



# PARENT GUIDE

<http://AutismToolbox.org>  
<http://AutismOregon.org>

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## Disclaimer

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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. Specific and current resources are listed at <http://autismoregon.org>.

Autism Toolbox does not take responsibility for the use of this information by individuals, nor does Autism Toolbox 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://autismoregon.org> and <http://AutismToolbox.org>

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## What is Autism Toolbox?

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Autism Toolbox (formerly Parents of Autistic Children of Oregon) was started in 2005 by parents and providers who attended Dr. Carbone’s “Introduction to Verbal Behavior” three-day workshop. Seeing the benefits of this approach, they were convinced this current line of research would yield the best results for children with autism.

The founders saw that even though there has been a dramatic increase in population with Autistic Spectrum Disorder, there has been no corresponding increase in enough trained professionals offering services using the research found in Verbal Behavior. In fact, no Oregon college offers a degree program leading to certification as a Board Certified Behavior Analyst (BCBA) using research-based approaches such as Applied Behavior Analysis and Verbal Behavior.

In April 2006, Autism Toolbox gained 501(c)(3) nonprofit status with a mission to provide scientifically based curriculum and training to parents, teachers, and related personnel who provide direct services to children with autism and other developmental disabilities.

### Our Mission

Autism Toolbox seeks to create curriculum and train teachers and parents in the principles of applied behavioral analysis, direct instruction, precision teaching and other teaching procedures that research has shown to be effective for teaching children with autism.

Autism Toolbox’s purpose is to involve parents, teachers and other “stakeholders” in the highest level of decision making regarding the education of children with autism.

Autism Toolbox’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.

## What is Autism?

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Autism is a disorder that severely impairs a child's communication and social interactions. Unable to learn from the natural environment as most children do, the children with autism shows little interest in the world or people around them. 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 repetitive 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. According to the Centers for Disease Control (CDC), autism occurs in one in every 110 children. 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 causes including genetics, environmental toxins such as lead, mercury, and waste products, vaccinations (MMR), and viruses (rubella in first 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 scientifically based and proven teaching methods.

## The Research...

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Autism can be overcome! Led 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 by 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. Characteristics of intensive behavioral treatment are:

- At least two years of therapy including 30 to 40 hours per week of one-on-one behavioral intervention. The more hours, the better the results.
- One-on-one teaching by trained therapists of specific cognitive, language, social and self-help skills.
- The use of positive reinforcers – not punishment.

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.

## Just Diagnosed and Feeling...

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Your life has been turned upside—the vision you had for child’s future has been dramatically altered.

Some parents report feeling some kind of relief after getting a diagnosis, often after a long and frustrating process. At last, they have a diagnosis for the peculiar behaviors and lack of verbal skills. This relief often soon wanes, however, and is replaced by an array of feelings and emotions common in any process of grief. You have the right to grieve; these feelings are justified and should not be considered an over-reaction. The grieving process is different for each person involved with a child with autism—siblings, grandparents, aunts, uncles, and friends may grieve differently. Some of the emotions you and others may feel include:

**Shock & Depression:** Receiving the news that your beautiful child has a neurological disorder can be a devastating blow. You might see the future image of your Harvard graduate slip away.

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. Some find professional help necessary to keep their lives and families together.

**Denial:** “But he looks so normal. It’s too early to tell if it is really autism. He’ll grow out of it.” These are common responses. Many people, especially parents, are stuck in the denial phase. A label is no reason to avoid or delay helping a child. At best, the child will delay development in areas such as social and communication. At worst, the child learns inappropriate communication skills such as tantrums, damaging belongings, or hurting siblings that are very difficult to replace without herculean effort, time, and money. Time and effort early on pay off in the long run in heaps.

**Guilt:** 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, or even what we breathed. We might try to apply a genetic factor to our situation and run through the family card catalog in our heads, “I remember Uncle Jim as suffering from schizophrenia or depression.”

Some parents are convinced that their child’s affliction is punishment for something they as parents 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 teach you more than you can imagine, and bring you great joy.

**Panic:** “How do I tell my family, relatives, and 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? How do I pay for the therapy?” 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. Newly diagnosed parents often exhibit an urgent zeal to know everything possible. Remember, this is a marathon, not a sprint. The likelihood is that your child will need some level of support for several years, possibly for an entire lifetime. For this reason, you’ll need to prioritize your life and carefully analyze your work situation and finances. You must take one day at a time. 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 my child?” 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.

