperger, in 1944 (one year after Leo Kanner's first paper on autism). In his paper, Dr. Asperger discussed individuals who exhibited many idiosyncratic, odd-like behaviors (see description below). Often individuals with Asperger's syndrome have many of the behaviors listed below:

Language

- lucid speech before age 4 years; grammar and vocabulary are usually very good
- speech is sometimes stilted and repetitive
- voice tends to be flat and emotionless
- conversations revolve around self

Cognition

- obsessed with complex topics, such as patterns, weather, music, history, etc.
- often described as eccentric
- I.Q.'s fall along the full spectrum, but many are in the above normal range in verbal ability and in the below average range in performance abilities
- many have dyslexia, writing problems, and difficulty with mathematics
- lack common sense
- concrete thinking (versus abstract)

Behavior

- movements tend to be clumsy and awkward
- odd forms of self-stimulatory behavior
- sensory problems appear not to be as dramatic as those with other forms of autism
- socially aware but displays inappropriate reciprocal interaction

Researchers feel that Asperger's syndrome is probably hereditary in nature because many families report having an "odd" relative or two. In addition, depression and bipolar disorder are often reported in those with Asperger's

syndrome, as well as in family members. At this time, there is no prescribed treatment regimen for individuals with Asperger's syndrome. In adulthood, many lead productive lives, living independently, working effectively at a job (many are college professors, computer programmers, dentists), and raising a family.

Sometimes people assume everyone who has autism and is high-functioning has Asperger's syndrome.

However, it appears that there are several forms of high-functioning autism, and Asperger's syndrome is one form.

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<http://www.autism.org/asperger.html>

Appendix 4

Referral and Evaluation Agencies

Call the Office of Special Education to located your designated Referral and Evaluation Agencies (ask by county) for screening and evaluations for early intervention services for children ages birth to kindergarten.

Office of Special Education
Oregon Dept. of Education
Public Service Building
255 Capitol Street NE
Salem, OR 97310-0203
(503) 378-3600 x2337
<http://www.ode.state.or.us/sped/>

Education and Service Districts

Listings of the Educational Service Districts (ESDs) in Oregon by County. The ESDs house the Low Incidence Regional Programs. These are the Programs that support the Early Intervention/Early Childhood Special Education programs and school districts in providing educational services for your child ages birth to 21 in the areas of vision, hearing, deaf-blindness, severe orthopedic impairment and **autism**.

The “Regional Program” may be able to provide you with information about autism but it is the **EI/ECSE** program which will provide services.

For school aged children (kindergarten-12), Regional Program or ESD may provide some services, but most will be provided by the school district.

To find your Regional Program and ESD, call the office of Special Education at (503) 378-3600 or search for Regional Programs and ESD at <http://www.ode.state.or.us/sped/>

Appendix 5

Glossary

ABA - Applied Behavioral Analysis - Applied behavioral analysis employs methods based on the scientific principles of learning theory to build socially useful skills and reduce behavioral excesses and deficiencies. Various treatment approaches under the ABA umbrella include, discrete trial teaching, verbal behavior, precision teaching, pivotal response training, and incidental teaching. The term ABA does not automatically imply an intense program. ABA uses behavioral methods to teach targeted behaviors and records data regarding the effectiveness of those methods. **ABA is not synonymous with Discrete Trial Teaching.**

AIT - Auditory Integration Training - Developed in France by Dr. Guy Berard, an otolaryngologist. AIT was originally used to rehabilitate disorders such as hearing loss or hearing distortion. However, distortions in hearing or auditory processing also often contribute to behavioral or learning disorders, and the AIT method has been used to assist individuals with these disorders as well. For example, an individual who is hypersensitive to certain frequencies of sound may become overstimulated, disoriented or agitated in the presence of these sound frequencies. AIT is designed to normalize hearing.

Apraxia - a neurologically based disorder which often (but not always) occurs as a consequence of a stroke. The person has difficulty sequencing movements (e.g. may be able to lift and wave arm but not when consciously intending to do so). Apraxia may be related to speech or to the movement of body parts.

ASD - Autism Spectrum Disorder. Includes the following (as listed in the DSM-IV): autistic disorder; Asperger's disorder, PDD-NOS; childhood disintegrative disorder; and Rett's disorder.

BCBA - Board Certified Behavior Analyst - A person with certification from the Behavior Analyst's Certification Board (BACB) - see bacb.com

BCABA - Board Certified Associate Behavior Analyst - A person with certification from the Behavior Analyst's Certification Board (BACB) - see bacb.com

CARS - Childhood Autism Rating Scale: a diagnostic tool for autism. The child is rated in 15 areas on a scale up to 4, for a total of 60. Ranges within this are considered to be non-autistic, autistic, and severely autistic.

