



The Link

"Linking Exceptional Families in Contra Costa County"

CARE PARENT NETWORK

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NEWS FROM CARE PARENT NETWORK

Parent Advocacy Training

Does your child receive services from the Regional Center of the East Bay? It's never too early to begin thinking about challenges to the system of services and supports for children with special needs, and how you can advocate to preserve services. You will receive this issue of The Link at about the same time the Governor will release the 2004-2005 budget. We anticipate many threats to both the funding and entitlements in our system again next year. We would like to mobilize a group of parents so that we are ready to respond effectively, and are planning a special training session for parents who are interested in educating our policy-makers on the importance of the services their children receive. This activity will include a special workshop to be held in February as well as follow-up information and support. Parents will be linked to an advocacy list serv to alert them when it is time to take action. As preparation for the training, we encourage you to attend a presentation by Cliff Allenby, Director of the Department of Developmental Services, on January 25 in Oakland. (Details are in the Calendar.) Mr. Allenby will be discussing the future of the developmental services system. If you are interested, please call us and you will receive more information.

Field Trip to the M.I.N.D. Institute

A number of people have expressed an interest in car pooling together to attend one of the lectures at the M.I.N.D. Institute in Sacramento. Possible dates and topics are February 9, "New Approaches toward Understanding the Brain Basis of Autism" which will be presented by Dr. Geraldine Dawson, University of Washington; or March 9, "Order and Disorder in the Emotional Brain" which will be presented by Dr. Richard Davidson, University of Wisconsin. Lectures begin at 6 p.m. This trip could be combined with a tour and visit to the Resource Center. If you would be interested in participating in this, please let us know which date you would prefer, and whether you can drive or would like a ride.

Early Childhood Interagency Coordinating Council

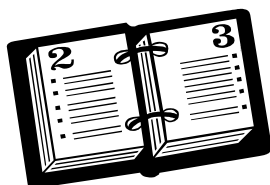
The ECICC will sponsor an interagency training on Friday, March 4, 2005 from 9:00 – 1:00 at the Willow Creek Center, Concord. This training is for staff from public and private agencies who want to learn more about the complex and specialized system of services and supports for children (birth to 5) with disabilities or special health care needs. It will provide comprehensive and accurate information about available services and how to apply for them. Advance registration is required. If you would like more information call Anne Struthers, Early Childhood Coordinator, at 925-313-0999, Ext. 107.

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.

FAMILY SUPPORT

- E** Drop-In Clinics on the IEP and IFSP are offered on the first and third Tuesday of the month from 10:00 a.m. until 12:00 p.m. (noon). Please call first so we can determine if this will meet your needs and review with you what to bring to make this session productive for you.
- E** Make & Take Care Notebooks to help organize paperwork for parents of children with special health care needs are scheduled by request. Call Joan Crook at 925-313-0999 x 104.
- E** Padres Latinos is a group for Spanish-speaking parents that usually meets the first Saturday of the month at 2 p.m. The dates are January 8, February 5, March 5, and April 2. For information please call Angela Quiroga at 925-313-0999 x 105.
- E** Just for Fathers meets on the first Wednesday of the month in Martinez at 7:30 pm. The dates are January 12 (note date change), February 2, March 2 and April 6. Please call for more information.
- E** Support for Moms meets on the first and third Thursday of each month at 7:00 pm in Concord. The dates are January 6 & 20, February 3 & 17 and March 3 & 17. Call Louise Schneiders, Family Support Coordinator, to discuss attending the group.

CALENDAR-2005



January 6-7: Early Start Supervision Institute, Sacramento. Information: 916-492-4012.

January 22: Preschool and Parenting Fair, 9-noon, Pleasant Hill Community Center.

January 25: "An Evening with Cliff Allenby", a community forum to inform the community about Gov. Schwarzenegger's proposed budget for services to people with developmental disabilities. Elihu Harris State Building, 1515 Clay, Oakland, 7:00 pm.

January 26-27: Core IIb: Meeting the Needs of Children with Specific Developmental Characteristics—Vision, Hearing, Health, and Behavior, Sacramento. Information: 916-492-4012.

February 28-March 1: Annual Family Resource Centers Network Conference, San Jose. Information: 916-492-4012.

March 15-16: Core III: Putting it All Together, El Segundo. Information: 916-492-4012.

April 11-13: Service Coordination Institute: Foundations, Sacramento. Information: 916-492-4012.

April 30: Summit 2005, a conference for parents of children with special needs and child care providers, Contra Costa College, San Pablo. Sponsored by Contra Costa Child Care Council. Information: Ange Burnett, 926-676-5442.

"Where there's life, there's hope." Terence

RESOURCES

New Rett Syndrome Clinic

Katie's Clinic for Rett Syndrome at Children's Hospital Oakland is one of a few centers in the United States specializing in the diagnosis and comprehensive care of girls with Rett Syndrome. The purpose is to assist the child's primary care doctor in addressing those aspects of Rett Syndrome that affect health and development. The medical concerns and development of girls with Rett Syndrome include seizures, sleep and breathing disturbances, behavioral concerns, motor disabilities, and communication challenges. They are unique and therefore require specialized care. Though there is no cure, there are many treatments to be offered which can improve quality of life. The specialists at Katie's Clinic are experienced in meeting the medical, developmental, psychological, and social needs of girls with Rett Syndrome in a comprehensive and coordinated manner. The clinic meets the second Friday of each month from 1:00 – 4:00 p.m. It is open to girls age 18 and under who must be referred through their primary care provider. Most insurance plans are accepted, including Medi-Cal. For more information, contact Cathy Quides, RN, MS at 510-428-3351, Ext. 2673. Be sure to let them know if you need an interpreter at the time of making an appointment. Thanks to Paige Nues for her hard work and advocacy which resulted in the development of Katie's Clinic for Rett Syndrome.

