



LA FEAT

Families for Effective Autism Treatment
Los Angeles Chapter

Newly Diagnosed Parent Meeting

What is LA FEAT?

- LA FEAT is Los Angeles Families for Effective Autism Treatment
- LA FEAT is a non-profit parent support organization for families of children with Autism Spectrum Disorder (ASD).
- We provide
 - ❖ Parent support in the form of monthly meetings, informal coffees and newly diagnosed meetings
 - ❖ Parent education
 - ❖ Lists of local providers of various services related to autism
 - ❖ Guidance in navigating “the system” and getting your child services



Welcome!



- Introductions
- Overview of Autism and Related Disorders
- Where to start
- Effective therapies and services
- Navigating the system
- Know your rights
- Discussion



Autism Facts

- Autism is a neurological disorder affecting roughly 1 in 166 children.
- Every child with autism is different, and displays different symptoms and behaviors. Individuals may be mildly or severely affected; hence the term “spectrum.”
- Autism is four times more likely to affect males than females.
- Autism is diagnosed based on symptoms and behaviors displayed by the individual.
- There is no biomedical test for autism.
- The cause of autism is not known. Experts believe autism is caused by a combination of genetic and environmental factors.



Components of Autism

**Impairment in
Social Interaction**

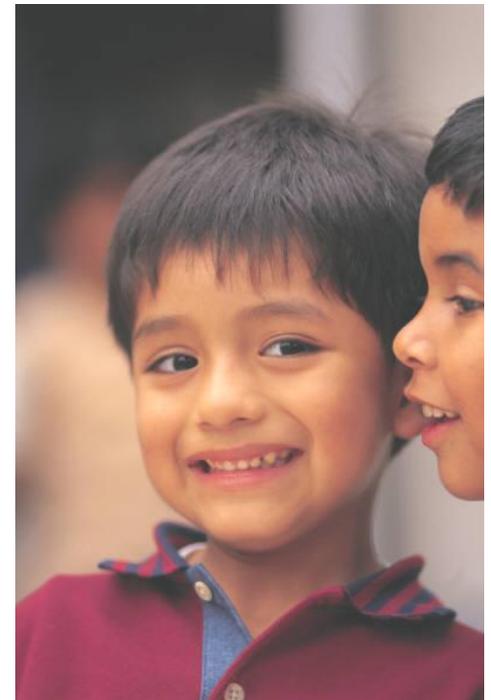
**Impairment in
Communication**

**Restricted, Ritual, or
Stereotyped Behaviors**



Impairment in Social Interaction

- Non-verbal behaviors: eye contact, facial expression, body language
- Failure to develop peer relationships
- Lack of sharing enjoyment, interests, or achievements with others (e.g. by a lack of showing, bringing, or pointing out objects of interest)
- Lack of social or emotional reciprocity



Impairment in Communication



- Delay in, or lack of, language development
- Impairment in the ability to initiate or sustain a conversation
- Stereotyped or repetitive language
- Lack of imaginative play or social play appropriate to developmental level



Restricted, Repetitive, or Stereotyped Behavior

- Restricted, repetitive, or stereotyped behavior
- Preoccupation with stereotyped or restricted patterns of interest
- Inflexibility; adherence to non-functional routines or rituals
- Stereotyped and repetitive motor mannerisms (eg hand-flapping, toe-walking, spinning, twisting)
- Persistent preoccupation with parts of objects



Related Disorders: PDD-NOS



- Pervasive Developmental Disorder Not Otherwise Specified
- Used when the individual has many symptoms of autism but does not meet all criteria
- Sometimes used when evaluator wants to avoid an autism diagnosis
- May not qualify for as many services as an autism diagnosis



Asperger's Syndrome

- The individual is impaired in social functioning and stereotypical behaviors are present, but there is no impairment in communication.
- Characteristics include:
 - concrete and literal thinking
 - obsession with certain topics
 - excellent memories
 - being 'eccentric'
- Considered high-functioning
- Capable of holding a job and of living independently.



