Families for
Early Autism Treatment

Dedicated to Effective Treatment for All Children and Adults with Autism • *feat.org*

Dear Parent:

Welcome to **Families for Early Autism Treatment**. We trust you will find useful information included with this letter that will assist you in your journey to learn more about autism and to obtain best outcome treatment and services for your child.

The issues for children with Autism Spectrum Disorder (ASD) are complex. New parents, as well as seasoned FEAT parents, are in a constant learning and coping process to navigate daily life while fighting hard for their child's right to receive best outcome treatment and support.

The criterion for the autism diagnosis has changed with the introduction of the DSM-5 threatening to eliminate services for as many as 40 percent of individuals with autism. Finding affordable quality Applied Behavior Analysis (ABA) therapy is an ongoing challenge. Parents encounter daily obstacles from school districts, insurance companies, even well-meaning family members.

Families for Early Autism Treatment (FEAT) is a non-profit volunteer driven organization of parents, educators and treatment professionals dedicated to providing Education, Advocacy and Support for the Northern California autism community. FEAT was founded in 1993 by parents and professionals to bring best outcome treatment to the Greater Sacramento area. Services and assistance are provided by parent volunteers who have children or grandchildren with autism. FEAT's goal is to ensure that all individuals with autism can live with their family, maximize their potential, avoid institutional placement, and live as independently as possible.

With the new CDC statistics of **one in 50 children** now affected by autism, FEAT must fight even harder for our children's right to Free Appropriate Public Education (FAPE) and to address the daily pleas from local families for guidance and support.

To understand the mission of FEAT, please read the following pages of this information packet.

Sincerely,

The Families and Board Members
Families for Early Autism Treatment - FEAT

Online Links to FEAT & Autism Advocacy Information

Thank you for your interest in Families for Early Autism Treatment (FEAT). For general information about autism, or if you are new to FEAT:

- Visit our website
- Join FEAT's Facebook page
- Wrightslaw answers your special education legal questions and maintains a comprehensive Question & Answer library by topic

DISCLAIMER: *The information and resources provided by FEAT are for educational and informational purposes only. It is not a substitute for care or advice from a professional.*

About Families for Early Autism Treatment—FEAT

EDUCATION

- FEAT informs and educates via Website, Parent Resource Book, Newsletters and FEAT-News
- Each month, FEAT's Family Resource Meeting is a forum for varied topics to keep parents current on best-outcome, scientifically proved treatments; advocacy and legislative issues; insurance reform; and to give parents opportunities to develop a network of support
- FEAT's conducts Parent Workshops periodically to provide in depth education
- FEAT's Lending Libraries provide a variety of free resources, including treatment supplies and reading materials

ADVOCACY

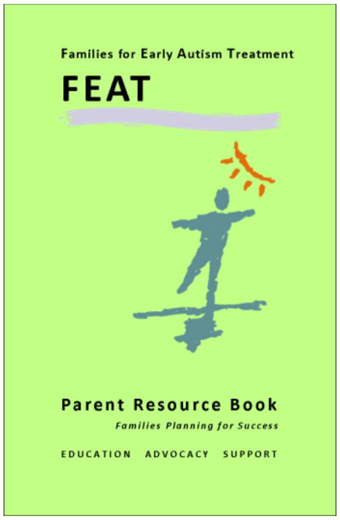
- FEAT's goal is to ensure that all individuals with autism have the opportunity to live with their family, to maximize their potential, to avoid institutional placement, and to live as independently as possible
- FEAT's Volunteer Parent Coach Program teaches parents how to become their child's best advocate
- FEAT actively represents the autism community on many key, statewide autism committees that shape legislative and agency policy affecting services and support for your child

SUPPORT

- FEAT plans and underwrites Family Events like the *Annual Pool Party*, *Film Screenings* and *Bishop's Pumpkin Farm* to keep costs low and to provide families (who are often isolated) with opportunities to make new friends. The annual FEAT Walk/Spring Carnival is also a family favorite event and fund-raiser.

Services include:

1. FEAT Website: feat.org
2. FEAT Volunteer Parent Coaching Meetings
3. FEAT News: Meeting Notices and Advocacy Updates via Constant Contact Email
4. FEAT Family Events (Annual FEAT Walk/Spring Carnival; Pool Party; Bishop's Pumpkin Farm)
5. FEAT Lending Libraries – Free



FEAT's Parent Resource Book is online at **feat.org. Printed copies are out of stock.**

Search Documents at feat.org to find answers to frequently asked questions about Autism Spectrum Disorder along with information about greater Sacramento's Advocacy, Meetings, Public Service Agencies, Compliance Complaints, Special Education, Other Education Options, Therapy Providers, Consultants, Attorneys, Nutrition, Biomedical, Medical, Dental, Community Programs, Learning Activities, Sports Recreation, Faith Based Services, Recommended Books, Diagnostic and Statistical Manual excerpts, and quotes from FEAT parents.

Families for Early Autism Treatment

The earlier the treatment
The better the outcome

FEAT

What is Autism?

Autism affects one in 50 children.

Autism is a complex neurobiological spectrum disorder encompassing Autistic Disorder, PDD NOS and Asperger's Disorder. Children do **not** grow out of Autism Spectrum Disorders.

Autism occurs in all racial, ethnic and social groups and is four times more likely to strike boys than girls.

Autism impairs a person's ability to communicate, understand and relate to others socially and emotionally.

Autism is also associated with unproductive repetitive behaviors; sensory sensitivities to light, smell, sound and touch; eccentric behaviors and rigid routines; preoccupation with subjects and obsessions such as obsessively arranging objects.

Symptoms can range from more moderate to profoundly severe. Autism in all degrees of severity typically results in functional disability.

How does Families for Early Autism Treatment help?

Education: We educate families about best-outcome treatment and increase public awareness by providing information about Autism prevalence, incidence and variance.

Advocacy: We advocate for children with Autism while training their parents to become their most informed and effective advocate.

Support: We provide resource groups and social activities for children with Autism and their families. FEAT supports children, young adults and adults who are living with Autism.

Why early and continuing intervention?

Simply stated, the earlier the treatment, the better the outcome. Every day that passes without treatment permanently diminishes the likelihood of independent living. Without early intensive treatment, children with Autism are unable to function in the world around them.

The goal of providing early intensive treatment is to assure that all individuals with Autism have the opportunity to live with their family, to maximize their potential, and to avoid an institutional placement.

Autism can be treated. If you suspect Autism, urgently contact your doctor and the **Alta California Regional Center at (916) 978-6400** for a diagnostic assessment.

For more information, visit www.feat.org
or call FEAT at 916/303-7405

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FEAT's United Way Number: 3180

> *"If it hadn't been for FEAT guiding me through this process of getting help for my child, I would never have heard those three precious words, I love you!"*
>
> FEAT Parent

FEAT Volunteer Opportunities

Since 1993, local parents and extended family members of children with autism have gone beyond the boundaries of their challenging home life, demanding jobs, and practically non-existent free time to do the work of FEAT.
For more information, contact: Margala Woods (margala.woods@feat.org).

