



NETWORKER

WarmLine Family Resource Center

Serving Families and Professionals Involved with Children with Special Needs in Sacramento, Placer, Yolo, Nevada, El Dorado, and Alpine Counties Since 1993.

August 2011 Edition

Sacramento:

2025 Hurley Way, Ste. 100
Sacramento, CA, 95825
916-922-9276 * 800-660-7995
Español—916-922-1490
email: warmline@warmlinefrc.org
www.warmlinefrc.org

Placer County:

6960 Destiny Dr., Suite 106
Rocklin, CA 95677
916-632-2100
Español—916-922-1490
email: placervl@warmlinefrc.org
www.warmlinefrc.org

Yolo County:

907 3rd Street,
Davis, CA 95616
530-759-1127
Español—916-922-1490
email: yolowl@warmlinefrc.org
www.warmlinefrc.org

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Support Groups

For a listing of support groups in WarmLine's six county area, please go to www.warmlinefrc.org/support-groups.html

New WarmLine Website!

Thanks to the hard work of our friend, Andrew Perez, WarmLine has a new, interactive website. The new site will include a page which will allow people to register for our trainings and activities online and connect with other families. Soon, it will also feature a section specifically for Spanish speaking families.

Every effort has been made to make sure that all of our event calendar entries have been transferred and that all of the links are "live", however, if you discover activities missing from the calendar or problems with links, please let us know at Cid@warmlinefrc.org or call 916-922-9276.



The future belongs to those who believe in the

beauty of their dreams."

Eleanor Roosevelt

River City Bank Supports WarmLine

River City Bank, a long-time supporter of WarmLine's Annual Golf Tournament with players and a \$10,000 Hole-in-One prize, has donated "gently used" office furniture to our Sacramento office.

Thanks to River City Bank CFO (and WarmLine Board Member), Anker Christensen, WarmLine will have "new" file cabinets, desk, chairs and conference table.

Special thanks go out to Camille Lasky, Facility Manager of River City Bank, for her help with choosing furniture that would be the most useful for us and arranging delivery.

Please visit our Sacramento office soon and see how nice it all looks.



Dear Parents, Grandparents,
Siblings, Teachers, Therapists,
Nurses, Physicians &
Many Valued Friends,

WarmLine Family Resource Center is a place for families to turn when they discover that their child has a special health care or developmental need. We are parents who have "been there" and our goal is to provide a link to whatever you may need on your journey, including parent-to-parent support and other important services.

Families *and* professionals are encouraged to contact WarmLine for assistance. We offer information, referral and support. We also have resources including books, videos, workshops and opportunities for families and professionals to share and learn with each other about a wide variety of conditions, educational options and supports. WarmLine Family Resource Center is a community of families, friends and professionals working together for each other and for our children.

WarmLine Staff:

Diane & Lori in Yolo County; Candace, Courtney, Deanna & Raymond in Placer County; Nancy in South Lake Tahoe; Laura, Cid, Erin & Kelly in Sacramento County

WarmLine Board Members:

Joseph Androvich, Cathy Mikitka, Teresa Androvich, Michael Rosenberg, Anker Christensen, Sue Winar, Shirley Skadan-Smith, Rebecca Akroyd

WarmLine Family Resource Center
Mission Statement

"Our mission is to provide support, information, and education to promote and strengthen the foundation of families and children with special needs so they can face the challenges of the present and create new dreams for the future."

WarmLine Digital Updates

About two years ago, WarmLine discontinued mailing the *Networker Newsletter* in order to better utilize scarce resources. At the time, we were sending out our newsletter to approximately 700 families and professionals. Since going "digital", we now have almost 1300 people on our distribution list and it has continued to grow.

Because of the growth, this spring we subscribed to a new service which manages those 1300 email addresses more efficiently. With that, we've begun sending an email notice about every two weeks to alert families and professionals about new WarmLine events, ongoing WarmLine trainings and support groups, and (space permitting) information about upcoming events with some of our community partners.

Our *Networker Newsletter* will retain it's previous format, which families tell us is very family-friendly. At the top of the bi-weekly email, we will include an alert that the newsletter has been uploaded to the website and a link. Because we're updating the activities frequently, the newsletter will be mostly focused on articles and information of interest to families and professionals.

...And Data Updates



In an effort to better serve our families, WarmLine has begun compiling information from the people who call us; such as parent and child's names, zip code, child's birthdate and ethnicity. The information we gather will be used in the future to help support grants and contracts for which WarmLine applies. *All information which WarmLine gathers has always been confidential and will continue to be so!*

Individual Family Service Plan (IFSP)

What is an IFSP?



The IFSP is a written plan for meeting the unique needs of your family and your child birth to three years old who has a developmental delay and who is receiving services through the California Early Start (Early Intervention) Program. It is based on your child's strengths and your family's concerns and priorities. The IFSP is the foundation of services that are family centered.