Fragile X Syndrome



- A form of mental retardation in which the long arm on the X chromosome is constricted.
- Approximately 15% of people with Fragile X Syndrome exhibit autistic behaviors:
 - delay in speech/language
 - hyperactivity
 - poor eye contact
 - hand-flapping
- The majority of these individuals function at a mild to moderate level.
- As they grow older, their unique physical facial features may become more prominent (e.g., elongated face and ears), and they may develop heart problems.



Landau-Kleffner Syndrome

- Individuals appear normal until sometime between ages 3 and 7
- Good language skills in early childhood but gradually lose their ability to talk
- They have abnormal brain wave patterns which can be diagnosed by EEG during an extended sleep period



Rett Syndrome



- Degenerative disorder affecting mostly girls
- Develops between 6 months and 1½ years old
- Characteristics:
 - ❖ Loss of speech
 - ❖ Repetitive hand-wringing
 - ❖ Body rocking
 - ❖ Social withdrawal
 - ❖ May be severely to profoundly mentally retarded



Williams Syndrome

- Characterized by several autistic behaviors including:
 - ❖ developmental and language delays,
 - ❖ sound sensitivity,
 - ❖ attention deficits, and
 - ❖ social problems.
- But, unlike many autistic individuals, those with Williams Syndrome are quite sociable and have heart problems.



Terms you should know

- **Echolalia** – repeating words and phrases
- **Stereotypic behaviors**
- **Perseverative behaviors** – insistence on sameness, routines; also referred to as “rigidity”
- **“Stim” and “Stimmy”**
- **“Expressive” and “Receptive” language**



Getting Assessed

- Autism can be diagnosed by a clinical psychologist, or a neurologist or other physician specializing in developmental disorders.
 - Free multidisciplinary assessments are provided by your local Regional Center.
 - For children age 3 and older, your School District will also provide a free assessment.
 - **However**, we generally recommend obtaining an independent psychological assessment, depending on your child's needs.
 - LA FEAT has a list of local providers



Finding someone to assess your child

➤ Questions to ask:

- What is your background in autism?
- How long have you been doing assessments?
- How much do you charge?
- Do you work with insurance companies, the Regional Centers or School Districts?
- When can I expect to receive your report?
- Do you ever attend IFSP, IEP or other Regional Center or School District meetings to represent the needs of the child?
- What kinds of recommendations do you make for children with autism? Do you recommend certain therapies more than others? If so, what are they?



Components of a quality assessment

- Specific diagnosis (not preliminary or provisional)
- Developmental testing scores and analysis
- Direct observation of the child, preferably across environments (provider's office, child's home, school)
- Parent interview
- Teacher or therapist interviews
- Assessment of skill levels for each developmental domain (cognitive/academic, social, language, adaptive/self-help, motor, etc.)
- Specific treatment recommendations including number of hours of therapy per week



Diagnosed – What now?

- Join a parent support group
- Begin learning about the disorder and how it relates to your child
- Consider getting independent evaluations of your child
- Contact your Regional Center to begin the intake process
- If your child is over 3, contact your School District to begin the assessment process
- Contact ABA providers to get on waiting lists for services



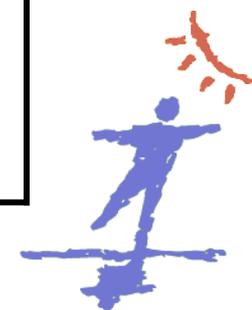
The Universe of Autism Therapies and Services

Behavior-based Therapies

- Applied Behavior Analysis (ABA)
- Discrete Trial Training (DTT)
- Natural Environment Training (NET)
- Verbal Behavior

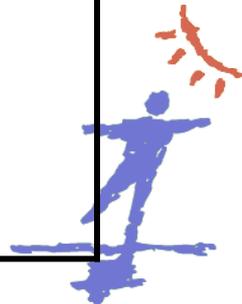
Developmental-based Therapies

- Floortime
- Relationship Development Intervention (RDI)
- Pivotal Response (has some behavioral elements)
- Son-Rise