CCC-SLP - designation for a speech language pathologist who has been nationally certified by the American Speech, Language and Hearing Association (ASHA).

CHAT - CHecklist for Autism in Toddlers; a diagnostic tool for autism.

Direct instruction (DI) - A set of teaching materials published by SRA (see sra4kids.com) where the teacher follows a script to guarantee that the teacher is communicating to the student clearly and without ambiguity (the reason for doing discrete trials). The script, however, is secondary to other teaching procedures including explain, model, guide, and practice that are used to ensure that each student responds according to predetermined criteria.

DTT - Discrete Trial Teaching - The UCLA or Lovaas approach incorporates DTT, especially in the beginning stages, as a primary technique within a hierarchical teaching program. The child is presented with tasks broken into very easy steps. For example, the instructor may say "Do this" and the child is to imitate a gross motor movement. If the child does it correctly, he is immediately rewarded. If he is not correct, he is prompted with the correct answer and then given an independent trial to determine if he has learned the task. Although the tasks increase in difficulty and complexity over the course of time, the program is designed to maintain a high success ratio and thus high rates of reward for the child. For most children to be successful in a DTT program it must be intense: a minimum of 30-40 hours a week of one-on-one instruction.

Echolalia - the repetition or parroting of words or phrases

EI - Early Intervention - the public program that provides services from birth to 3 years.

EIBI - Early Intensive Behavioral Intervention. An ABA approach to teaching young children.

ECSE - Early Childhood Special Education - the public program that provides services to 3-5 year olds.

ESY - Extended School Year

FAPE - Free and Appropriate Public Education - One of the rights your child is entitled to under the federal law, known as IDEA. Technically, the FAPE entitlement begins at age 3. However, due to the nature of autism, there have been some due process cases involving autism where the FAPE standard began immediately following diagnosis. (Gary Mayerson)

GF/CF - A diet free of gluten and casein. GF - gluten-free (gluten is found in wheat, barley, oats, and rye, among other foods). CF (c/f) - casein-free (casein is found in dairy products)

Hyperlexia - the ability to read at an early age, but often without linking words to meaning.

Hypotonia - low muscle tone.

IDEA - Individuals with Disabilities Act; a law mandating free and public education to all individuals with disabilities between the ages of 3 and 21.

IFSP - Individualized Family Service Plan - The federal government has mandated under the Individuals with Disabilities in Education Act (IDEA) that each state provide children with a free and appropriate public education (FAPE). For Oregon children from 0-5 years of age the family works with their local (EI/ECSE Program) to develop an appropriate IFSP for their child. This is a legal document and will include an evaluation, annual goals and objectives for the child, as well as the services provided by the EI or ECSE program to help the child meet those goals and objectives. Social services such as family counseling may also be included in this document.

IEP - Individualized Education Plan - The federal government has mandated under IDEA that each state provide children with a free and appropriate public education. In Oregon, when children turn 5 they transition from services provided by the local EI/ECSE program to services provided by their school district. Sometimes this is the same agency but sometimes it is not. The IEP will be very similar to an IFSP except that it will not include a "family outcomes" page.

Inclusion (also called Mainstreaming) - Taking a child out of segregated settings and placing him in a regular education classroom with support (e.g. aide).

ITT - Intensive Teaching - Teaching that takes place generally at a table. Learning is usually fast paced and more intensive than NET.

NET - Natural Environment Training - Teaching in the natural environment such as the kitchen or playground with specific goals in mind.

ODE - the Oregon Department of Education

Occupational Therapy (OT) - therapist who specializes in improving the development of fine motor and adaptive skills.

PDD - Pervasive Developmental Disorder; part of the autistic spectrum disorder.

PDD-NOS - Pervasive Developmental Disorder Not Otherwise Specified. A diagnosis of PDD-NOS may be made when a child meets some but not all the criteria for autism, and there is a severe and persistent impairment in specified behaviors.

PECS - Picture Exchange Communication System - A picture system sometimes used to help a child develop requesting behavior when a child is unable to speak.

PLOP - Present Level Of Performance - This is discussed at the beginning of an IFSP or IEP to aid in the development of educational goals. It is a list of the child's current skills including any evaluation information that is pertinent. The PLOP serves as a benchmark for the difference between what the child is doing and needs to learn to do.