Social Language Groups

The new session for this program will run from January 26 to April 13. Prior to enrollments, children must be assessed. If you are interested in a program that uses a communication-based approach to teaching social skills, call them at 510-530-3085.

No Child Left Behind

This federal act includes new responsibilities for local school districts that often remain a mystery to parents of children with disabilities. To help parents understand how the new provisions of No Child Left Behind can help them, the National Center for Learning Disabilities and Schwab Learning have published a 22-page guide. It is available free from www.LD.org/NCLB or www.SchwabLearning.org/NCLB.

SSA Disability Starter Kits

These starter kits are for parents whose children qualify for Supplemental Security Income (SSI) benefits from the Social Security Administration (SSA). They provide information regarding what SSA requires from its beneficiaries, as well as general information about SSA programs and their decision-making process. The starter kit contains fact sheets, a checklist, and a worksheet to help gather and organize information. You can access a starter kit by going to: www.ssa.gov/disability/disability_starter_kits.htm. If you do not have access to a computer, remember that you can come to our office and use our computer (we'll even train first-time users!).



“Pick battles big enough to matter, small enough to win.”
Jonathan Kozol

RESOURCES (continued)

M.I.N.D. Institute Research Studies

The M.I.N.D. Institute's clinical research program is seeking children of all ages to participate in studies about autism and other neurodevelopmental disorders. Many research studies are currently underway. Participants who are included in the studies also benefit from state-of-the-art assessment techniques, valuable feedback from the clinical researchers, and advice about possible interventions. Some studies even offer financial compensation. If you would like more information, contact Meridith Brandt at 916-703-0320. You will be sent a brief survey to complete and will be contacted when an opportunity to participate becomes available.

Regional Center Family Cost Participation Program

Beginning January 1, 2005, some families who receive services funded by the Regional Center of the East Bay will be required to pay for part of the services. If your family receives respite, day care, or camping, this may affect you if you meet the following conditions: your child is between 3 and 17 years of age, your child lives at home, the child does not receive Medi-Cal, and your family income meets a certain limit. You will be responsible for a portion of costs called "family cost participation". To inform you about how this new law will affect you, the Department of Developmental Services has developed information that is posted on their web site (<http://www.dds.ca.gov/fcpp/index.cfm>). You will find a Family Cost Participation Program Guide, Frequently Asked Questions, and a Family Cost Participation Calculator. If you do not have access to a computer please call us and we will mail the information to you.

Dental Education for Parents of Children with Special Needs

In 2004, the Contra Costa Children's Dental Summit selected dental education for parents of children with special needs as a priority. They have formed a committee to develop a dental curriculum and training for parents including: the basics of good dental health and total health, avoiding bottle tooth decay, rewarding good behavior without using sweets, how to communicate your needs to your dentist, and dental resources. The committee is looking for parent groups and organizations that would like to sponsor this training, which will also be available in Spanish. For more information call Khadijah Uqdah at 925-313-6539.

Free Special Needs Trust Workshops

The Dale Law Firm will host a series of free workshops in Walnut Creek on how to provide financial support for your adult child through a Special Needs Trust and Limited Conservatorship to protect your child with a developmental disability once he or she becomes an adult in the eyes of the law. The dates are: January 8, Special Needs Trust, 10-2 pm; Limited Conservatorship, 1-3 pm; February 8, Special Needs Trust, 10-2 pm; Limited Conservatorship, 1-3 pm; March 26, Special Needs Trust, 10-2 pm. All these workshops take place at 1670 Riviera Ave., Suite 101 (between Pringle Ave. and Parkside Dr.). Please note the schedule is subject to change. Call Genevieve at 925-280-0172 for information, to confirm dates, or to reserve a space.

Winter Workshop

Protecting Your Child From School Bullies

In this training we will discuss common views about bullying and types of bullying that occur in the school setting. The workshop will introduce parents to strategies for talking with your child about bullying, selecting appropriate intervention strategies, and teaching your child how to respond to bullying. The training will define disability harassment and the role of school policy to respond to and prevent disability harassment.



When: Saturday, February 26, 2005
9:30 to 12:30

Where: Conference Room
1340 Arnold Drive, Suite 115
Martinez

Who: Eileen Crumm, DREDF Parent Advocate

Please register by February 22 using the form below.

Mail to CARE Parent Network, 1340 Arnold Dr., Suite 115, Martinez, CA 94553 or Fax to 925-370-8651 or email to CAREofARC@aol.com.

Questions? Call 800-281-3023.

Name: _____

Street Address: _____

City/Zip: _____

Daytime Phone #: _____

_____ **Yes, I will attend February 26 .**

SPECIAL THANKS TO:

- *Erika Buckman
- *Doug Dildine
- *Susan DuPuis
- *First 5 Contra Costa
- *Dawn Graeme
- *Jennifer Hanson



- *Cathy Nicoll
- *Rachel O'Shea
- *Elizabeth Wilson Palmer
- *Pam Thomas
- *Sharon White

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