



CARE PARENT NETWORK

The Link

"Linking Exceptional Families in Contra Costa County"

Volume XII, Issue 4 Published quarterly Summer 2004

Update from CARE

Don't forget our address has changed to 1340 Arnold Drive, Suite 115 in Martinez. And, be sure to visit our website (www.careparentnetwork.org) for up-to-date information and resources.



Staff Update

Angela Quiroga, our bilingual Family Support Specialist, will be on maternity leave from August until October. During her absence, we will continue to provide support to Spanish-speaking families through Victoria Sanabria as well as volunteers from our Mentor Parent Program. We thank everyone for stepping in to help ensure that there

will be no interruption of services to our Spanish-speaking families. And, we wish Angela well during her time off to welcome a new baby.

Save the Date

On **November 6**, CCS will be sponsoring a special one-day conference for families whose children receive services from CCS. We will be working with them to plan and put on this conference. It will be held at the Willow Creek Center in Concord and will be a day packed with useful resources and information, as well as a unique opportunity to meet and network with other families. We will also be offering continuing education credit for registered nurses and look forward to having professionals join us. Please call us for more information.



New Barrier-Free Playground



The Roberts Regional Recreation Area in Oakland has just opened a new barrier-free playground. It features interactive panels, a swing set, and other play structures, and is located next to the wheelchair-accessible pool. The playground also includes concrete pathways wide enough for wheelchairs, more handicapped parking spaces, bathrooms renovated to conform with ADA requirements, and Braille signs. The playground is open during the summer from 8:00 am until 8:00 pm; parking is \$4 per vehicle.

Planning is actively underway for a barrier-free playground at Hillcrest Community Park in Concord; watch for updates!

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.

SPECIAL THANKS TO:

- | | | |
|-------------------|-------------------|-----------------------------|
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| * Dawn Heider | * Janie Miller | * Rocio Smith, Area Board 5 |
| | * Evelyn O'Dell | * Emlyn Struthers |
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Resources

- Ability Resource Center providing services to children and adults with learning and attention differences has opened in Walnut Creek at 1415 Oakland Blvd., Suite 100. The phone number is 925-695-0409 and on the web at www.abilityrc.com.
- UCTV's "Med Ed Hour" presents a six-part M.I.N.D. Institute Series on Neurodevelopmental Disorders beginning July 1. The series airs on Tuesday and Thursday at noon throughout July and repeating through August and September. This series can be viewed via: direct broadcast satellite on Dish Network channel 9412; cable TV on community channels (see www.uctv.tv/cable for details) or Internet live webcast and on-demand streaming video at www.uctv.tv.
- East County has a new program that meets at the Brentwood Community Center for all families with teens and young adults with developmental and/or physical disabilities ages 13-24. The Friday Night Activities are designed to promote socialization, and increase recreational and leisure development. Activities include dances, games, community events, arts and crafts, movies, and Bocce Ball. For more information call 925-516-5444.
- A website for elementary school children with learning and attention differences, www.sparktop.org is provided by the Schwab Foundation. Children can play games, connect with others, get information and have fun. Their website, www.schwablearning.org is a superb resource for parents of children with learning and attention differences.
- Creative Dance for Children with Special Needs is sponsored by the San Ramon Valley Dance Academy. For more information call the academy at 925-837-4656.
- Special Needs Trusts and Limited Conservatorships for Persons with Developmental Disabilities free workshops offered by the Dale Law Firm. Call Bahar at 925-280-0172 for more information.

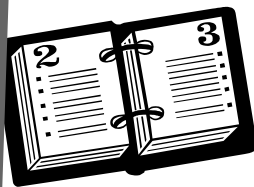
Science Project

Jordan Bishop, 13, a 7th grader at Portola Middle School in El Cerrito, won first place at the San Francisco Bay Area Regional Science Fair in March. He took his project to the Cal State Science Fair in Los Angeles last May. His brother, who has autism, responds to music, but is sound-sensitive so Jordan wanted to do a project that would help his brother and other people with autism, "So the things they liked wouldn't make them miserable at the same time." Jordan decided to do a science project that would determine what kind of music would have the most calming effect on a person with autism. He tested four styles of music, including jazz, classical piano, rock & roll and opera, and determined that opera had the most calming effect. Thank you, Jordan, for pursuing such a wonderful science project! We are all proud of you.

