

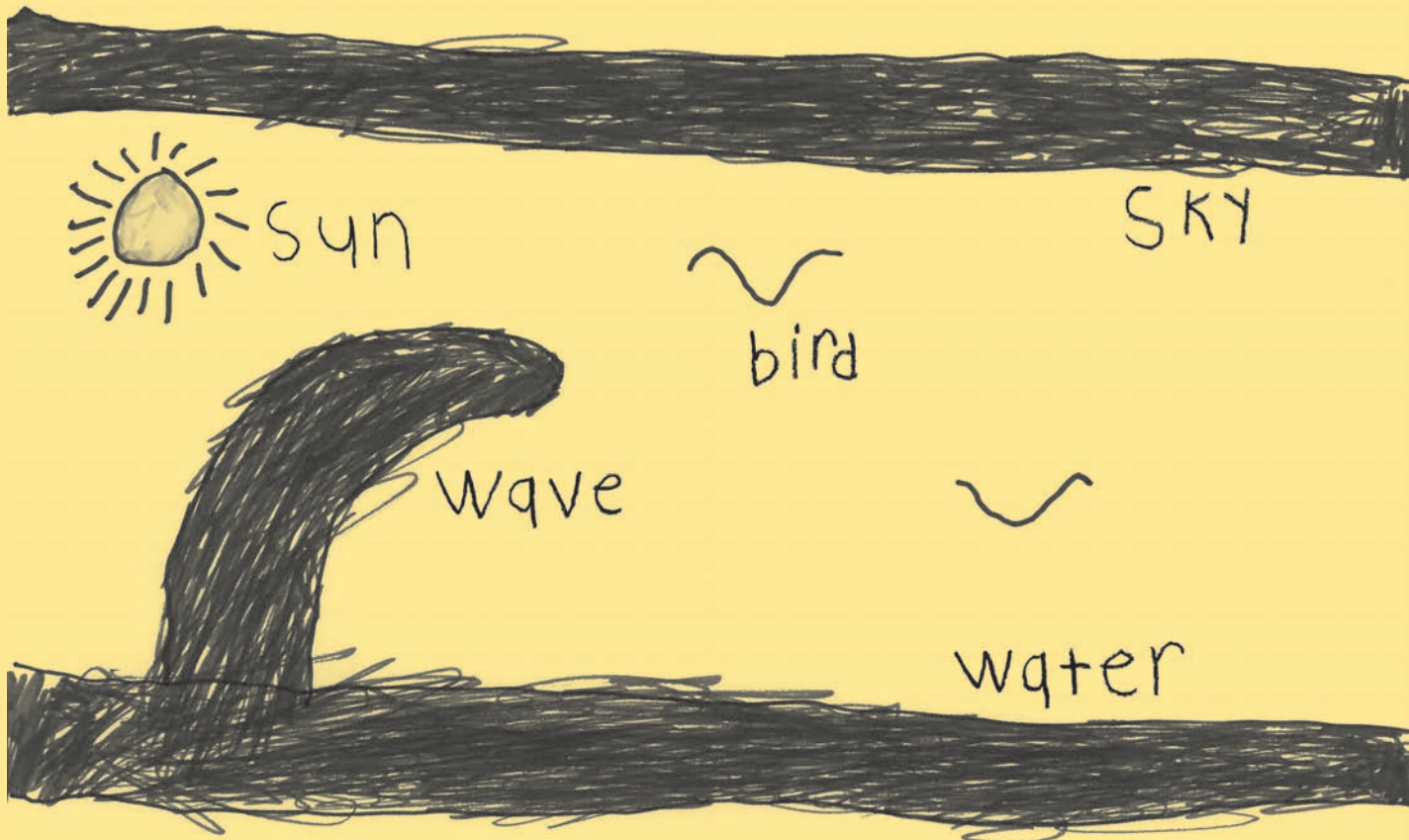


AUTISM NEWS

of Orange County
& the Rest of the World

Fall 2006

Volume 3, Issue 2



I went to the beach with dad.

I made a sand castle. I had lots of fun!

CONTENTS

Editorial	3
Research	
JumpStart: Learning-to-Learn	6
Education/Therapy	
Educational Services and Asperger's Syndrome.....	10
Sibling Interview: Sandra Harris	12
Parent/Family	
Poem: I Wonder Why	5
Local Artist: Garrett Black	9
Life With Kim	14
Using Digital Pictures	17
Understanding Joey	18
Friendships, Relationships and Autism	22
Grandparent Autism Network.....	25
News/Highlights	
Task of the Month	13
News Corner: Rockband	26
Calendar of Events	28

COVER FEATURE

We are pleased to feature one of our local artists, **Garrett Black**. Read more about Garrett on page 9.

Mission Statement

Autism News of Orange County & the Rest of the World is a collaborative publication for parents and professionals dedicated to sharing research-based strategies, innovative educational approaches, best practices and experiences in the area of autism.

Submission Policy

The Autism News of Orange County *RW* is available free of charge to parents and professionals of children with autism. The opinions expressed in the newsletter do not necessarily represent the official view of the agencies involved.

Contributions from teachers, therapists, researchers and relatives/children of/with autism are welcome. The editors select articles and make necessary changes.

Please submit articles in Microsoft Word using font size 12, double spaced, and no more than four pages in length (2600 words). Photos are encouraged and when submitted with articles the permission to include is assumed.

Please email all correspondence to:

Dr. Vera Bernard-Opitz
vbernard@ocde.us

Please visit our website: www.verabernard.org

Editorial Team

Vera Bernard-Opitz, Ph.D., Editor
Ginny Mumm, Associate Editor

Editorial Board

Teri M. Book, RN, MSN, CPNP
Joe Donnelly, M.D.
Andrea Walker, M.A.
Janis White, Ed.D.

Advisory Board

LOCAL

Pauline A. Filipek, M.D.
University of California, Irvine
For OC Kids

BJ Freeman, Ph.D.
Autism Consultant

Wendy Goldberg, Ph.D.
University of California, Irvine

Belinda Karge, Ph.D.
Cal State University, Fullerton

Jennifer McIlwee Myers
Orange County, California

Connie Kasari, Ph.D.
University of California, Los Angeles

Marian Sigman, Ph.D.
University of California, Los Angeles

Becky Touchette
Saddleback Valley Unified School District

NATIONAL/INTERNATIONAL

Jay Birnbrauer, Ph.D.
Murdoch University, Australia

V. Mark Durand, Ph.D.
University of South Florida, St. Petersburg

Patricia Howlin, Ph.D.
St. Georges's Hospital London, England

David Leach, Ph.D.
Murdoch University, Australia

Gary Mesibov, Ph.D.
University of North Carolina,
Chapel Hill Division TEACCH

Fritz Poustka, M.D.
University of Frankfurt, Germany

Salwanizah Bte Moh.Said
Early Intervention, Autism Association, Singapore

Diane Twachtman-Cullen, Ph.D., CCC-SLP
ADDCON Center, Higganum, Connecticut

Editorial

By Vera Bernard-Opitz

Welcome to our latest edition of Autism News, which stresses the important topic of family issues. In comparison to previous newsletters, contributions for our family section were so overwhelming that we decided to focus this edition primarily on education and family.

Since my background is in applied research, I cannot resist this opportunity to summarize some important recent research findings and suggest directions for future research efforts.

Families and professionals alike are aware that autism has a strong genetic component and that we may deal with different subtypes of the clinical picture. We also are aware that there have been major increases in the diagnosis of Autism Spectrum Disorders (ASD) over the last 20 years. While our parents may never have seen a child with this diagnosis, clinics, kindergartens and schools are now often overwhelmed by the number of referred children with ASD. There are some indications that the trend observed in the United States holds true for many other countries as well. As a personal example: while I could only find three children with this condition in Singapore in 1987, now this Asian state, with a population of only 4 million, has an estimated 200 children diagnosed with ASD each year.

“Why are there so many young children at risk for autism?” and – echoing the poem by Deanna Pyeon, nine-year old sister of a boy with ASD – “I wonder why my brother is autistic?” (page 5) “Can anything be done to prevent these developments?” There are several areas of research that could provide us with clearer answers.

Various possible causes have been cited to explain the increase of ASD in children who are biologically vulnerable to autism. Besides the assumption that hormonal changes related to prenatal stress or “selective breeding” (people with “object interest” instead of “people/relationship interest” select partners with similar interests) contribute to the so-called “autism epidemic” (Baron-Cohen, 2002; Attwood, 2000), environmental factors have also been cited, ranging from

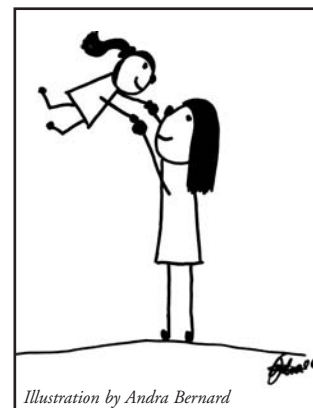
exposure to toxins to deficiency of vitamins to oversensitivity to certain diets (Pfeiffer et al, 1995; Palmer et al, 2006; Elder et al, 2006).

Some important evidence comes from recent MRI studies, which have demonstrated that mirror neurons are less active in children with ASD, causing problems with joint attention, imitation and empathy (Lindsay Oberman, in print; Williams et al, 2001). This may explain the communication and social problems seen in lower-level as well as higher-level individuals with ASD. One hope is that by activating these brain circuits through early intervention, we can cause a possible re-wiring of the brain and more normalized behavior.

Intensive early intervention and parent training have been shown to be effective, often leading to significant progress and positive long-term outcomes. Interestingly, varied treatment approaches, from traditional behavioral intervention to more naturalistic interventions stressing joint attention, engagement and play, have demonstrated success (Whalen et al, 2006). So could it be that various approaches focusing on core skills linked to defective brain circuits can positively affect development? And could early parent involvement make a difference?