Sometimes the school system brings our anger and frustration to a head. Remember, many schools have limited funds, training, and personnel and are unable to give every student with disabilities the time and help he or she needs. It is up to the parent to fill in the holes.

Anger can be deep, painful, and justified, but the energy that it creates can lead to a positive drive to educate yourself and others about autism.

**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 blessing. 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 a deeper 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 with autism are successful in college, marriage, and jobs with great responsibilities. They are writers, artists, technology experts, teachers, and Ph.D.'s. Who is to say they have limits? Our children will continue to amaze and educate even the most educated among us.

With continued research, individual and family support, and public awareness the hopelessness of autism will fade away. Remember, by and large, parents do the best they can for their children.

# Autism and ABA FAQs

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## 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 (see DSM-IV Criteria for Autistic Disorder).

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

A medical diagnosis uses the DSM-IV. The definition of 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 the 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 four areas: communication, social, sensory and repetitive/restrictive/stereotypic interests and activities. The team determines "significance" together with the guidance of the specialists. Currently, a medical diagnosis does not guarantee services for autism in public education.

## 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.

## What are some other therapies?

Some treatments that are used in conjunction with educational models may 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, vision therapy, and dance therapy.

Autism Toolbox 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 provider, 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, Resperdal, secretin, Cloradine, anti-virals (Valtrex, Famvir), anti-fungals (Nizoral, Diflucan), 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://autismoregon.org/providers> - 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. Many can be found by searching for groups under <http://groups.yahoo.com>.

### **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. 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,—two to four years of age—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 are successful in getting Early Intervention or the School District to pay. Many rely on Developmental Disability Services, Disability Social Security, Insurance, Intensive In-Home Services, Respite Care, family generosity, fundraising, 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 at <http://autismoregon.org>. 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 (FAPE).

## For Parents of Newly Diagnosed Children

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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 visit: [http://www.ode.state.or.us/gradelevel/pre\\_k/referralcontactsbrochure.pdf](http://www.ode.state.or.us/gradelevel/pre_k/referralcontactsbrochure.pdf)
3. Join local and national listserves, support groups, and informational groups like:
  - Autism Toolbox  
<http://yahoogroups.com/groups/autismtoolbox>
  - Autism Society of Oregon  
<http://autismsocietyoregon.org>
  - Autism-Oregon  
<http://yahoogroups.com/groups/autism-oregon>
4. Be wary of magic cure-alls and snake oil salesmen. The easier it sounds, the more likely it is not true and will waste precious time.
5. There are two main categories of treatment: MEDICAL and EDUCATIONAL. Autism Toolbox focuses on behavioral education.

**EDUCATIONAL** Therapies have three main approaches:

- A. **Behavioral** - Applied Behavior Analysis (ABA), Pivotal Response Training (PRT), Discrete Trial (DTT), Lovaas, Precision Teaching
- B. **Developmental** - Structured Teaching (TEACCH), Greenspan's Floortime, Social Stories
- C. **Eclectic** - A combination of Behavioral and Developmental approaches along with various other complimentary treatments

**MEDICAL** Therapies have Biological and Drug approaches:

- A. **Biological:** vitamins, supplements, minerals, and more
  - B. **Drug:** chelation, anti-yeast therapy, IVIG, secretin, Prozac, and more
6. Choose your teaching methodology. It is important to not waste time on a method by switching around thus not ensuring that you use the method with consistency and get poor results. See pages on Behavior, Developmental, and Eclectic approaches for a more detailed description.
  7. 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. See <http://autismoregon.org/providers> for a DAN! list of doctors.

8. 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—at least several weeks—to work before passing judgment. It's okay to try things when you are sure they do no harm to your child and family physically, financially or emotionally.
9. Learn the law and your child's rights. Contact Developmental Disabilities Office, RISE or a local advocate for help on IFSP/IEP goals and services.
10. Consider getting extra evaluations 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.
11. 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.
12. Your school district and professionals may not share your beliefs of educational and biological approaches. Try to work on win-win relationships 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 CANNOT eat. Volunteer with the PTA or in the classroom. Once they get to know you, they'll most likely provide more engaged help for your child.

13. Do not spend all your time and effort on the child with autism at the expense of your marriage, your other children, 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.
14. 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.
15. Autism is a marathon. Build a network of support so you don't have to go at this alone. Many other parents (even grandparents) are dealing with the same emotions and stress.