Family Support

- 1 Drop-In Clinics 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.
- 1 Make and Take workshops for parents of children with special health care needs are scheduled by request. Please call Joan Crook at 925-313-0999 x 104.
- 1 Padres Latinos is a group for Spanish-speaking parents that usually meets the first Saturday of the month at 2 p.m. While Angela is out on maternity leave call Emmarielle Hernandez at 925-260-6934 for more information.
- 1 Just for Fathers meets on the first Wednesday of the month at our office in Martinez at 7:30 pm. The dates are September 8, October 6, November 3 and December 1. Please call for more information.
- 1 Support for Moms meets on the first and third Thursday of each month at 7:00 pm in Concord. The dates are September 9 and 23, October 7 and 21, November 4 and 18, and December 2 and 16. Call Louise Schneiders, Family Support Coordinator, to discuss attending the group.

Calendar



September 9: Unilateral Hearing Loss Workshop, sponsored by Parent Links & Children's Hospital and Research Center, 5:00 pm. Call Karen Mahoney-Wilson, 510-351-6748, for more information.

September 11: Fall IEP Training, sponsored by CARE Parent Network and DREDF, 9:00 am – noon. Call 800-281-3023 for more information.

September 17: Special Needs and Autism, Marriott Hotel, San Ramon. See www.ennetwork.org for registration information.

September 18: Parent-to-Parent Training, sponsored by CARE Parent Network, 9:00 – 3:00. Call 800-281-3023 for more information.

September 25: The Morgan Center Autism Conference: Challenges - Today and Tomorrow, Santa Clara University, Santa Clara. Call 408-241-8161 for more information.

October 2: 4th Annual Monument Health Fair, Meadow Homes Park, Concord, 11 am-4 pm.

October 2: Harambee, Fifth Annual Day of Information, for African-American Families, Oakland. Call Sonia Jackson at 510-547-7322 x 15 for more information.

October 9: Congreso Familiar, Annual Conference for Spanish-Speaking Parents, Hayward. Call Cecelia Zepeda at 510-758-6777 for more information.

October 9: Fall Harvest, Los Medanos College, Pittsburg. Call Ange Burnett at 925-676-5442 x. 3254 for more information.

October 23: A Parent Tool Kit for Alternative Dispute Resolution, sponsored by CARE Parent Network and DREDF, 9 am to noon. Call 800-281-3023 for information.

November 5: Tenth Annual Early Start Symposium, All Kids Count: Supporting Inclusion Opportunities for Young Children With Special Needs, featuring Sharon Walsh. Sponsored by Family Resource Network, Stockton. Double Tree Hotel, Modesto. Call 209-472-3674 for information.

November 6: CCS Conference, Willow Creek Center, Concord. Sponsored by CCS and CARE Parent Network. Call 800-281-3023 for more information.

Parent-to-Parent Support: A Unique Experience

When parents first learn that their child has a disability or special health care needs, they often feel a myriad of intense and sometimes painful emotions. It is not uncommon for new parents to be overwhelmed with the experience. Many parents find it very helpful talking with another person who has had a similar experience. The opportunity to have someone listen with understanding, and to have someone encourage you to express your feelings can be supportive. This mentor relationship assists parents as they begin to cope with their new role as a parent of a child with special needs and lets them know that they are not alone.