A few words of caution:

- 1) At this point we do not have sufficient data on early diagnosis and its stability, especially in very young children and high-level children with ASD (Fombonne, 2005).
- 2) The request for further research on more intensive parenting should in no way imply that parents are to be blamed for their child’s developmental problem. Researchers are just beginning to explore the importance of early stimulation on vulnerable brains and the positive effect of early intervention on children with ASD.
- 3) While some children have shown marked positive



developments when parents spend more time with them, there is no guarantee that children with biological vulnerability to ASD will benefit. Besides parental involvement with their infant or intensive early intervention by trained staff, the level of the child's disability, the severity of his behavior problems and co-morbid features, such as attention deficit or seizure disorder, all predict the long-term outcome.

Only recently has research looked into early interaction patterns of infants at risk for ASD and their parents. Findings by Sigman and Siller (2006) suggest that parents' success in managing a shared interest in external objects or events with their infant is developmentally linked to children's long-term language outcomes. Along the same lines, Kassari has demonstrated that 30 minutes a day of training in joint attention and symbolic play over a six-week period not only increased these skills in parent-child interactions, but also led to enhanced language skills (Kassari, 2004). Training parents in these pivotal skills should be an important component of best practice programs.

If we consider these and similar findings under the questions: "Why do we have so many children with the diagnosis of autism?" and "Can we prevent further red flags for autism?" psycho-social changes over the last decades and the importance of parenting come to mind.

While parenting used to be a full-time job in many countries twenty years ago, it is now only one among many competing demands parents face. Multi-tasking, workplace efficiency and career competitiveness are regularly regarded as more important than playing peek-a-boo and pretending that a teddy bear has a life of its own. Children no longer have time for play with friends or siblings, but are instead often engaged in passive leisure skills, such as watching TV or playing computer games, or are bussed to tutoring centers and enrichment classes. There is enormous pressure for ever-earlier development of self-help skills, language and pre-academics. Consequently, many parents have learned to trust specialists more than their own parental instincts.

So could the current psycho-social situation be a social risk factor for those children who are biologically vulnerable and can we turn some children at risk around before they need intensive early intervention by alerting parents, caregivers, service providers and policy makers to the importance of early social engagement of infants and young children? I believe we need help from the research community in addressing these issues.

And while researching these aspects of psychosocial behavior may not answer Deanna's question, "Why is my brother autistic?" it may help parents feel more empowered to contribute to their children's positive development.

With these thoughts off my heart, I am now happy to announce a fascinating spectrum of perspectives on family issues:

- The article by **Michelle Ficcaglia**, Program Director and **Bryna Siegel** (UCSF) on the JumpStart Program gives an exciting account of a Parent Training program which matches treatment components to children's learning styles. Parents learn to combine direct child instruction with play teaching in everyday settings. Besides helping children through best practice methods, parents are supported in selecting and transitioning to appropriate programs.
- **Barbara Bloomfield** shares her valuable experience with educational services for a student with Asperger's Syndrome, both in her role as his grandmother and as a speech/language pathologist. She clearly outlines the need for matching interventions to child and family characteristics, focusing intervention goals on daily living skills as well as on social communication and academics.
- Parents often worry about the well being of the siblings of children with autism. Here the interview with **Sandra Harris** (Rutgers University) can be helpful, since it provides concrete suggestions on how to help siblings understand autism and facilitate positive interactions among siblings.
- The honest account of **Elaine Weber** will be appreciated by many. She describes her journey with her daughter Kim through various detours,

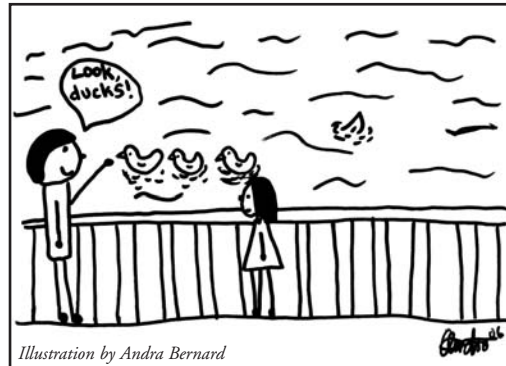


Illustration by Andra Bernard

finally finding an approach which proved helpful. This story mirrors the path of many parents, who “never, never give up.”

- The highlight by **Kelly McKinnon** (San Juan Capistrano) on using digital pictures will be welcomed by parents and professionals alike who are trying to elicit language and recall of recent events.
- Often classmates wonder about the unusual behavior of children with autism. The pictured booklet “Understanding Joey,” by his mom, **Linda Varblow** (TEACCH) gives ideas on how to explain the similarities and differences among students in a way classmates can understand.
- As a happily married “Aspie,” **Jennifer McIlwee Myers** shares her highly relevant inside perspective on developing friendships, stressing the importance of volunteering and finding people with common interests. Her summary sheds light on the critical role of parents in pointing out social rules.
- Supporting their children and being advocates to their grandchildren are some of the important goals of the newly formed Grandparent Autism Network. **Bonnie Gillman** manages this program with a lot of enthusiasm and shares with us some of her activities and visions.
- Last but not least, we very much appreciate the contributions by two children:
Our artist **Garrett Black**, who contributes such a cheerful cover picture and **Deanna Pyeon**, 9-year-old sister of a boy with autism. Deanna, your questions about why your brother is autistic and why you are not are very important. Let us hope that many people around this world will try to find answers to your questions and at the same time help children like your brother.

With the hope for more research into the causes of autism, better predictors for treatment effectiveness and ways we all can help to make the world better for children with autism and their families, I wish you happy reading.

Vera Bernard-Opitz, Ph.D.

Clin. Psych., Editor

<http://verabernard.org>

email: verabernard@cox.net

(References can be sent upon request.) ♥

I Wonder Why

By **Deanna Pyeon** (age 9)

I wonder why my brother has autism.

He wasn't born with autism. He developed it afterward. He is a four-year-old child right now. He is always happy, and always active. He is tough and funny a lot of the time. He is a healthy eater. He loves vegetables. He enjoys eating mushrooms.

I wonder why my brother has autism.

He is pure and has no sin. He never makes people upset and never fights. He doesn't speak bad words. He is just like my dad - smart, good-looking, and laughing all the time.

I wonder why my brother has autism.

My brother smiles at people almost all the time, even when people don't smile at him. He makes my family pray for him every night. He makes us think about what we take for granted and appreciate what we have.

I wonder why my brother has autism.

He makes sounds I've never heard before. He speaks words I don't understand. He ponders little things as if they are important. He runs as if he is free from anything.

I wonder why my brother has autism.

Perhaps he lives in a world where he doesn't need our language. He looks at things differently than we do. He has values we cannot understand.

I wonder why we don't have autism. ♥

Get a FREE SUBSCRIPTION to Autism News!
Made possible through the following website:

<http://verabernard.org>

JumpStart: Learning-to-Learn

A New Model for Pre-Service Parent Training

By Michelle Ficcaglia and Bryna Siegel



Parents who suspect their child has an Autism Spectrum Disorder (ASD) are faced with the daunting job of sorting through huge amounts of confusing, contradictory and often erroneous information. There are at least two different standards for diagnosis (medical and educational), three diagnostic categories (autism, pervasive developmental disorder, not otherwise specified, and Asperger's syndrome), and, in California, two different service funding agencies (Department of Developmental Services and Department of Education) each with their own system of care. Additionally, no universally agreed-upon standard of care for individuals with ASDs exists, often resulting in heated debate about appropriate intervention techniques among professionals and nonprofessionals alike. Navigating productively through all of this information when stressed by a new diagnosis is a nearly impossible task.

JumpStart Learning-to-Learn (**JumpStart**) is a new approach to family training. Consisting of a two week, intensive program designed to begin just after the diagnosis of an ASD, Jumpstart is a "pre-service," parent-focused intervention designed to precede early intervention services. Jumpstart seeks to help families learn the autism-specific life skills they will need to support their child's development as he or she grows.

The program is based on the premise that teaching therapy techniques directly to parents helps them to:

- 1) Gain a greater appreciation of the "active" ingredients of the therapy process;
- 2) Develop an understanding of the skills they will need to evaluate their child's future therapists and teachers; and
- 3) Develop a sense of control over conditions that benefit their child's ability to learn.

History

JumpStart began in 2004 as a pilot research program at the University of California San Francisco

Autism Clinic under the direction of Bryna Siegel, Ph.D. In 2006, JumpStart became an independent nonprofit in order to serve a wider range of children. JumpStart maintains a close relationship with the UCSF Autism Clinic, collaborating on a variety of clinical research projects including evaluating the efficacy of JumpStart and its individual curriculum components.

Theoretical Foundation

JumpStart is organized along a developmental model in which ASDs are seen as collection of "Autistic Learning Disabilities" and "Autistic Learning Styles" (Siegel, 2003) which are derived from descriptions given by the DSM (Diagnostic and Statistical Manual) diagnostic criteria. Each criterion specifies a needed area of remediation and/or delineates an available or non-available modality for perceiving, processing, and output of stimuli. In turn, the learning profile defined by these Autistic Learning Disabilities helps specify the types of intervention and treatment modalities that are likely to fit the learning strengths and weaknesses of the individual child.

For instance, a child who meets the DSM criteria for "marked impairment in the use of multiple non-verbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction" likely has a specific "autistic" learning disability in the area of modeling or imitation. Meeting this particular criterion also specifies that explicitly teaching the child to read non-verbal cues is needed if the child is to learn language the way typically-developing children do. Interventions using a behavioral philosophy such as DTT (Discrete Trial Teaching) and PRT (Pivotal Response Training) are designed to teach compensatory skills in imitation and therefore are the optimum choice for addressing this specific Autistic Learning Disability. In contrast, behavioral interventions are less successful than more child-initiated interventions such as Floor-time at addressing Autistic Learning Disabilities in the area of Theory of Mind. Table 1 provides a more detailed

description of the Autistic Learning Disability targets of the various intervention approaches used in a JumpStart program.