The Universe of Autism Therapies and Services

Other therapies	Ancillary Therapies
<ul style="list-style-type: none">• Rapid Prompting• Facilitated Communication• Auditory Integration• PECS• Music Therapy	<ul style="list-style-type: none">• Speech Therapy• Occupational Therapy• Physical Therapy
	Biomedical Therapies <ul style="list-style-type: none">• Food elimination diets• Vitamin & nutrition supplementation• Chelation



Applied Behavior Analysis (ABA)

- Based on research done by Dr. Ivar Lovaas published in 1987
- Of 19 children treated with an intensive ABA program, 9 (47%) achieved a “best outcome” result of normal functioning in all areas, including IQ, making them “indistinguishable” from typical peers
- An additional 40% showed significant improvement, and only 10% made minimal gains
- Since 1987, there have been numerous studies conducted that back the efficacy of intensive ABA



The importance of early diagnosis and treatment

- It is likely 90% of children with autism who do not receive effective early intervention will require special or custodial care throughout their lives.
- Each year, millions of dollars are spent on autism therapies with no proven efficacy.
- Research has shown that effective early intervention for children with disabilities can reduce the need for specialized services later on.
- Cost effectiveness studies show that there are substantial cost savings over the long term if children receive effective, early intervention.



Parent concerns about ABA

- “It’s too intense”
- “He’s just a child. Why does he have to work so hard?”
- “I don’t want those people in my home”
- “ABA seems so unnatural”
- “I don’t like the idea of using food to reward my child”
- “Isn’t ABA like training a dog or a monkey? I want my child to be spontaneous. I don’t want my child to be a robot.”
- “I don’t want to fight with my school district or regional center.”
- “I’ve heard such great things about my school district’s program”
- “Won’t my child be isolated in a home program? I want her to be around other children.”
- My child is high functioning (or very affected). Isn’t ABA for children who are worse (or better) off than my child?”



Where are adults with autism today?

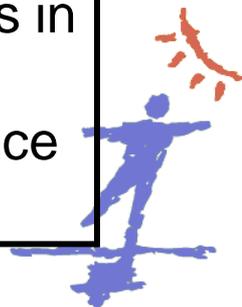
- 49% of adults are still living at home with their parents
- 33% are in residential care
- Only 3% live fully independently
- 8% live independently with support
- 12-14% are in full-time paid employment
- 65% report difficulty making friends
- 31% are in no social activities at all
- 72% have unusual or anti-social behaviors
- 56% have suffered from depression



Differences in outcomes: Intensive ABA vs. Eclectic

Therapy	Outcome
Intensive ABA: (25-30 h/wk for child under 3 and 35-40h/wk for child over 3)	Children showed significant improvement in virtually all skill domains
Eclectic: Public school autism classrooms, plus a variety of therapies (DTT, PECS, TEACCH, SI, speech therapy) for 25-30 h/wk	Mean scores in skill domains were substantially lower for this group than the first group, and showed losses in some areas over 14 month period.
General: Public school special ed programs for all disabilities, for 15h/wk	Negative mean change scores in multiple skill domains. No statistically significant difference between 2 nd and 3 rd groups.

**Howard et al, 2004, based on 14 months of intervention*



What is an effective intervention?

- Emphasis on skill development through positive reinforcement;
- Individualized based on the child's current skills and deficits; instructional objectives, teaching methods, pacing, skill sequences, and reinforcers are all customized to the characteristics and needs of each child;
- Addresses all skill domains;
- Uses frequent direct observation and measurement of individual performance to determine if progress is occurring, and adjusts instructional methods accordingly;
- Trains family members to participate in the program
- Is directed and supervised by individuals with postgraduate training in behavior analysis plus extensive hands-on experience in providing ABA intervention to young children with autism.