Parent-to-parent support provides a unique type of support usually unavailable in traditional therapeutic settings. Mentor parents are able to assist a newly referred parent in meeting their emotional and informational needs. Mentor parents are able to relate emotionally to a newly referred parent because they have been in a similar situation with their own child. They have shared many common experiences in learning to cope with the challenges of parenting a child with special needs. Mentor parents are “veterans” when it involves understanding the system of special services available to new families and can offer information about services that they accessed for their child. These experiences are unique, as is the support a trained mentor parent can offer.

CARE Parent Network will be presenting a three-part workshop for parents of children with special needs who are interested in providing support to parents of a newly diagnosed child. Participants will have the opportunity to share their personal story, practice active listening skills, learn about the many different ways people cope with challenges, and explore the grieving process as it relates to parents of children with special needs. As a participant you will learn how to provide support in an empathetic and non-judgmental way.

There is no fee for this workshop and participants will be provided with a copy of Parent-to-Parent: A Resource Manual for Mentor Parents.

If you are interested in taking part in this interactive training, please call for an application. If you have questions regarding our Parent-to-Parent Support Program or this workshop, please contact Louise Schneiders at 925-313-0999 x101 or email lschneiderscare@aol.com.

DATES & TIMES: Saturday, September 18, 2004, 9:00 am – 3:30 pm
 Tuesday, September 21, 2004, 7:30 pm – 9:30 pm
 Tuesday, September 28, 2004, 7:30 pm – 9:30 pm

PLACE: CARE Parent Network, 1340 Arnold Drive, Suite 115, Martinez

EXTRAS: Lunch and refreshments will be provided.

*“In helping others, we shall help ourselves,
 for whatever good we give out completes
 the circle and comes back to us.”*

Flora Edwards



Confidentiality

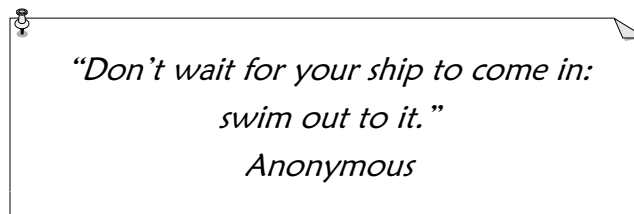
Confidentiality is a topic that has recently been getting a lot of attention in our office. It is a broad topic with various definitions, and is subject to different interpretations. Parents have rights to privacy that vary from agency to agency. Beyond the legal requirements, common sense and high professional standards would dictate that parents want sensitive information about their child and family to be respected and safeguarded.

Confidentiality has become a hot topic partly because of a new law, the Health Insurance Portability and Accountability Act (HIPAA). You have probably received written notice from your family's health care providers about your rights to protection of your health information under HIPAA. And, parents of children who receive services from a local educational agency (students receiving special education services through an IEP) or from a regional center (including services paid for by a regional center) have rights guaranteed under state and federal laws, including the Federal Educational Rights Privacy Act (FERPA), the Individuals with Disabilities Education Act (IDEA), and the California Early Intervention Services Act. By law, representatives of these agencies must provide you with a copy of your rights. If you do not have a copy in your child's records, be sure to ask your service provider.

These laws, in general, protect your right to privacy in the following ways:

- Ensuring your right to examine and obtain copies of your child's records, and to request that information be amended or removed
- Request a meeting to discuss any information contained in the record
- Have personally identifiable information maintained in a confidential manner and have its source, access, use, and policies explained to you
- Ensure that medical information that identifies you is kept private

One of the reasons why this has become a hot topic for us is that numerous parents have shared distressing examples with us about breaches of confidentiality they have experienced or witnessed. These breaches have been committed by professionals who work with children with special needs, and also between and among parents, including parents who serve as district Resource Parents, on Community Advisory Committees (CACs), and in other support capacities. This has prompted us to write an article about this important topic so that parents clearly know what to expect with regard to their right to confidentiality, and to give them the knowledge and confidence they need to assert their rights to confidentiality, whether it is in the context of a professional relationship, or as part of their involvement in a parent group. *Continued on page 6*



*“Don’t wait for your ship to come in:
swim out to it.”
Anonymous*

Confidentiality

Continued from page 5

If you are involved with a parent group, you have the ability to support another parent simply by listening. This one-to-one support from another parent is important and can give us an opportunity to share feelings and happenings in our daily lives and can help us to give our experience some perspective. To be truly helpful to another parent we need to develop trust and establish ourselves as a “safe” person; one who will not discuss what has been shared personally with others.

