



The Link

"Linking Exceptional Families in Contra Costa County"

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NEWS FROM CARE PARENT NETWORK

NEW STAFF AT CARE PARENT NETWORK

We are pleased to announce the addition to our staff of Susy Garcia as a Parent Liaison to the California Children Services (CCS) program. Susie joined us in April and brings a wealth of compassion, information and understanding to families who have children with special medical needs. She is in the office on Tuesday and Thursdays and can be reached at ext.106.

PARTNERS IN POLICYMAKING

We congratulate Rosa Valledor, Lacie Friedman, Karla Bueso and Joan Crook on being selected to participate in Partners in Policymaking. This is an advocacy-training program designed for parents of children with developmental disabilities and adults with developmental disabilities. Partners in Policymaking creatively trains its members to team up with elected officials, employers, school personnel, and other policy makers who make decisions about services for children and adults with developmental disabilities. The training takes place once a month for 8 months in Sacramento.

SPOTLIGHT ON THE EARLY EDUCATION COUNCIL

CARE Parent Network's Early Education Council (EEC) is a group of early educators, early intervention service providers and service coordinators who work together to serve children with special needs and their families in Contra Costa County.

The EEC is an information resource for both parents and professionals. For parents, the EEC distributes "Early Childhood Connections", information about services for infants and toddlers with special needs. For professionals, the EEC produces a monthly email newsletter with the latest information on education practices, and services and supports for children with special needs. In addition, the EEC hosts regularly scheduled meetings and special half-day trainings to provide professionals with up-to-date information on best practices in serving children with special needs in Contra Costa County.

One goal of the EEC is to increase inclusion of children with special needs in community programs in Contra Costa County. "May I Play, Too?", a very successful workshop held in May, gave over 40 childcare providers and preschool staff the opportunity to learn by example from local colleagues who are successfully including children with special needs in their programs. Each participant received a very popular, easy-to-use kit of inclusion resources and a reference binder of information about services for children with special needs and their families. The workshop was so well received that it will be repeated for a new group of participants in October.

Deborah Penry is the coordinator of the Early Education Council and its activities. She can be reached at dpenryCARE@aol.com or (925) 313-0999 x107. The next EEC meeting is scheduled for September 12 from noon to 1:30 pm at the CARE Parent Network offices, 1340 Arnold Dr, Suite 115, Martinez, CA.



NEWS FROM CCS

LEVELS OF SERVICE IN CALIFORNIA CHILDREN SERVICES PHYSICAL AND OCCUPATIONAL THERAPY

Children receive physical therapy (PT) and occupational therapy (OT) in the California Children Services (CCS) Medical Therapy Program at various levels. A doctor's prescription is required. When treatment begins the therapist evaluates the child to determine his strength, flexibility, functional movements and skills. The goals of treatment and the level of service, including *active*, *monitoring*, or *clinic only* therapy, are established. Ongoing evaluation is done to determine the child's response to treatment and to set further goals.

Active therapy involves scheduled visits with the therapist at least once per week. This level is provided to meet specific goals. In order to receive active therapy the child must be making measurable change every six months. The change can be big or small. Some examples of measurable change are: sitting without support, drinking from a cup, crawling, reaching, or grasping an object. As a child makes change new goals are determined and a new therapy prescription is written. If a child is not making measurable changes or is not meeting the goals of therapy, monitoring therapy will be recommended.

Monitoring therapy is prescribed to maintain functional skills. Therapy is scheduled on a monthly or less basis. The therapist will check on and update home and classroom exercise programs, assess equipment needs and provide consultation to caregivers and teachers. Examples of monitoring therapy are: modifications to a wheelchair to accommodate a child's

growth, consultation with a classroom teacher regarding computer access, or a home exercise program to maintain strength and flexibility.

Children who receive Clinic Only Therapy are seen once a year in the Medical Therapy Conference with the therapy team for a re-assessment. The team includes a doctor, supervising therapist, and OT and PT. The doctor may prescribe increased therapy services if needed.

Throughout the course of CCS treatment, the level of service may change. A child may start with active therapy and move to monitoring therapy. Following a surgery or growth spurt, or to work towards a specific skill, a child receiving monitoring may go back to active therapy.

California Children Services assists children to achieve their maximum level of independence. We encourage parents and caregivers to communicate with their child's therapists and therapy team about the therapy program, goals and level of service.

Thanks to Sharon White, CCS Chief Pediatric Therapist, for this article.

EQUIPMENT AVAILABLE

- Pony Walkers -- 3 Small, 1 Medium, 1 Large
- Ring Walker - Medium
- Hydro-Lift Bath Seat
- Rifton Walker without Attachments - Medium
- Rifton Stander with Tray - Prone - Medium
- Hydraulic Self-Stander
- Otterbach Reverse Walker - Small
- Jenx Prone Stander - Small with cute



RESOURCES

WEBSITES:

- www.kidshealth.org
- www.handsandvoices.org
- www.aboutautismlaw.com/autism_child_preparing_for_iep_meeting_iep_checklist.html

THE FATHERS CIRCLE

(www.TheFathersCircle.org)

The fathers circle is a meeting for men raising children with special health care needs and developmental disabilities. You will meet men who share a similar experience and help start a community support that we can all benefit from.