## Getting Started with a Behavioral Program

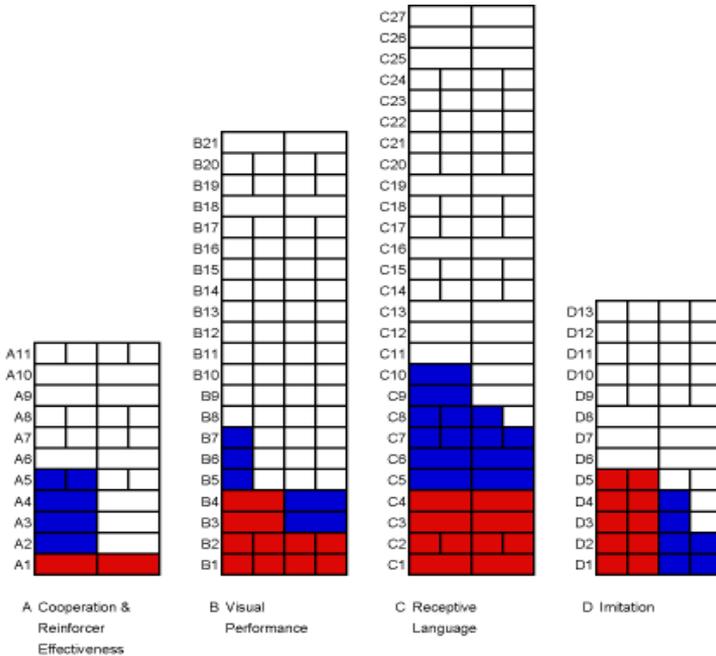
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1. If the child hasn't already received an Autism Evaluation by the Education System, call Early Intervention or Referral and Evaluation Agency at (503) 378-3600 x2337 or see <http://www.ode.state.or.us/sped>
2. Obtain a computer, an email account, and an internet connection.
3. Build your own network of support by joining local and national ABA listserves, support groups, and informational groups like:
4. AutismOregon listserv - <http://yahoogroups.com/groups/autism-oregon>
5. AutismOregon forum - <http://autismoregon.org/forum>
6. Me-List listserv - <http://yahoogroups.com/groups/me-list>
7. DTT-NET list - <http://yahoogroups.com/groups/dtt-net>
8. VerbalBehavior list - <http://yahoogroups.com/groups/verbalbehavior>
9. Get a copy of *The Verbal Behavior Approach* by Mary Barbera, *Teaching Language to Children with Autism or Other Developmental Disabilities* by Mark Sundberg and James Partington, and *Behavioral Intervention for Young Children with Autism* by Catherine Maurice. Some are available in your public library.
10. Go observe a home program. By joining various email lists you can find local people that have sessions that you can view. Begin learning about special education law (see back of book). Contact Developmental Disabilities Office, Oregon Respect, Inspire, Support, and Education (RISE) Partner Program or a local advocate for help on IFSP/IEP goals and services.
11. Contact and interview ABA providers in order to determine which program is best suited for you and your child's needs.
12. Recruit, interview, and hire program therapists. Join the Autism Toolbox-or list at <http://yahoogroups.com/groups/autismtoolbox> or post requests at <http://autismoregon.org/forum> to find potential therapists or referrals.
13. 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.
14. Keep learning. Try to not become overly confident or stagnant in your knowledge. Continue to attend conferences to remind you of the foundational principles of ABA.
15. Understand child developmental milestones. You can track your child's past and current skills by completing *The Assessment of Basic Language and Learning Skills* (ABLLS). This assessment is highly recommended.

## ABLBS - The Tool of Choice

The Assessment of Basic Language and Learning Skills (ABLBS) is a criterion-referenced assessment (not a norm-referenced assessment) that measures current skills of a child. This assessment helps design your home program and is an excellent tool for developing an IFSP or IEP. It is best to complete the ABLBS as soon as possible so that you can get your home program started.

ABLBS is a set of over 400 questions designed to track your child's progress in various skill areas: communication, social awareness, play, and academic. 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 two different colors: red and blue. In this case, the red depicts an earlier assessment period. The blue may have taken place 3 months later. A chart at the top will indicate the assessment date for each color. The ABLBS is given every three to six months so you could end up with several colors that represent many assessment periods.

