



# AUTISM NEWS

of Orange County  
& the Rest of the World

January 2004

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*This is the First Issue of Autism News Orange County & the Rest of the World.*

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**Editorial Team**

Vera Bernard-Opitz, Ph.D., Editor  
Tresa Oliveri, Associate Editor

**Editorial Board**  
Teri Book

Joe Donnelly, M.D.  
Andrea Walker  
Janis White, Ed.D.

**Cover Feature**

The drawing entitled “Clinic” is done by Richard Schwaab, an adult with autism, who draws in seconds on whatever paper he can find. The drawings have to be removed from his sight right away. Drawings were taken with kind permission from the book by Dorothea Schwaab: *Pictures and Drawings from People with Autism* (Germ.)

Our logo is inspired by Jonathan Book, and the editors appreciate his contribution.

**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 11, double-spaced, and no more than four pages in length. Longer articles should have pre-approval from the editor. 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.autismnewsoc.org](http://www.autismnewsoc.org)

## Advisory Board

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University of California, Irvine  
For OC Kids

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Autism Consultant

**Wendy Goldberg, Ph.D.**

University of California, Irvine

**Belinda Karge, Ph.D.**

Cal State University, Fullerton

**Connie Kasari, Ph.D.**

University of California, Los Angeles

**Marian Sigman, Ph.D.**

University of California, Los Angeles

**Becky Touchette**

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**Salwanizah Bte Moh.Said**

Early Intervention, Autism Association,  
Singapore

## Mission Statement

**Autism News 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.**

## How it all started:

From the **Autism News Singapore** to the **Autism News Orange County & the Rest of the World (ANOC-RW)**

### Vera Bernard-Opitz

**I**t takes about 21 hours to travel from Singapore to Irvine, but to turn the **Autism News Singapore** into the **Autism News Orange County** took almost a year and was an adventurous story.

Transitions are a roller coaster as you leave steady states of life: familiar people, places, routes, ways of communicating, the safety net of friends, doctors, school and work environments.

For fifteen years Singapore had been our home: the tropical heat, the mixture of cultures and languages, the way to my office at the Dept. of Social Work and Psychology past the huge dragon of a Chinese theme park, my work as an Associate Professor of

Psychology, the research and clinic sessions at the **BICC (Behavioral Intervention Center for Children) of the National University of Singapore** and last but not least the great team of parents and professionals involved in the **Autism News Singapore**.

**Autism News Singapore** had started in 1992 as a magazine aimed to increase public awareness for autism, to share information about new ideas and developments and to give parents a platform to report experiences with their special child.



When I came to Singapore in 1989 autism was rather unknown and the first Singaporean children with autism were only found after a detour through the database of Dr. Bernard Rimland in San Diego. With the support of Ann Devadas, the first Principal of Margaret Drive Special School, we started the first Singaporean school program for children with autism called **STEP (Structured Teaching for Exceptional Pupils)**. The center combined structured teaching in one-to-one settings with small group instructions. Supervising up to 100 children over ten years along with a full time teaching commitment turned out to be quite a challenge. Topics shared with the readers of the Autism News covered a wide range of areas such as:

### Autism News Singapore

- Language Songs
- Integrated Play Groups
- Computer Assisted Instruction
- Using mild distress in teaching
- Effect of teaching conversational skills on Theory of Mind
- Enhancing speech through the IBM Speech Viewer
- Comparison of various forms of parent training
- Epidemiology of autism in Singapore
- Teaching joint attention etc.

Parents, siblings and children with autism shared the 'high' and 'low lights' of their lives and readers got a glimpse into the family aspect of autism and changes over the years. Colleagues from the US, Australia and Europe came to Singapore to give talks and workshops and the **Autism News shared the highlights with 800 readers in 14 countries.**

Over the years the number of children with autism in Singapore grew rapidly and we had to open another center as the number of students went beyond 100. With improved public awareness demands for services increased

dramatically inside Singapore as well as its surrounding countries. Services diversified with schools and private centers starting to offer programs for children with autism. A very active **Autistic Society of Singapore** was formed, which started an impressive **Early Intervention Program** under the competent guidance of Salwanizah and an **Autism Resource Center** developed with an excellent resource library and continued education and training for parents and autism teachers. All this was reported in the **Autism News** by our enthusiastic team of parents, students and professionals, who had many late sessions at our home to bring the latest news to the readers. Without the ideals and the drive of the editorial board, especially my co-editors Juniper Lee, Dr. Kwok Kian Woon and Lee Hong Eng all this would not have been possible. It was difficult to leave such a motivated group of colleagues, who had turned into friends and to give up the idea of the **Autism News Singapore.**

But just as I searched years back for children with autism in a country that claimed not to have them, I looked for a comparable publication in our new hometown, Irvine. To my surprise it didn't exist, but colleagues at the **Orange County Department of Education and For OC Kids** were very enthusiastic about the idea of such a newsletter for Orange County. The warm welcome by Andrea Walker, Coordinator of the **S.U.C.S.E.S.S. Project** and the sparkling eyes of Dr. Joe Donnelly, Pediatric Neurologist at **For OC Kids**, on presenting the idea of an **Autism News Orange County** will not be forgotten. The first meeting at the **Interagency Autism Group** felt like coming home. My presentation of a possible new Autism News was received with so much enthusiasm and support, that I knew the newsletter **Autism News Orange County & the Rest of the World (ANOC-RW)** had found a new home.

Our new publication has been made possible by joint funding of the **Orange County Department of Education, the Regional Center, the Council for Exceptional Children and For OC Kids**, agencies, which are introduced on the following pages.

We are happy that a multi-disciplinary team of autism specialists, from the US, Europe, Australia and Asia, has agreed to be on our **Advisory Board**. Parents, teachers, therapists and well-known autism researchers join hands to share the perspective of family, education/therapy and research.

We hope that our new group of readers will benefit and enjoy the **Autism News Orange County** just as much as our Singaporean group did and that the information provided is relevant not just for Orange County, but to some extent for the Rest of the World.

Vera Bernard-Opitz, Ph.D.  
Clin. Psych., Editor



*Members of the Interagency Autism Group*

litigation prompted the importance of all entities to work together on behalf of children with autism and their families.

To this end, the **Interagency Autism Group** was born. Made up of all identified representative groups and co-chaired by Bill and Larry, it is a time, monthly to discuss issues through what Bill Bowman calls "dynamic tension." The outcome has been many positive changes in Orange County.