FEAT needs caring people to step into these volunteer roles:

- Summer Pool Party
- Bishops Pumpkin Farm
- Film Events
- FEAT Walk & Spring Carnival

Assist with upcoming FEAT information/outreach booths:

- United Way Awareness Events
- PIG Bowl
- Community Awareness Fairs

FEAT Family Resource Meetings
(Monthly meetings at Shriner's Hospital Auditorium or Kiwanis Family House, Sacramento)

- Participate with planning and/or assist at Meetings
- Purchase/provide refreshments (Reimbursed by FEAT)

Regularly attend and take notes at:

- Public agency community meetings (Regional Centers, School Districts, State Agencies)
- Capitol meetings/hearings

Regularly video and/or audiotape at:

- Public school board meetings, committee meetings, disabilities agency meetings

FEAT Website Needs:

- Develop and maintain a calendar of all local meetings and send to the FEAT webmaster for posting
- E-Scrip volunteer

Other:

- Assist FEAT Librarians with organizing resources for Parents
- Proofreading publications such as the FEAT Parent Handbook
- Fundraising

Ways to Generously Give to FEAT: ***(FEAT is a 501 C3 all donations are tax deductable.)***

- Donate online at feat.org
- Mail your tax-deductible check to:
  FEAT, P O Box 255722, Sacramento CA 95865-5722
  You will receive receipt/Tax ID information
- Give through United Way - FEAT No. 3180
- Ask your employer to match charitable donations
- Make a donation in honor or memory of a birthday, wedding, anniversary or other special event
- Make a monthly or quarterly gift to FEAT—maximize your gift and minimize the effect on your budget
- Support corporate sponsors and businesses who have donated to FEAT, so they can afford to continue their support
- Plan garage sales or events to raise funds on behalf of FEAT
- Remember FEAT in your Estate Giving

FEAT's Basic Expenses —"Just to Keep the Lights On"

Insurance:	$2100
Accounting, Tax Preparation, Government Required Forms, Professional Audit:	$9400
Website, Telephone, Fax, Postage:	$5880
Meeting Space:	$1100
Professional Memberships	$1475

This is only the beginning of FEAT's annual expenses and does not include Family Resource Meetings, Family Activities, Newsletters, New Family Welcome Materials, Lending Libraries, Awareness Events, Parent Resource Books, Parent Training, Advocacy Training, Parent Coaching, and many other vital community advocacy and outreach activities; as well as the thousands of hours provided at no cost by FEAT volunteers.

- ***Did you know*** that everyone serving on FEAT's Board of Directors is a volunteer parent with children who have autism?
- ***Did you know*** that instead of paying for office space, FEAT's Board Members, Parent Coaches, Volunteers and Program Assistants work from home?
- ***Did you know*** that FEAT relies on private donations and does not receive federal or state funding? Your regular support is essential to services that are not provided anywhere else.

Consider this: One Volunteer FEAT Parent Coach's time to coach a new family for meetings requires 2-3 hours of preparation, 2-3 hours of telephone consultation, and 3-4 hours or more to attend meetings as well as costs for gas and child-care for their own children. Although FEAT provides advocacy training and access to advocacy coaching free of charge to its member families, these services cost real money. (A professional advocate can charge as much as $150/hour.)

Your donations, no matter the amount, provides direct help for children and families just like yours.

Make your tax-deductible donation online today at feat.org

NEW PARENT CHECKLIST

Autism Spectrum Disorder (ASD), or Autism, includes Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Disorder also known as Asperger's Syndrome (AS).

☐ Join FEAT. (Email askfeat@feat.org and request the **JOIN FEAT** form.)

☐ Read the **FEAT New Parent Information packet and the FEAT Parent Resource information on www.feat.org**.

☐ **Read Special Education Rights and Responsibilities, Chapter 1 Information on Basic Rights**

☐ **If you have any questions or problems with your child's school read Chapter 4 Information on IEP Process and any other relevant chapter(s)**

☐ **For all other questions, including regional center, health benefits, IHSS, social security go to DRC Publications List and read the applicable publication.**

☐ Attend monthly FEAT Family Resource Meetings which hosts informative presenters and a variety of topics. This is the best opportunity to network and receive and share valuable support and advocacy information from other FEAT parents.

☐ Obtain a diagnosis using best practice guidelines for your child from a developmental pediatrician or a clinical psychologist.

☐ If you already have a diagnosis, consider getting a confirming diagnosis that is developmentally based.

☐ Video tape your child's behavior for diagnoses documentation.

☐ Get Insurance denials in writing.

Arrange for evaluations and services with the following public agencies:

☐ The School District where you reside (if your child is three years old or older.)

☐ Alta California Regional Center

Important! Parents of babies please read: AFTER JUNE 30, 2009, THE CRITERIA FOR ELIBILITY FOR TODDLERS 24 TO 36 MONTHS TO RECEIVE EARLY INTERVENTION SERVICES WILL BE SIGNIFICANTLY MORE RIGOROUS AND IT WILL BE MUCH MORE DIFFICULT TO QUALIFY. THEREFORE, IT IS IMPERATIVE FOR FAMILIES, CHILD CARE PROVIDERS AND HEALTH CARE PROVIDERS, ESPECIALLY PEDIATRICIANS, TO BE VIGILANT. After July 1, 2009, any infant or toddler with a suspected delay will need a written referral to the regional center. The date on the referral will be the date that is used for evaluation purposes and to apply the criteria. For example, if the child is referred at 23 months old, but the evaluation period is not complete until the 25th month, the lesser criteria of 33% delay in one developmental area applies.

Unfortunately, if the child is referred at 24 months with the evaluation taking place in the 25th month, the more strict criteria of 50% delay in one developmental or 33% in two or more areas is applied. Note that the underlined wording below is the new, stricter eligibility criteria:

Infants and toddlers with a developmental delay in one or more of the following five areas: cognitive development; physical and motor development, including vision and hearing; communication development; social or emotional development; or adaptive development. Developmentally delayed infants and toddlers are those who are determined to have a significant difference between the expected level of development for their age and their current level of functioning. This determination shall be made by qualified personnel who are recognized by, or part of, a multidisciplinary team, including the parents. A significant difference is defined as a 33% delay in one developmental area before 24 months of age or, at 24 months of age or older, a delay of 50% in one developmental area or a 33% delay in two or more developmental areas.

☐ **Document, Document, Document! Purchase two binders with dividers.** Label one ACRC, and the other the name of your school district. Record EVERY interaction with both agencies, including: the date and time, with whom you spoke, their title, all pertinent details of the conversation, questions you asked and answers the answers you received, as well as a summary of the conversation.

It is a good idea to put all of the above information in an email and send it to the person with whom you spoke. If they do not reply with any additions or corrections to your email, your email then becomes the record of that conversation. If they reply, and if you disagree with anything in their reply, reply back and reiterate your understanding of the conversation. Ask for further clarification if necessary. Whenever you leave a message, record the time, date, and for whom.

Be sure to monitor whether your messages are being returned. If not, call that person's superior and report the dates/times messages were left, including going all the way up to the Executive Director at ACRC or the Superintendent of your school district if necessary.

When possible, all correspondences should be done via email or letter, and print out the emails for a section in your binder that tracks a written record of all communications with both agencies. This becomes an ongoing permanent documentation for future use.

☐ Contact your local school district (Age three or older)

Request, in writing, specific comprehensive evaluations/ assessments in all areas of suspected disability to accurately establish baseline functioning and identify appropriate services:

☐ Communication—including expressive/ receptive and pragmatic (social) language

☐ Functional skills assessment—including daily living skills, self-help skills, group participation skills, play skills, community access skills.

☐ Occupational Therapy/ Sensory Integration (OT/ SI)—including handwriting

☐ Assessment to plan for a 40 hour per week comprehensive ABA participation program. This assessment should be done by a qualified behavior analyst with extensive experience in the effective, research-backed treatment of autism.

☐ Fine and gross motor skills assessment including assessment for Dyspraxia or Apraxia.

☐ Social-Emotional Functioning

☐ Pre-Academic and Academic—including visual-auditory processing.

☐ Learning Style

☐ Executive Function which includes organizational and planning abilities, working memory, inhibition and impulse control, self-reflection and self-monitoring, time management and prioritizing, understanding complex or abstract concepts, and using new strategies.

When signing the consent to an assessment plan, be sure to add to the document near your signature, the following in writing, "Please provide all written assessment reports, including subtest scores, and any other documents to be considered in the IEP meeting, one week prior to the scheduled IEP date."

Retain a legible copy of the signed assessment plan.

Know your legal rights BEFORE attending Individualized Education Plan (IEP), Individualized Family Service Plan (IFSP), and Individual Program Plan (IPP) meetings.