Once filled out (especially the first page), the ABLBS represents the skill set of a five-year-old child.

## Whoa! How do I pay for this?

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Autism Toolbox exists because the education system does not practice the principles of Direct Instruction, Applied Behavior Analysis, or Precision Teaching. If schools were to analyze the progress of the children in their care, they would find that many children, if not most, do not make nearly the progress they should.

### 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 people 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. Contact the CIIS department for a CIIS Intake.
4. There is also limited funding via the Staley case (funding gained through the shutdown of Fairview State Hospital). Contact Children's In-Home Intensive Services (CIIS) at <http://www.oregon.gov/DHS/dd/children/in-home.shtml>.
5. Fundraise for your child, just as parents do with their child who 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 much like any other medical condition such as a stroke. Search the internet on how this can be attempted.

## How to Choose a Consultant

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According to Association of Behavior Analysts, it is recommended that at minimum consultants:

- A. Hold a master's degree in psychology, special education or related field;
- B. Have 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 can be difficult. It is best to find a Board Certified Behavior Analyst (BCBA) or at the very least a Board Certified Assistant Behavior Analyst (BCaBA). However, because of the lack of certified professionals and the high demand for ABA consultants, 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. Email listserves are one way families can get in touch with each other to hire a consultant.

## Hiring a Home Therapist

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Shown below is a sample therapist ad which families can modify and use to suite their own needs when looking for therapists. People have had success in posting ads at churches, colleges, universities, with special education professors, high schools, and even craigslist. 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. It is sometimes helpful to give a bonus for working six months with certain minimum number of hours worked per week.

### Sample Therapist Ad:



### WANTED

Someone to make a difference in the life of a child with autism. Committed person needed to tutor four year old between 11am and 6pm weekdays in Corvallis for six to 10 hours per week.

Weekends/other hours negotiable. Initial and continual training provided. Six month minimum commitment needed. Pay starting at \$8 per hour (depending on experience). Join our team!

Call John or Jane Doe at (555) 555-1212.

# Suggested Interview/Discussion Topics for Therapists

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## 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 Aid 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. What would you like to know about our child?
26. If you had \$50 to spend on my child, how would you spend it?

## IV. Applicants the Applicant's Personality

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 do we supply them?
  6. How long would you like to be in this position? Long term plans?

## Therapist Contract

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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 the following:

1. A description of services
2. Procedure for missing a session
3. The number of hours per week they 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

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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. The following is a list of common misconceptions and rebuttals.

1. **Myth:** ABA is experimental. **Fact:** ABA is research-based. It is the culmination of procedures that have been validated through a long history of empirical research. Case studies and replication studies are ongoing.
2. **Myth:** ABA utilizes punishment. **Fact:** 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. **Myth:** ABA is mechanistic. **Fact:** 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. **Myth:** ABA produces robotic children who do not generalize. **Fact:** 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. **Myth:** One-on-One instruction isolates children. **Fact:** 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. **Myth:** ABA is too demanding. **Fact:** 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. **Myth:** ABA teaches splinter skills. **Fact:** 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. **Myth:** ABA robs children of their childhood. **Fact:** 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. **Myth:** ABA only benefits high functioning children whose parents aim for recovery. **Fact:** ABA has proven to be highly effective for children with autism at all levels of severity. The critical measure of success is improvement.
10. **Myth:** ABA is delivered by inexperienced personnel. **Fact:** 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. **Myth:** Any professional who understands behavior modification can serve as a program consultant. **Fact:** 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 résumé including the possibility of references from families with whom they have worked previously.
12. **Myth:** ABA is the same as Lovaas and Discrete Trial (DTT) . **Fact:** No, ABA is a broad field of study and application with a wide breadth.
13. **Myth:** ABA does not work past age six. **Fact:** ABA is used in everyday life with all kinds of people and even animals. Many older children and adults have made huge gains with the application of ABA.

## ABA Basics

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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.