Our current “best practices” understanding of autism intervention supports the idea that there is no one way to treat autism, but rather that intense, developmentally-appropriate, consistently-administered, teaching which can be generalized fosters neuro-developmental change (National Research Council, 2001). Drawing on our understanding of best practices and the Autistic Learning Disabilities model, JumpStart has developed a unique approach to intervention. Rather than offering intervention following one treatment model or another, it individualizes treatment based on the Autistic Learning Style of the child. Thus the intervention model consists of an eclectic mix of:

- 1) Developmentally informed behavioral techniques;
- 2) Play-based techniques; and
- 3) Speech therapy techniques.

ASDs are seen as collection of “Autistic Learning Disabilities” and “Autistic Learning Styles”

Curriculum

The two week JumpStart parent training program serves both as an extended diagnostic period wherein different treatment approaches are tried and fine-tuned and the child’s learning style explained for parents and future service providers, as well as providing an opportunity for parents to experientially learn this process so they can continue working to change their child’s treatment as his educational needs change. Additionally, in the course of parent training, children gain initial learning readiness skills. JumpStart also works to strengthen long-term family functioning as it is affected by the major life stressor of an atypical child.

The JumpStart curriculum involves five teaching strands, each designed to help parents become experts in the treatment of their child’s ASD.

TEACHING STRAND 1 *Direct Child Teaching*

This teaching strand uses developmentally-appropriate applied behavior analysis methods that incorporate discrete trials and pivotal responding methods

(e.g., Koegel & Koegel, 1995) to develop the child’s initial compliance, motivation, and attention to instruction and to help in identifying the child’s relative readiness for oral, visual, or sensory-motor (e.g., motor prompting) based instruction. It also introduces visual interaction augmentation (VIA), a visually-augmented communication approach, that teaches responses to gesture, gaze and facial affect used in communication along side photographs of requested items which are linked to auditory and visual words (Siegel, 2003). VIA is similar to other purely behaviorally-based augmentative communication systems such as Picture Exchange Communication System (PECS). VIA is distinguished by its emphasis on teaching communication behaviors (e.g., giving an icon) which promote compensation for the core communication deficit of absent spoken words alongside the pre-linguistic, non-verbal foundations for spoken language (e.g., eye gaze, gesture) which are also deficient (Siegel, 2004). During direct teaching sessions parents learn to: 1) identify appropriate best practice techniques and evaluate the elements of good intervention; 2) evaluate their child’s development and choose interventions which are appropriate to meet the child’s individual needs; and 3) implement best practices techniques with their child during non-therapy hours.

TEACHING STRAND 2 *Direct Child Teaching – Teaching-In-Context*

The best natural teaching opportunities for children with autism are in the context of the routines of daily living. Under the supervision of a JumpStart therapist, parents learn how direct teaching techniques can be used in naturally occurring contexts (e.g., eating meals, playing in the yard, taking a bath, or getting ready for a nap).

TEACHING STRAND 3 *Teaching-In-Context Play Sessions and Play Teaching*

This strand is designed to teach parents the importance of meaningful play experiences which provide intensity while promoting generalization of concepts

Table 1: Autistic Learning Disability Targets of Various Intervention Approaches in JumpStart Programs

Area of Specific Learning Disability	Behavioral Techniques (ABA, PRT)	Play Based Techniques (Floor-time, RDI, SCERTS)	Speech Therapy Techniques (Hannen, VIA*)
Low response to social reward	YES through paired associations	YES through child choice	NO
Infrequent social reference / joint attention	NO	YES Main focus	YES Significant focus
Limited modeling or imitation	YES through forward / backward chaining	NO	NO
Poor comprehension / limited use of nonverbal communication	PARTIAL Taught by rote	YES In context of social regulation	YES Significant focus of VIA
Slow auditory processing / parsing of speech	PARTIAL (shortened grammatically incorrect sentences)	NO	YES Significant focus of VIA
Preference for visual over auditory modalities	YES Use of visuals and procedures	YES Pairs words with activities	YES Especially VIA
Poor theory of mind / perspective taking	NO	YES Anticipation / prediction of other's actions	YES
Lack of imagination	PARTIAL Taught by rote	YES Main focus	NO
Preference for repetition over novelty	YES Adult direction, visual schedules	YES Main focus	NO
Sensory modulation difficulties	YES Desensitization	YES Gradually building reciprocity	NO

* VIA is a visually-based augmentative communication system developed at UCSF that simultaneously provides a method for non-verbal children to communicate and teaches them to use and respond to non-verbal signals such as eye gaze, gesture, and affect. For more information see Siegel, 2003, 2004.

initially acquired in direct teaching. By learning to facilitate their child’s development playfully, parents develop confidence that their interactions are meaningful, stimulating time spent with the child which can promote habilitation in many of the same ways as interactions labeled formally as “therapy.” Intervention strategies or models for intervention, such as Floor-time (Greenspan & Wieder, 1998), SCERTS (Prizant, Wetherby, Rubin, & Laurent, 2003) and Relationship Development Intervention (RDI) (Guttstein & Sheely, 2002), are used to teach parents to identify openings in the child’s activity that can be leveraged into increasingly sustained social interaction, re-enactment, and reinforcement for emerging linguistic concepts, as well as building on and expanding the child’s natural interests as intrinsic reinforcers.

TEACHING STRAND 4

Direct Parent Didactics and Parent Support

The parent didactics sessions teach parents about ASDs and their treatment. Parent learn: 1) our best understanding about causes and treatments for ASDs; 2) the mechanics of public education and developmental disabilities services; 3) observation and interview techniques for choosing appropriate services for their child; and 4) negotiation skills to have a productive, low-stress relationship with the child’s service providers. Additionally, this strand is used to provide parents with emotional support. We feel that an essential part of the intervention is helping parents develop an emotional “vocabulary” so they can talk about autism with each other, and with

siblings and extended family, and see that they are not alone with this stressor.

TEACHING STRAND 5

Transition to On-Going Treatment

JumpStart personnel are available to parents and IFSP or IEP teams to consult as the transition is made to ongoing services. Program staff serve as guides, helping parents learn to view programs from a professional's perspective in order to determine whether proposed ongoing educational services will meet their child's needs. As part of this strand, parents are encouraged to include future tutors, nannies, and relatives, as well as educators and therapists in selected aspects of the child's program.

Outcomes

We believe that the JumpStart program provides an essential support for families in the confusing and emotional period just after diagnosis. **Without such support, parents are most vulnerable to the various "snake oil salesmen" who promise false cures.** We see JumpStart as both a tool to instill in parents the necessary skills and confidence to care for their child with autism using evidence-based techniques, and an "inoculation" against ineffective interven-

tions that inevitably renew grief and prolong the initial emotional period following diagnosis.

For more information about the JumpStart program, please contact **Michelle Ficcaglia, Ph.D.** at (415) 476-7160 or ficcagliam@lppi.ucsf.edu. ♥

References

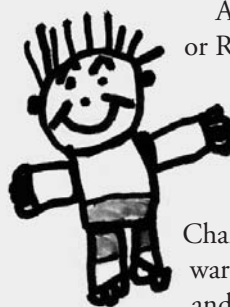
- Greenspan, S.I., & Wieder, S. (1998). *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*; Reading, MA; Perseus Books, 449-483.
- Gutstein, S.E. & Sheely, R.K. (2002) *Relationship Development Intervention with Young Children: Social and Emotional Development Activities for Asperger Syndrome, Autism, PDD and NLD*. New York; Jessica Kingsley Publishers.
- Koegel RL, Koegel LK. (1995) *Teaching Children with Autism-Strategies for Initiating Positive Interactions and Improving Learning Opportunities*. Baltimore, MD; Paul Brookes.
- National Research Council *Educating Children with Autism* (2001) Washington DC; National Academy Press.
- Prizant, B.M., Wetherby, A.M., Rubin, E., & Laurent, A.C., (2003) The SCERTS Model: A transactional, family-centered approach to enhancing communication and socio-emotional abilities of children with autism spectrum disorders. *Infants and Young Children*, 16(4), 296-316.
- Siegel, B. (2003) *Helping Children with Autism Learn: Treatment approaches for parents and professionals*. New York; Oxford University Press.
- Siegel, B. (2004) VIA: Visual Interaction Augmentation. *Autism News of Orange County & the Rest of the World*, Vol. 1(3), 8-11.

Artist: Garrett Black

By Julie Meves

Garrett is an 11-year-old 6th grader at Canyon View Elementary School in Irvine. Garrett loves to draw. He started drawing when he was two years old and drew all lines. At home he loves to draw with his sister Kaylee, who is seven years old.

Garrett enjoys reading Harry Potter stories and anything that pertains to Napoleon Dynamite. He likes to share his favorite parts of these stories. Currently, Garrett has mastered and performs the entire Napoleon Dynamite Dance. He performs this dance perfectly with each and every move! He plans to perform the dance for the school's annual talent show in the spring.



At home Garrett enjoys riding his bike or Razor scooter with his family. He is an excellent swimmer and loves swimming with his friends and family on the weekends.

Garrett's best friends are Bob, Chandler, Katie and Sarah. He looks forward to going to middle school next year and being with his friends again.

Julie Meves

*Teacher, Canyon View Elementary School
Irvine Unified School District
Special Education Program* ♥

Educational Services for a Student with Asperger's Syndrome:

What Mattered the Most?