In general, maintaining confidentiality conveys respect. When discussing confidentiality between and among parents there are some guidelines that can be followed. Parents who are acting in a helping role should agree to respect the confidentiality of the personal information that is shared parent-to-parent, whether it is in a support group or with a mentor parent or resource parent. This confidentiality is maintained by not discussing details of what has been shared outside of the group or one-to-one relationship. If you feel it is necessary to share a reaction to something that was shared you may do so, not by disclosing personal details or by judging what was shared, but by describing how the one-to-one exchange made you feel or what you learned from the experience.

There are some limitations to confidentiality. If in a helping role, and presented with a situation that concerns you or makes you feel uncomfortable, you should speak with the coordinator of the program. It is disrespectful to discuss your concerns with another parent. Sometimes, with good intention, parents violate the trust of another by discussing a personal situation that has been shared with other parents. The very time when confidentiality is most important may be the time when a support parent feels unable to respect the confidentiality. Listening, parent-to-parent, and providing support is a skill that requires practice and should always involve confidentiality.

What can you do as a parent to take an active role in protecting your own rights to privacy? Here are some suggestions:

- Ask what the confidentiality policy is and request a copy in writing
- Clearly state your expectations with regard to your right to privacy
- Be specific about what information can be shared, and with whom
- Ask that you be notified before any information is shared
- If you are concerned about a possible breach of confidentiality, speak with a supervisor

Again, confidentiality conveys respect; whether it involves parent-professional interaction or parent-to-parent support. Providing a safe and confidential place for families to have their service and support needs met is of the utmost importance.

“If you always give, you will always have.”

Chinese Proverb

Fall IEP Training

WHEN? Saturday, September 11, 2004

WHERE? 1340 Arnold Drive, #115, Conference Room, Martinez.

WHO? **Parents of children with special needs** who want to learn more about the IEP process.

WHAT? *This workshop will include an overview of the special education process with a special focus on how parents can be effective participants in the development of an IEP which meets their child's needs. All materials will be provided.*

There is NO COST for this workshop!



This workshop is co-hosted by Disability Rights Education Defense Fund (DREDF) and CARE Parent Network.



9:00 - 9:30 a.m. Registration & Coffee

9:30 - noon An Overview of Special Education & the IEP Process
Presenter: Parent Advocate, DREDF

Please register 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 September 11 (check box) (please register by 9/3).

When Do I Keep My Child Home From Child Care or School?

A good gauge is to ask yourself: *If my child was perfectly healthy, would I want him or her near a child with these same symptoms?* Here are some symptoms that may signal a need to stay home (these should be used as a guide, and not in place of calling your health care provider advice line).

-  Repeated diarrhea and/or vomiting within the past 24 hours.
-  Severe cold with fever, sneezing and thickened nasal discharge.
-  Sore throat when combined with fever or swollen glands.
-  A cough that keeps a child awake at night, worsens with increased activity, or is combined with other symptoms.
-  Fever (rectal temperature of 101, or oral/ear temperature of more than 100, or child with temperature of 100 who is pale, achy, and tired).
-  Earache that is severe and persistent.
-  Redness in whites of eye, yellow discharge and matted eyelashes.
-  Rashes that are blistering, oozing or sore.

When to send a child back to child care or school? Children should be without fever or symptoms for at least 24 hours. If an infection has been treated with antibiotics, such as an ear or throat infection, a child usually can return to school after taking the medication for 24 hours. (Adapted from, "When to Keep a Child Home", Bay Area Parent, East Bay Edition, October 1999.)

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