Applied Behavior Analysis (ABA) is a science that studies the relationship between a person's behavior (communication, how s/he acts) and the person's environment (items, people, what is said or done). ABA uses specific principles to change behavior such as teaching adaptive behaviors and reducing inappropriate behaviors. Pioneered by B.F. Skinner, ABA is currently the only research-based treatment recognized by the U.S. Surgeon General for children with autism. The use of Applied Behavior Analysis emphasizes the teaching of important lines of ABA research:

- **Functional Assessment**—Classifying and selecting treatments based upon the function of a problem behavior
- **Motivative Operations**—Understanding and control of what happens before a behavior occurs
- **Matching Theory**—Changing teaching strategies (speed, simplifying) increase student answers/following directions
- **Skinner's Analysis of Verbal Behavior**—How to teach communication of wants, needs, and information to persons who do not acquire it typically

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

The basics of Applied Behavior Analysis 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 read books, 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.

### First Step: 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 fives 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 slowly added 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”

Pair the teaching environments with reinforcement: Initially, correlate the teaching environment (such as the table, chair, flashcards, and non-preferred toys) with highly valuable reinforcers.

Pair the parent, teacher, or therapist with reinforcement: “Pairing” refers to associating yourself with the delivery of reinforcing items and events. When a session begins, the child should run to you, not away from you. Through pairing you establish yourself as a reinforcer. The child looks at you knowing their world will get better and

they will get things they like. Your job is to build the work in such a way that the child has no idea learning is taking place.

Avoid the use of escape (“Go Play”) as the reinforcer for responding during intensive teaching sessions such as table work. Therapists can also use non-contingent reinforcers or “freebies” while you are pairing and the child is not exhibiting inappropriate behavior.

## Verbal Behavior

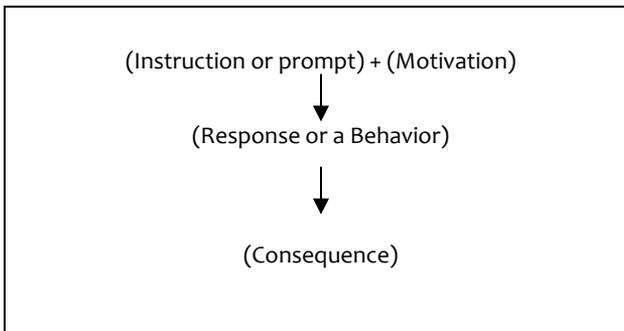
Many programs for young children with autism teach skills that do not advance a child's motivation to improve their vocal skills. By implementing Skinner's *Analysis of Verbal Behavior*, children are started on a program to teach requesting behavior (Manding) along with some initial identifying skills (Tacting) and following directions skills ("Do this").

Advanced verbal skills are then taught with enough foundation skills in requesting, identifying and following direction using Intraverbals which include fill in the blanks within songs and sentences, answering and asking questions, and general conversation skills.

See *The Verbal Behavior Approach* by Mary Barbera and *Teaching Language to Children with Autism or Other Developmental Disabilities* by Mark Sundberg and James Partington.

## Behavioral Principles

It is important to know how and why behaviors happen. This allows us to figure out how to change them. The basic principles of behavior include a four-part formula:



Where:

Instruction can include "Touch your nose" or "Point to the cat."

Prompting can include the act of putting your hand over the child's hand to show how to dry their hands using a towel or pointing to a correct answer.

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 or a favorite drink.

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 most often used, where 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, where 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
- ✓ Specific complements such as “Nice work putting away your clothes”
- ✓ Games

## Types of Punishment

In general, punishment should be used sparingly and carefully. Punishment can lead to control issues, gives an example to children that punishment is OK, can lead to abuse, and can often be avoided if positive reinforcement is done correctly.

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 s/he hand flaps.)

## 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.

## Other Behavioral Procedures

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, as well as 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 desire for tangible 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 (stim):

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, then 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 (motor skills and flash card identification)
- ✓ Teach to fluency (skills are demonstrated correctly and quickly)

## Direct Instruction

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

Direct Instruction is a system of teaching which includes a set of teaching principles and specifically developed curriculum. Many use the DI curriculum developed through SRA. 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 a) are clear, b) are able to predict likely misinterpretations and therefore reduce confusion, and c) assist in forming generalizations.

DI is a highly structured, intensive teaching program that aims to absolutely prepare the educator in such a way that all children learn to 100 percent 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
- Choral responding (all students answer a question verbally at the same time on a specified cue)
- Teacher models -> Group practice -> Independent work

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.

## Precision Teaching (Fluency)

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By looking at learned skills that are observable (number of words read, how many times you can pick up a pencil), you are able to measure the skill and focus on improvements by using a chart. Often, this is done in 1 minute increments.