A Family Shares their Experiences and Recommendations

By Barbara C. Bloomfield

We are the family of Max, a deeply cared-about thirteen-year-old boy diagnosed with Asperger's Syndrome. Parents, grandparents and sister – we love Max dearly, worry about him frequently, and nurture him however we can. From his early preschool days to his current enrollment in eighth grade, we have planned for, advocated for, and, when we thought it necessary, fought for Max's educational opportunities.

Two of us are special educators. I am Max's grandmother and a speech/language pathologist specializing in therapy and consultation services for individuals with Autism Spectrum Disorders (ASD). Max's mother, Amanda, is a special education teacher and often mentors colleagues and other families in their efforts to meet the needs of students with autism.

The thoughts that follow are our shared reflections on which services have contributed the most to Max's progress. Overall, we considered five types of educational services to be the most beneficial:

1) Educational Services that Focus on the Family as Well as the Student

Despite having special educators in the family, we were a needy group. I suspect that few families are ever really prepared for the challenges of raising a child with autism. At times we just couldn't find our way through all the emotional clouds to band together in our efforts to assist Max. We needed an educational team that could keep the whole family abreast of available services and of Max's particular needs.

Max's busy parents needed someone to teach them an educational style that would be effective in their parenting interactions. How could they, using the environment and objects in the household, develop a teaching approach that could easily be

used for everyday routines? The most effective assistance came from teachers and therapists who pushed their way into Max's home and classroom and who solicited parent observation and involvement in Max's educational programs.

Beneficial educational services focus on:

- 1) the family as well as the student
- 2) individual student needs and family preferences
- 3) functional skills
- 4) structured teaching and visual supports
- 5) a "bully-proof" school environment

Their "Watch what I do – now you try it" style had a huge positive impact on the competence and confidence with which family members pursued home intervention efforts. Max's parents particularly treasured those educational team members who appreciated that, despite their great love for Max, parents could sometimes lose momentum as educa-

tors. Not enough sleep, super busy schedules, disappointment, frustration, and fear can compromise the efforts of caregivers. Educational teams need to give families the best available advice on how and what to do for their child, but sometimes the solution can be as simple as just "giving the family a break."

2) Educational Services that Focus on Individual Student Needs and Family Preferences

By the time Max began elementary school, his family had moved to a rural section of Virginia. We were all concerned that Max's new little school in the country seemed relatively uninformed and unprepared to program for a young student with Asperger's Syndrome. We could not



have predicted what followed. Perhaps it's easiest just to say that Max's new school more than made up in "heart" for what it lacked in experience. The staff truly listened to Max's parents' concerns and everyone worked together to figure out what Max needed. The school team valued him. He was theirs and they always seemed to try their best. Max flourished.

Today Max continues to flourish as a student. He has moved on from his country school, and teachers since then have been more or less insightful, but all have seemed to genuinely care about helping Max.

3) Educational Services that Emphasize Functional Skills

Our family was shocked recently by the dramatically grim employment statistics for students with Asperger's Syndrome. Employment estimates that we have seen range from 3% to 25%. We have been told that job coaches cite four areas of deficient work skills among students with Asperger's Syndrome: Limited ability to work independently; poor social communication skills; poor planning and organization (e.g., invading the space of other workers, not putting materials back after using them, needing prompting to complete tasks, etc.); and poor daily living skills (e.g. unclean clothing, dirty unkempt appearance, etc.).

We have been very grateful to those teachers and therapists who began teaching skills in each of these areas as early as preschool and who found ways to thread them in and among their work on state learning standards. As Max's grandmother, I am delighted with his academic accomplishments, but my heart brimmed with pride when I learned that on school days, Max wakes to an alarm, showers, dresses, makes and eats a piece of toast and walks to a nearby school – all by himself!!!!

4) Educational Services that Offer Structured Teaching and Visual Supports

From preschool onward, Max has been a student who responds very, very positively to the use of structured teaching – well engineered classrooms, visually clear instructions, visual schedules, etc.

"Just show me what you mean" could be the theme of Max's attempts to understand teacher expectations. Even something as impromptu and simple as a quickly printed schedule on the back of a napkin has been a "lifesaver" strategy for Max.

5) Educational Services that Emphasize a "Bully-Proof" School Environment

Our family's pressing concern in regard to school now involves the prevention of bullying by other students. Although the school team regrets that bullying occurs, they still need to actively "bully-proof" Max's school day. We are hopeful, though, that this will be handled just as well as previous issues have been. An "Anti-Bullying Campaign" may be something other children would also be grateful for, not just Max!

In our experience, a good balance of these five educational service areas can lead to great success not only for the child with ASD, but for the entire family and sometimes even for his peers!

Barbara Bloomfield lives in Goshen, NY. She specializes in treatment, consultation, and conference services for students with Autism Spectrum Disorders (ASD). Barbara travels extensively both nationally and internationally to present information on autism and the use of practical teaching strategies.

For further information please contact **Barbara Bloomfield** at bcbloomfield@yahoo.com. ♥

**No one
deserves to
be bullied.**

Get a
FREE SUBSCRIPTION to



Made possible through the
following website:

<http://verabernard.org>

Siblings of Children with Autism:

An Interview with Sandra Harris

Interview by Allison Martin

Sandra L. Harris, Ph.D., is a Board of Governors Distinguished Service Professor at Rutgers, the State University of New Jersey and the founder and Executive Director of the Douglass Developmental Disabilities Center at Rutgers. Her book, co-authored with Beth Glasberg, Ph.D., *Siblings of Children with Autism*, explores the impact of raising a child with autism on the family, especially on brothers and sisters. In this compelling interview she discusses ways to cope with the impacts of autism on your family.

What do studies show about the effect of autism on other siblings in the family?

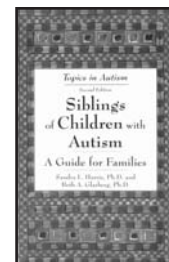
Sandra Harris: There are really two aspects to this question: one is the extent to which the siblings of children with autism pose more problems needing professional attention than other children; and the other is to what extent their sibling's autism influences what they think and worry about. I think it is important to distinguish between them. In terms of the first issue, general research on the siblings of children with autism suggests that most of them are much like other children their age. There is, however, a small group of these children who are more vulnerable to worry and anxiety or to "acting out" behavior than is true for other children. So, while having a sibling with autism does not usually mean that a child needs professional attention, there is that subgroup of children for whom this is important. The child who is often worried, moody, sad, or angry for extended periods may benefit from the assistance of a mental health professional.

I think parents sometimes confuse those clinical issues with the more common concerns that are part of growing up with a sibling with autism. In thinking about that it is important to put the experience in perspective. Each of us is shaped by the environment in which we grow up. For example, if we live

in poverty, have a parent with a chronic illness, experience the death of a grandparent or our parents get a divorce - all of those things shape the person we become. The same is true for having a sibling with autism. That experience influences what we think about, how we view ourselves, and what our worries might be. These kinds of issues are different from the kinds of clinically significant problems I mentioned. All of us had worries and concerns when we grew up. Childhood, like the rest of life, is rarely free of stressors that are inherent in living. Our concerns focus on the things we see around us and how they impact on our lives. That is true for siblings of children with autism just as it is for every child. The good news is that caring parents can help children deal with these kinds of concerns, as they do for other issues that arise in a child's life. Having a sibling with autism poses problems that must be solved, but it does not mean that one's childhood will be without joy and delight.

What can parents do to help siblings understand autism?

Sandra Harris: I think the key thing in helping a child understand autism is to adjust what you say to your child's age and ability to understand. Very young children will not benefit from a discussion of the details of autism, but they do need to be reassured regarding their concerns about a sibling's behavior. Older children can gradually come to understand how autism influences their sibling's life. Younger children will primarily notice the visible behaviors of their sibling such as tantrums or other stereotypical behavior. Older children will understand that it is the impersonal challenges that are most daunting.



How can parents encourage more positive interaction between their children?



Sandra Harris: The best way to encourage positive interaction is to make sure both children have the skills to play together. I think it is a good idea from early childhood to find simple things your children can enjoy together. The child with autism should be taught some games he can play with his siblings. It may start with rolling a ball or playing catch and gradually become more elaborate as they grow older. Older children might jog or shoot baskets. If they have a tradition of spending even a small amount of time together, the time can gradually be expanded. Older siblings in particular may enjoy learning some basic teaching skills so they can be “teachers” of play. David Celiberti and I did some research in which we taught older children how to teach basic play to younger brothers with autism. The videotapes we made showed how much both children came to enjoy these play times. Beth Glasberg and I discuss that kind of interaction in the latest edition of the sibling book.

How can parents deal with resentment and competition from younger siblings?



Sandra Harris: A certain amount of jealousy and competition between siblings is almost universal. I think it is important for parents to remember that and not over-react to expressions of jealousy when they see them. On the other hand, it is important that every child has the experience of feeling perceived and valued by his or her parents. That means making sure to find some time that is private, special time with your typically-developing child(ren). It might, for example, be the time spent driving with dad to the store on Saturday morning and a half hour with mom at bedtime each night. What you do is not as important as the fact that it is time that belongs to the child and that he or she has your focused attention.

In closing I would like to add that what has impressed me most about families of children with autism is the resilience and strength they bring to that experience. I have known hundreds of families over the past 30+ years, and one of the important lessons they have taught me is about learning to carry life’s hard demands with grace and humor. ♥

Reprinted from www.comeunity.com/disability/autism with permission from Sandra Harris.



Many children with ASD have special interests and frequently Thomas the Tank is one of them. Incorporating these interests often enhances attention to a task.