☐ **Read Autism: Asserting Your Child's Right to a Special Education by David Sherman. (Complimentary copy available upon request: Email margala.woods@feat.org)**

☐ Read **Special Education Rights and Responsibilities, Chapter 1 Information on Basic Rights**

☐ After reading the above, talk with your FEAT parent coach.

Consider the following before attending the Individualized Education Plan (IEP), Individualized Family Service Plan (IFSP), and Individual Program Plan (IPP) meetings.

☐ Give 24-hours written notice for audio recording of the meeting. A short email is sufficient.

☐ Take home a legible copy of the school IEP or Regional Center IFSP (under three years old) or IPP meeting documents and read carefully before agreeing to any portion. You may sign and agree to some, all or none of the services offered in the meeting document. Agreeing to some services is called signing "with exception."

1. **You do not have to sign anything. You may sign the meeting document "in attendance only" at the end of the meeting.**

2. Carefully consider the services offered, obtain additional information if needed, consult with a FEAT Parent Coach, bring your document to a FEAT parent meeting for input and then prepare your written response to the services offered indicating areas of agreement and disagreement, making sure that the services provided are evidenced-based to meet the child's unique needs in the least restrictive environment, which means living and learning with typical peers in school and in the community. You may bring anyone you want to the meeting. It is strongly recommended that you bring a friend, relative, or another parent to take notes and to offer you support.

3. You can attach a "parent addendum"- often a parent submits information or writes his/her own version of the IEP meeting notes in this form. In order to assure that this input becomes part of the IEP legal document, it should be referenced on the signature page, i.e. something like "see parent addendum/attachment titled/dated and incorporated by reference"

☐ Contact your family health care provider to monitor the overall health of your child.

UTILIZE the following websites and free resources:

Wright's Law Website:

http://www.wrightslaw.com/ Parents, educators, advocates, and attorneys go to Wrightslaw for accurate, reliable information about special education law, education law, and advocacy for children with disabilities.

Begin your search in the Advocacy Libraries and Law Libraries. You will find thousands of articles, cases, and resources about dozens of topics:

DRC Publications List

Leginfo.ca.gov also has current legislation and all chartered laws in easily accessible/searchable format

National Autism Center's National Standards Project
http://www.nationalAutismcenter.org

NY Dept. of Health Early Intervention Program www.health.state.ny.us/nysdoh/eip/index.htm

Cambridge Center for Behavioral Studies-
www.behavior.org/Autism

ABA Qualification Resources:

Behavior Analyst Certification Board-
www.BACB.com

Association for Behavioral Analysis Autism Special Interest Group Consumer Guidelines-
http://ww.apbahome.net/guidelines_consumer.php

Choosing a quality Applied Behavior Analysis (ABA) program for your child with Autism is perhaps one of the most important steps you can take in ensuring that he or she meets their maximum potential. FEAT suggests that you use the following guidelines in selecting a program that best meets your child's needs.

Intensity & Best Outcome Treatments
Quality intervention is intensive in number of hours of treatment. Studies show that there is a correlation between the number of hours provided and outcome. In other words, more hours typically produce better results. For the majority of young children, this requires 40 hours per week of 1:1 intensive treatment, typically in the home. ABA treatment hours are not equivalent to treatment hours in other therapies or at non-ABA, 1-1 school or special education group programs.

As children learn the skills that allow them to be successful in group environments, they should be provided opportunities to utilize these skills in social and community settings ("generalizing").

High quality providers recommend best outcome treatments regardless of funding agency demands and maximize the number and types of opportunities to learn and respond. Quality providers know and utilize the concepts and specific curriculum for best outcome ABA programs.

ABA Program Design LINK:
http://www.thelovaascenter.org/index.php?pname=about%20lovaas%20aba%20for%20Autism

Best Outcome Research LINK:
http://www.thelovaascenter.org/index.php?pname=research%20supporting%20lovaas%20aba

Professional Ethics & Confidentiality
Quality providers never reveal personal information about the individual or family without express consent from parents. Their primary obligation is to the client and family, thus they ensure confidentiality when dealing with school districts, funding providers, insurance providers, and all other business relationships.

Quality providers never give up on individuals receiving treatment and provide support throughout the lifespan. They never blame the child or family for lack of progress and take responsibility for treatment success. They recommend treatments when the individual can benefit from treatment, regardless of arbitrary factors such as age, I.Q., or functioning level. Quality providers do not act as expert witnesses for funding agencies or insurance companies in due process complaints or appeals against an individual or their family.

Quality providers recommend and provide best outcome treatment regardless of legal and/or funding limitations.

Developmental Domains & Supervision
Effective ABA programs address each aspect of a child's disability including: communication, social, play, self-help, cognitive and academic skills, and behavioral challenges. Quality providers develop goals to address each of the individual child's needs, strengths and weaknesses in lockstep with parents. They

regularly review goals and progress with parents and aides, and seek immediate solutions when something is "not working". They identify new areas of strengths and weaknesses on an ongoing basis and adjust the program curriculum continually with the ultimate goal of increasing skill levels to maintain independent success in a typical setting. Supervisors in quality programs should have education and experience in ABA and should themselves be supervised by a PhD level psychologist and/or Board Certified ABA Therapist in the development and ongoing review of an individual's program.

Data Analysis

Quality ABA programs are data-driven and regularly record, review, and analyze data related to an individual's progress. Data can include duration, intensity, and frequency of the desired and undesired behaviors and is specific and measurable. Data does not include anecdotal information such as "He did well today and was happy" or "She is making lots of friends at camp." Data must be recorded by someone trained to look specifically at the individual child's goals and needs. In other words, this person must be knowledgeable about your child and Autism Spectrum Disorders.

The Professionals

The most important aspect of a quality ABA program is the people who work on your child's behalf. They must strive for the highest quality of life for the individual with Autism so that he or she can thrive both within the family and community. The provider knows that they are privileged guests in the individual's life and home and acts with that in mind. The provider is appreciative of the opportunity to work with your child and never oversteps their area of discipline. A quality provider does not provide recommendations, commentary, judgment or obstacle to any other treatment for any illness, medical issue or disease of the individual. A quality provider supports the physical health of the individual.

Next Steps

If you have researched and selected one or more potential ABA providers and would like to further discuss choosing the best program for your child, you can email *connect@feat.org*

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DSM-IV Criteria

Pervasive Developmental Disorders
(also known as Autism Spectrum Disorders)

299.00 Autistic Disorder

An autism screening tool must meet all three primary areas defined by the DSM-IV description for autistic disorder (#'s 1-3 under A below) to qualify for a positive rating from First Signs:

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication, as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)

(d) persistent precoccupation with parts of objects

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

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

PROPOSED DSM-V- As Made Public by the APA in 2012

American Psychiatric Association DSM-5 Development (Retrieved from www.dsm5.org)

Autism Spectrum Disorder

Must meet criteria A, B, C, and D:

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,
2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).

2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).

3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning.

Severity Levels for ASD

Severity Level for ASD	**Social Communication**	**Restricted Interests & repetitive behaviors**
Level 3 'Requiring very substantial support'	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 'Requiring substantial support'	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest.
Level 1 'Requiring support'	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Rituals and repetitive behaviors (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

Social Communication Disorder

A. Social Communication Disorder (SCD) is an impairment of pragmatics and is diagnosed based on difficulty in the social uses of verbal and nonverbal communication in naturalistic contexts, which affects the development of social relationships and discourse comprehension and cannot be explained by low abilities in the domains of word structure and grammar or general cognitive ability.

B. The low social communication abilities result in functional limitations in effective communication, social participation, academic achievement, or occupational performance, alone or in any combination.

C. Rule out **Autism Spectrum Disorder (ASD)**. Autism Spectrum Disorder by definition encompasses pragmatic communication problems, but also includes restricted, repetitive patterns of behavior, interests or activities as part of the autism spectrum. Therefore, ASD needs to be ruled out for SCD to be diagnosed.

D. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).

Individualized Education Plan—IEP

By Nancy Fellmeth, President

Another school year has begun, and with it will come changes that can be exciting, scary or both. The planning for this school year should have begun before the end of the last one, with an **Individualized Education Plan IEP** to review present levels of performance and agree on challenging, realistic and measurable goals with appropriate services and supports. The school year will look different for each child, but ensuring that their irreplaceable time is effectively used is important regardless of placement, services or goals. Even with careful planning, once your child is out of your sight in school, there are many factors over which you have little control, so constant communication is needed with the staffs who work with your child.

If you have an in-home ABA provider, cooperation between the home and school staffs is imperative. At the pre-school and elementary school level this teamwork is logistically easier than in middle or high school when the child usually has multiple teachers. How do you establish this collaboration? Always communicate daily with your child's instructional assistant (IA) to gain objective information, ideally in the form of data. If your child's IA is a part of your in-home ABA services, this information should be shared with the team that covers any after school therapy. A notebook, which can be sent back and forth, works well. Vague notations such as "he had a good day" or "his behavior was bad" are not helpful because they lack any specific data against which change can be measured and fail to note observed or hypothesized antecedents, do not identify the behaviors that were "good" or "bad" and leave out the consequences. Helpful information from the IA will also include frequency and duration data for behaviors, both those you are trying to increase and decrease. Especially at the beginning of the school year, it's critical to speak with the teacher (s) at least weekly, and convene regular meetings of your entire team from school and your in-home providers, even if it's by phone conference. This way you are more likely to catch problems early so a new plan can be designed to address them. Will all school districts be willing to do this? No, but it should still be documented in the notes of the IEP that you asked for this collaboration.

Preschool

For many of our families, this year is your first school experience for your child, or perhaps for your family. A pre-school setting for some portion of the day is usually the first "transition". In California, from the perspective of the public school and Alta, this should happen at age 3, since this is when IDEA kicks in to share the funding of services between these two public agencies. Your child is not required to be in school until they are 6 years of age, and should only attend pre-school when they have enough prerequisite skills to benefit from the experience. The classroom should be teacher directed, not child directed, because that is the structure of most elementary schools and because children with Autism lack the social, play and language skills to benefit from unstructured activities. A classroom with a consistent routine and strong teacher control is important. Positive behavior and language models can be beneficial to all of our children, especially those that have strong imitation skills. The converse is that they will imitate poor behavior as well, since that often receives more attention in the classroom than the appropriate behavior. Therefore, it's important to select a teacher, regardless of the grade, who uses positive behavior strategies, thus recognizing and reinforcing appropriate behaviors

For many FEAT families, this occurs when the child moves from a 40 hour/ week in-home ABA program into typical pre-school for some part of the day, accompanied by their ABA tutor. This plan benefits the child because it maintains the consistency of the ABA teaching methodology. The tutor understands of the child's skills across all goal areas and many environments, and there is follow through in areas of need once the child returns home to continue the in-home hours. If you are fortunate to live in a school district that places the benefit for the child above the convenience or control of the school district, then your first school experience will be more collaborative than combative. It is a pleasure to work as a part of an IEP team that actually follows research-based programming recommendations, concerned with the long range benefit to the child, the family, the community at large. However, for many families, their IEP to transition to pre-school will be dominated by school district directives rather than well reasoned discourse. Rather than a true continuum of options, as the IDEA mandates, you will be offered the district or county Autism classroom which is not based on any peer-reviewed research and for which there are no corroborated outcome measures. The staff is not required to be highly trained and experienced in implementing scientifically backed Autism treatment. The school district, who is just getting to know your child through reports and some brief assessments, is proposing to radically alter the existing ABA program by adding a second set of instructors, differing expectations, goals that don't necessarily mesh with those of the intensive in-home ABA program and behavioral strategies that are not required to be designed or monitored by a Board Certified Behavior Analyst. There is no evidence to support an eclectic program as effective Autism treatment.

For a variety of reasons, other families may not have participated in an early intervention ABA program and so when they consider placing their child into a district or county designed Autism classroom they need to consider that this is the only service their child will receive, and it is generally only 15-20 hours per week, which is below the minimum of 25 hours per week that is recommended by the National Research Council. FEAT recommends that these families contact their Alta case worker to begin an in home ABA program in addition to the school district program, after which they can evaluate the effectiveness of each program and decide how to proceed.

Do not agree to any special education classroom until you have visited and have considered these questions. Are there enough 1:1 teaching opportunities to keep your child on a catch-up trajectory with his typical peers? If there is 1:1 discrete trial teaching, how much time is recommended for your child and is the staff trained and monitored for correct procedure? Are classroom transitions and directions given via icon strips rather than oral directions, is that how your child functions in their in-home program or within your home or the community? If your child communicates using PECS, who trained the staff, and is PECS used throughout the day for all communication? If your child is verbal, how much of the classroom is focused on verbal communication? How many of the other children are verbal? How are inappropriate behaviors managed? If the home program has already introduced play dates with typical peers, are typical peers available as part of the district Autism class and if so, how are the interactions facilitated?

If you feel that the district's Autism classroom is an appropriate way to use 15-20 hours of your child's day, you may have avoided a battle with the district, but you are far from being able to sit back and relax. If this is in addition to your in-home program, you need to keep close track of any skill regression, behavior excesses, slowing of skill acquisition, falling further behind typical peers, or any other adverse changes that could result from two sets of expectations and a fragmented treatment program. If this is your only program, is progress against the objectives being reported in an objective, data driven manner? Are any of the skills being generalized to the home? Is it easier to go out into the community with your child? Is your child more communicative with you? Has your child picked up inappropriate behaviors from the other children in the classroom? Do you feel that the teaching is individualized for your child?

Kindergarten

The transition into Kindergarten involves critical choices that are likely to set the course for the remainder of elementary school. Do you include your child with typical peers in a regular education classroom, or opt for a special day class (SDC), where the classmates all have disabilities, though not necessarily Autism? This depends on what you value from the educational experience , what kind of supports you already have in place, such as an in-home ABA program; whether your child has a peer group, the attitude of your neighborhood school toward inclusion of children with Autism spectrum disorders, and your child's abilities and anxiety level. If you feel that your child could benefit from the social aspects of the school day, but could not keep up with the academic parts, you can opt for partial inclusion. For inclusion to be effective, our children require a 1:1 instructional assistant (IA), who is trained in Autism and experienced working with children who function at your child's level. If you have an in-home ABA provider, a tutor from this program is an appropriate aide because of the consistency, familiarity and follow-through with the in-home program. Kindergarten is usually your child's first experience in the neighborhood school and it needs to be a success. A district aide who is not a part of your in-home ABA program is not familiar with your child or the way he has learned, will splinter your ABA program into two parts and reduce the effectiveness of the proven ABA methodology. If your only option is a district aide, insist on one that has been trained in the fundamentals of Autism treatment and behavior strategies. Also, build in cross training with your ABA provider, with criteria to evaluate when the district aide can function independently, and then schedule consultations between your ABA provider and school staff. Make certain this is written into the IEP.

By kindergarten, some families feel that their child could not keep up with the pace of a regular education setting, either academically or socially. The rationale for a special day class is that the teaching is supposed to be tailored to the disability. Before considering this offer, consider what methodologies and experience the teacher and staff have with children like yours. Is the curriculum structured to address your child's unique needs or is it just a slower version of the regular curriculum? If your child has done well in typical peer interactions, what are the opportunities for facilitated activities with typical age peers? If your child lacks social skills, how is this addressed in the SDC? How is progress measured and reported?