How many states can you identify in one minute? How many math facts can you do in one minute? How many situps can you do in one minute? These are just a few examples.

## Oregon/SW Washington Resources & Information Providers:

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This list is not exhaustive. Please see <http://autismoregon.org> for a listing of information and service providers including: Applied Behavior Analysis providers, audiologists, auditory integration training, autism diagnosis and evaluation providers, Defeat Autism Now! (DAN!) doctors, dentists, Direct Instruction providers, eclectic providers, educational program providers, information providers, lawyers & advocates, learning disability testers and evaluators, leisure and exercise providers, lending libraries, medical resources, national autism organizations, occupational therapists, optometrists and eye doctors, Oregon Department of Education resources, physical therapists, psychologists/psychiatrists, Relationship Development Intervention (RDI) therapists, reading specialists, respite providers, schools, sensory integration, social skills groups/therapy, social workers, speech-language pathologists (SLP), statewide autism organizations, Structured Teaching (TEACCH), and a listing of trained aides and/or childcare providers.

### [AutismOregon.org](http://autismoregon.org)

<http://autismoregon.org>

### [Autism Society of Oregon](http://autismsocietyoregon.org)

<http://autismsocietyoregon.org>

P.O. Box 13384

Salem, OR 97309

(503) 234-5729 / 1-888-AUTISM-1

### [Child Development and Rehabilitation Center - OHSU](http://www.ohsu.edu/cdrc/)

<http://www.ohsu.edu/cdrc/>

3181 SW Sam Jackson Park Road

Portland, OR 97239-2941

(503) 494-8311

### [Autism Toolbox](http://autismtoolbox.org)

<http://autismtoolbox.org>

[info@autismtoolbox.org](mailto:info@autismtoolbox.org)

### [Families for Effective Autism Treatment of Washington \(FEAT of WA\)](http://featwa.org)

<http://featwa.org>

## Useful Web Sites

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### Association for Direct Instruction

<http://adihome.org>

### Association for Science in Autism Treatment (ASAT)

<http://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.

### Autism Toolbox

<http://autismtoolbox.org>

A site that includes free assessment tool, IEP/IFSP goals, curriculum and an online support structure.

### Behavior Analyst Certification Board

<http://bacb.com>

### Cambridge Center for Behavioral Studies

<http://www.behavior.org>

### National Institute for Direct Instruction (NIFDI)

<http://nifdi.org>

### The Precision Teaching Book

<http://theprecisionteachingbook.com>

### Precision Teaching/Standard Celeration Society

<http://celeration.org>

### Precision Teaching Wiki

<http://precisionteaching.pbworks.com>

### Verbal Behavior Wiki

<http://verbalbehavior.pbworks.com>

### Verbal Behavior Network

<http://abatraining.com>

An excellent website with much information and videos.

## Oregon Department of Education Special Education (SPED)

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**<http://www.ode.state.or.us/search/results/?id=40>**

*A variety of information about education in Oregon including the administrative rules and regulations for special education, how funds to school districts are allocated, complaints, due process, and publications and reports.*

**IFSP: Individual Family Services Plan for children in pre-school**

**IEP: Individual Education Plan for children Kindergarten to Graduation or 21.**

The IFSP/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 IFSP/IEP team must consider the parents' concerns and the information that they provide regarding their child in developing, reviewing, and revising IFSP/IEPs (Secs. 300.343(c)(iii) and 300.346(a)(1) and (b)).

The IFSP/IEP team should work toward consensus, but the public agency has ultimate responsibility to ensure that the IFSP/IEP includes the services that the child needs in order to receive "Free and Appropriate Public Education" (FAPE). It is not appropriate to make IFSP/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."

# Special Education Law & Advocacy

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## **The Council of Parent Attorneys and Advocates (COPAA)**

