

NETWORKER

SPRING 2008

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Has your email address changed?

Please let us know to ensure you continue to receive updates & our monthly e-newsletter, *The Networker Express*. Send your updated information to: express@matrixparents.org

Raise your Voice: Take Action!

Empowerment is central to the vision of Matrix. We believe all parents have the ability to be powerful advocates and effective leaders for their children and communities, yet some parents do not realize how powerful they really are or can be. It is a well known fact that people feel more confident and willing to take action when given additional skills and information. Our goal as a Parent Training and Information Center (PTI) and a Family Empowerment Center (FEC) is to help parents gain the knowledge, skills, and confidence they need to recognize the power of parent leadership and the collective strength of their voices on the many decisions that affect children and families.

Elected representatives need and are eager to hear these voices – they make many decisions that directly affect your life and the lives of your children. With their votes, legislators make laws that protect your civil rights and decide how those rights will be protected – now more than ever, know your rights! Your elected representatives need to hear from the people they represent to know what services and programs are needed because they are the ones that decide how much money will be available for regional centers, mental health agencies, education, transportation, and affordable housing. We have

seen firsthand the power of parent leadership and involvement and encourage all parents to accept the challenge. In her article, "Testifying at The State Capitol: One Parent's Story", Jennifer Wolke-Barber describes how exciting and empowering legislative participation can be:

"THIS was important! I had the opportunity to make a difference for something I believe in! With a twinge of the jitters, I began my testimony. I was empowered! The committee was impressed by my testimony that day; they asked plenty of questions. I feel that personal testimony has great impact at the state level. More parents should write on behalf of a voiceless population – their children and other's kids."

In addition to knowledge and confidence, a key characteristic of an effective leader is the ability and the desire to take action, so we have included in this newsletter steps to help you take action in your own life. Tell your representatives how their votes will change the quality of your life and the lives of your children. With supports and services, people with disabilities can have inclusive, productive, independent, and empowered lives. See our **Tips For Contacting Your Elected Representative** on page 3 to help you raise your voice.

All About Matrix...

Matrix Parent Network is a 501(c)(3) organization founded in 1983 to serve families of children with special needs. We serve Marin, Napa, Solano and Sonoma Counties.

MISSION STATEMENT

Empowering families of children with special needs to successfully understand and access the systems that serve them.



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Congratulations Nora!

Matrix ED, Nora Thompson, was recently awarded the *California Interagency Coordinating Council on Early Intervention (ICC) Parent Leadership Award*. Nominated by the Marin Early Start Roundtable Team, Nora was selected for this prestigious award based on the extraordinary contributions she has made as a parent leader.

Message from the Director

What is Parent Leadership?

This issue of the *Networker* features information about strengthening parent leadership, using our voices effectively to be the best advocates for our children. As a new parent, I distinctly remember meeting some amazing parent leaders, Joan Kilburn (one of the Matrix founders) among them and thinking to myself, "I will never be able to stand in front of people, lawmakers, school personnel, or anyone and speak with such passion and authority about issues and concerns for families of children with disabilities." I was in awe of the ease and grace in which Joan and others conducted themselves, making a huge difference to the lives of many families, while I was struggling to understand how our family would just function in this new, strange role.



I did know I had to learn some skills quickly, in order to help my child -- things like how the convoluted systems of services worked, how to clearly identify and say what my child needed, and how to not take "no" for an answer. But this seemed miles removed from those smart, articulate folks who were working on positive systems change for all children. After all, I was just a mom... what difference could I possibly make? I certainly wasn't equipped to do what those parent leaders were doing.

Turns out, that is exactly how those parent leaders started out, trying to learn and do what was best for their child and in the process, seeing that the changes they sought for their child could be better tackled by seeking changes for all families and children. So as I learned how to use my voice for my child, eventually I was recruited, lured, whatever you want to call it, into a broader role.

When parents or family members work up the nerve to attend an IEP to speak from the heart about their child, they are parent leaders. When parents stand up and testify to lawmakers and policymakers about the impact their decisions have on families and children, they are also parent leaders. Is one more important than the other? No. Does every parent who finds their voice need to use it on behalf of all families? No. Is there a place for both types of parent leadership? Absolutely.