Grade School

After kindergarten, the ante gets raised higher with each grade level. The amount of written and auditory material increases and the visual cues decrease. If your child is a visual learner, has an auditory processing delay or difficulty with reading fluency or comprehension, the challenges will increase each year. However, your child has the legal right to necessary supports to allow him to access the regular education curriculum. This could include a 1:1 aide; pull out services for resource, a modified text, modifications to the amount of class work and homework, preferential seating, etc. At the end of every school year you will need to weigh your options, considering the academic and social challenges and benefits of each placement. As always, consideration of the teaching staff and classroom structure is important. If your child has been in the SDC for kindergarten, he might remain in the same setting. Be certain to monitor his progress on goals and when slow, do not wait until the year end meeting to call a program review to find out how the teacher proposes to teach the skill. Likewise, when the goal has been met, make certain a new one is written. If you feel that he would receive more educational benefit by being fully included in regular education, request a change of placement. It's also possible that he is ready to mainstream for part of his day into the regular education setting, for subjects in which he has strengths. The present levels of performance and goals to address current needs should determine the appropriate placement. By law, your child has the right to the least restrictive environment, which includes regular education in the neighborhood school.

What happens if you don't agree that the district's offer of FAPE is indeed appropriate? At this point, your FEAT Coach or advocate will help you with next steps (if you don't have a FEAT Coach, now is the time to find one from your school district listed in the FEAT Handbook). Effectively handling a disagreement with your school district requires an individualized plan based on the unique conditions of your case. All of us, even those who have experienced difficult IEP's can benefit by learning or refreshing our knowledge of special education rights.

One of the best ways to network with other parents is to attend the FEAT Family Resource Meetings on the 3rd Wednesday night of each month 7-9pm. See the FEAT Handbook for the contact information to confirm location.

DISCLAIMER: *The information and resources provided by FEAT are for educational and informational purposes only. It is not a substitute for care or advice from a professional.*

Adding the School Component to a Comprehensive ABA Treatment Program—Planning a Successful Integration

It is the goal that by receiving an early, intensive, comprehensive ABA program beginning with the home and community components, including peer play, your child will one day successfully benefit from a typical classroom in your neighborhood school. For the older child or for one who was not provided appropriate treatment as a youngster, the goal remains the least restrictive, community environment in the neighborhood school or participation in the typical activities of individuals who are of a similar chronological age.

Parents should approach the initial phase of planning for this component of therapy with a sole focus upon therapeutic benefit for the child. Therapeutic design mistakes can be made when obstacles or limitations presented by the school district or regional center are weighted during the planning process. When one has progressed to the point where one has designed the fitting therapeutic plan, practical considerations can then be applied with suitable ranking of importance for each therapeutic recommendation.

The purpose of school for the young child is the generalization of skills learned in the home and community components. Generalization is basically understood as the functional application of previously learned skills over an extended period of time, with differing people, and in differing places under varying conditions. There are many factors that will prepare your child to successfully generalize skills to a classroom environment.

General Considerations

No Pre-Determined Age or Time when a Child is Prepared to Add a School Component to the ABA Program: Parents, ABA providers, and school staff must be fully aware that there is no magic age or predetermined time when a child with Autism is ready for school. It is child-specific depending on a number of factors: the current developmental functioning level of the child, the prerequisite skills needed for the desired school placement, the level of support the child will need to be successful at school, the availability of that support, how school will benefit the child at a particular juncture, and family requirements that may need consideration.

The Behavioral Tutor and Comprehensive ABA Program Will Be Needed For Many Years: In almost all circumstances, the child with Autism will need a trained behavioral tutor to accompany him/her at school through the second grade, and often, much longer. It is also critical for the child's home and community components to continue when the child attends school, to maintain that which has already been taught, to continue targeting new skills needed for school, home, and community, and to support the child in all areas for as long as needed. The ABA provider which has supervised the child's ABA program must stay in place, now supervising along with the parents, both the home, community, and school components of the child's program. The provider should reduce treatment only as the child's needs can be met as a typical child and when complex social skills needed in adulthood are functionally mastered. For some children, this may happen in seven to eight years from the onset of treatment; for most others, the need for an ABA treatment program continues indefinitely. Highest functioning children may continue to need a trained behavioral assistant for some hours of the school day. The assistant may be known or unknown to the student with Autism and their classmates, and the hours of assistance may be randomized throughout the day and week.

A Behavioral Assistant or Tutor is not an Instructional Assistant: Parents should work with the ABA provider to learn of the qualifications and experience needed for each treatment team member. A behavioral assistant or tutor who is a member of the treatment team working in any one of the three component environments, at minimum, must attend clinic meetings, implement ABA treatment in all environments, and communicate skillfully with all members of the treatment team including parents and school teaching staff.

Reduce The School Day: The child should only be at school for the length of time and for activities where the child is successfully meeting their identified targets. It is the rare exception when a child can benefit from the classroom environment for the length of the school day when first enrolled. Analysis of the data should determine how long the child is successful at school. Add time and activities as the data indicates to ensure successful, socially appropriate attending behaviors are exhibited at school at all times.

Assign the Strongest Daily Therapy Team Member: When the child is ready to add the school component to the home component, it is of utmost importance to assign the child's most experienced, carefully trained and most effective tutor from his/her program. Consistency from the home component to the school component is essential to ensure success for the child. This is not the time for the school to assign an inexperienced and unfamiliar aide to the child, as he/she would have no knowledge of the child, the child's ABA program and targets, and the child's unique needs.

Learn About IDEA and the Lanterman Act: The school district is obligated to provide at no cost, a specialized program for the child in the least restrictive environment with aides and supports to make success possible. The program is required to meet the unique needs of the child. An education is a service provided by the school district in all places of learning: home, community, and in school buildings. Where and how the education is provided is determined by the IEP team where the parents are integral in all decision making and whose permission is required for any service to begin. The Lanterman Act, which governs the regional centers, requires the coordination and provision of services and supports including educational services that will maximize the opportunities for each individual. The regional center is required to make certain that there are no gaps in services. This is particularly important when the generic services like the school districts do not provide services that are satisfactory or where the generic agency is by law limited in the type, quality, and duration of service that they can provide. These books are highly recommended for all members of the IEP team: Wrightslaw: Special Education Law and From Emotions to Advocacy, both by Peter W. Wright and Pamela Darr Wright. To order online go to: Wrightslaw.com Also, Autism: Asserting Your Child's Right to a Special Education, by David A. Sherman.

Development of Prerequisite School Readiness Skills and Goals

Teaching and Mastery of Prerequisite Skills to Meet Targets in a Classroom: Parents must work closely with the ABA provider to develop a list of prerequisite skills that your child will need to possess to be successful at school. Determining which placement you are aiming for will help determine your list of needed prerequisite skills. Be sure that the parent and the behaviorist are developing curriculum in the child's home program that is targeting these necessary school skills. At this point, it is very helpful to observe different school options, both public and private, to determine prerequisite skills that will be needed for a particular placement. Detailed notes should be taken for each classroom visited. After the parent narrows the options, a request should be made to the ABA provider to observe the top 2-3 options. Parents may need to request additional hours from the funding agency for the ABA provider to help in assessing different school options.

Develop Targets for School Environment: Behaviorist and treatment teams should be developing potential goals that are specific to the school environment. This can take some time, so getting an early start on it is good for planning.

Selection of Appropriate School, Classroom, and Teacher

Network with Parents: Networking with other parents is a great way to learn how they best added the school component to their child's ABA program. Parents will often have recommendations about the quality of different schools and teachers. Other parents can also be encouraging and supportive to the parent who is making these life affecting decisions.

Typical Classroom in the Neighborhood School with Appropriate Aides and Supports: The classroom should be at the typical neighborhood school where the child would have attended if he/she had not been disabled. The school should be a school where the students will matriculate together from the preschool, to elementary school, to middle school, to high school. The school should have children who participate with the child with Autism in peer play, on sports teams, in recreation activities like gymnastics, dance or karate, and from the activities at the child's place of worship.

Therapeutic research is clear that children with Autism should be engaged with typical peers as they provide more interactive and appropriate models of behavior than do children who have complicated developmental challenges.