So who are the participants that belong to this group? They are as follows:

- The **Regional Center of Orange County (RCOC)** which is a state and federally funded non-profit agency that operates under the umbrella of the Department of Developmental Services. They provide IDEA Part C Services to children under the age of three and services for those over three who have a diagnosis of autism, mental retardation, cerebral palsy, uncontrolled seizures, or similar disabilities.
- The **Orange County Department of Education**, which supports the 28 school districts in Orange County and has a Special Schools division that teaches children requiring specialized and intensive service.
- Other entities include, but are not limited to: **UCI Medical Center, For OC Kids, Behavioral Health Services**, representatives from school districts, private practitioners such as psychologists, speech/language

## Where it All Began:

The Interagency Autism Group

**Janis White**

**I**t all began in 1995 when Bill Bowman, the new Executive Director for the Regional Center of Orange County, walked into the office of Larry Belkin, Chief of Special Education Services with the Orange County Department of Education, and talked about the idea of collaboration. One of the main issues that both organizations were struggling with was in the area of autism. The growing number of children being diagnosed, uncertainty of an increasing number of programs that did not appear to be research-based, and growing

pathologists, occupational therapists, physical therapists, physicians, and parents.

There have been many exciting outcomes of this group. The opening of an Orange County Department of Education program for children under three with a diagnosis of autism, funded by the Regional Center - The Interagency Assessment Center – has been a collaboration we are very proud of. It has expanded to two classes in South County and one in North County. A third site is under consideration in Santa Ana. Other results have been the Parent/Professional Symposia, coordinated by Dr. Janis White, which brings experts in the field to Orange County to discuss various research and information in the area of autism. Another exciting outcome is the S.U.C.S.E.S.S. Project, coordinated by Andrea Walker, which provides a matrix of teacher training and support. The Interagency Autism Group also offers physician outreach and is currently addressing social skills for the adolescent and high school age student. We will be highlighting some of these programs in subsequent articles.

The Interagency Autism Group continues to evolve and grow as it strives to obtain the latest information and provide quality programs to meet the needs of children with autism. Through the collaborative efforts of those at the table and behind the scenes, we are making a difference for the children in Orange County.

**Janis White, Ed.D. Chief Operating Officer  
Regional Center of Orange County.**

### **Outcomes of the Interagency Autism Group**

- Interagency Assessment Centers (IAC)
- Parent/Professional Symposia
- S.U.C.S.E.S.S. Project
- Physician Outreach



**F**or OC Kids is a multidisciplinary center, and a collaborative project between the University of California, Irvine and Children's Hospital of Orange County, for autism and other developmental disorders. Created by Dr. Pauline Filipek from a grant from the Children and Families Commission of Orange County, the mission of For OC Kids is to assess and treat children with autism in Orange County. In addition it provides educational opportunities for parents and professionals who care for them. The clinic also offers medication management and developmental surveillance for children diagnosed with autism and a variety of other neurodevelopmental disorders.

Onsite speech, occupational and physical therapy are offered by The Children's Therapy Center of Garden Grove and Speech Pathology Associates of Irvine. Currently in operation is a toddler program for children under three vendored with the Regional Center of Orange County that includes speech therapy, occupational therapy and physical therapy with a strong parental education component.





### Mission

The OCDE provides over 163,000 students with a world class education that emphasizes standard-based skills in a safe and orderly learning environment. These students attend the following county-operated programs and services: **Outdoor Science, Regional Occupational Program, Special Education and Student Programs.**

- We partner with our districts to provide a world class education to 500,000 students.
- We serve as a connecting agency among Orange County school districts and community college districts, local, state and federal governmental agencies, and community agencies.
- We respond to district and community requests for staff development, administrative, business, educational and support services.
- We partner with parents, businesses, and the community for student success in Orange County.

*Text adapted from:*

The "Values and Mission Statement of the OCDE"  
 William M. Habermehl – County Superintendent of Schools. [www.ocde.k12.ca.us](http://www.ocde.k12.ca.us)



**R**egional Center of Orange County (RCOC) is a nonprofit agency that contracts with the State of California Department of Developmental Services and is the entry point to the system of services for people with developmental disabilities, including mental retardation, autism, cerebral palsy, and epilepsy. There are 21 Regional Centers in the state and each addresses the unique needs of their community.

**We are the third largest Regional Center in the state and provide service coordination for 13,000 people** in Orange County. Any resident of Orange County, who has or is suspected of having a developmental disability that originated before age 18, is entitled to receive an assessment to determine eligibility. Services are provided for the entire life of a person with a developmental disability who is substantially disabled.

RCOC is also the lead agency for the **California Early Start program** which is mandated by IDEA Part C and coordinates early intervention services to children, birth to 36 months of age, who have developmental disabilities, significant developmental delays or who are at risk for having a delay.

If you are interested in learning more about becoming a client of Regional Center, please call our Intake Department at (714) 796-5354. [www.rcocdd.com](http://www.rcocdd.com)



## Council for Exceptional Children

### Overview

The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted. CEC advocates for appropriate governmental policies, sets professional standards, provides continual professional development, advocates for newly and historically underserved individuals with exceptionalities, and helps professionals obtain conditions and resources necessary for effective professional practice.

### Services Provided

Professional development opportunities and resources

- 17 divisions for specialized information
- Journals and newsletters with information on new research findings, classroom practices that work, federal legislation, and policies
- Conventions and conferences
- Special education publications
- Information services such as the ERIC Clearinghouse, the National Clearinghouse on Careers Serving Children with Disabilities, and the IDEA Partnerships, in cooperation with the U.S. Department of Education

### Audience

Teachers, administrators, students, parents, paraprofessionals, related support service providers.

*For more information: [www.cec.org](http://www.cec.org)*

## Home Videos and Parent Reports of Regression for Young Children with Autism

Wendy A. Goldberg

### Abstract

The aim of the current study is to analyze the correspondence between parent-reported regression and independently-coded observations of regression from early home videotapes. Data are reported on 53 children with early autism or autistic regression. All children were infants and toddlers on the home videotapes and were, on average, 6 years of age when they entered the UC Irvine Autism Research Project (P.I.: M.A. Spence) for diagnostic testing and assessment. Parental reports of regression came from the Autism Diagnostic Interview - Revised and the Regression Supplement Form. Home videotapes were coded using an adapted version of the Osterling & Dawson (1994) coding scheme. Consistency between parent reports of regression and behaviors coded from videotapes ranged from a low of 62% for loss of play to a high of 83% for language regression.

### What is Regression in Autism?

Regression in autism applies to the phenomenon of apparently normal early development followed by the loss of previously acquired skills and manifestation of symptoms of autism. Autistic regression -- loss of language and other skills --- typically occurs in the middle of the second year (Tuchman & Rapin, 1997). Estimates of the frequency of regression in autism range from 10-50% (Hoshino et al., 1987; Tuchman & Rapin, 1997).