So as you find your voice on behalf of your child, please know that you are a parent leader, whether you know it or not, whether you want to or not. No one knows your child better than you and can be as passionate and committed in advocating for his or her needs. Those are the seeds of parent leadership; passion, commitment and the love for your child. Nurture these seeds -- over time you will be amazed by the leadership you will grow!

Nora Thompson

Tips for Contacting Your Elected Representatives...

(Adapted from *Practicing Democracy* by Area Board 4 on Developmental Disabilities)

When Meeting in person:

- If you have the time, meet with your representative in person. Before the meeting, make clear notes or write a letter so you can refer to these during the meeting.
- Be concise – try to focus only on one issue in the meeting. Get to the point quickly and keep the meeting short. Your elected representatives have many responsibilities and appreciate when others value the time they have to give to their constituents.
- Be personal – Say how the issue you are talking about will directly affect you. This will help your representative understand what is important to you.
- Always be respectful. A positive attitude during the meeting and about the issue that affects you will bring better results than being rude and negative – remember, you want to educate and persuade your representative to your point of view.
- Be sure to thank your representative for meeting with you.

When you write a letter...

- Address your letter correctly – elected representatives are addressed, “The Honorable” followed by their name and address.

- Tell the representative who you are, where you live, and if employed, what you do for employment.
- Tell the representative if you are a registered voter... this is important!
- Keep your letter direct and to the point. Be concise and choose one issue or point to focus on in your letter.
- Use your own words to say why this issue is important and how it affects your life personally.

When time only allows a phone call. . .

- Be prepared to share your thoughts and concerns. Be polite and concise, best to focus on one issue with each call.
- The elected official’s phone staff is there to listen and take down your ideas and concerns. You can indicate that you would like a follow-up to your phone call.
- As above, let the staff know that you are a registered voter and why this issue is important to you personally.
- In all your communication, remember, elected officials are there to serve their constituents – meaning you! Many of the best legislative ideas originally come from people just like you.

If you are not sure who your elected representatives are contact the Registrar of Voters in your county:

Marin County	(415) 499-6456
Napa County	(707) 253-4321
Solano County	(707) 421-6675
Sonoma County	(707) 565-6800

The Marin Human Race, May 10th, 2008



LeighAnn Moore and her son, Mark, celebrate after this year’s Marin Human Race.



Proud Matrix Participants at the Marin Human Race 2008

Matrix raised over \$5000 to support client services at the Marin Human Race this year – our highest total ever for this event! Top Matrix earners, client **LeighAnn Moore, with her son Mark, and Board Member Heidi Peratoner**, won the prizes Matrix awarded to the leading fundraisers. Toss Designs and Zenith Instant Printing sponsored Matrix. Other Matrix participants were Madeleine Bludeau, Brenda Gates-Monasch, Bryan Hedgy, Megan McKeon, Paul Miles, Colleen Revill, and Paul Podwojski. Congratulations to all of our participants -- thank you for your support!

An Interview with Anne Ford, Author and Activist



Nora Thompson and Anne Ford at the celebration luncheon.

In celebration of our 25th year, Matrix hosted two special events on May 21, 2008 featuring nationally recognized author and disability rights advocate Anne Ford. Ms. Ford was an inspiring speaker at a fundraising luncheon in Corte Madera and an evening discussion in Petaluma. Attendees of both events were able to have Ms. Ford and her co-author, John Richard Thompson, sign copies of their books, *Laughing Allegra* and *On Their Own: Creating an Independent Future for Your Adult Child with Learning Disabilities and ADHD*. We sat down with Ms. Ford for an interview to learn her thoughts on parenting, empowerment, and the importance of self-advocacy.