**Based on the research of Guralnick (1998) and Ramey and Ramey (1998).*



Some ABA terminology

- Probing – skill assessment
- Stimuli – “stuff” used to teach
- Reinforcement – activity, item or food that will motivate your child to learn
- Prompt – a supportive cue to help the child follow the instruction given (types: verbal, modeling, physical, gestural, positional)
- Drill – a discrete trial, from beginning to end

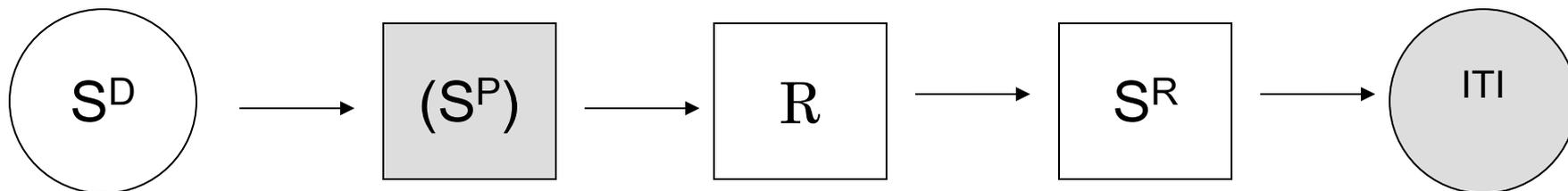


Learning in an ABA Program

- At home
 - ❖ Discrete trials (at the table, in various rooms of the home, outside)
 - ❖ Natural Environment Training (on the floor, throughout the home, outside)
 - ❖ Play dates with typical peers (supervised by trained aides)
- At school
 - ❖ Trained aides support the child's successful participation in the program (and recess, too!)
- In the community
 - ❖ Supervised practice going to the store, library, park, etc.
 - ❖ Support in community sports activities, summer camp
- Everywhere
 - ❖ A consistent, planned approach to handling challenging and self-stimulatory behaviors



The Discrete Trial



- the **discriminative stimulus** (S^D)-- the instruction or environmental cue to which the teacher would like the child to respond
- the **prompting stimulus** (S^P)-- a prompt or cue from the teacher to help the child respond correctly (*optional*)
- the **response** (R)-- the skill or behavior that is the target of the instruction, or a portion thereof
- the **reinforcing stimulus** (S^R)-- a reward designed to motivate the child to respond and respond correctly
- the **inter-trial interval** (ITI)-- a brief pause between consecutive trials



Advantages of the Discrete Trial

- Tasks are broken down into short, simple trials. This is helpful for children with attention difficulties
- Children are motivated to learn by using reinforcements that they respond to
- Clear, consistent teaching environment
- Planned approach to skill generalization
- Skills are explicitly taught, so children don't have to rely on observational learning
- Short, clear instructions benefit children with language difficulties



Analyzing Behavior

- The goal is to find out what the purpose or function of the behavior is, not just to describe what the behavior looks like
- A behavior might serve one or more of these functions:
 - ❖ Task avoidance
 - ❖ To get attention
 - ❖ To get a specific item
 - ❖ Sensory pleasure or avoidance of discomfort



Analyzing Behavior

- **ABC:**
 - ❖ **Antecedent** – what happens immediately before the behavior occurs
 - ❖ **Behavior** – description of the behavior itself
 - ❖ **Consequences** – what happens immediately after the behavior (reinforcement)
- Frequency – how often the behavior occurs
- Duration – how long it lasts
- Intensity



Behavior Strategies

- Extinction
- Manipulation of the environment, antecedents, and reinforcement
- Teaching alternative replacement behaviors that are more acceptable
- Premack Principle: first my way, then your way
- Token systems
- Shaping – reinforcing successively closer approximations of the desired behavior
- Chaining – linking of component behaviors into a more complex behavior



Components of a Quality ABA Program: Intensity

- Analysis of recent studies shows that there is a correlation between the number of hours of intervention and the outcome of the therapy.
- Programs that are more intensive in hours produce better and longer lasting results.
- Research indicates that 40 hours per week is appropriate for the majority of young autistic children.
- An ABA provider should make recommendations for hours based on research and the child's needs, not what the school district or regional center is willing to fund.