### Aim of the current study

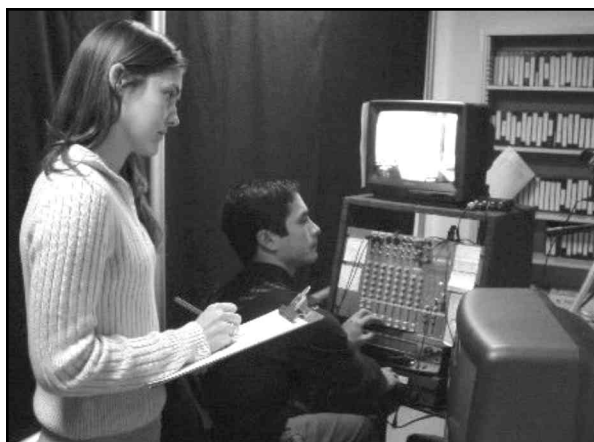
The aim of this study was to examine whether there is consistency between parents' retrospective reports of losses in language and other domains and observer-rated videotapes of children's behavior during the early years. Based



on other studies that have compared parental reports and observational data, moderate concordance was expected.

#### Participants in the current study

Fifty-three children, mostly males (87%) met criteria for this study. Children were age 6 on average when they came in to the UC Irvine Medical Center for IQ testing and other assessments. Most children completed the Stanford-Binet: FE assessment and had an average IQ score of 76.33 (range 37-116;  $n = 30$ ); some children took the Mullen Scales and scored 48.32 on average (range 19-89;  $n = 20$ ). Ethnicity was 55% Caucasian, 23% Hispanic, 7% Asian and 15% other. Due to some non-informative videotapes, the actual sample size for the comparisons ranged from 29-44.



#### Study Measures

##### Observer-coded Videotape Measures

Home videotapes were brought in by families and were edited for up to 15 minutes of tape at 6, 12, 18 and 24 months; expressive language was coded from all available tape. Tapes were coded by 2-4 trained research assistants who were "blind" to diagnostic category and who had established good inter-coder reliability. Frequencies for the behaviors of interest were calculated as the number of behaviors divided by the minutes of tape available. Language and non-language behaviors were coded from the videotapes.

#### Parent-report Measures

*Parent reports of regression in autism came from two sources:*

**Autism Diagnostic Interview - Revised (ADI-R;** Lord, Rutter, & LeCouteur, 1994) and **Autistic Diagnostic Observation Schedule - Generic (ADOS-G;** Lord et al., 1989). These assessment instruments were used to diagnose Autism Spectrum Disorders. The ADI-R is a standardized interview, conducted with caregivers, which includes questions about the child's family, schooling, history, and behaviors commonly associated with autistic disorder. The ADI-R also taps the loss of skills in domains such as communication, social interest and responsiveness, play and imagination. The ADOS-G is a structured observation measure, which provides an evaluation of communication, reciprocal social interaction, play, stereotypic behavior or restricted activities within standard contexts.

*Regression Supplement Form (RSF;* Goldberg et al., 2003). The Regression Supplement Form probes for type of loss, timing of loss, and possible regain of 18 specific skills, along with concurrent events. Consistent with the ADI-R, the skills represent the domains of spoken language, non-verbal communication, social interest and responsiveness, play and imagination. The RSF has been shown to have good inter-coder reliability (91%) and validity. It provided detailed information about the timing and course of parent-reported regression.

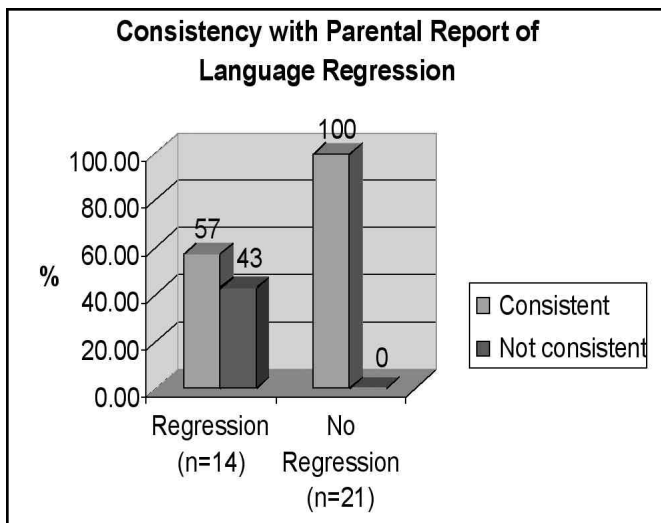
What defines consistency between videotapes and parent report?

Criteria were set a priori for determining whether or not regression occurred in language and other domains based on the videotape codes. If behaviors increased or did not change over time, then "no regression" was coded. If behaviors dropped by 50% or more with increasing age, then "regression" was coded. These videotape-derived codes were compared to parent reports to determine "consistency".

Study Results

More consistency was found for Language Regression (i.e., loss of language) than for Other Regression (e.g. social skills, gaze, play).

As depicted in the graph, consistency was greater for reports of No Language Regression compared to reports of Language Regression.



Skill Lost	Consistent		Not Consistent		Total N	Can't Confirm N
	N	%	N	%		
Social Skills	23	65.71	12	34.29	35	18
Nonverbal Communication	22	75.86	7	24.14	29	24
Orient to Name	19	65.52	10	34.48	29	24
Gaze	23	79.31	6	20.69	29	24
Play	21	61.76	13	38.24	34	19
Language	29	82.86	6	17.14	35	18

Do parent reports and independently-coded videotapes yield similar conclusions?

- A qualified "yes": Results of this study indicated moderate to high consistency between parent reports of regression and observer-coded home videotapes. More consistency was found for reports of language regression than for other types of losses.

Early Concerns

- No gesturing or joint attention by 12 months
- No babbling by 12 months
- No single words by 16 months
- No symbolic play
- Loss of language or social skills at any age

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Wendy Goldberg, Ph.D., Professor Clinical Psychology  
University of California, Irvine

## The SCERTS Model

Teri Book

**T**he SCERTS Model is a comprehensive multidisciplinary approach to organizing assessment and interventions to enhance the communication and socio-emotional abilities of children with Autistic Spectrum Disorders. It was developed in collaboration by Prizant, Wetherby, Rubin, Laurent and Rydell.

These three basic areas provide the back-bone of the framework for appropriate assessment and intervention for children with autism and their families.

The framers of the model recognize that the most meaningful learning experiences in childhood occur in everyday activities within the family and school. The SCERTS framework has been set up to focus on setting goals in social communication and emotional regulation by implementing

transactional supports throughout the child's daily activities. With the support of a multidisciplinary approach involving general and special education, speech-language pathology, occupational therapy, psychology and social work, the SCERTS Model seeks to provide support for the child's overall development.