The goals in this example are two-fold: 1) To help the student understand that sequencing letters is spelling; and 2) To let them know that important information is available in reference material, such as this picture dictionary. For beginning spellers, we use words that the student understands and finds meaningful. From these first steps, we hope that our students will be able to access more advanced reference materials and spell words that have more practical or academic significance. The visual and physical properties of this task also help the student’s success. The alphabet letters are large and are presented separately rather than cluttered in a box, and magnetic letters on magnetic trays create a finished product that stays as placed.

Reprinted with permission.

For further information visit www.tasksgalore.com. ♥



Life with Kim Communication at Last and Ongoing Successes

By Elaine Weber

I'm going to be honest with you – the following article could sound like sour grapes; we tried various therapies with our daughter but they didn't "cure" her autism. On the contrary, this is a brief summary of taking a journey down a path of hope, lost dreams, denial, acceptance and hope again. If this sounds a little like the grieving process, it is. When we have children who appear to be "normal" at birth, we have hopes and dreams for their future. When autism comes into the picture we have to put those hopes and dreams away, create a new future, and re-evaluate what is really important.

who provided various inaccurate guesses as to what was going on with her unusual behaviors. Finally, 13 months later, we received an accurate diagnosis. She was two years, ten months old and our whole world was about to be rocked in ways we could not imagine.

The more we learned about autism, the more scared we became. Kim was non-verbal, threw impressive tantrums and still mouthed toys. At age three, she started in an **Orange County Department of Education Special Schools Program**. We began seeking out parent support groups to learn more about what the future could possibly hold for our family.



Kim at the beach

On January 20, 1995, it was made official - our daughter, Kimberly (Kim), was diagnosed with autism. We knew something was different about her since she was 21 months old. We had visited numerous doctors

I met with a mother whose son had been diagnosed with autism, and who was about to begin an **at-home applied behavioral analysis (ABA) program**. She was convinced this was the path to "curing" her child's autism. That sounded like a great plan to me at the time. I could go on for several paragraphs about my child's experience with ABA, but I'll summarize: after four years of ABA, Kim was still autistic.

Another parent suggested I try **Prozac** with my daughter since it really helped her son. I even got a prescription from my daughter's neurologist but I never used it. By the time Kim was three-and-a-half and she had been diagnosed with a seizure disorder. I was too worried about giving her Prozac in addition to her seizure medications, so I passed on the Prozac experiment. This parent who recommended Prozac told me, "I give my son his morning dose then I take a little of the Prozac myself so I can handle taking care of him!" I thought that was a combination of creativity and reality.

Another parent absolutely insisted on “**mainstreaming**” her child. That sounded like a good idea too. If we put our child with autism in a classroom with typical children, her behavior will naturally improve, right? I imagined she would be sitting in a classroom with typical kids, but with an aide, doing a separate curriculum. However, the more I started looking at that type of school setting for Kim, the more I realized she couldn’t really be mainstreamed due to the severity of her autism. I also started thinking, “most of the people she is with aren’t autistic and she hasn’t picked up on their skills” so I didn’t think a regular classroom would be the most beneficial program for her. Please don’t get me wrong; mainstreaming is a great idea for some kids. To meet Kim’s unique needs, we opted to keep her in the special day class, with a higher adult to student ratio.

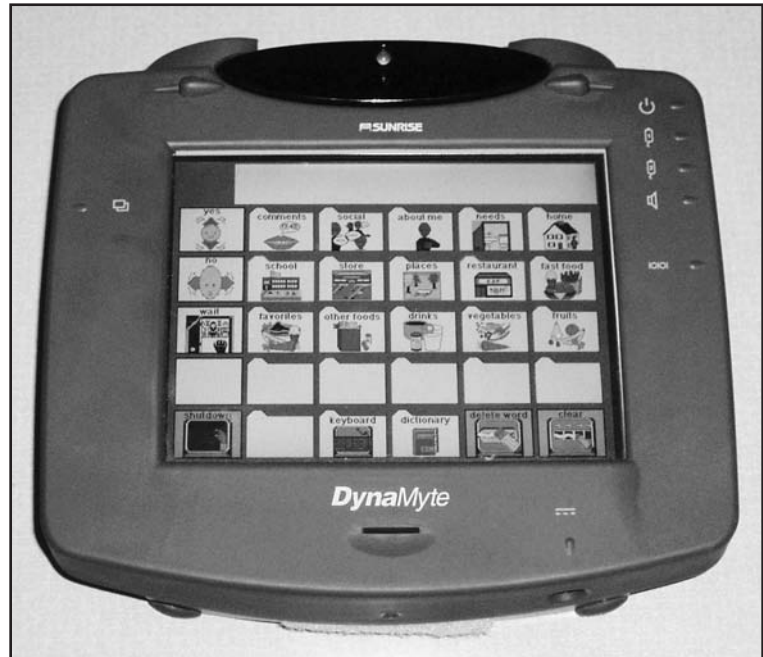
When Kim turned five she still had very little language and what words she did have would rotate out; at any one time she couldn’t seem to accumulate more than a 30-word vocabulary. We began to view her tantrums as an outlet of the frustration she must feel from not being able to effectively communicate. **As I parent, I tried to envision being in a foreign country and how aggravating it would be not to have anyone understand what I wanted.** Would I get angry and frustrated too? Of course!

At that point, **PECS (Picture Exchange Communication System)** entered our world. Where sign language and verbal communication failed, PECS succeeded. Kim understood how to build the “I want ...” sentence strip and let us know what she wanted. It was wonderful to see her have some mode of communication.

After our success with PECS, we started changing our viewpoint of what was important for our daughter. **The realization that the grip of autism was firmly part of her being had finally sunk in, so we changed our focus from turning Kim into a “normal” child.** Among other changes, we adapted her

IEP goals to be more *functional*, with the premise of allowing her to live comfortably in a “normal” world.

In 2000 Kim was eight years old and outgrowing her PECS options. She wanted to communicate



DynaMyte 3100

more but we couldn’t keep up with all of the pictures she needed. I still don’t know how I found **ATEC (Assistive Technology Exchange Center)** but I am so grateful I did. They conducted an evaluation of Kim’s abilities using the different augmentative communication devices they had: voice output, keyboards and everything in between. They recommended the DynaMyte 3100 from DynaVox. It’s a wonderful device, but at \$6,400, one that we that we didn’t want due to the cost. The ATEC evaluator was very clear; by not obtaining a **DynaMyte 3100** we would be doing her an “injustice” because Kim was capable of navigating the screens and of using dozens of optional dictionary icons. This device matched many of her current skills and developmental levels. So how could we make it possible?

By providing documentation of Kim’s capability with the DynaMyte 3100 and with the support of our wonderful program specialist, the school district agreed to purchase the device. The DynaMyte 3100

is a very powerful “portable computer” which is customized for each child. I picked the voice output, copied dozens of icons onto various screens and worked with Kim’s outstanding teacher. We then proceeded to see how Kim would use this communication tool inside and outside the school environment.

It was an immediate success. Kim built sentences, requested items, food, toys and activities. My disappointment in her not talking was appeased somewhat. You see, I had read in an article that, “if an autistic child wasn’t talking by five years old he or she probably never would.” Kim wasn’t verbally talking but she was communicating, and that was our goal for her. We realized the device provided an extremely functional method of meeting her needs.

There are some negatives to this type of communications device. Since it is portable, it can be dropped or jostled which can cause it to stop working, and then it must be sent to Pittsburgh for repairs. It was distressing for Kim when the device was unavailable because her “voice” had been taken away.

Within the past year, during one of those times when the DynaMyte device was gone for repairs, Kim wasn’t too upset, which I found rather interesting. I realized her verbal communication was increasing and she was relying less on the device. At age 13, Kim was using more verbal communication than ever! Her communications were not full sentences, usually one- to three-word utterances that contain a variety of words used in appropriate settings. So much for the theory that “not talking by five means not talking at all.” Her communicative intent was solid, be it by pointing to the object, utilizing the communication device or keyboard, handwriting the request or using verbalizations. It all worked for me because it was functional.

Kim is now 14 years old and has done better in the last two years than I thought possible. Her



Kim using the DynaMyte 3100

tantrums are now infrequent. She loves taking plane rides and even asks to have her fingernails painted. Her communications continue to improve and overall she seems to be in a good mood the majority of the time. (Not bad for any teenage girl!)

What I’ve learned over the years since her diagnosis in 1995 is to trust my instincts as her mother and caregiver as to what is best for her growth and development. Autism is not the path I would have chosen for my daughter but it is the path we are on. The support of family, friends and the school system has been instrumental in her ongoing improvement.

Is Kim “normal”? No. Is Kim “happy”? Yes. Do I hope that someday the cure for autism is found? Absolutely! In the meantime, Kim continues to accumulate life skills and I continue to marvel at her ability to learn and improve every day, just like any typical child.

For more information, please contact **Elaine Weber** at elaineweber@hotmail.com. ♥

Using Digital Pictures to Support Free Recall and Language in Children with Autism

By Kelly McKinnon

The use of visuals to support extensive language can be extremely effective for children with autism. Rote memory and recognition tasks often remain intact in individuals with autism. On the other hand, memory tasks that require free recall without explicit retrieval cues can be much more problematic. Individuals with autism also tend to be less able to gain access to information that is relevant to the rapidly-changing social context; they rely more on concrete retrieval cues to remember language information (Tager-Flusberg & Anderson, 1991) and to initiate spontaneous communication.

In our clinic, digital cameras are used to help with the problem mentioned above. After several events during the social group session, digital pictures are put together and a child is asked, "What did you do today?" The pictures are then used to support recall of the events. Next, as students join their parents, parents are taught to ask their children,



I sat in circle and raised my hand!

"What did you do in your class today?" The pictures are available for immediate recall if needed, with a simple typed description for the parent to support the recall language. Finally, parents bring



Look at the giant spaceship we made together!