PRT - Pivotal Response Training - This technique is under the ABA umbrella but it is significantly different from DTT. PRT is child directed and the motivation to give a response is "built-in" to the task. There is social praise for correct responses; however in pure PRT no external rewards are used. Thus, the technique is considered more "naturalistic" than DTT.

Precision Teaching - The goal of precision teaching is to establish responding that is fluent (i.e., performed without hesitation). Fluency is and of itself is not the goal but becomes the outcome of being able to perform skills fluently.

PT - Physical Therapy

Sensory Integration - Sensory integration focuses primarily on three basic senses—tactile, vestibular, and proprioceptive. Their interconnections start forming before birth and continue to develop as the person matures and interacts with his/her environment. The inter-relationship among these three senses allow us to experience, interpret, and respond to different stimuli in our environment. Sensory integrative dysfunction is a disorder in which sensory input is not integrated or organized appropriately in the brain and may produce varying degrees of problems in development, information processing, and behavior.

SLP - Speech Language Pathologist - This person is trained to work with children with speech and language impairments. They may or may not have behavioral training.

Stimming - The informal term for behaviors whose sole purpose appears to be to stimulate one's one senses.

UCLA PROGRAM (Lovaas) - This is a reference to a landmark study done in 1987 at UCLA by Dr. O. Ivar Lovaas. His 1987 study demonstrated that, provided with intensive, primarily discrete trial, one-on-one behavioral intervention, approximately 47% of the autistic children in his study group "recovered" from autism. The definition for "recovered" in this particular study included at least 3 criteria:

1. The children were mainstreamed into first grade without instructional aides.
2. The IQ's rose from the mentally retarded range to normal ranges.
3. On multiple tests measuring a variety of social skills, adaptive behaviors, and language skills, the children were indistinguishable from normal peers, as assessed by independent evaluators who had no knowledge of the study.

Verbal Behavior (Skinner) - Based on B.F. Skinner's 1957 book titled *Verbal Behavior*, outlining his analysis of verbal behavior, which describes a group of verbal operants, or functional units of language. Skinner's thinking was that language can be analyzed into a set of functional units, with each type of operant serving a different function. He came up with terms that didn't exist (to separate these operants from anything described by traditional linguistics) for these operants. The three that are most often discussed in popular discussion are mands (to request, or to obtain what is wanted), tacts (label of something in the environment), and intraverbals (a response to the language of another person).

Appendix 6

Autism Best Practices

- Parents should receive training and consultation to help teach new skills and reduce behavior problems
- Parents should have input into programming
- Children should receive individualized programs that help them progress in social and cognitive abilities, gain verbal & nonverbal communication skills, gain adaptive skills, reduce behavior problems and generalize skills
- Goals should be observable and measurable and be achieved in one year
- Assessed frequently and adjust intervention accordingly
- Early identification and start of early start of intervention
- The child be actively engaged in an intensive program with planned teaching opportunities (i.e. NET & ITT)
- The child receives year round schooling, 5 days a week for a minimum of 25 hours a week
- The child receives one to one or small group instruction
- Staff should be trained with lots of hands-on practice opportunities, active involvement, and ongoing consultation

Educating Children with Autism by National Research Council/National Academy Press, 2001

Appendix 7

Developmental model: Structured Teaching

Project TEACCH (Treatment and Education of Autistic and related Communication handicapped CHildren) was established in 1972 at the University of North Carolina, Chappel Hill. It is based on cognitive developmental research.

Early research: Wundt, Piaget, Gardener, Sperry,

More modern research: Schopler, Mesibov, Bristol-Powers, Cox, VanBourgen, Watson & Lord

Goals of Structured Teaching: early and lifespan support to gain independent work and functioning and the inclusion of people with developmental disabilities into a community that accepts and adapts to needs of disabled. With this **approach**, Structure fits the “culture of autism” and encourages a cultivation of strengths and interests.

Structured Teaching uses an ongoing **assessment** called the PEP (Psychoeducational Profile). The assessment includes ratings of passing skill, emerging skill (high, middle, lower), and failing skill.

The **curriculum** includes understanding autism, developing appropriate structures, promoting independent work skills, emphasizing strengths and interests, fostering communication, and developing social and leisure outlets.

Structured Teaching uses a **system** that includes Work routines (finish basket), physical structure (work area vs recreation area), transition schedules (object/pictures/print words that show where and when), visual instructions (how to do tasks), prompts and prompt fading, and the use of motivations.