The **Social Communication** component addresses the child's need to communicate in order to participate in social activities; to learn to play and enjoy interactions with both adults and children. To be successful at these activities

children must acquire capacities in two major areas: joint attention and symbolic behavior. These are two of the building blocks of social communication. Increased joint attention allows the child to share attention, emotions and express intentions with social partners. The development of symbolic behavior involves learning to play, a necessary tool to engagement and interaction with peers. Stress is placed on developing symbolic communication, flexibility to use verbal and non-verbal communication and the ability to coordinate various means such as words and gestures or pictures and vocalizations, rather than having to rely on only one-way communication. With these abilities, a child will

be better able to develop satisfaction in being able to relate to others.

The **Emotional Regulation** component of the SCERTS Model is focused on helping children to regulate their emotional arousal level. Autism is a disorder of extremes of emotional regulation that makes it difficult for learning.

The goal of the SCERTS Model is to help a child learn to maintain 'optimal arousal', not too high or too low, which inhibit the child's ability to engage in learning opportunities. There are many factors (cognitive, physical, sensory, motor, interpersonal, and social) that influence a child's ability to engage optimally. The SCERTS Model's goal is to help a child adapt and cope with their individual daily challenges.

**Transactional Support** is the ability to coordinate efforts among all the partners

The acronym "SCERTS" is derived from the major components of the actual model

SC - Social Communication

- Joint attention

- Symbolic behavior

ER - Emotional Regulation

- Optimal arousal

TS - Transactional Support

- Coordinated efforts

involved in interaction with a child and family. It involves the development of a complex, dynamic and transactional relationship between caregivers, professionals and other service providers with the family. The SCERTS Model



*Sensory stimulation can help children be more motivated for learning*

stresses the importance of **trust, respect and empowerment** for the child and family so they can learn to be competent and independent in supporting their child's development. Support is essential for families and professionals, and it comes in different forms:

- Families: education and emotional understanding for parents and interpersonal skills for children with the opportunity for enhancing their educational and therapeutic abilities.
- Professionals: Emotional support to cope with the challenges of working with children with ASK to prevent burnout.

The SCERTS Model is designed to provide stated core values and principles to guide

educational efforts for children with ASD. **Application of this model should be focused on the most functional and meaningful goals for the child and be respectful of the child and family.** It is not a curriculum but rather is a way of addressing the core developmental challenges faced by children with ASD. Designed to be flexible for children at all levels, the SCERTS Model is a systematic and semi-structured tool to provide guidance and direction to professionals and families attempting to organizing interventions for children with ASD.

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Teri Book  
Pediatric Nurse Practioner, For OC Kids.



### GOOD IDEA CORNER

Kids with and without autism and their parents may enjoy clip on timers

that remind them when play or outside time is over, how much time they have for a chore or just how long they need to brush their



teeth. They can be found in paper stores and often range below \$5.00.

We are interested in sharing "Good Ideas" among parents and teachers. If you'd like to share yours, please e-mail the editor: [vbernard@ocde.us](mailto:vbernard@ocde.us)

## A Short Summary of The S.U.C.S.E.S.S. Project of Orange County

Andrea Walker

In 1995, after one of our very first presentations, I read a comment in the evaluations, which stated, "Great session but you spelled success wrong!" We have been explaining our acronym since those early days. **The Systematic Utilization of Comprehensive Strategies for Ensuring Student Success (S.U.C.S.E.S.S.) Project** is now in its 8th year. It represents the integration of the current trends and researched interventions that are effective in providing services to students with Autism Spectrum Disorders and other related special needs, preschool through adult. The **13 Special Education Local Plan Areas (SELPAs)**, within Orange County, made that a collaborate commitment, each providing financial support to the maintenance of this project. Our beginning focus was on the early preschool programs (ages 3 to 5). We worked with a core group of staff for the first 2 years. Our Quality Indicators (see below) and Belief Statements were established in year 3. They have been reviewed by many of our consultants and national experts. Currently there is at least one contact person for each SELPA who focuses on the educational issues for students with autism and their assigned staff. This group meets monthly and continues to collaborate on local program and staff development needs.

The support to staff is critical as they are faced with the challenges of providing quality educational opportunities for their students with Autism Spectrum Disorders. **Ongoing inservices, trainings and workshops are available to parents, staff and other professionals within the Orange County area.** Recently the S.U.C.S.E.S.S. Project has opened some

slots to those outside of our local area. Annually, over 1200 participants attend our sessions, which are offered at very reasonable fees. In addition, more emphasis on the needs of the older students and their families is provided. **(See page 23 of the upcoming trainings in 2004).** We have developed ongoing relationships with many outstanding experts in the field of autism. Mentor groups and focus meetings are provided to facilitate the improvement of skills after an initial training. **Some of our educational programs and their staff are now receiving local and national recognition for their quality.** School districts also provide local support to their staff and community.

"Best Practices" are foundational to the educational approaches and model implemented in the Orange County area. We recognize that the power of "collaboration" is essential. **Through the efforts of the Interagency Autism Group, collaboration between the educational system, Regional Center, parents and local professional agencies continues to enhance the quality of services for families and their children.** At the core of these services is the

recognition of the unique developmental needs of each student, which are addressed in a comprehensive Individualized Educational Program (IEP).

As we continue to face the challenges of providing effective educational services to our students and support to their families, we remember a quote, seen on a local marquee: **"The road to success is always under construction!"** Each year parents, students and staff members share new success stories.

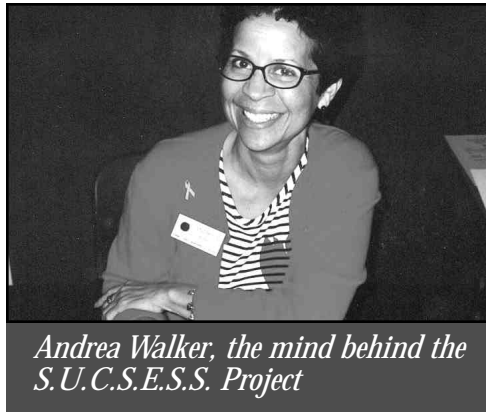
For further information contact:

Andrea Walker

S.U.C.S.E.S.S. Project Coordinator

a.walker@ocde.us

Phone: 714-966-4198



*Andrea Walker, the mind behind the  
S.U.C.S.E.S.S. Project*

## Quality Indicators

### STAFF DEVELOPMENT

Staff receives training and support in assessment and evaluation, characteristics of Autism Spectrum Disorder (ASD), confidentiality, effective instructional methodologies, curriculum, family support, applied behavioral analysis and planning, utilization of paraeducators, IEP development, data collection and analysis and the integration of current research in the area of Autism.