I practiced walking in a line to the park!

the pictures home so that a second parent can ask the same question, promoting delayed recall of an event.

For further information please contact
Kelly McKinnon & Associates, Inc. at
kellymckinnon@kellymckinnonassociates.com.
www.kellymckinnonassociates.com ♥



I built with Legos!

Understanding Joey

By Linda Varblow

If you were an Explorer last year, you already know Joey, but some of the kids that were Pathfinders last year might not know him. If you have seen Joey around, you know that he is a little different from you, but you might not know why.

knows why. For every girl who has autism, there are four or five boys. Some kids who have autism don't seem much different from other kids, but some kids with autism are obviously different from other kids.

Joey is really good at some things, but **having autism makes some things very hard for him.** He is pretty smart; he could read when he was only three and he knew all his letters before his second birthday. He surprised the ladies at his day care by looking at letters and saying what they were. This was long before he could speak words! Joey does well in school and his great memory makes taking tests less stressful for him than for some other kids.

Having a conversation is REALLY hard for Joey. He sometimes has trouble understanding what people are saying to him. This makes it very difficult for Joey to make friends. He really likes to be around other kids, but it is hard for him to join in.

Body language is something that most of us understand without even thinking

about it. The way we say things and how we move our body when we are saying it give other people a lot of information.

For people with autism, body language, gestures and facial expressions don't mean as much. Joey is learning to "read" this unspoken language, however, it is still difficult for him. Sometimes he might ask you if you are being sarcastic because he isn't always sure just from listening to you.



Joey at the beach on Lake Michigan

Joey has a form of autism called "high-functioning autism" or HFA. Some kids with high-functioning autism are said to have Asperger's Syndrome or AS, but we say that Joey has HFA.

You might be surprised that even though Joey is different from you in some ways, he also has a lot in common with other kids his age.

You can't tell that a kid has autism by looking at him. Most kids with autism are boys, but no one

Looking into other people's eyes while he is talking is also hard for Joey. Some people say that people with autism never look into other people's eyes. This isn't true, but it is true that talking to you and looking into your eyes at the same time is very hard. **He can either concentrate on listening to you, or talking to you, or looking at you, but not all three at the same time.**

The tone of voice that you use might not make sense to Joey either. If you speak with urgency, he might not understand that you need something right away. When something needs to be done right away or if there is an emergency, it is best for you to use "concrete language," so he understands that you mean business. **Using concrete language means saying exactly what you mean, not using slang or words that could have other meanings.**

The reason Joey doesn't understand the subtleties of language is because he is a concrete thinker. This means that he understands the literal meanings of words. Figures of speech, slang words or idioms that everyone understands don't always have meaning for Joey.

Speaking clearly to Joey or explaining things more clearly than you normally would helps Joey understand the meaning of what you are saying.

Joey gets frustrated when he doesn't understand something. He's not mad at you, he just gets a little stressed when he is confused. At times, it is almost like English is a foreign language to him, even though it is his native language.

Middle school is hard for all kids. You all try to make friends and fit in with the other kids. Joey doesn't really know how to do this. Fortunately for Joey, he's pretty comfortable being Joey. **Because making friends is so stressful for Joey, he is okay with the fact that he doesn't have tons of friends.**

Because Joey is "developmentally delayed," he might seem to be much younger than 12. He still likes some things that you may have given up for more mature things. He still likes Pokémon, and stuffed animals and the little kids rides at Disneyworld. But he also enjoys some things that

you might like, such as strategy games on the computer, surfing the Internet, big roller coaster rides at amusement parks, and TV shows like the Simpsons and Family Guy.

People with autism sometimes have a different reaction to sensory input than other people. This is true for Joey. He is especially sensitive to sound. He can hear frequencies that the rest of us can't hear, kind of like dogs can. He can see little specks of things that the rest of us wouldn't notice. **It is almost like the volume is turned up on all of his senses.** When he was little, the feel of clothes on his body bothered him. Some people don't like the feel of tags in their clothes, but for Joey it was like that over his whole body!

Assemblies are hard for Joey because all the activity is confusing to him and the loudspeaker bothers his ears. Sometimes when he goes to the movies, he has to wear ear protectors because the sound hurts his ears. If you are in the band, you might have noticed Joey wearing them in band when it is too loud for him.

Many of you know that glitter also bothers him. It always has. Where you just see a little shiny thing, he sees a big light flashing at him. This is another example of how the volume is turned up on his senses.

If you were in any classes with Joey last year, you might have noticed that sometimes when the class was doing group work, Joey worked by himself. This is because it is easier for Joey to work by himself or in very small groups. The more people that are in a group, the more difficult it is for Joey to concentrate and participate. **If a lot of people are speaking at the same time, he won't understand what is going on.**

If Joey gets confused, sometimes he may say or do things that seem unfriendly or are upsetting to you. Most of the time, he is simply confused and isn't trying to be unfriendly. Just as he doesn't always understand body language, he doesn't always understand how to speak to other people and sometimes says things that he doesn't really mean. When he gets frustrated, he often speaks too loudly because he doesn't really understand how to regulate tone or volume in his voice.

Everyone likes routines and predictability in their days. People with autism need routines and predictability more than other people. Routines help us understand the world around us and make things manageable for us. **Joey likes routines.** The school year is easier for him than the summer because he knows what is expected of him every day. Weekdays are easier for him than weekends, because the days are more predictable.

For a person with autism, Joey is pretty flexible as long as someone lets him know what the schedule will be. If the schedule is going to be changed, that is fine if Joey knows what is coming next. He doesn't even mind doing homework or practicing the piano as long as it is on his schedule!

Like most people with autism, Joey is a “visual learner,” which means that he can process infor-

mation he sees much more easily than things he hears. Writing down instructions for Joey is very helpful. If you are trying to tell him something and he doesn't seem to understand, write it down and he won't have any trouble figuring out what you are trying to tell him.

Joey has several “special interests.” Everyone has things they like, but when people with autism like something, they tend to learn everything they can about these interests, almost to the point of obsession. You might like Bionicles, but Joey REALLY likes them. He has almost every one ever made. He has read all the books about Bionicles and visits the website to find out more information. Currently his special interest is a game called Kingdom Hearts. He reads the strategy guide and draws pictures of things from the game. He likes to find out about all



Joey and his brother, Jesse, along with their Godsister and Godbrother stand under “Sue” the T-Rex during a trip to the Field Museum in Chicago.

How can you help Joey and kids like him?

- Speak slowly and don't use too much slang so that he can understand you.
- Realize that he does want to be around other kids and be friends, it is just really hard for him.
- Understand that when he gets upset, it is usually because of a communication misunderstanding and he is frustrated or confused. He can't help this.
- Know that he might not want to join in a group. He is not on the periphery because he is unfriendly; he is very friendly when you get to know him!

the details of the game almost more than playing the game itself. He also is very interested in mythology.

Often it is hard to get kids with autism to talk about something other than their special interests. Sometimes they start talking about something from a movie or TV show without first letting you know what they are talking about. They might assume that you know what they are talking about and that you are interested in the same things that they are. They won't be able to read your body language and know that you want them to stop. **It is okay to remind Joey that you aren't interested or that he is going on for too long about something as long as you are polite.**

Some people with autism turn their special interest into a career, just like other people turn their interests into careers, so having these special interests isn't a bad thing.

You might have noticed that sometimes Joey's desk is up against the wall or is at the edge of a row. His desk is there because he can concentrate better with fewer distractions. He can listen to the teacher better if he doesn't have too much to look at.

Sometimes, Joey even needs to go outside the room and jump around a little bit. He isn't trying to get out of doing his work. **Because his senses get overloaded easily, he needs to get away sometimes to refocus and then he can sit down and do his work again.** He needs to do the same thing at home while doing his homework. After a short break of running around or bouncing on the therapy ball, he can concentrate better and complete his work.

People who have autism will have it for their whole lives. It isn't a disease that you can take medicine for and get better. Parts of Joey's brain work differently than most other people's brains. Joey is smart and likes to learn and is learning the things that come naturally for other kids. The fact that he learns differently doesn't mean that he won't grow up and be able to do most things that other people do; it just may take him longer to get there.

Because autism is a "spectrum disorder," it affects everyone who has it differently. Some kids who have autism, like Joey, are as smart as you and can be in regular classes with lots of kids. Other kids need more help and need to be in a special class with fewer kids and specially-trained teachers.

If you haven't been around kids with autism before, don't be concerned about Joey's differences, except to understand them. **Joey loves to be around other kids, so if you can accept his differences, he will like you and be happy. Mostly, he is a kid. He just happens to have autism. Just like some kids wear glasses and some kids have asthma. They are still kids first.**

Please take this home and share it with your family. There are lots of people with autism in our community because one of the best autism centers in the country is right here in Chapel Hill.

Remember that Joey likes a lot of the same things that you like. He especially likes to travel.

If you or anyone in your family would like more information about autism, please contact Joey's mom, **Linda Varblow**. She is a psychoeducational therapist at the TEACCH Center in Chapel Hill. You can contact her at Linda_Varblow@med.unc.edu. ♥

Friendships, Relationships and High-Functioning Autism

By Jennifer McIlwee Myers

Many parents and professionals wrestle with the problem of helping people with autism, high-functioning autism (HFA), Asperger's Syndrome (AS), or Pervasive Developmental Disorder: Not Otherwise Specified (PDD:NOS) develop friendships or sustain relationships with the opposite sex. As a happily married adult with AS who grew up undiagnosed, I would like to share the ways I was able to learn to develop friendships. These methods have been used by many adults with AS with success.

Note: In this article, I refer to people with High-Functioning Autism, Asperger's Syndrome or PDD:NOS as "people with AS" or "aspies" (as we sometimes call ourselves). While the ideas here are easiest to apply when dealing with a person with AS who is basically high-functioning, some ideas can be adapted for people with more involved Autism Spectrum Disorders.