Structured Teaching Resources/Contacts:

- Mary Ann Seaton OTAC/Autism Collaborative Project 503-364-9943 (www.otac.org)
- Sharone Lee, Threshold 503-375-9462 (www.understandingautism.org)
- University of North Carolina, Division TEACCH (www.teacch.com)
- Book: Teaching Spontaneous Communication to Autistic & Developmentally Handicapped Children by L Watson, Lord & Schopler

Appendix 8

Behavioral model: ABA

A behavioral approach involves Applied Behavior Analysis (ABA) under the science of behavioral research.

Early research: Pavlov, Watson, Skinner, Bandura, Baer, Wolf, Risley

More recent research: Koegel, Horner, Smith, Sundberg, Krantz

Current models include Skinner's Verbal Behavior, Lovaas Discrete Trial Training/LIFE, Koegel/Schreibman Pivotal Response Training, and Lindsley/Binder Precision Teaching.

Goals of ABA: to teach child to fit into society by an **approach** of shaping social and verbal behaviors with the use of reinforcers.

ABA utilizes a high degree of **assessment and curriculum** through various methods including Discrete Trial Data, probes, the ABLLS assessment tool, standardized tests, and curriculum based on basic developmental skills.

The ABA system often includes:

- Breaking down tasks/language into smaller parts and teaching each part
- Evaluating whether there are changes and if attributed to the applied process
- Generalizing skills so that the skills are durable over time, place, and transfers to other behaviors
- Using prompts and prompt fading
- Errorless teaching
- Establishing reinforcers – (EO)
- Direct Instruction curriculum by SRA

ABA Resources and Contacts:

- POAC of Oregon (poac-or.org)
- FEAT of Oregon (www.feator.org)
- Behavior Analyst Certification Board (www.bacb.com)
- Assoc. for Behavior Analysts (www.wmich.edu/aba/)
- Book: Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals by C. Maurice, G. Green, S.C. Luce (ed)
- Book: A Work in Progress by R. Leaf & J. McEachin
- Book: Teaching Language to Children with Autism or Other Developmental Disabilities by M. Sundberg & J. Partington

Appendix 9

Eclectic model

An eclectic model often includes parts of a behavioral model, developmental model, speech therapy (Articulation/Apraxia), and sensory integration in varying degrees. Eclecticism is a matter of picking and choosing techniques within each model and putting them together.

Research does not exist as it is based on the model's use in public schools and adult services.

Goals of an eclectic model: to meet IFSP/IEP Goals & Objectives and mainstreaming. The eclectic **approach** attempts to provide intensive early intervention, considers adaptive communication systems, remediates autism, and tries to increase independence.

The **assessment and curriculum** often uses the ASIEP-2 Autism Behavior Checklist (Arick/PSU), GSI – Generic Skills Inventory, and various standardized tests.

An eclectic **system** may include:

- Pivotal Response Training (PRT) (Behavioral)
- Discrete Trial (DTT) (Behavioral)
- Structured Teaching workbasket system (Developmental)
- Natural Environment Teaching (NET) such as playing with a dollhouse
- Circle time with songs and activities
- Snack time - often used for requesting skills
- Visual cues (Developmental)
- Schedule system(s) (Developmental)
- Greenspan's Floortime (Developmental)
- Carol Gray Social Stories (Developmental)
- Sensory Integration (sand/water table, big ball, swing)
- Occupational Therapy (handwriting, bike riding, skipping)
- Speech Therapy

Eclectic Resources/Contacts:

- Oregon Regional Programs
- Books by Janice Janzen
- OTAC (see Oregon Autism Resources)

Appendix 10

What You May Be Feeling

Am I reacting normally to the news of the diagnosis?

A majority of parents report feeling some kind of relief after getting a diagnosis, often after a long and frustrating process. At last, they have a WORD to use for the peculiar behavior they have been so concerned about (validation!) and, thankfully, they are not alone! This relief often soon wanes, however, and is replaced by an array of feelings and emotions common in any process of grief. All of these feelings are justified and should not be considered "over-reactions." Refer to the illustration below for a sample cycle of grief. Do not think that you must follow this cycle step by step or experience any or all of these feelings in any particular order to reach a point of "healthy closure" to, and acceptance of, your child's autism. Everyone deals with this news differently. We can't debate over what is the right or wrong way to grieve since there is no one answer for every parent.