### UTILIZATION OF VARIOUS INSTRUCTIONAL STRATEGIES

Staff utilizes an integrated model of instructional strategies, which are considered best practices for use with students with Autism Spectrum Disorders. These methods focus on a structured environment, intensive behavioral instruction, generalization skills and integration strategies to enhance social, communicative and other functional skills.

### CURRICULUM

Staff utilizes and adopts core curriculum as well as providing adaptations and modifications as needed to individualize the students' instruction. In addition, the curriculum addresses functionally based adaptive skills, communication and language, social skills, technology, vocational and independence training.



### STRUCTURED ENVIRONMENT

Staff provides a safe and structured environment which incorporates age appropriate instructional settings, heightened systems of reinforcement, positive behavioral support, visually well defined areas, predictable routines and schedules, low staff to student ratio and support in transitions throughout the day.

### EVALUATION OF STUDENT PROGRESS

Staff utilizes methods to evaluate student progress, program effectiveness and the selection of appropriate instructional strategies and placement.

### SUPPORT SERVICES

The allocation of non-student time is essential for student progress meetings, parent collaboration and conferencing, staff and parent training, and team meetings. Multi-disciplinary teams include credentialed, licensed staff and paraeducators.

### SUPPORT FOR FAMILIES

Staff provides ongoing parent education, progress reports and regular communication to foster home-to-school collaboration. Support may include parent groups, referrals, establishment of a family resource center, and collaboration with other agencies.



### GOODIDEACORNER

Visual timers are a good alternative to regular timers for visual learners as well

as for children who are sound sensitive and dislike the sound of alarms. Children with ASD as well as children with ADHD can benefit. Check the internet or ask us for further information!



## Developmental Adaptations to the Traditional Picture Exchange System (PECS)

Laurie Lennon

**A**ugmentative and alternative communication (AAC) strategies have become increasingly popular in the field of autism over the past ten years. Because autism is a disorder that involves a social communication impairment and a unique learning style, AAC strategies are often quite beneficial. One of the most well-known AAC programs is the Picture Exchange Communication System (PECS).

PECS is a teaching method developed to help children and adults with autism to rapidly acquire functional communication skills (Bondy and Frost, 1994). The PECS system clearly has a number of strengths. First, it involves the use of a physical and pragmatic exchange that facilitates **initiation**. More specifically, an individual is required to physically **give** a message that is represented in the form of a photograph or picture in order to **receive** something. Next, the use of photographs and picture communication symbols is beneficial because children with autism often demonstrate a preference for visual, non-transient versus auditory transient information (Prizant and Schuler, 1987; Schuler, 1995).

While transient information such as words or gestures disappear after the communicative act, non-transient information such as photographs, line drawings, and written words stay and provide an individual with retrieval cues about "what to say". Photos, pictures, line-drawings and written words have not only been found to support the development of symbolic

communication skills in children with autism, but also can facilitate the use of verbal communication (Fay and Schuler, 1980; Mirenda and Schuler, 1989). An individual is able to visually scan an array of pictures and choose the appropriate one to form appropriate word combinations, simple and complex sentence structures. Pictures and written words can also serve as a means of assisting an individual in making choices, decreasing reliance on verbal prompts, and increasing spontaneity.

Despite the benefits of the traditional PECS protocol, it presents with a number of limitations. First, it addresses a restricted range of communicative functions. Young, pre-verbal children typically communicate for a wide range of functions, which include **both instrumental (e.g., requesting or protesting for/against objects or action) and social (e.g., showing off, requesting a social routine, calling another's attention to an item of interest) purposes**.

Children with autism, who are faced with social-communication challenges often have difficulty with learning to communicate for social functions, thus, early intervention efforts should focus also on social functions

of communication. Next, the PECS protocol does not follow a developmental sequence of language acquisition.

Typically developing children learn to use a wide range of single words, known as semantic relations. Examples of one-word semantic relations include but are not limited to naming, calling, action words, negation, attributes, locations, possession, and agents (e.g., a person or character who performs an action).

Once a child has acquired a vocabulary of 50 – 60 words, he will combine words into two— and three—word utterances which are also

### Strengths of PECS

- Facilitates spontaneity
- Utilizes visual system
- Helps with choices

known as semantic relations. His use of language is flexible and he is able to combine words to formulate numerous creative utterances. Conversely, children with autism often present with a "gestalt" language learning style (Prizant, 1983). They use their rote memory strengths to acquire word combinations or "chunks" of words that they use as a whole unit without understanding the meaning of each word. This language learning style can present a challenge because a child who does not understand the meanings of individual words within a "chunk" will not combine those words with other words in a flexible manner.

An example of this is the chunk, "I want." Children often learn this chunk as a single word and do not combine the individual words, "I" and "want" with other words in a flexible manner (e.g., "I go", "Mommy want.") The early stage of the PECS protocol facilitates a child's acquisition of object labels and then, the word combination, "I want + object/food label". In later stages, the program addresses attribute + object word combinations (e.g., "red car") and promotes a child's ability to combine the chunks "I want" and "I see" with object labels. A child who uses this traditional system is at risk for developing a

limited language base. A number of speech and language pathologists who specialize in autism have made adaptations to the traditional PECS protocol in order to address the core challenges in children with autism, specifically problems in acquiring social communication and a flexible language system. **Colleagues in Baltimore, Maryland and New England developed the use of a color-coded**

**communication system.** An example of this system was also featured in a recent issue of *The Jenison Autism Journal*, edited by Carol Gray, which introduced the SCERTS model (Prizant,

et al, 2002). Like PECS, it involves the use of a pragmatic exchange, but also considers an individual's unique profile of communication strengths and weaknesses. Since many individuals with autism have greater difficulty with initiating communication for social purposes and joint attention the development of social interaction (i.e., requesting social games or routines), joint attention (i.e., calling another's attention to an item of interest), and strategies for emotional regulation (i.e., requesting hugs) is a core feature of the new adapted visual communication system. **Picture symbols should not only be**

**introduced for the purpose of requesting preferred foods, toys, and/or activities (e.g., bubbles, balloons, crackers); but should also allow a child to request social routines (e.g., peek-a-boo, chase, familiar songs, etc.); action words (e.g., eat, drink, jump, crawl, clap, etc.);**

- Concerns of PECS**
- Restricts Communication
  - Not developmentally based
  - Enhances rigid communication

<b>Color Coded System</b>		
<b>Semantic Relation</b>	<b>Border Color</b>	<b>Example</b>
Agents	Red	"mom" "dad" "child"
Actions	Green	"kick" "roll" "throw"
Attributes	Blue	"red" "big" "soft"
Objects	Yellow	"ball" "train" "car"
Emotions	Pink	"happy" "sad" "mad"
Social Routines	Purple	"songs" "chase" "peek-a-boo"



common environments (e.g., playground, pool, etc.); attributes (e.g., size, colors) and internal states (e.g., mad, happy, sad).