Why Is Friendship So Hard?

Many people with AS have trouble developing basic friendship skills: the give-and-take of mutual conversation, the issue of being clean and neat, and other basics often elude us. The main reason we do not develop friendship skills is that we do not develop friendships. **Friendships are especially difficult for us, since we spend most of our childhoods exposed to people we cannot make friends with.**

The reality is that most typical peers, especially from ages five to twenty, are not suited to aspie friendship. These typically-developing kids go through an assorted set of rapidly discarded social skills and expectations. These skills change every few months, so that what was completely cool for the kids who were three months into sixth grade is totally geeky for kids who are five months into sixth grade. This goes on for at least one and a half decades of life!

Most social skills programs for children with ASDs involve teaching rules, however, the real rules of childhood interactions change fast and it is almost

impossible for those of us on the spectrum to figure out which of last year's rules are still right and which have suddenly become wrong for no logical reason. You "neurologically typical" people (NTs) are very hard to figure out! Being among typical peers makes us feel a lot like you would feel if you were in a foreign country where you didn't speak the language.

There is, however, another option. **For aspies, the best basis for long-term friendships, relationships, and marriage is a solid foundation of common interests and similar values.** Knowing this, take a guess: how likely is it that a teen with AS is going to find someone they can have a close relationship with who also fits the NT profile of an appropriate friend or partner?

The answer is: not very likely! The good news is that there are a lot of grown-up people out there, both male and female, who share the kinds of interests and ideas of fun that we aspies have. They may either be completely normal, or on the far end of the autism spectrum. They are sometimes called "geeks."

The "Geek World"

I had the good fortune to spend some time talking to Temple Grandin, Ph.D., at a recent conference in Pasadena. When I told her that I give talks and write articles for parents and

professionals, she told me that it was *very important* to get out the word that there is a whole world of "geeks" out there.

She told me that she'd often heard people refer to the statistic that only one in ten people with AS is employed. Having worked with a lot of engineers, scientists, and computer programmers, she knew this was wrong. **The technical professions are full of people who are overwhelmingly aspie.** So are other professions where skills with inanimate objects (or animals) are much more important than people skills.

Common special interests are the most important social tool and basis for social contacts among "aspies."

Dr. Grandin also emphasized to me that many NTs really do not realize that there is a large segment of society in which things like forgetting (or refusing) to get a haircut or wearing almost the same outfit every day is not a drawback. That geek world is very important to those of us with AS. In the engineering department, no one cares about your sense of fashion – and you can groom horses in any old clothes, the horses don't care.

There is also a social side to this geek world, where people with AS can form friendships and relationships. So where does a young aspie go to meet people? He or she meets them in common interest groups!

There are dozens of science-fiction book clubs, model train clubs, Sherlock Holmes readers societies, Scrabble® clubs, jigsaw puzzle societies, and other groups of dedicated geeks, wonks, and nerds.

In fact, **common special interests are the most important social tool and basis for social contacts among aspies.** Read that again. And again. And again. Okay, now you can stop and go on.

While socializing and/or dating over the Internet can be fraught with peril, the Internet is still a great place to find special interest groups that meet in the real world. Enter the kind of special interest and your location into any decent search engine and you have a good chance of finding something.

Special interest groups also increase the possibility of dating and relationships.

You may not feel your son's dream girl should speak fluent Klingon, but he may be happiest if the couple writes their own vows in this language. For some girls with AS, what matters most is size – the size of a fellow's Lego® model train layout, that is. And other girls will go ga-ga over a guy who has been on every major wooden roller coaster east of the Mississippi.

Even if your daughter's special interest is focused around *Pride and Prejudice*, and the Jane Austen club is a little short on available men, it's a great way to get social. Friendships skills are relationship skills.

If the local model train club consists entirely of happily married old fellows, that will still provide the aspie with a chance to develop friendships and learn to relate to other people. Even a ten-year-old with AS is more likely to make friends in such a group than at school.

And everyone in that model train club, Jane Austin book club, or other group will also have a family and friends. They have sisters, brothers, children and grandchildren. The granddaughter of a model railroad buff or other special interest geek is more likely than average to be "AS-friendly" – she has been programmed by genetics and upbringing either to be one or to live with them!

Can I Get a Volunteer?

No special interest groups around? There is another opportunity no person with AS should miss: volunteering!

When I was in my early teens, my mother got

good and sick of having me mope at home all summer. She did a little research and found that I was old enough for the summer volunteer program at a local nursing home. She knew that particular home very well, as my grandfather volunteered there often.

At the nursing home, *everyone* was happy to see me – it was like the opposite of school. The residents liked having someone to talk to, and the nurses liked the fact that the volunteers raised the morale of the residents. My special interests of Fred Astaire movies and old-time radio shows were of much greater interest to people at the home than to any typical peer.

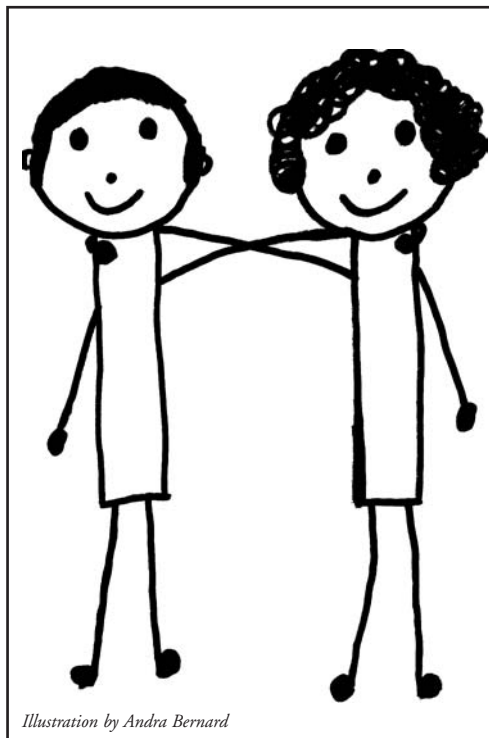


Illustration by Andra Bernard

Just as good was the fact that I got clear but kind feedback from the volunteer supervisor, so I knew when I made social errors and got helpful suggestions to correct them. It was so great I did it for several summers, and put in more hours than any other teen volunteer!

Trust me, you learn a lot about relationships in a nursing home. Many women there had pictures of themselves with their late husbands as young people, and many women missed their late husbands sorely. They would have gladly put up with all the snoring and golf talk in the world to have that special fellow back for another day. When you come face-to-face with the fact that life is short and some things just aren't so important in the long run, it sticks with you.

Make Me Smile

By Jennifer McIlwee Myers



My brother Jimmy has autism. He has recently mastered basic money concepts. As his big sister I sometimes spoil him by buying small presents. Jimmy usually is very polite, but likes to ask me for presents.

Recently, he asked me for a figurine of the adult Bambi (the deer) from the Disney cartoon "Bambi II." After looking for some time, I emailed him and explained that the only figurine of the adult Bambi that exists is too expensive. Below is his emailed reply.

Subject: I'm sorry about that!

Dear Jennifer:

I'm sorry the figurine of Bambi as an adult you found was too expensive!

Maybe you could get more money by mowing some lawns and delivering pizzas from Pizza Hut! If you don't have a lawn mower, you could borrow someone else's, (if they don't mind that is)!

I hope you like this idea!

Love,

Your brother Jimmy

The great thing about volunteering is that the very things people think are "**problem interests**" in aspies **can be beneficial when volunteering**. While the whole family may be very tired of hearing their aspie talk about horses, ducks, snakes, rabbits, cats, or dogs, there are rescue and education groups who always need an extra hand to help with rescued animals or clean out the snake exhibit at the science museum. In those situations, the child's voluminous knowledge and obsessive interest can become an asset, not a drawback.

Talk About It

These opportunities for developing friendship skills are something that typical folks don't need to be alerted to, but we with AS do. People with AS need to be told out loud about how to use these chances for developing social skills, and that these skills apply in more than one place.

Fortunately for me, my parents talked with me frequently and in many situations about how to learn about people through experience and observation. For example, they talked with me during the commercials when we watched TV. Many aspies learn a lot about social skills from watching television, which means they learn bad behaviors. My father would actually ask me, "What would happen if someone did that in real life? Is that something that would work?"

In other words, my parents kept pointing out social rules in real life and helping me to analyze social situations around me.

The combination of special interest groups, volunteering, and direct parental coaching all helped me to be able to function socially. This combination may not make the average aspie a "social butterfly," but it can be used to improve social functioning, reduce isolation, and improve overall quality of life.

As for me, I have been happily married for more than twelve years even though I have AS – to a fellow I met in a science-fiction book discussion group. I knew he really was in love with me when he bought me a bust of Boris Karloff for Valentine's Day – something no NT guy would do! Life is good.

Jennifer McIlwee Myers

jenn_the_aspie@earthlink.net ♥



Grandparent Autism Network

By Bonnie Gillman

There is often an instant connection when you meet another grandparent of a child with autism – a shared experience, a common language. We are passionate about improving the quality of life for our children and grandchildren. As grandparents we often feel isolated, helpless, and confused about how to best help our families. **The Grandparent Autism Network** enables us to learn more about the wide range of needs our children and grandchildren have and to find out about helpful services and programs.

Many of us want to learn which treatments and assistive technologies are most effective for the unique needs of our grandchildren. It is important for us to understand various therapies, and the dietary, pharmaceutical, and environmental interventions available for children with autism. For most of us, it does not matter whether we agree with a particular methodology; we need to know why it is being recommended.