If you could go back and change one thing you did related to raising your daughter, what would you do differently? I wish I had let go a little sooner, given her more independence earlier. This is one of the greatest challenges for a parent of a child with disabilities. It's ironic: we spend years trying to instill independence in our child, and all too often end up becoming the greatest obstacle to that independence. We convince ourselves that our child can't possibly manage without our constant hovering. Well, guess what -- they really can manage much more than we believe they can. The trick is to know when to step in and step out...it will be different for every parent and every child, and it was a very hard lesson for me to learn.

What was your greatest fear as the parent of a child with Learning Disabilities? How did you deal with it? How did you move from feeling fearful to feeling empowered? My greatest fear was the thought that she would never be able to live on her own. And again, our constant worry and attention can inadvertently delay or even prevent the very thing we have worked so long and hard to achieve. I tried to teach Allegra the value of self-advocacy. I taught her how to explain her own disability to another person, and how to stand up for herself.

How did you make the transition from working just for your child to working for all children? What one piece of advice would you give young families just starting this journey of advocacy and empowerment? Allegra ended up attending a school over 200 miles away. When she was away, I felt so lost and alone. All that energy directed toward my daughter was left behind with nowhere to go. I joined the Board of the National Center for Learning Disabilities, and was soon asked to serve as Chairman, a position I held for twelve years. After I stepped down I wrote my first book. Parents may find great comfort and value in joining disability advocacy organizations. Of even greater comfort is to ensure that your child is empowered to advocate on his or her own behalf as early as possible. Don't view the journey of advocacy and empowerment as one you make on your own -- let your child be your partner on this journey. It will smooth the way for both of you.

"Don't view the journey of advocacy and empowerment as one you make on your own -- let your child be your partner on this journey. It will smooth the way for both of you."

What's the most crucial thing you said or did for your daughter, something that made a significant impact? Without question, introducing her to figure skating, helping her pursue this interest throughout her childhood, and allowing her to make the decision (against lots of professional advice) to continue skating when she became an adult. Skating helped with her self-esteem and really has improved her self-confidence in all areas of her life. I interviewed several CEO's for my book, *On Their Own*, including Richard Branson and Charles Schwab. Every one of them gave the same advice: Find something that interests your child, and do everything you can to help develop that interest.

Effective Advocacy for Your Child's Education

Your child's education is not happening the way you think it should -- what should you do, how can you make the difference? If, as a parent, you react to concerns you have about your child's educational program without being an effective advocate, you risk having those concerns ignored or addressed in ways that are not satisfactory. **So what does effective advocacy involve?**

• Research • Planning • Preparation • Good Communication • Willingness to Solve Problems

When advocating effectively, it is important to remember to focus on your critical areas of concern, your "interest" versus your "position," what is NOT worth fighting about, and ensuring that your emotions do not interfere with your objective. Separating emotions from advocacy is difficult, but so very necessary.

Here are some things to do to help you be an effective advocate:

1. Learn the rules of the game: Legal requirements; Procedures; How decisions are made and by who.
2. Gather information and organize it.
3. Don't jump to conclusions.
4. Talk to all of the involved parties, take good notes.
5. Keep written records of IEPs, assessments, correspondence, and phone calls in one place.
6. Ask questions and listen – it's ok to not know something.
7. Identify problems/barriers.
8. Be a problem-solver.
9. Bring in strategic people to overcome barriers.
10. Don't blame, accuse or make things personal.
11. Propose solutions.
12. Use the facts, not speculations.
13. Discuss issues, not positions. By discussing your concern (your interest) rather than proposing a single solution (your position), you allow everyone to brainstorm options that might be different/better than your original solution or the IEP team might come to the same conclusion as you.
14. Find common interests. If behavior is your concern, it is probably a concern of school staff as well and every one, including your child, will benefit with a solution that is well thought out – not a "band-aid" action such as sending your child to the office.
15. Don't rehash the past – focus on what can be done today.
16. Brainstorm –think outside the box.
17. Make offers and proposals.



It is always important to communicate respectfully, without being aggressive or blaming others. Instead, by being assertive, your concern will be the focus of the discussion and others in the room will be less defensive. And finally, always acknowledge good efforts and good intentions and thank those who have worked with you. You are building a relationship with those who educate your child.