When: 4th Tuesday of the month
 Where: Pleasanton Main Library
 400 Old Bernal Ave.
 Pleasanton, (the Big Room)
 Time: 6:30-8:30 pm
 Other: Please email any questions to
TheFathersCircle@gmail.com

AAC: NEW PARENT GROUP FORMING

Parents of children using AAC devices have expressed an interest in forming a new group to share information and resources. The first meeting has been scheduled for **Wednesday, September 19 at 7:00 p.m.** in the CARE conference room. If you are interested in attending please RSVP to Louise Schneiders at 925-313-0999, Ext. 101. Interest in forming this group comes from Gina Hales, parent of a child using an AAC device. Her child's story is included in this newsletter as an example of the value of AAC (see page 4).

TRANSITION TO ADULT LIVING RESOURCE GUIDE

The new **Transition to Adult Living** resource guide has been published by

CalSTAT. It can be obtained by requesting a free copy from CalSTAT, California Institute on Human Services, Attn: Transition Guide Request, 311 Professional Center Drive, Rohnert Park, CA 94928. You can also view it on line at www.calstat.org/info.html.

FREE EARLY LITERACY ACTIVITIES IN ENGLISH AND SPANISH

Free reproducible language and early literacy activities in English and Spanish: These materials include forty-six home and community activities for preschool children that encourage early language and literacy development in young children. They are appropriate for children with disabilities as well as children who are developing typically. Each of the forty-six activities includes: 1) an activity description; 2) hints for making the activity fun and developmentally appropriate; and 3) a brief self-evaluation form that cues parents and other caregivers to notice the child's skills and also cues adults to reflect on their own interactions with their children. The materials are specifically designed to address the three key skills of language development, phonological awareness, and general print awareness. To download materials go to www.wlearning.com and click on the purple button that says "Free Parent Education Handouts" on the home page.

IN OUR LIBRARY

Thanks to David Sherman, who donated a copy of his new book [Autism: Asserting Your Child's Right to a Special Education](#). This book is an in-depth guide to every aspect of the educational process and will be a valuable resource to parents of children with autism. If you would like to browse through this book, please visit our library any time! Copies can be purchased online at www.aboutautismlaw.com. If you would like to visit David Sherman's web site, check out www.specialeducation.info/.



EMMA'S STORY

Emma's story is the now all too familiar one of a child with autism. At 18 months, she had almost 80 words. By twenty months, she stopped talking. Within weeks, she was sitting alone in the corner, screaming, flapping her hands and banging her head. On her third birthday, we learned that Emma had tested positive for Rett Syndrome. Rett Syndrome changed all of us in profound ways, but the most important aspect of the diagnosis for us is its impact on communication.

Like almost all girls with Rett Syndrome, Emma lost control of her hands. Within a year of her diagnosis, she could no longer use the sign language she had struggled to learn. She was screaming several hours a day, every day. Her speech therapist started using Picture Exchange Communication Systems (PECS). Initially, this worked; the tantrums became fewer, and she seemed happier. But it was not long before she could not even hand a card to us. No one knew to use eye gaze. Emma lost interest in the activity and began looking away when she saw the cards. The tantrums began again.

In the face of all evidence and the school district's stance that her failure to communicate was due to severe cognitive impairment, I remained convinced that Emma had things to say if we could only find a way to communicate. I just didn't know where to begin until another family suggested we try using YES and NO cards. Her teacher was reluctant, saying, "It's hard to tell if she could, there is not a lot of *there* there". Emma learned to use the yes and no system rapidly, in spite of blunt doubts from her IEP team. At first we would ask her basic questions like "Are you hungry?" Even with this simple intervention, the tantrums stopped. Emma delighted in having increasing control over her environment.

Soon, we began asking her more complex questions. One day, sitting at the table,

Emma's sister was talking about "imagination." I asked her what she liked to imagine. Emma interrupted by leaning forward in her chair and uttering her attention signal. When I looked at her, she held my gaze intently. I asked her if she imagined things, and held up her cards. She indicated "yes." Her sister suggested that Emma liked to imagine being Cinderella (a good guess, as that is Emma's favorite princess). Emma, however, rolled her eyes, giggled, and slapped the "no" card. She held my gaze as if she were willing me to see what she wanted to say. I caught my breath and said, "Do you imagine you can talk?" She just leaned forward and grabbed the yes card out of my hand. As I hugged her and cried, she laughed and patted my face. I had been right, there was a little person in there, waiting for us to find her.