Everyone benefits by having all children receive the opportunity to be educated together. Expected standards are naturally raised for appropriate school and social behavior and typical students who have relationships with persons who are disabled enable the community to better embrace the unique diversity of the population.

Schedule the Meeting with the Potential School: Parents should decide when the best time is to schedule a meeting with the principal or admissions director of the school the parent has selected as best for the child to attend. This meeting may be best scheduled before or after the parent observes potential placements. Observing the placement before and after the meeting may be helpful in decision making.

Educate The Admissions Directors About Autism and Provide Overview Of Child's Progress and Needs: Educate the principal about Autism, ABA treatment, the child's progress and current level of functioning, and the support the child will need at school to make it the best placement for him/her and for all other students and teachers. It can be reassuring to a principal to know that an incoming student is arriving with the necessary prerequisite skills and trained support, and that after enrollment the necessary skills to remain successful will be targeted intensively in a home program. Parents of children with Autism who are providing comprehensive ABA treatment should prepare their children to be a good school citizen who enhances the learning of all students.

Preparing For the First Day

Introduce Teacher to ABA Teaching Procedures and Components of a Comprehensive ABA program, and to Child's Baseline of Skills and Specific Targets: Offer recent reports regarding the child's progress and targets for the teacher to review at his/her convenience.

Identify Highly Motivating Reinforcers that can be Available in the School Environment: The ABA team should conduct a reinforcement inventory of available reinforcers. Consult with the teaching staff to identify a place in the classroom to keep reinforcers brought from home.

Select Seating in the Classroom and Prime Classroom Signals: The selection of seat should be one where the tutor can easily see the face of the child and the other students and where the student can be near other students to use as models of behavior. For the child who is new to using appropriate social behaviors or who needs a reinforcer that is outside of the classroom, a seat in the aisles nearer the door can be less distracting for the other students when entering and exiting frequently. Pre-teach individual classrooms signals such as clapping in unison with the teacher to signal that it is time to be quiet; "eyes on me" to mean that the child is to look at the teacher's face, etc. Each teacher has their own classroom management signaling routines.

Arrangements to be made at the IEP:

Classroom Teacher to Visit Home Component of ABA Program: At the IEP, ask if it would be possible for the child's future classroom teacher to come and visit the child's home program, so they can have a better understanding of the child, how he/she learns, current targets, meet the child's tutor(s) and consultant, ask questions, etc. Teachers are often eager and willing to do this during breaks from school. When requested in the IEP, the district can pay the teacher for their time as part of necessary training to learn about the child.

What method and How Often Will Supervising Behaviorist Consult with the Classroom Teacher: At the IEP, establish what method, and how often, the parent and the child's Senior behaviorist can communicate with the teacher. There are many options for maintaining good communication with the child's teacher. Email, voicemail, and conference calls are excellent tools.

Supervising Behaviorist School Observations: Reassure the child's teacher that when the child's consultant visits the classroom to check on the child's progress and needs, the consultant is there to observe the child and determine future targets, not to critique their teaching. The consultant should be quiet and not intrusive during the clinical visit. The teacher should be shown the data collection sheets to have a better understanding of the focus upon the child's progress and not upon the teacher's teaching performance. Determine if there will be a few minutes each time the consultant makes a visit for him/her to talk with the child's teacher.

Meetings and All Correspondence Should Always Involve the Parent: Meetings regarding the child should only take place with the parent in full participation. A regular meeting schedule should be determined at the IEP. The frequency of the meeting schedule may be more intensive for the first few months of the new placement and then reduce as the year progresses with an increase at the end of the school year when previous goals are modified and new goals will be written. When calculating the number of hours needed from the supervising behaviorist, one must include the school, and home and community clinical supervision and training.

Daily Communication with the Child's Teacher: Communicate regularly with the child's teacher to make sure that he/she is comfortable in implementing team recommendations.

Daily Communication with the Child's Behavioral Tutor: Daily, verbal reports and sharing of data is necessary between the tutor who worked in the classroom, parent, and other team members. A school journal and data binder kept by the tutor, and possibly by the teacher, is essential. Parents and all home component team members should read it daily. The time necessary for daily communication should be written into the IEP, as additional staff time may need to be allotted.

Appointment(s) for Child and Parents to Visit the Classroom and Playground prior to the First Day of School: Make arrangements with the classroom teacher for the child to visit the classroom to familiarize him/herself with the school environment. This is also a good time for parents and teachers to ask one another last minute questions before the start of school. Do not linger on the playground so as to not give the child the idea that he/she will be without demands placed upon him/her in the school environment.

Inform Staff of Special Medical Needs: Parents should inform teachers, assistants, and room representatives of any dietary restrictions, food and environmental allergies, restrictions of exposures to Playdoh and allergenic ingredients in cooking demonstrations. Ask staff to inform the parent of any potential exposures to an allergen as soon as possible. Ask staff to notify the parent in advance when an activity is planned where an allergenic exposure is likely so that the parent can plan to use similar or alternate materials for the lesson. Report any other medical issue that may have an effect upon the child's performance in the classroom. Children with Autism can have gastrointestinal disease resulting in constipation and/or diarrhea, sleep disorder, eating disorder, eczema, seizure disorder, asthma, skin rashes, pica, and self injurious behaviors.

Inform Staff of Sensory Processing Difficulties: Parents and treatment team members should inform the school staff if the child has any sensitivities to loud noises, passing bells, music, certain odors, different kinds of touch, hugging, fabrics, textures, or lights. The treatment team should provide a plan to avoid exposures to problematic stimuli until such time as desensitization targets have been met.

Inform Staff of Special Instructions If Emergency Medical Treatment is Needed: Many parents do not wish their child to be vaccinated in the emergency room when receiving emergency medical treatment. Parents should indicate special instructions in clear, highlighted language on all copies of the emergency card and to notify school staff that the instructions in the event of an emergency are stated on the emergency cards.

When School Begins

Plan for Success: Regular, thorough planning will prevent socially inappropriate behaviors from occurring in the school environment. The child should only associate appropriate, successful skills with the school environment. If the child is demonstrating socially inappropriate behaviors at school, it is time to determine where therapy technique needs to be honed and modified. Take data on school activities, indirect prompting of other children, model prompts using other students or adults, data on typical peers' behavior rates for comparison.

Timely Clinical Notes for the Classroom Teacher: The consultant should email notes to the teacher as soon as time allows after the visit. The notes should include information and updates with specific clinical recommendations regarding progress and targets to allow the teacher to stay involved, up-to-date, and be able to help implement the child's goals appropriately.

Parents Must Regularly Observe Their Child in the Classroom: In order to be the most effective treatment team members, the parents must see with their own eyes how their child is performing in the classroom.

Behaviorist Must Regularly Observe Child in the School Environment: Schedule clinical observations with senior behaviorist as much as possible in advance as schedules book quickly.

Positive Experience and Opinion from School Staff and Classmate Parents: It is critically important for parents and other treatment team professionals to develop and maintain positive relationships with school staff, other students, and the other students' parents. One of the best ways to do this is to be sure that parents are sending their child to school with the necessary prerequisite skills so they are successful in school, and are not disruptive to the other students' learning environment.

Scheduled Education Opportunity for Classmate Parents: It is helpful to educate the staff, students, and parents as much as possible, so they do not make inaccurate assumptions about the child, his/her disorder, or his/her impact on their child's classroom. Often, it is possible for parents to make a brief presentation at "Back to School Night" to the parents of the students in the child's class. If they understand that the child is ready for school, will come with an appropriately-trained aide, and will not disrupt their child's education, any concerns they have may be alleviated. It is also helpful to share with them how hard the child has worked to achieve the skills necessary for school, and that the child will continue to work hard before and after school, and on weekends, to learn what comes naturally to their children. This shared knowledge can gain support, empathy, and understanding for the child. The parent of the child with Autism can share how the typical children can be of help to the child with Autism in developing his/her communication, social, and play skills. Many parents of "typical" children want to be helpful, and view their child's helping a child with a disability as a very positive experience. It can also be helpful to talk to the students in the child's class in the first week of school, to explain why the child will be accompanied by a tutor, the child's strengths, the child's unique behaviors, likes, how they are the same and different in their interests and possibly a description about the disorder of Autism. When children have a better understanding of children with Autism, they are often much more helpful and compassionate.