NAPA/SOLANO DOWN SYNDROME PARENT SUPPORT GROUP

In March of this year parents and other family members of children with Down Syndrome began meeting on the first Saturday of the month in Fairfield – there were 25 families at the first meeting! In the planning stages: a respite/date night for parents in June; a BBQ in July; and a presentation by a developmental therapist in August. Meetings include the children so there is time for play and socializing for all! There is also a Yahoo! group formed specifically for Down Syndrome support -- go to Yahoo! Groups and search for Solano County Down Syndrome Support. For more information on this group call Virginia at (707) 803-2164. For a listing of all Matrix support groups in Marin, Napa, Sonoma, and Solano Counties visit our website at www.matrixparents.org

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New! Matrix Online Teen Forum

When I was younger I always looked forward to Sibshops. Sibshops (Sibling Support Workshops) are an opportunity for brothers and sisters of kids with special needs to spend time with other kids like themselves. You talk, share experiences, and learn about disabilities -- you learn you're not alone. As I grew older resources like these were no longer available. I felt too old to attend Sibshops and they became less interesting to me as a young adult. But now, thanks to the youthful inspiration found in fellow sibling Asher King Abramson and myself, Matrix has put together an online teen forum for siblings of children with disabilities to talk about problems, ask for advice, or just meet other teenagers like themselves.

From the success of the Yahoo! Matrix Parent Forum, we thought that a group such as this would be beneficial for teens. High school students are busy with school, sports, and other extracurricular activities; they may not have the time or the willpower to attend support meetings. This is why creating an online community is an exciting way to support and empower teenagers who have siblings with disabilities.

The new Matrix Teen Forum gives members the freedom to speak their minds and talk about tough issues that may be embarrassing or challenging to address in person. This site is carefully monitored by its Moderators who work hard to keep the forum a safe and positive place for teenagers to communicate and thrive. Our plan is to create a supportive community through this forum online and then eventually have in-person activities if desired by the members; these would be similar to Sibshops but designed for teenagers to further connect members. Matrix has always found ways to help empower parents, siblings and children with disabilities, and now there is a new way to empower teens through a medium that we're very familiar with -- the internet! **Create a Yahoo! profile, join the forum, and help create a support system for teens in Marin and Sonoma County. To join visit <http://groups.yahoo.com/group/matrixteenforum/> or call Chris at (415) 475-2119.**

Contributed by Rachel Fichman

Empowering Sage



Sage on the ball field.

The weekends are always interesting with Sage. She could be in a good mood, a bad mood, or any combination of the two. We always struggle with what to do next. Then we came across information about Challengers, a Little League team sponsored by the Benicia Little League. There are two teams available for children of all ages with physical and mental disabilities. We never thought Sage would cooperate and go along with playing, or even keeping her ball cap on, but she is really loving it. And so are we.

This is truly what the game of baseball is about -- fun. The stands are filled with fans who cheer, not only for their kid or team, but for every player on the field. It's a wonderfully uplifting and empowering experience for all who attend. There's no umpire, no three strikes, no foul balls, no coaches arguing with the call. It's just honest to goodness fun! Our faces often hurt from smiling through a whole two hour game!

We're over a month into the season and the thrill of it all is still amazing. We pull up to the field, Sage claps from the backseat, and we smile and look for her favorite teammates. They run up to greet us, walk Sage to the field, and ask how we have been since last week. We are truly making connections to other kids and their parents. It's a wonderful way to spend a Saturday morning. I can't imagine a more positive way to engage and empower our daughter than through the sport of baseball. I take that back...I just heard about a soccer program that starts after baseball season. Gooooooal!

Contributed by Jenny Huff

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We have made every effort to acknowledge all of our donors. We apologize if we have overlooked someone. Please notify us so that we can make the correction in our next publication.

SAVE THE DATE!

Matrix 25th Anniversary Family Party

Saturday, September 13, 2008

Noon to 4 PM

Please come celebrate with us!

parent network
+ resource center



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www.matrixparents.org



Networker • Empowerment • Spring 2008

Our mission: To empower families of children with special needs to successfully understand and access the systems that serve them.

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