CYCLE OF GRIEF (typical pattern)

SHOCK -> DEPRESSION -> DENIAL -> GUILT -> SHAME -> ISOLATION
ACCEPTANCE <- HOPE <- BARGAINING <- ANGER <- PANIC <-

Shock & Depression: Receiving the news that your beautiful child has a neurological disorder called autism is a devastating blow. It is indeed like suffering the loss of a loved one. After all, the image of your healthy child and the plans you have made for his future have suddenly "died," and you are faced with living with that loss. Many parents, especially mothers, are left in "mourning," and indeed are entitled to grieve as such.

It is important to recognize that each family member may grieve differently. Some may throw themselves into work or school, keeping extremely busy and involved. Others dive head first into educating themselves about the disorder, intent on conquering it with knowledge. Some may even seem to skip any kind of grieving process, claiming they're just thankful that the situation isn't worse.

However you and your loved ones grieve, it is important to be respectful of the others' pain and how they cope. Keep the lines of communication open and don't be afraid to cry. Feelings of depression are justified and crying is very therapeutic!!

Denial & Guilt: "No way can this be happening!! He was born so perfect!! There must be a mistake!" Does this sound familiar? One day we're convinced that our child is perfectly normal, the next we're reminded of why we sought a diagnosis in the first place. The roller coaster of denial has extreme peaks and valleys.

Seldom is there a parent who doesn't think, "Was it something that I did, or didn't do?" We sometimes strain our minds to remember the pregnancy, what we consumed, what we breathed even.

We might try to apply a genetic factor to our situation and run through the family card catalog in our heads, "I remember Uncle Waldo being a little strange. Did this come from me and my bad genes?"

Most commonly, parents are convinced that their child has been afflicted as punishment for something they did, said, or felt in the past.

These feelings of guilt are widely felt by parents, especially immediately after the diagnosis, but will dwindle as you become more educated about the disorder. Instead of feeling responsible for your child's autism you'll focus on what you are responsible for: loving, and supporting this special child who will (believe it!) teach you more than you can imagine, and bring you great joy.

Shame & Isolation: There may be a period of time post-diagnosis when you feel as if you just don't "fit" anywhere you go. At church, you may feel as if you're the only parents who have no control over their child, or you wonder if you'll ever again be able to eat in a public place. A feeling of shame nags at you, scolding that you should be able to control your child because YOU are the parent, and YOU should be the one in charge!

The day-to-day isolation often created by these feelings can really take its toll if you don't seek support. This is when it is especially important to network with other parents as a reminder that you are not alone in your struggle. Often times it is this bonding with others that puts your life back into perspective with the acknowledgment that your situation is ~ so unique, and that there are aspects of it that could be worse.

Panic: "How do I tell my spouse...family..friends....? What do I say? What do I do first? How am I going to handle all of this? Will I have to keep him home? Will he ever be independent? Does he have a future?" At the onset of the diagnosis, most of us will run through all of the "worst case scenarios" in our minds. Initially, autism is a scary mystery to us. We, therefore, often feel we need to know everything possible about autism immediately. We fear that any time lost from early intervention will have

irreversible effects on our children.

We must become an expert overnight! Of course, this is not true. We are just being conscientious parents who want the best of what is available for our children. You have the diagnosis, which is the biggest hurdle for a lot of parents. Now that you know what you're dealing with, there is no place to go but forward.

Anger: "Why me?", or more likely, "Why my child?" How come there are people out there who couldn't care less about the welfare of themselves and others in general, but have perfectly healthy children? Why, when we so carefully planned our pregnancies, and did all the healthy things, should our babies have been burdened with this disability? We have all asked these questions, and have cursed our situations. We are all angry that our children must bear this burden and live a life with a disability. We would trade places with them in a moment to alleviate them from their predicament.

This anger is deep, painful, and justified, but the energy that it creates can lead to some very positive things and metamorphosize into a thirst to educate yourself and others about autism.

There are no answers to our "whys?", other than those that come to us on their own. These answers stem from the wisdom our children bestow upon others and us. You'll learn that your child will be among the world's greatest teachers, and you'll eventually find peace in his existence.

Bargaining: "I swear that I'll do everything humanly possible, and more, if this will just go away. I'll be nice to everyone and I won't make waves. I'll pray more in the hope that it will then make life easier for me and my child."

Bargaining is an if/then situation. We fill in our "ifs" in the hopes that a "then" will make life easier for our child and us.

At this point we're reaching for hope, but we're not quite there yet.

Hope & Acceptance: In time, as you come to understand how autism affects the thinking process and how your child perceives the world, you will realize that all is not lost. You'll know what is necessary to help your child, enabling you to deal more confidently with the array of professionals involved in your lives. This is a major step in setting in motion programs specifically suited for your child.