<http://www.copaa.net>

## **Disability Rights Oregon**

<http://disabilityrightsoregon.org>

620 SW Fifth Ave, Suite 500

Portland, OR 97204-1420

(503) 243-2081 or (800) 452-1694

## **Gary Mayerson**

<http://mayerslaw.com>

## **U.S. Department of Education (ED) Home Page**

<http://ed.gov>

## **Wrightslaw**

<http://wrightslaw.com>

## Autism/ABA/Support Email Listserves

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### ABA Parents List

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

### Autism-Oregon List

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

### Autism Toolbox List

<http://yahoogroups.com/groups/autismtoolbox>

### Direct Instruction List

<https://lists-prod.uoregon.edu/mailman/listinfo/di>

### DI Market List

<http://yahoogroups.com/groups/DImarket>

*A email listserv for selling and buying Direct Instruction curriculum.*

### DTT-NET List

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

### Me-List

<http://yahoogroups.com/groups/me-list>

### Verbal Behavior List

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

# Behavioral Intervention / Special Education Books

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## **A Work In Progress**

Ron Leaf and John McEachin

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

## **Behavioral Intervention for Young Children With Autism : A Manual for Parents and Professionals**

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.*

## **The Precision Teaching Book**

Richard Kubina & Kirsten Yurich

## **Teaching Language to Children with Autism or Other Developmental Disabilities**

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.*

## **The Verbal Behavior Approach**

Mary Barbera

*An excellent short primer on behavior analysis and verbal behavior.*

## **When Everybody Cares: Case Studies of ABA with People with Autism**

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**

Bobby Newman (Editor), Dana Reinecke (Editor), Leo Newman (Editor)

*Full of examples of behavior analysis used to help 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.*

# IEP/IFSP Development & Special Ed Law Books

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## **ABLLS - The Assessment of Basic Language and Learning Skills**

Partington & Sundberg

*A wonderful way parents, teachers, aides can assess your child every six 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**

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.*

## Pick a Teaching Method: Autism Best Practices

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- 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
- Students should be 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, five 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 with competent professionals

### Educating Children with Autism

National Research Council/National Academy Press, 2001

## Behavioral model: ABA

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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 applications 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.

**Assessment:** ABA utilizes a high degree of assessment and curriculum through various methods including Discrete Trial Data, probes (taking data the next day to see if the skill has been learned), the ABLLS assessment tool, standardized tests, and curriculum based on basic developmental skills.

### ABA often includes:

- Breaking down tasks/language into smaller parts and teaching each part
- Evaluating whether there are changes and if attributed to the applied teaching procedure
- 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
- One-to-one or small group teaching
- Working at the table for early learner skills and Natural Environment Teaching (NET) for generalization and skills taught more effectively in a non-table environment

### ABA Resources and Contacts:

- Autism Toolbox (<http://autismtoolbox.org>)
- Behavior Analyst Certification Board (<http://bacb.com>)
- Association for Behavior Analysts (<http://www.abainternational.org>)
- 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

## Developmental model: Structured Teaching (TEACCH)

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

**Assessment:** ongoing through 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 to help the person with autism successfully live and work within society, promoting independent work skills, emphasizing strengths and interests, fostering communication, and developing social and leisure outlets.

### **Structured Teaching 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
- Use of motivations

### **Structured Teaching Resources and Contacts:**

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

## Eclectic model

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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. This methodology is prevalent in Oregon schools and early intervention.

**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.

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

### An eclectic approach may include:

- STARS program developed by Joel Arick of PSU
- 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 and Contacts:

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

# Special Education Law Timelines

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## 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 five 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

## Glossary

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**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 or Lovaas.**

**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 Certification Board (BACB) - see <http://bacb.com>

**BCaBA** - Board Certified Assistant Behavior Analyst - A person with certification from the Behavior Analyst Certification Board (BACB) - see <http://bacb.com>

**CARS** - Childhood Autism Rating Scale: a diagnostic tool for autism. The child is rated in 15 areas on a scale up to four, 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).

**CDRC** - Child Development and Rehabilitation Center. Assessment/diagnostic services for persons with developmental disabilities and other special health care needs.

**CHAT** - **C**hecklist for **A**utism in **T**oddlers; a diagnostic tool for autism.

**Direct instruction (DI)** - A set of teaching materials published by SRA where the teacher follows a script to guarantee that the teacher is communicating to the

student clearly. The method of teaching uses explain, model, guide, and practice to ensure quickest learning to mastery.

**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 three 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 three- to five-year olds.

**ESY** - Extended School Year – services provided when school is not in session.

**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 three. 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 - 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 three 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 birth to five 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 five 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. Often a skill such as naming states or even pinching a pencil is timed and charted on a celebration chart.

**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. Examples might include hand flapping, rocking, or dangling an object in front of the eyes.

**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 percent of the autistic children in his study group “recovered” from autism. The definition for “recovered” in this particular study included at least three 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).