Learning in a 1:1 environment

- Because many young autistic children lack the social and communication skills necessary to be successful in a group environment, the ABA provider often will begin teaching skills in a one-on-one setting, typically in the home.
- After the skills are learned in that setting, they are generalized to other settings, such as school and the community.



Program addresses all developmental domains

- An effective program will address all aspects of the child's disability:
 - ❖ Communication
 - ❖ Attention
 - ❖ Social
 - ❖ Play
 - ❖ Gross motor/Fine motor
 - ❖ Adaptive/Self-help
 - ❖ Cognitive/Academic skills
 - ❖ Behavioral challenges
- Targets for each area should be developed based on the child's individual strengths and deficits in each area.



Emphasis on generalizing skills

- Generalization means that the child can perform a particular skill in any environment, with any person, objects or instructions.
- A quality ABA program has a systematic, continuous plan for generalizing skills learned in the therapy room.



Quality Supervision

- Supervisors should meet regularly with the parents and aides regularly to discuss the child's progress, identify new areas of strength and weakness, and adjust the program curriculum.
- Supervisors should have experience and education in ABA and should work with either a PhD level psychologist or Board Certified ABA Therapist in developing the child's program.



Data Analysis

- ABA is a data-driven treatment.
- The program should regularly record, review and analyze data related to the child's progress in the program.
- The results of this analysis should be used to develop an individualized curriculum and behavioral strategies for the child.



Goal is independence in a typical setting

- In a quality program, the goal is to increase the skill levels of the child to the extent that the program is no longer required in order to maintain success in a typical setting.
- While this is not a goal that can be realized by all autistic children, the ABA provider should be building skills to achieve independence to the maximum extent possible.



Can you really do 40 hours per week with a young child?

- Yes!
- Remember, not all hours are spent at the table.
- The child can do ABA while dressing, eating, or playing at home, at the park, in a store
- Hours in school (with an aide) are included in the total
- Most programs have at least one shift on Saturdays
- Overall, ABA should be a fun, rewarding experience for your child



How do I get this program?

- Contact local ABA providers and request information about the intake process
- Ask to be placed on any waiting lists
- Talk to the different providers to find out which one meets your needs best. Each provider has their own “personality”.
- Learn about your child’s rights under IDEA and the Lanterman Act to receive appropriate services that meet your child’s needs



Getting Funding: If your child is under age 3

- You can get services through the Early Start Program
- Mandated under the Individuals with Disabilities Education Act (IDEA)
- Provided through Regional Centers
- Eligibility is determined through assessment by a multi-disciplinary team of qualified individuals
- Services provided include special instruction, speech therapy, occupational therapy, physical therapy, respite and other services, depending on the child's needs.



Getting Funding: If your child is over age 3

- Both the school district and the regional center have a responsibility to provide services



School District Responsibilities

- To provide a “Free Appropriate Public Education” or FAPE
- Free means that all services and supports in the IEP are to be provided without charge to the families
- Services must be based on the individual needs of the child, not the child’s disability
- Districts must provide a “floor of opportunity” in which the child can obtain “meaningful educational benefit”
- Districts are not required to provide the best possible program
- Students must be educated in the “Least Restrictive Environment” or LRE
- Governed by Individuals with Disabilities Education Act (IDEA)



Regional Center Responsibilities

- Provide services and supports that will allow people with disabilities to have the “most independent, productive and normal lives possible”
- Standards under Lanterman are higher than those under IDEA
- Must provide “unmet needs” that are not addressed by the school district
- But, parents must attempt to secure services from the school district before the regional center is required to provide
- Regional Centers are required to advocate for services from the school district and any other “generic” funding sources



Preparing for your IFSP or IEP Meeting

- Gather all current reports on your child's current skills, strengths and deficits
- Make some notes on areas you think should be targeted in your child's goals in each developmental domain, if appropriate.
- Make a list of the services you want for your child and how you want those services to be provided (eg through a specific agency, the school district, etc.)
- Consider obtaining independent assessments to support your requests for services
- Bring a friend, advocate or attorney with you to the meeting



Final Thoughts



Questions and Answers