Soon, you will begin to see your child making progress. Autism will no

longer be a horrible mystery. You'll see your child as a unique human being...who just happens to have autism. This will not happen overnight.

You will have traveled a certain course or journey of divergence before you reach a point of hope and acceptance.

Along the way, some changes may have come to pass regarding your beliefs, your faith, your lifestyle, and especially your fears. What you once may have considered a punishment or curse may become a beatitude beyond comprehension. You will see ordinary things in a new way. Moments that the average person takes for granted will be moments that you will savor and cherish. A realization that you have been given the opportunity to see the world through different eyes, and feel it with an ethereal appreciation will mark the beginning of a new journey of promise and peace. You have walked the walk, and now you must decide what to do with your newfound wisdom.

Some people who experience autism have gone on to college, married, and now hold responsible jobs. They are writers, artists, technology experts, teachers, and Ph.D.'s. Who is to say what is their limit? Our children will continue to amaze and educate even the most educated among us.

If research, individual and family support, and public awareness continue to be put at the forefront in the field of autism, and differences in people are celebrated instead of condemned, then hope will always be at the forefront as well.

Your life has been turned upside down, and you can no longer recall the predictability and ease of your former life. This change in roles can put great stress on the family unit, especially one that has always relied on Mom or Dad's constant availability. It is a MUST that you prioritize your life and discuss the necessary changes with your family. Everyone can (should) pitch in to pick up the slack and ease the burden of the primary care giver. This will help re-create a balance in your personal and family life, and give your supporters a sense of worth.

Keep in mind that, by and large, parents do the best they can for their children, given their situations. Don't expect perfection of yourself in every (any!?) circumstance.

Appendix 11

Special Education Law Timelines

Autism Evaluation

The evaluation should be completed within 60 school days unless special circumstances require a longer period.

Prior Written Notice

The request for any changes to an IFSP/IEP by the parent should be made in writing. It might be a good idea to request a Prior Written Notice if the request is denied within a reasonable period of time, like 10 working days. Ensure that specific reason(s) for the denial is in the letter.

Letter of Complaint

The Superintendent shall issue a written decision that addresses each allegation in the complaint and contains findings of fact, conclusions, and reasons for the Department's final decision. The decision shall be issued within 60 days of receipt of the complaint or amended complaint, unless exceptional circumstances related to the complaint require an extension. Exceptional circumstances include but are not limited to an extension requested or agreed to by the complainant to pursue local investigation/ resolution or mediation.

Request for Judicial review must be filed within 60 days

Corrective action must be implemented within 30 days of the decision

Due Process

Disclose evidence 5 business days prior to hearing

Hearing decision within 30 days

Records Access for parents

Without unnecessary delay before an IEP, or due process, never more than 45 days from request

Appendix 12

When things go bad at the IFSP/IEP table

According to Suzy Harris, the Legal Specialist for Oregon Department of Education, “The district has discretion to decide how it will proceed when the team cannot reach consensus. Frequently, the district representative at the meeting, who may be the special ed director, will make this decision.”

Appendix A of the federal regulations under the IDEA states:

”9. What is a public agency’s responsibility if it is not possible to reach consensus on what services should be included in a child’s IEP?”

The IEP meeting serves as a communication vehicle between parents and school personnel, and enables them, as equal participants, to make joint, informed decisions regarding the (1) child’s needs and appropriate goals; (2) extent to which the child will be involved in the general curriculum and participate in the regular education environment and State and district-wide assessments; and (3) services needed to support that involvement and participation and to achieve agreed-upon goals. Parents are considered equal partners with school personnel in making these decisions, and the IEP team must consider the parents’ concerns and the information that they provide regarding their child in developing, reviewing, and revising IEPs (Secs. 300.343(c)(iii) and 300.346(a)(1) and (b)).

The IEP team should work toward consensus, but the public agency has ultimate responsibility to ensure that the IEP includes the services that the child needs in order to receive FAPE. It is not appropriate to make IEP decisions based upon a majority “vote.” If the team cannot reach consensus, the public agency must provide the parents with prior written notice of the agency’s proposals or refusals, or both, regarding the child’s educational program, and the parents have the right to seek resolution of any disagreements by initiating an impartial due process hearing.

Every effort should be made to resolve differences between parents and school staff through voluntary mediation or some other informal step, without resort to a due process hearing. However, mediation or other informal procedures may not be used to deny or delay a parent’s right to a due process hearing, or to deny any other rights afforded under Part B.”