Parents Determine What Kind of Information will be Shared: How much information to share with others at school is also dependent on many factors including the functioning level of the child, the parental beliefs, and self awareness of the child and peers. If the child achieves a high level of functioning, there may come a time when the parent does not wish to disclose the child's condition, but would rather describe the child's symptoms to others. Describing the symptoms can offer more information to the peers and their parents about how to be helpful.

Parents Should Occasionally and Individually Consult with the Teacher, Behaviorist, and Behavioral Assistants Privately: Parents are the bridge between the team members providing a private sounding board for the individuals on the team. Parents are able to work through difficulties and prevent miscommunications before a problem arises.

Schedule Meetings Convenient to the Classroom Teacher and After the Instructional Day: The classroom teacher will appreciate the parental courtesy in the scheduling of meetings during periods when students are not in session. Having a substitute teacher is taxing for the regular teacher and is a time when typical students are not learning optimally.

REGIONAL CENTERS CANNOT DISCONTINUE OR CHANGE THE CONSUMER'S CURRENT SERVICES UNILATERALLY

Even during hard economic times for the State of California it is imperative for all parents of consumers of the Regional Center to understand that state budget cuts should not reduce the child's current level of services. Consumers with services currently in effect **CANNOT** have those services discontinued or changed unilaterally by the regional center.

The Lanterman Act specifically states that parents are to be considered an **ACTIVE** part of the IPP team:
W and I code, 4646 (b) The individual program plan is developed through a process of individualized needs determination. The individual with developmental disabilities and, where appropriate, his or her parents, legal guardian or conservator, or authorized representative, shall have the opportunity to **actively participate in the development of the plan.**

What does this mean? This means that **ANY and ALL** decisions regarding the child's current or future programs **MUST** be decided as a team decision which includes consumers, parents, and guardians. .

Decisions CANNOT BE MADE BY SUPERVISORS OR CASEWORKERS about the child's services without the parent's involvement, permission, and without going through the IPP process.

Decisions about the child's services cannot be made BEFORE the IPP meeting. For instance, the child's caseworker cannot call the parent to inform them that services will be cut or modified without first discussing the services with the parent at the IPP and the parent agreeing to reductions, additions, or modifications.

Decisions about a consumer cannot be made by a regional center committee. All decisions regarding the child must be made by the IPP team members including the parent through the IPP process.

The law says regional centers must base any changes to the child's services on the child's needs. Regional centers can review services with parents through the IPP process to see if: (a) The services aren't being used appropriately; (b) y The parents agrees that the child's needs can be met with less, or (c) The regional center thinks the child doesn't need a service anymore.

Regional centers must work together with consumers and parents through the IPP process to resolve any disagreements about the determination and delivery of services.

During the IPP, the regional center should make clear in writing what services it wants to change and the reasons it wants to change them.

The regional center should provide parents with the purchase of service guidelines including the policy for exceptions that accompanies it.

Purchase of service guidelines cannot force maximum or minimum levels of service. The regional center has to meet the child's specific needs, even when the needed services are outside the regional centers' general purchase of service guidelines.

If the regional center does not provide purchase of service guidelines and written documentation of the regional's center's disagreement, the parent should request these in writing.

If irresolvable disagreements remain after the IPP, the regional center is required to provide the parent a "Notice of Action". This is basically a written letter stating what service the regional center would like to change or cut and why it is making the decision to pursue the elimination of the service through due process. Parents can appeal the decision within 10 days of receipt of the Notice of Action. Parents should read these documents carefully to be sure to respond appropriately within the time limits.

Services cannot change or be discontinued until the parent agrees to the change, the time limit for response to the Notice of Action has expired with the parent choosing to not continue due process, or if a judge orders the change.

If the parent continues through due process, the current level of service stays the same. No changes may take place to modify current services until the resolution of the due process. During this period the child's needs must still be met. New or different services can be added through the IPP process while the issues in the Notice of Action are litigated.

Nutrition, Diets and Autism

By Kim Christensen
FEAT Parent

I was very fortunate to attend the fall DAN! 2007 Conference in Garden Grove, CA and listened to Julie Mathews, certified nutrition consultant, speak on diets and nutrition. Most of the following diet and nutrition information is taken directly from Ms. Matthews conference presentation "Nourishing Hope: Essentials of Nutrition". Many kids on the spectrum do not eat a healthy, well-balanced diet, and some have maldigestion issues that contribute to leaky gut.

Here are a few simple guidelines to help ensure proper nutrition in our kids:

- remove junk food, sugars and foods that are overly processed
- avoid soy, MSG, aspartame and other artificial sweeteners/colors/flavors
- eliminate all trans fats
- avoid any food that causes red cheeks/ears and dark circles under the eyes

Gluten Free/Casein Free (GFCF)

The GFCF diet is the starting point for most parents doing dietary intervention. It eliminates gluten (the protein found in wheat, rye, barley, oats, kamut, spelt) and casein (the protein found in dairy). High pain tolerance, self-injurious behavior and other common opiate symptoms are associated with gluten and casein intolerance. Casein intolerance is most often associated with severe constipation. Most children on the spectrum demonstrate at least some level of improvement on this diet. For an overview of the GFCF diet, visit TACA's (talk about curing Autism) diet website at:
http://gfcf-diet.talkaboutcuringAutism.org

For a detailed guide on how to get started on the diet and be GFCF in only 10 weeks, visit the following website:
http://gfcf-diet.talkaboutcuringAutism.org/gfcf-in-10-weeks.htm

Specific Carbohydrate Diet (SCD)

This diet, adapted from Elaine Gottschall's book "Breaking the Vicious Cycle", is based on the principle that some individuals cannot digest carbohydrates and complex sugars due to intestinal mucosal damage. This maldigestion leads to the overgrowth of bacteria and yeast in the small intestine, creating further intestinal damage. The foods in this diet require little or no digestion, and are quickly absorbed into the system, thus eliminating the food source for bacteria and yeast overgrowth. This diet is recommended after children have been on GFCF diet without demonstrated improvement for their severe GI issues. For more information on the SCD diet, visit their website at http://www.pecanbread.com.

Low Phenols/Feingold Diet

Many individuals with Autism appear to have faulty sulfation and cannot process phenols well. Common symptoms of phenol intolerance include dark circles under eyes, red face/ears, diarrhea, hyperactivity, impulsivity, aggression, headache, head banging/self-injury, impatience, short attention span, difficulty falling asleep, night waking for several hours, inappropriate laughter, hives, stomachaches, dyslexia, speech difficulties, tics and some forms of seizures. There is no way to eliminate 100% of all phenols, so this diet is not an all or nothing program. Some people may need to be strict with keeping phenols very low, while others may need to only avoid high phenol foods such as apples, grapes, and bananas. For more information on the Feingold diet, see their website at http://www.feingold.org/. For more information on phenols and the Feingold diet, see Julie Matthews' website at: http://healthfulliving.org/Autism/diets/feingold.php

Low Oxalate Diet (LOD)
The LOD restricts high oxalate foods such as nuts, beans and greens. Oxalates are simple molecules that are found naturally occurring in high levels in certain foods. When the gut is leaky oxalates are absorbed and high levels end up in the blood, urine and tissues, creating inflammation and pain. LOD is a good choice for children with urinary problems, craving high oxalate food, GI or other pain within minutes or hours after eating. For more information on using the LOD with Autism, visit the following website:
http://www.stillpointhealth.com/LowOxalateDiet-HelpandSuggestion.html

Body Ecology Diet (BED)
The BED is great for candida overgrowth and many parents have seen great results with their children. It incorporates principles of food combining, low acid forming foods, low/no sugars and starches, easily digestible foods, fermented foods, and other solid nutrition recommendations to clear up candida overgrowth in the body. However, while some kids like or warm up to cultured vegetables and kefir, it can be challenging to get children to consume these fermented foods. For more information, visit their website at:
http://www.bodyecologydiet.com

There really is no downside to at least trying dietary intervention with your child. Even small improvements, over time, can make a big difference in your child's health!