The IFSP is not a final document; it is an ongoing process. Your child's needs may change quickly, so your family's IFSP should be reviewed frequently, at least every six months, and changed as necessary. If you feel your early intervention services need to be changed, contact your service coordinator to request an IFSP review. If this is your child's and family's first IFSP, the law requires that it be developed within 45 days of your child's referral for early intervention services. Generally, the meeting should not be held, however, until all of the necessary assessment information has been gathered.

Who attends the IFSP meeting?

You may invite anyone you want to the IFSP planning meeting. The people you include may be some or all the team members involved in your child's assessment, or any other person you would like to assist you in developing your child's plan including other family members or friends. If you would like to include people who are unable to attend, they may send written information to be included in the discussion.

Who is the service coordinator?

The service coordinator is the person who is responsible for coordinating all early intervention services and helping parents to identify and obtain the services and assistance they need to help their child's development. The service coordinator will typically be

either from Alta California Regional Center (ACRC), a Local Education Agency (LEA), or a local Infant Development Program (IDP).

How can I prepare?

It might be helpful to spend some time before the meeting thinking about the things you want to tell the rest of the team. You know your child best! Think about the services you think your child needs and your goals for your child. Write down and share your thoughts with the IFSP team. The staff at WarmLine would be happy to help you with this.

What will my role be?

What will I be expected to do?

You can decide how involved you want to be in the creation of the IFSP. Other members of the team would like to hear from you about your child and family. **You** make the decisions about the outcomes, activities, and services you would like included in the IFSP.

What will be discussed?

(Discussing some of these things may be difficult for you at first. You may feel that the professionals are asking personal questions that don't relate to your child's special needs. However, this information is needed to help them provide the best fit for you and your family and the many different services available.)

The IFSP Planning Meeting discussion will include:

- Your child's present level of development,
- If you choose, you may share your concerns and priorities about your child's development and your family's strengths and resources,
- Major goals/outcomes for the next 6-12 months,
- Specific services your child will receive,
- Any other services/resources needed by your child or family.



Please see IFSP, page 4

What will happen after the meeting?

Services will not begin until the IFSP is signed. If you need to take extra time to review the IFSP with your family, you may do so. You do not have to sign the document right away.

Before the meeting is over, be sure you are clear about what the next step will be, as well as what anyone else will be doing and when. If you have any questions, contact your service coordinator. Services should start as soon as possible after the IFSP meeting.



What the IFSP Contains

The IFSP contains:

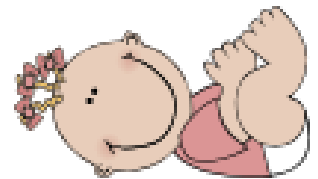
- Your child's present levels of physical development (including vision, hearing, and health), cognitive (thinking), communication and social or emotional development.
- What is important to you about your child's development, your family's resources, priorities, and concerns.
- The major goals that you and the team have agreed on, how and when the following will be measured:
 - a. How much progress is being made toward achieving the goals; and,
 - b. Whether changes in the goals or services are necessary.
- The specific early intervention services that your child will be receiving. This will include how often, where and how the services will be delivered, the natural environments in which the services will be provided, and the payment arrangements, if any. (The natural environment means settings that are "natural" or "typical" for the child's same-age peers who have no disability. It includes the home and community settings in which children without delays or disabilities participate.)
- Other services — medical and other services that your child needs, but that are not required under Early Start law, and the funding sources to be used in paying for those services.

- The dates for the start of the services and the anticipated duration of services.
- The name of the service coordinator who will be responsible for making sure the IFSP is followed and coordination with other agencies and persons.
- The steps to be taken to support your child's transition to preschool at age 36 months and the transition process.

If you have any questions about your child's IFSP, call your Service Coordinator or WarmLine. WarmLine has trainings to help you understand both the IFSP and the transition processes for three year olds "graduating" from Early Start.

Prevention Resource and Referral Services (PRRS)

Effective July 1, 2011, the California Department of Developmental Services was given the task of contracting with family resource centers, such as WarmLine, to provide outreach, information and referral services for children under 36 months of age who are otherwise not eligible for the California Early Intervention Program. The new program is called Prevention Resource and Referral Services (PRRS). Family resource centers support families of young children with intellectual or developmental disabilities, and those at risk for intellectual or developmental disabilities by ensuring the continuance, expansion, promotion and quality of local family support services, including coordination, outreach and referral to community resources.



For more information about PRRS, please call WarmLine Family Resource Center at 916-922-9276/800-660-7995.

Our next newsletter will feature information about the transition from Early Intervention to Special Education Services.

Including Samuel

Before his son Samuel was diagnosed with cerebral palsy, photojournalist Dan Habib rarely thought about the inclusion of people with disabilities. Now he thinks about inclusion every day. Shot and produced over four years, Habib's award-winning documentary film, *Including Samuel*, chronicles the Habib family's efforts to include Samuel in every facet of their lives. The film honestly portrays his family's hopes and struggles as well as the experiences of four other individuals with disabilities and their families. *Including Samuel* is a highly personal, passionately photographed film that captures the cultural and systemic barriers to inclusion.