A color-coded system is recommended to facilitate a child's independent communication. Individual phrase and sentence strips are created with color-coded boxes in order to promote the production of word combinations. For example, a sentence strip that involves a red box and a green box can promote an agent + action combination.

*Activities should be created that are specific to each child's interest, stage of language development and needs!*

A child can then match the appropriate symbols to their appropriate location on the board and exchange the whole board to his listener to make a request (e.g., "mom kick," "dad throw," and "child jump") or a comment (e.g., "baby doll + drink", "Elmo eat"). Once a child has developed the use of a wide range of two word combinations, this system can be expanded to form three- word combinations.

### Additional Ideas

1. Introduce a game of "Simon Says."

Place the photographs, picture communication Symbols or written symbols, or written words that represent the child and his communicative partner (the adult) on a felt board along with symbols which depict action words and a red and green sentence strip. Take turns playing the role of "Simon" and giving your partner a direction to follow by pairing a visual and a verbal word combination.

2. Use a felt board for a shared bubble blowing.

Targeted two-word semantic relations can include:

- Agent + action — (Mommy blow)
- Action + object — (blow bubble)
- Attribute + object — (big bubble)

Targeted three-word semantic relations can include:

- Agent +action +object  
(Child blow bubbles)
- Action +attributes +object  
(blow big bubbles)

3. Model commenting behavior during play with dolls and props.

An adult can pair her verbal models with a visual model to reflect a variety of word combinations such as "baby drink", "hug baby", "baby tired." etc.

4. Incorporate the system into predictable story-book routines.

Linguistic concept, commenting, and turn-taking skills can all be addressed within this context. For example, an adult can provide a visual and verbal model when reading books such as:

- *I Went Walking* by Sue Williams
- *Brown Bear, Brown Bear and Polar Bear, Polar Bear* by Eric Carle

*References are available upon request*

**Laurie Lennon,**  
**Speech and Language Pathologist,**  
**Speech Pathology Associates (SPA), Irvine.**  
**For OC Kids**

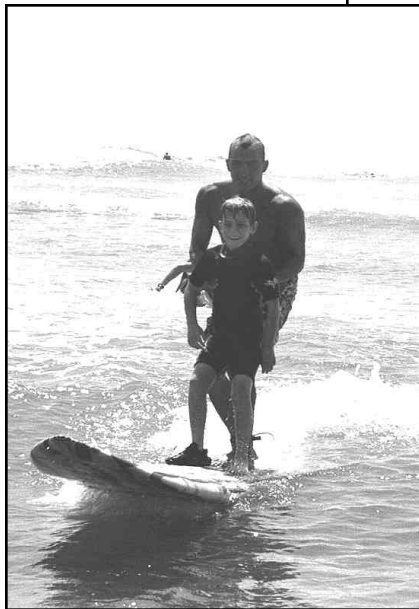
## Sea of Autism

**M**y son Trevor is 10 years old, he has big green eyes, he has a silly little giggle and he has autism. Trevor cannot speak. He uses a Picture Communication Book to tell me what he wants. In the future I expect he will use a computer device to communicate. Despite his many challenges from seizures, poor motor planning, hypotonia and reflux disorder, he manages

to wake up each morning full of energy with a big smile on his face and lots of hugs for Mommy and Daddy.

Trevor needs constant 1:1 supervision – he doesn't sit still for long nor engage in watching videos or Play Station games. We have had an ABA home program for six years. At present he attends a special day class where he is making progress communicating with others and learning functional skills.

Trevor loves summer surf camp, horseback riding, swimming, riding in cars, playing in the park and eating chocolate pudding (soy pudding that is – he is on a special diet). For years our family went through tremendously difficult and stressful times when behaviors were out of control and illness struck frequently. With the help of caring doctors, an understanding and patient psychiatrist, neurologist, knowledgeable ABA therapists, teachers, parent support groups and loving family – we have learned to adjust to the ever-changing world of autism. Trevor continues to make strides, we will forever help and guide him to be all that he can be.



## SEA OF AUTISM

The sun kisses your neck  
Our shadows grow tall,  
As we walk the beach silently  
You and I, my son, my little love

The waves crash against the shore  
Will it be like this forever more?  
Autism crushes against your soul  
Taking its toll  
Turbulent surf, stormy days,  
You communicate in different ways  
Tides change  
Raging squalls arise without warning  
Each wave, a new challenge  
Each night, the same longing

The seas are in turmoil  
We're caught in its curl  
I feel as if I'll drown  
In this Sea of Autism  
I'm afraid, I'm confused  
Yet you cling to me  
As if you can see

The unknown strength rising in me

I won't give in  
I fight, I struggle  
I pray for calm waters  
In this Sea of Autism

Adrift on the stormy sea  
I learn to survive  
Eventually, I come up for air  
Stop living in despair  
Ride the wave  
Balance the board  
Adjust, to endure the strain  
I learn to cut an edge and surf safely  
Through this Sea of Autism  
The peace of the calm is relished  
Lessons of the sea embellished in my heart  
As I learn to love and embrace this....  
Sea of Autism

We glide onto the shore  
Where we  
Walk the beach silently  
You and I, my son, my little love

**Dale Wood, proud to be Trevor's Mother**

## REACT Foundation

Jon Harb

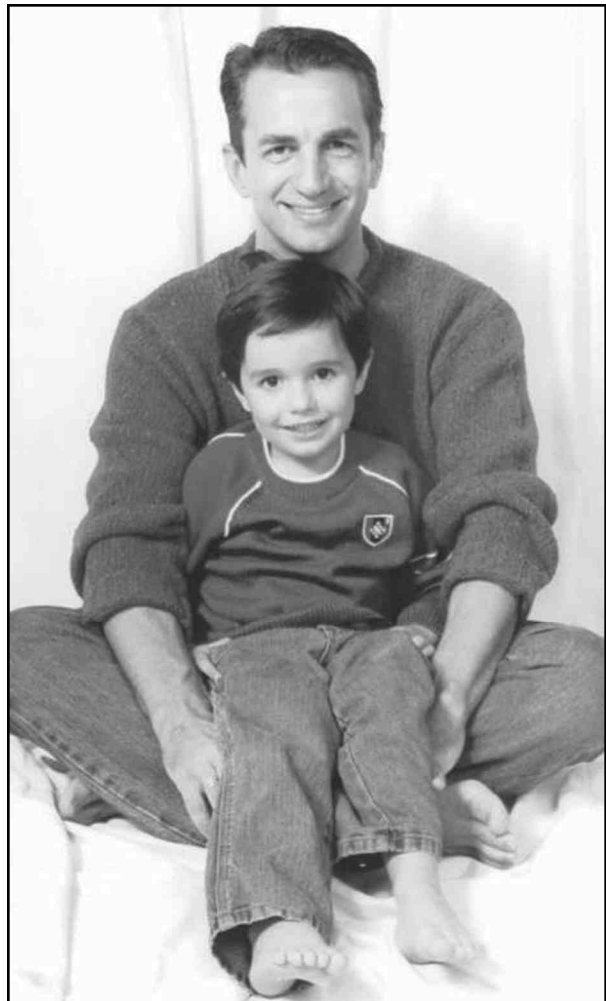
**A**fter 15 years in the high-tech fiber optics industry, I've decided to spend the majority of my time organizing an effort to help young children with autism develop and mainstream into their society as they approach grade school. I'm inspired by four-year-old son, Noah, a high-functioning child with autism to make REACT Foundation a success.