For more information on Julie Matthews book **"Nourishing Hope"** or a more detailed explanation of the information presented in this article, please visit her website at: http://www.nourishinghope.com

From March 21 2018 FEAT Family Resource Meeting Parent Packet
Presenter: Judy French, PACER's National Bullying Prevention Center
http://www.pacer.org/bullying/

The End of Bullying Begins with You

FEAT Parent Packet Content Links to Share:

1. **Bullying and Harassment of Students with Disabilities**
   http://www.pacer.org/publications/bullypdf/BP-18.pdf

2. **Use Positive Strategies to Protect Your Child with Disabilities from Bullying**
   http://www.pacer.org/publications/bullypdf/BP-16.pdf

3. **Notifying the School About a Bullying Incident—Template Letter**
   http://www.pacer.org/publications/bullypdf/BP-19.pdf

4. **OCR Colleague Letter & Fact Sheet re: Bullying**
   https://www2.ed.gov/about/offices/list/ocr/letters/colleague-201010.html

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Parents, pass this M-CHAT screening tool on to healthcare professionals:

www.feat.org

Modified Checklist for Autism in Toddlers (M-CHAT)

The M-CHAT is designed to screen for Autism Spectrum Disorders in toddlers (i.e., over the age of 12 months, and ideally over the age of 18 months). A parent can complete the items independently. The M-CHAT does not allow a clinician to make a diagnosis of an Autism Spectrum Disorder, but is a very useful clinical tool that has excellent sensitivity and specificity. Positive results suggest a high risk for an Autism Spectrum Disorder, and may necessitate referral. The M-CHAT does not require clinician observation. The CHAT, however, does require clinician observation, and has poor sensitivity, but excellent specificity.

INSTRUCTIONS: Please fill out the following about how your child *usually* is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

Modified Checklist for Autism in Toddlers

1.	Does your child enjoy being swung, bounced on your knee, etc.?	YES NO
2.	Does your child take an interest in other children?	YES NO
3.	Does your child like climbing on things, such as upstairs?	YES NO
4.	Does your child enjoy playing peek-a-boo/hide-and-seek?	YES NO
5.	Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?	YES NO
6.	Does your child ever use his or her index finger to point, to ask for something?	YES NO
7.	Does your child ever use his/her index finger to point, to indicate interest in something?	YES NO
8.	Can your child play properly with toys (e.g., cars or bricks) without just mouthing, fiddling or dropping them?	YES NO
9.	Does your child ever bring objects over to you (parent) to show you something?	YES NO
10.	Does your child look you in the eye for more than a second or two?	YES NO
11.	Does your child ever seem oversensitive to noise (e.g., plugging ears)?	YES NO
12.	Does your child smile in response to your face or your smile?	YES NO
13.	Does your child imitate you (e.g., you make a face – will your child imitate it)?	YES NO
14.	Does your child respond to his/her name when you call?	YES NO
15.	If you point at a toy across the room, does your child look at it?	YES NO
16.	Does your child walk?	YES NO
17.	Does your child look at things you are looking at?	YES NO
18.	Does your child make unusual finger movements near his/her face?	YES NO
19.	Does your child try to attract your attention to his/her own activity?	YES NO
20.	Have you ever wondered if your child is deaf?	YES NO
21.	Does your child understand what people say?	YES NO
22.	Does your child sometimes stare at nothing or wander with no purpose?	YES NO
23.	Does your child look at your face to check your reaction when faced with something unfamiliar?	YES NO

Have you ever filled out this form for this child before? YES NO

Turn page over for scoring instructions.

Scoring the M-CHAT: A child fails the M-CHAT when 2 or more CRITICAL ITEMS are failed or when any 3 items are failed. Yes/No answers convert to Pass/Fail responses. Below are listed the failed responses for each item on the M-CHAT. Bold capitalized items are CRITICAL ITEMS.

Not all children who fail the checklist will meet criteria for a diagnosis on the autism spectrum. However, children who fail the checklist should first be evaluated in more depth by the physician or referred for a developmental evaluation with a specialist.

1. NO
2. NO
3. NO
4. NO
5. NO
6. NO
7. NO
8. NO
9. NO
10. NO
11. YES
12. NO
13. NO
14. NO
15. NO
16. NO
17. NO
18. YES
19. NO
20. YES
21. NO
22. YES
23. NO

Original Paper
The Modified Checklist for Autism in Toddlers: A Follow-up Study Investigating the Early Detection of Autism Spectrum Disorders

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Abstract Autism spectrum disorders (ASD) often go undetected in toddlers. The Modified Checklist for Autism in Toddlers (M-CHAT) was used to screen 3,793 children aged 16–30 months from low- and high-risk sources; screen positive cases were diagnostically evaluated. Re-screening was performed on 1,416 children aged 42–54 months. Time1 Positive Predictive Value (PPV) was .36 for the initial screening and .74 for the screening plus follow-up telephone interview; values were similar for Time2 PPV. When separating referral sources, PPV was low for the low-risk sample but acceptable with the follow-up telephone interview. Children with ASD from the low-risk and high-risk samples were highly similar. Results indicate that the M-CHAT continues to be a promising instrument for the early detection of ASD.

Early signs of Autism

Is your baby *too good to be true*, makes no demands, does not cry often … or is your baby *difficult to handle*, highly irritable, never sleeps? Do you or other family members have concerns about your baby's development? One or more of the following can be indicators of **Autistic Spectrum Disorder**, which includes Autism, PDD-NOS and Asperger's Syndrome:

☐ Absence of smiles of recognition by six months or thereafter.
☐ Acts as though they cannot hear your voice.
☐ Absence of acknowledgment when a parent returns home or when a new person enters the room by six months or thereafter.
☐ Preoccupation or fascination with objects rather than with people.
☐ Impaired social interaction such as back-and-forth sharing of facial expressions by nine months or thereafter.
☐ Slow to imitate games like peek-a-boo.
☐ Giggling for no reason or when no one else is around as early as four months or thereafter.
☐ Extreme sensitivities to light, smell, sound, touch and taste by four months or thereafter.
☐ Hand flapping, hand gazing, body rocking or other self-stimulatory behaviors as early as six months.
☐ Absence of babbling by 12 months.
☐ Absence of back-and-forth gestures such as pointing, showing, or waving by 12 months.
☐ Fixation on audio/video stimulation by 18 months.
☐ Absence of words by 16 months or odd use of language or unusual tone of voice.
☐ Compulsively arranges non-toy items or lines up toys.
☐ Plays alone.
☐ Absence of initiating two word meaningful phrases by 24 months. Speaks only when coaxed.
☐ Any loss of first words or babbling or any loss of social skills at any age.
☐ Peculiar or rigid eating, dressing or sleeping habits.
☐ Strongly prefers or insists on talking about one subject without variation.
☐ Lack of daily progress. A developing child is constantly doing or discovering new things. *Every day without treatment is a lost opportunity for progress.*

Autism affects one in 50 children

The earlier the treatment
The better the outcome

Autism can be treated

FEAT—Families for Early Autism Treatment

www.feat.org
916.303.7405

Take Action

Trust your parent-instinct. Urgently pursue early diagnosis. Autism is a pervasive medical condition requiring effective treatment like diabetes or cancer. Children do not outgrow Autism Spectrum Disorder.