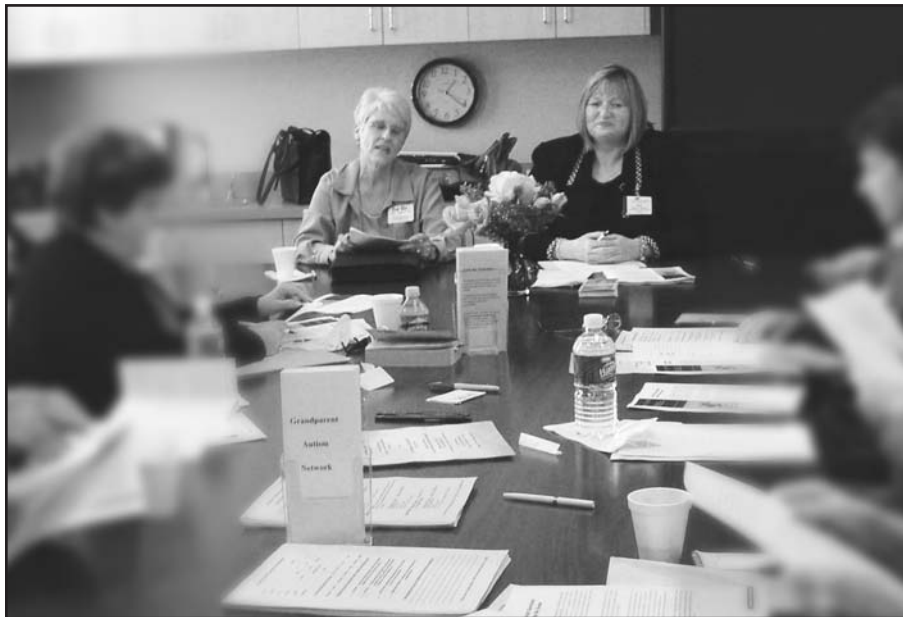
What can Grandparents and a Grandparent Network do?

Many grandparents want their grandchildren to grow up in a social environment that is both understanding and supportive. Because many of us share our grandchildren's frustration in coping with autism and delight in their hard-earned accomplishments, we have the motivation and potential to be their best advocates. We can increase community awareness and contribute to a more tolerant society. Many of us have the ability and time to support local and national autism causes.

Grandparents can learn how to best support our children in their daily struggle to make life better for their affected child and their family. Sometimes the most practical information a family receives is offered by grandparents networking with others who share their positive experiences.

"We may even share our grandchildren's frustration in coping with autism, while we applaud their hard-earned accomplishments."

Because autism often creates enormous financial and emotional strain on marriage, grandparents fre-



First meeting of the Grandparent Autism Network in Laguna with the presenters Hedy Hansen and Nancy McGovern from For OC Kids.

Unlike our children, who may be totally focused on their children's immediate needs, many grandparents are concerned about the overall effect of autism on the family and its future. How will autism affect their children, grandchildren and *even* future generations? What are the medical, educational, legal, behavioral, and social issues of ASD (Autism Spectrum Disorders)? Some of us want to know about current research studies and scientific breakthroughs. We seek answers about autism – the causes, positive interventions, and means for prevention.

quently play a significant role in helping their families. Many assist by providing respite time for their children, transporting their grandchildren to special programs, and underwriting costs to provide special services. Some of us are directly responsible for raising our grandchildren.

The **Grandparent Autism Network** was founded in April, 2006 to meet the unique needs of grandparents. While there are support groups and resources for parents of children with autism, we needed our own forum for mutual support and presentations on topics of interest from experienced professionals. We want to assist our families and help to decrease their stress in dealing with children with ASD.

Meetings are held in various cities throughout Orange County and are scheduled monthly during daytime or evening hours to accommodate the geographic and scheduling needs of grandparents. Whenever possible, meetings are on-site at local autism resource centers. Recent presentations have been given at the Orange County Regional Center and at the Interagency Assessment Center.



Cameron and her mother Teri Book are presented with flowers after Cameron's presentation of an inside perspective on autism.

Because we are an **all-volunteer organization** and require no fees for membership or meetings, we rely on community support and fundraising. We mainly focus on education, advocacy, social events, and shared activities with grandchildren, but we also support research and other worthwhile autism causes. We have many opportunities for involvement and very much welcome grandparents to join in our efforts. ***We know that grandparents, networking together, are a vital resource for autism ... and for each other!***

To learn more about the Grandparent Autism Network, please contact **Bonnie Gillman** at (714) 573-1500 or gangrandma@cox.net. ♥

News Corner



As reported in the January 26, 2006 edition of the *Chico Enterprise-Record*, a group of fifth and sixth grade students have recently formed a band which provides a wonderful opportunity for social interaction for all of its members, but has particular benefits for one boy, who has been diagnosed with Asperger's Syndrome. According to the article, the boy's parents have seen a marked increase in his self confidence as his musical abilities grow and he becomes known to others as a musician. You can find the article online at www.chicoer.com. ♥

We are grateful for the ongoing sponsorship of this newsletter by the following agencies:



WILLIAM M. HABERMEHL
County Superintendent of Schools



Upcoming Staff Development, Conferences and Parent Trainings

(Partial Listing — October 2006 to January 2007)

There are several opportunities for continuing education and support that will be offered by various organizations. For **OC Kids**, the **Regional Center of Orange County (RCOC)**, and the **S.U.C.S.E.S.S. Project of Orange County** strive to provide affordable fees to both families and staff. Each session has a specific focus, some pertaining to early interventions, some with more of an emphasis on the older-aged student. Registrations may be very limited, therefore call early! Other sessions will be provided throughout the year.

Date/Time/Place	Topic/Speaker	Developmental Level	Approximate Fee	Contact
Oct. 27, 2006 8:30 – 3:30 PM OCDE	Coaching Comprehension– Creative Conversation <i>Lauren Franke, Ph.D.</i>	All Ages	\$65	S.U.C.S.E.S.S. Project (714) 966-4137
Nov. 2, 2006 4:00 – 8:00 PM OCDE	Adolescents and Autism: Hope for the Future <i>Gary Mesibov, Ph.D.</i>	Middle elementary- to secondary-aged students	\$25	RCOC Karen Schaeffer (714) 796-5330
Nov. 15 & 16, 2006 8:30 – 3:00 PM OCDE	Icon to I Can– Using Visual Supports and Strategies <i>Barbara Bloomfield</i>	Early- to middle-age developmental levels	\$165	S.U.C.S.E.S.S. Project (714) 966-4137
Nov. 29, 2006 8:30 – 3:00 PM OCDE	“Integrated Play Groups” <i>Pamela Wolfberg, Ph.D.</i>	Early- to middle-age developmental levels	\$65	S.U.C.S.E.S.S. Project (714) 966-4137
Dec. 4, 2006 8:30 – 3:30 PM OCDE	Refresher Session for “Links to Language” <i>Lauren Franke, Ph.D.</i>	For those who are trained in “Links to Language”	\$50	S.U.C.S.E.S.S. Project (714) 966-4137
Jan. 11, 2007 4:00 – 8:00 PM Location to be Announced	Overview: “Social Thinking – I LAUGH Model” <i>Michelle Garcia Winner</i>	Developmental ages 8+	\$35	S.U.C.S.E.S.S. Project (714) 966-4137
Jan. 12, 2007 8:30 – 3:30 PM OCDE	Day Four: “Social Thinking – Organizational Skills” <i>Michelle Garcia Winner</i>	Developmental ages 8+	\$65	S.U.C.S.E.S.S. Project (714) 966-4137
Jan. 25, 2007 4:00 – 8:00 PM RCOC	“Importance of Play” <i>Pamela Wolfberg, Ph.D.</i>	Preschool to elementary	\$35	RCOC Karen Schaeffer (714) 796-5330

Locations: **OCDE** = Orange County Department of Education –
200 Kalmus Drive, Costa Mesa, CA 92628

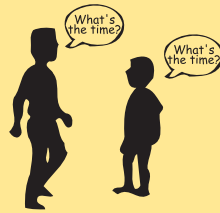
RCOC = Regional Center of Orange County –
801 Civic Center Drive West, Santa Ana, CA 92702

SOME EXAMPLES OF AUTISTIC BEHAVIOR

ALGUNOS EJEMPLOS DEL COMPORTAMIENTO DE PERSONAS CON AUTISMO



Avoids eye contact
Evita el contacto visual



Copies words like a parrot ("echolalic")
Repite las palabras como un loro
("en forma de echo")



Shows preoccupation with only one topic
Demuestra preocupación/interés en solo un tema/asunto



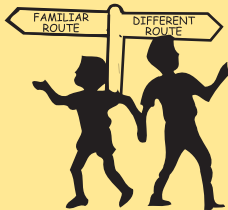
Lacks creative "pretend" play
Carece el juego creativo



Shows indifference
Demuestra indiferencia



Displays special abilities in music, art, memory, or manual dexterity
Demuestra capacidades especiales en musica, arte, memoria or destreza manual



Does not like variety: it's not the spice of life
No demuestra interés en variedad



Shows fascination with spinning objects
Demuestra fascinación con objetos que giran



Shows fear of, or fascination with certain sounds
Demuestra miedo de/ó fascinación con ciertos sonidos



Laughs or giggles inappropriately
Risa/reír inadecuadamente



Shows one-sided interaction
Demuestra interacción que es unilateral



Does not play with other children
No juega con otros niños

Some Examples of Autistic Behavior

Algunos ejemplos del comportamiento de personas con autismo

- Difficulty with social interactions.
Tienen dificultad para socializar con otras personas.
- Problems with speech.
Tienen problemas con su lenguaje.
- Disturbed perception.
Tienen una percepción anormal de los sucesos que acontecen a su alrededor.
- Abnormal play.
Su forma de jugar es anormal.
- Resistance to change in routine or environment.
Se resisten a cambios en sus actividad rutinarias ó a su medio ambiente.