REACT Foundation stands for Resources for Autistic Children's Therapy. It is dedicated to helping young children with autism through early intervention, speech, language, occupational, and social therapies. Especially with all the budget cuts in our schools and the slow economy, it's important that we stay focused on the critical early years, which is a key time for childhood development. By providing these increased services to children in the 2-5 year-old range, the key typical development years for language, the opportunity for these children to mainstream can be maximized. The goal is to build on the strengths of children with autism, while helping them develop the basic requirements for socialization – speech, language and typical physical requirements to be able to interact more normally with their peers. Funds will be raised from industry and the private sector in general with a focus on high-tech, entertainment and the general population. Currently planning for the use of the funds is under consideration.

REACT Foundation is focused on help now that will have an immediate effect on young children with autism. The Foundation's overhead will be limited to 25% and will maximize the effectiveness of every donation dollar. The majority of the initial funds will be focused in Orange County and Santa Clara County in California, but our goal is to eventually expand to other areas.

REACT Foundation is now being finalized and will be ready to accept donations soon.

For further information please contact  
jonharb@cox.net or  
www.reactfoundation.org  
REACT Foundation,  
25108 Marguerite Pkwy, Suite B300,  
Mission Viejo, CA 92692.  
Ph: 949-837-1163



## Life with Bryan

Tresa Oliveri

No, this isn't a review of a Monty Python movie or a TV sitcom, but my life does have some surreal qualities. My 13 year old son, Bryan has autism. Our journey is no more remarkable than others who live in families with children affected by autism, but I'd like to share some experiences we've had so far.

When we began our family, I read lots of books and prepared myself for motherhood. Robert was born and two years later Bryan joined our family. We were a pretty typical family – two kids and a dog.

At Bryan's 18-month old check up the pediatrician suspected he had a hearing loss since he didn't react to auditory signals given during that exam. That began a long road filled with numerous assessments and enrollment in the School for Communication and Language Disorders on Long Island, NY and continues today with Bryan as a student in the Orange County Department of Education's County Program at Rancho San Joaquin, Irvine.

The early days after learning of Bryan's diagnosis were a confusing time of learning about autism I began reading about autism and none of the information was encouraging. Adding to the family's stress was the fact my husband was commuting back and forth from California, and we were struggling with the decision of whether to move or not.

A family friend, aware of our search for help understanding Bryan's diagnosis, arranged for an appointment with Dr. Stanley Greenspan. We wanted guidance about what kinds of interventions would be effective in helping Bryan learn to communicate with us. Dr. Greenspan recommended the elements of treatment we could continue when we moved. He gave us an outline of his preferred intervention – "Floor-time" – as well as other components he supported. He stressed the importance of interacting with Bryan on his level, but as Bryan became a toddler he was becoming a

mystery to me. My attempts to engage Bryan and close the "circles of communication" as Dr. Greenspan recommended were usually ignored, and I sensed his withdrawal. I doubted my ability to change that course.

We moved to California in 1993 and enrolled Bryan in Irvine's district preschool program. Assessments revealed that his deficits were too significant to address in the district's program so we enrolled him in the County's preschool classroom at Culverdale Elementary. We were naturally disappointed that Bryan's deficits warranted a move I perceived as a step backwards. Instead – what happened was something very lucky for both Bryan and myself – **we walked into Diane Gallagher's classroom.** Diane is a dedicated and sensitive teacher, and we forged a partnership to help Bryan. I'm not the only one who recognizes Diane's talents in the classroom. She was honored this year an Orange County's Teacher of the Year.

Shortly after our move to Irvine, I became aware of a group of parents that were forming an organization, ACCESS, focused on bringing awareness to parents of the benefits of Applied Behavioral Analysis. I joined as a board member and

**Throughout my experiences with Bryan I've met people with an immense capacity for compassion and others whose cruel comments still sadden me.**

was surprised as our mailing list grew to about 700 families in a very short time. We held seminars to educate parents about how to start ABA programs; and we collaborated with UCI's School of Social Ecology and offered

training to students for home programs parents had started. Unfortunately ACCESS was not able to sustain itself as an organization due to several factors, including a lack of funding and time demands of our own families.

Throughout the years, I've learned how to advocate for Bryan's needs and have broadened my advocacy efforts by joining the Interagency Autism Group 8 years ago where I continue to lend my perspective as a parent. Currently I'm learning about the importance of being active in the Legislative process as a Board Member at Regional Center Orange

County. Throughout my experiences with Bryan I've met people with an immense capacity for compassion and others whose cruel comments still sadden me.

I've spent countless hours listening to experts who study autism and suggest treatment protocols and reading books. Over the past 13 years I've learned about - **Floortime, pivotal response training, ABA, GFCF diets, yeast over-growth, good language-good speech, vitamin therapy, Auditory Integration Therapy, TEACCH** – to name just a few. With financial help from our families we've tried many of them.

Along the way we learned Bryan has some cognitive deficits as well as autism that no doubt affect his progress. I can't tell you what was the one thing we did that helped Bryan learn to talk, but over time I developed a confidence in my ability to make an impact in his life. For me, the curriculum that accompanied our home program probably had the biggest impact. I learned as Bryan learned how to connect the dots of skill acquisition. For example, once he learned to recognize and label colors, a trip to the supermarket became an opportunity to label, count, and categorize fruits and vegetables.

When I had children I assumed I'd teach them things and prepare them for adulthood. That hasn't changed, but what surprised me was how much my children would teach me. Instead of sending Bryan off to school like I did with Robert, my 15 year old son, and going back to work as I had planned, I learned how to navigate the assessment and IEP process and a myriad of other terms and educational strategies associated with special education. I have continued to attend seminars and often learn something to enrich my abilities to parent. I also learned the importance of working collaboratively with the professionals involved in Bryan's life. However, most importantly I learned to cherish the

everyday things most parents take for granted. Bryan has many limitations to be sure – he'll probably never be able to carry on a conversation that most people would recognize, or live independently, but he loves to travel on airplanes and go to bookstores with his dad. He is funny, artistic and happy.