WarmLine Family Resource Center has copies of *Including Samuel* (including Spanish subtitles) to loan to individuals and groups. There is a \$30 refundable deposit. Please call 916-922-9276 or 916-632-2100 for more information.

Inclusion Means...

- Individuals are given opportunities to learn from their peers in all aspects of community life and does not require an individual to learn in isolated groups;
- Providing necessary services and supports within the community without jeopardizing an individual's safety and well-being;
- Supporting programs and schools in meeting the person's individual needs;
- Supporting the needs, wants, and choices of the individual and their family;
- Supporting individuals' access to age appropriate opportunities in school, work, recreation, and life.
- Promoting opportunities for social relationships between non-disabled and disabled people;

- Providing an appropriate person-centered plan that facilitates opportunities for participation in community life;
- A person is not required to be "ready" or "earn" his or her way into life opportunities.

Tips for Encouraging Speech Production

By Jennifer Twachtman-Reilly

1. Even if your child is non-verbal, give frequent language input by modeling words and phrases, and by describing events as they occur.
2. Use sign language and picture to help facilitate comprehension, as well as to provide a means of expression for your child when speech is not available to him/her.
3. Encourage frequent oral exploration of safe and socially appropriate materials of varying tastes, temperatures, and textures, e.g., lemonade concentrate, brushing the tongue, etc.
4. Incorporate familiar songs and nursery rhymes into your interactions with your child, and be sure to use manual signs and/or accompanying gestures as you sing or say the words.
5. Utilize familiar fill-in-the-blank phrases, e.g., "ready, set, _____"; "Jack be nimble, Jack be _____", rather than direct imitation, to facilitate production of words and phrases.
6. Stop in the middle of a familiar song, or during the repeating line of a familiar book, to encourage your child to continue the verse or phrase on his/her own.
7. Pair speech with corresponding motor movements, where possible, e.g., Say: "jump, jump, jump" while your child is jumping.
8. Use your hand to tap out the syllables in a word as you say it.
9. Place your child's hand on the front side of your neck or on your lips as you speak, to give him/her increased tactile input.
10. Imitate the words/wounds that your child says without expecting him/her to imitate you in return.



On Being the Sibling of a Child with Special Needs...

Andrew Perez

Everyone has layers. Some layers are deep-seated like a person's faith, morals, or cultural and family heritage. Then there are the layers like being a spouse, a parent, a brother or sister. For some of us, however, these layers are much more multi-faceted than for others.

As a brother of a young man who has special needs, I have had much different experiences than most of my friends. Most people are not inherently able to understand what it means to have a sibling with special needs or how that affects a person's life. I was recently told by a co-actor that I am "a lot more well-adjusted than [he] was at [my] age." I responded casually that it's the kind of thing that happens when one grows up from the age of five helping to take care of someone with as many medical needs as my brother. He looked at me with a face displaying 10% pity and 90% confusion. I believe that's how a lot of the world looks at siblings of people with special needs.

Parents, though for the most part initially unprepared for the struggles of raising a child with special needs, find support everywhere they turn. There are groups, organizations and events targeted at



parents of children with special needs to provide them with the resources they need to get educated and supported. For a sibling, however, it's much more difficult.

Children, upon hearing "Your brother is disabled." don't automatically think "I should find a good support group!" Unfortunately, that's when that need is greatest in a sibling's life. In those formative years, growing up with the challenges of having a special needs sibling but without any peer support can be overwhelming. Siblings need a place where they can go and not have to feel the sting of peers using the "R" word, where they don't have to explain that their little sister throwing a radio in a tantrum is fairly normal, where they don't have to preface a funny story about their

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sibling with "Okay, well, my brother's disabled, so..."

I attended Sibling Meetups when I was young and I cannot express how much value I got from them. The games are totally silly and wild, but the message comes through loud and clear (through all the canned cheese, dangling powdered donuts and tug-of-war): "I'm not alone. I do not have to bear this on my own." I firmly believe that my, at least seeming, "well-adjustedness" comes in large part from these Sibling Meetups and the friends I made in them and the support I gained from them.

On July 23, WarmLine held a Sibling Meetup that was attended by five **very** enthusiastic siblings of children with special needs. It is our goal to provide Sibling Meetups as often as possible. Please check out WarmLine's website and event calendar for upcoming dates!

Want to Learn More About Sibling Issues & Support?

The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

They believe that disabilities, illness, and mental health issues affect the lives of all family members. Consequently, they want to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues.

Their mission is accomplished by training local service providers on how to create community-based peer support programs for young siblings; hosting workshops, listservs, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, lifelong, and ever-changing concerns through workshops, websites, and written materials.

Please visit the Sibling Support Project at (www.siblingsupport.org) to learn more about the valuable work they do to support siblings and families.