Now Emma is using multiple communication tools, including a computer. She is trialing different speech-generating devices at school and learning to count and read. More importantly for us, she is participating in her regular education classroom, and making friends on campus. She talks with her sisters about kid things, like which movie to watch, and plays hide and seek with us. Communication has changed her life almost as much as Rett Syndrome did.

One thing we are learning is that it is not possible to learn what a child knows without access to language. Too often, professionals have been quick to assume that Emma's failures to communicate, to learn sign language and to use PECS were due to her cognitive disability or "sensory processing disorder" or lack of interest in social interaction due to autism. We are finding that she wanted to communicate and only needed access to ways that she could actually use. Now that we know, we will never allow her to be silenced again. It has been a long and difficult journey with Emma's service providers, but we have many years ahead of us to continue advocating for and learning about AAC.



SPECIAL THANKS

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| <ul style="list-style-type: none"> ☆ Marianne Balin, Kaiser Permanente ☆ Teresa Basa, Down Syndrome Connection ☆ Sylvia Castillo, Kaiser Permanente ☆ Ana Chuey ☆ Cheryl Clift ☆ Susan DuPuis, MSW ☆ Julia Greenwell ☆ Maria Grosskopf ☆ Lupe Henriquez, Delta First 5 Center ☆ Christina Hood |  | <ul style="list-style-type: none"> ☆ Gina Jennings, Developmental Disabilities Council ☆ Mary Grace and Jon Livesay (In memory of Mark Schneiders) ☆ Steffany Lohn ☆ Colleen O'Healy Silva ☆ Rocio Smith, Area Board 5 ☆ Pam Thomas, RCEB ☆ Rosa Valledor ☆ Cathy Weddle |
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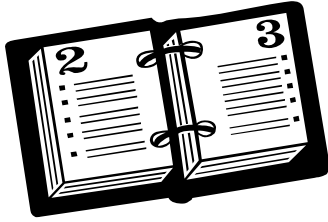
SUPPORT GROUPS

<u>NAME OF GROUP</u>	<u>LOCATION</u>	<u>FACILITATOR(S)</u>	<u>SCHEDULE</u>	<u>PURPOSE</u>
Support for Moms	Brentwood	L. Schneiders	1st Tuesday morning	All disabilities
Support for Moms	Danville	C. Clift (volunteer)	3rd Tuesday evening	All disabilities
Support for Moms	Martinez	L. Schneiders	1st Thursday evening	All disabilities
Central County Mothers' Group	Martinez	L. Schneiders (volunteer TBD)	TBD	All disabilities
Padres Latinos	Antioch	A. Gattis	1st Saturday afternoon	Spanish-speaking parents, all disabilities
Grupo de Autismo	Martinez	C. Zepeda	1st Friday morning	Spanish-speaking parents of children with autism
Caminemos Juntos	Richmond	H. Mariscal (volunteer)	1st Friday morning	Spanish-speaking parents, all disabilities
Voces de Amor	Martinez	Susy Garcia	2nd Wednesday of each month	Spanish-speaking parents of children with special health care needs

If you are interested in attending a support group, please contact CARE Parent Network at 800-281-3023.



CALENDAR 2007



July 19, 2007: MINDS behind the M.I.N.D.: Uncovering the Mysteries of Autism. Lectures by David Amaral, Ph.D., Judy van de Water, Ph.D., Robin Hansen, M.D., and Sally Rogers, Ph.D. M.I.N.D. Institute, Sacramento. Information at 916-703-0280. (Free)

***September 12, 2007:** Early Education Council. Conference Room, CARE Parent Network. Speaker TBA. RSVP to 925-313-0999, Ext. 107. (Free)

September 22, 2007: Congreso Familiar. Annual conference for Spanish-speaking families. Chabot College, Hayward. Call CARE Parent Network for more information. (Fee, scholarships available)

September 29, 2007: Special Education Resource Fair. For parents of children receiving special education services in West Contra Costa. Cameron School, El Cerrito. Watch for more information. (Free)

October 6, 2007: "May I Play, Too?" Workshop in inclusion strategies for early care and education professionals. Diablo Valley College, Sponsored by the Early Education Council. Call 925-313-0999, Ext. 107 for more information. (Free)

October 13, 2007: Parent-to-Parent Support Training. For new parent mentors. Sponsored by CARE Parent Network. Call 925-313-0999, Ext. 101 for more information. (Invitational)

October 18, 2007: MINDS behind the M.I.N.D.: TBA. Lecture at the M.I.N.D. Institute, Sacramento. Information at 916-703-0280. (Free)

October 20, 2007: IEP Training. Basic information for parents new to the IEP process. Conference Room, CARE Parent Network. Call 925-313-0999, Ext. 102 for more information. (Free)

Opinions expressed in **The Link** do not necessarily reflect the endorsement of CARE Parent Network or any of its associations. We do not recommend any treatment, therapy, institution or professional system, etc.

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