Several years ago during a family visit to New York, my husband surprised us with tickets for "The Lion King" on Broadway. While Bryan loved the movie, I was apprehensive about his ability to sit through a stage show and didn't want his presence to be a distraction for others. Our tickets were on the aisle, and I'll never forget the look on his face as the animals made their

way through the theatre onto the stage. He was mesmerized and loved every minute of it. It was magic. I couldn't have imagined that moment when I sat in the neurologist's office and heard the word autism, but there we were.

Some time ago we added bicycle riding to Bryan's IEP goals. He accomplished that goal recently and was riding a bike up and down our street – just like the other kids. I'd been nervous about letting him ride a bike, since that made him very mobile, but in typical Bryan fashion, he's learning the rules about riding safely. **Once again Bryan is my teacher. I love being his student.**

When Bryan was newly diagnosed, it seemed as though all my hopes and dreams for him were snatched from me. In some ways they were, **but** I still wish for Bryan what I wish for Robert – happiness and contentment on their life's journey. So far so good for both boys.

*P.S. We're still a typical family with one change – now we have two dogs.*

# NEWS

## Event Highlights

**M**ark Durand, Ph.D., Professor and Dean at the University of South Florida, gave a talk at the Regional Center Orange County about 'How to distress', focusing on functional analysis and intervention in sleep disorders. His latest research stressed the important role of optimism and cognitive restructuring in parent intervention programs for children with autism.

**I**n an enlightening talk held at the RCOOC **Betty Freeman, Ph.D.**, Professor of Medical Psychology at the University of California Los Angeles highlighted the need of educational goals for children with autism to be functional and appropriate to their developmental level.

**P**egs play a central role in the **Links to Language** program. In an interesting workshop organized by the S.U.C.S.E.S.S. Project **Pamela Payne** and **Lauren Franke, Ph.D.**, described the way pegboards are used as visual reminders of number of tasks to do before switching to new activities or getting a break. Children are only allowed to take out a peg if a specific task is done satisfactory. (Editors Comment: It would be interesting to compare the traditional token system, where children get a peg for good responding, to a system that is more escape motivated.)

**T**he workshop by **Michelle Garcia Winner** on **Enhancing Organizational Skills** in Children with Autism also organized by the S.U.C.S.E.S.S. Project was overbooked, indicating the needs professionals and parents with children with autism see in developing methods in this area.

## Moringa Tree Play Group at For OC Kids

**A**n interdisciplinary playgroup for children below the age of 3 years is offered at For OC Kids. The Moringa Tree Play Group is a therapy based program, which utilizes components of the SCERTS model to address the specific needs of children who are at risk for or diagnosed with Autism Spectrum Disorder. The program is vendored through Regional Centers.

For more information call Tisha at The Children's Therapy Center (714) 892-6828.



*Moringa Tree Play Group*

## Upcoming Events

### SEE PAC

### Support Education and Empowerment for Parents of Autistic Children

This is a 10 week educational program provided in collaboration by the ATSC (Assessment and Treatment Services Center), the Regional Center of Orange County and For OC Kids starting in January 2004. The program is free of charge and babysitting will be provided. Space is limited.

## Upcoming Staff Development, Conferences and Parent Trainings

(Partial Listing — January to June 2004)

There are several opportunities for continuing education and support that will be offered by various organizations. The S.U.C.S.E.S.S. Project of Orange County strives to provide affordable fees to both families and staff. Most of the sessions are held at the Orange County Department of Education in Costa Mesa. 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 limited, therefore call early!

<b>Date/Time/Place</b>	<b>Topic/Speaker</b>	<b>Dev. Level</b>	<b>Apprx. Fee</b>	<b>Contact</b>
Jan 21 4-8pm OC Dept. of Ed. OCDE	Overview Social Thinking M. Garcia Winner	Older students - +8 yrs and older	\$20.00	S.U.C.S.E.S.S. Project (714) 966-4137
Jan 22 8:30-3:30pm OCDE	Day 1 Social Thinking Social Thinking	Older students - +8 yrs and older	\$45 - \$55	S.U.C.S.E.S.S. Project (714) 966-4137
Jan 23 8:30-3:30 OCDE	Day 2 Social Thinking M. Garcia Winner	Older students +8 yrs and older	\$45 - \$55	S.U.C.S.E.S.S. Project (714) 966-4137
Jan 30, 31 8:30-3:30pm OCDE	Apraxia Dr. Edy Strand	All ages	Varies for CSHA members, non-members Students, etc.	Calif. Speech/Hearing Assoc. District 8
Feb. 5, 4-8pm OCDE	Asperger's Syndrome Dr. Brenda Smith Myles	Older Students	\$20-\$25	S.U.C.S.E.S.S. Project (714) 966-4137
Feb. 6, 8:30-3:30pm OCDE	Social Issues/Autism Dr. Brenda Smith Myles	Older Students	\$45-\$55	S.U.C.S.E.S.S. Project (714) 966-4137
Feb. 17, 8:30-3:30pm Riverside Co. Office of Education	Autism & Social Skills Dr. Roger Cox	All ages	\$100	So. Cal. Autism Training Collaborative (SCATC) (562) 926-5566 x21060
Feb. 17 & 18, 8:30-3:30pm OCDE	Links to Language Dr. Lauren Framke	Early to mid. age students	\$235 (includes manual)	S.U.C.S.E.S.S. Project (714) 966-4137
Feb. 20, 8:30-3:30pm OCDE	Advanced Day Icon to I Can Barbara Bloomfield	All ages	\$45-\$55	S.U.C.S.E.S.S. Project (714) 966-4137
March 4-6 All day Long Beach	Cal Speech Hearing Assoc. (CSHA) State Conference	All ages	Varies for CSHA members, non-members Students, etc.	CSHA
March 27 All day OCDE	Parent/Professional Symposium	All ages	\$50	Regional Center of OC (714) 796-5256
April 28-29	Picture Exchange Communication System (PECS) PECS Staff	Early Intervention	\$250.00 (includes manual)	Regional Center of OC (714) 796-5256

# SOME EXAMPLES OF AUTISTIC BEHAVIOR

## Algunos ejemplos del comportamiento de personas con autismo



Avoids eye contact  
Eviata 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 preocupacion/interest 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 music, arte, memoria or destreza manual



Does not like variety: it's not the spice of life  
No demuestra interest in variedad



Shows fascination with spinning objects  
Demuestra fascinacion con objetos que giran



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



Laughs or giggles inappropriately  
Risa/reir inadecadamente



Shows one-sided interaction  
Demuestra interaccion que es unilateral

### 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.



Does not play with other children  
No juega con otros niños