

The Early Edition

A Publication of Matrix Parent Network and Resource Center • Winter 2009

W E L C O M E

Matrix Parent Network and Resource Center welcomes you to join with other parents who have found help and support through our services. Together we are stronger for our children.

MATRIX EARLY START Parent Advisors are parents of children with special needs who have received early intervention services, so they share a unique understanding of the families' experiences.



Building Your Network of Support

Many mention the safety instructions given by flight attendants to put on our own oxygen mask before assisting our child as the same instructions needed when parenting our little ones with special needs. The message is clear. We need strength and clear thinking in order to best help our child. It is easy to get tired or overwhelmed and at times we need to grab on to the mask to rejuvenate.

One key ingredient in our oxygen mask is a support network – a network of others who listen, understand and help us find a

path that works for our child and family. Taking care of a little one with special needs can be isolating. It can take its toll on marriages. If there are siblings, they too are affected.

To help, here are some ways for you to reach out to meet other parents in similar situations:

- Ask your Early Intervention Provider about ways to connect;
- Explore on-line chat rooms that are often sponsored by disability organizations (Matrix has a Yahoo! group);
- If you are still connected with a Children's Hospital, ask about

support groups;

- Call Matrix to learn about opportunities to network with other parents.

You'll also want to seek out others to get organized or find fresh perspectives, such as:

- A friend or family member who is a good listener;
- An exercise partner or group class to provide a physical break or introduce you to new interests;
- A counselor or therapist who can provide support and perspective and help you focus on building your strengths and inner resources.

Serving Marin, Napa, Solano, and Sonoma Counties • www.matrixparents.org

94 Galli Dr., Ste. C, Novato, CA 94949 • 1615 West Texas St., Ste. 4, Fairfield, CA 94533

800.578.2592 • Baby Line (Birth to Age 3) 415.475.2123

Matrix Early Start Services

How Early Start at Matrix can help:

- A Parent Advisor is available to talk or meet with you about your questions and worries and to celebrate your child's gains;
- You can have someone help you organize your paperwork and records on your child, so that you are better prepared to meet and work with professionals;
- Useful information is provided in a designated Early Start section on our website with our new Early Start Matrix Welcome packet and other resources (www.matrixparents.org);
- A parent training in Marin County on **Accessing Regional Center Services** will be held on Saturday April 25, 2009, from 10:00 AM to 12 Noon. Registration required. Call 1.800.578.2592 to register.
- Parent trainings on **Transition from Early Start services to Preschool**
 - Marin County:** Saturday, March 14, 10 AM to 12:30 PM, Location: Matrix Novato Office
 - Solano County:** Transition workshops are held throughout the semester at the school *Infant Programs*. Call 707.423.2545 for dates.
 - Sonoma County:** Saturday, March 21, 2009, 10 AM to 12:30 PM, Location: TBD*Pre-registration is required for all trainings. Call 1.800.578.2592 to register.*



Working with Regional Centers

Regional Centers contract with the California Department of Developmental Services (DDS) to determine eligibility and needed services, purchase services and provide case management for children and adults with developmental disabilities. It is important to apply for services as soon as possible. For young children, within 45 days of application, assessments must be completed and a meeting held to determine needs. Services are available to not only your child, but to your family as well. Services for your child include special instruction, therapy, assistive technology, etc. It is critical to discuss any needs that arise in your family as a result of your child's disability— regional center can purchase respite care, counseling, transportation, etc. However, all of the needs must be documented in what is called an Individual Family Service Plan for families whose children are under 3 years of age. Supports and services are required to be family focused, respectful of family decisionmaking and choices, flexible, creative and responsive to changing needs. Your case manager should discuss your family's needs with you and help you identify ways that those needs can be addressed. Disagreements with the regional center can be addressed through several avenues that are available to parents. For more information contact a Matrix Parent Advisor or go to www.dds.ca.gov.

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A Parent's Journey: Background Music

by Carol Gonsalves

Your baby was recently born with a disability or special need. This may have been a big surprise for you or you may have known during your pregnancy that something was “not quite right.” I would like to share with you my experience of having a child with Down syndrome.

Martin is now 13 years old. He was born when I was 31 years old and his having Down syndrome was totally unexpected. I took good care of myself and felt that I must have done something wrong for this to happen. But, truly the incidence of Down syndrome and most other disabilities is random and just occurs with some babies.

It seemed that I continually cried those first few weeks and thought my heart would break in two. Despite what people said about ME being special I did not feel special at all—just scared.

I read something once about how the sadness of having a child with special needs becomes the background music of your life. At first that music crashes and drowns out everything else—it is ever present and inescapable. It takes over your life. But then there is a lessening of the loudness so that other parts of your life can be heard and come forward.

The first few months for me were intensely painful, and then the first few years brought joy mixed with sorrow. Now it seems that my sorrow is much more subtle, the background music has diminished to a whisper, although I will always regret that Martin did not have the benefit of “normal” chromosomes which would ease his movements through life.

As Martin grew and developed his personality as well as his skills the fact of his differentness was so greatly overshadowed by this emerging little person. My son is delightful and has taught our family so much. My one regret is that I wasted some of his baby time mourning



who he was not rather than simply relishing who he is.

Family and friends can be hard to deal with. As you are trying to sort out your own feelings and take care of your baby, all of these people in your life are doing the same thing. I found that those who spent time with Martin in his daily routine most readily accepted him and moved on in terms of dealing with their feelings. The time I spent caring for Martin is what helped me move beyond my sorrow. And the hope that I was given by so many gave me strength and courage to move forward.

The wonderful interventions and therapies and treatments that are now available will help maximize your child's potential. You will be thrilled at any progress you see and seek out an array of strategies to help your baby. But in the end, your baby is your baby. He needs what all babies need—your love, your cuddling, your encouragement and your delight in his being.

My fears for Martin have not been played out. He is in his second year in middle school with a modified curriculum and 4 general education classes. He reads, loves rock music, takes swimming lessons and tolerates baseball so he can be with his friends. He hates haircuts, loves steak dinners and now refuses to dress up for mom or anyone. I guess he is more a 13 year old boy than a child with a disability. I don't hear that background music right now.

Carol Gonsalves is the Coordinator of Staff Development & the Solano/Napa Office for Matrix. Her son, Martin, is now 25 years old.

Early Start Resources

BOOKS

If you have time to read, the books listed below include short vignettes on how others have approached parenting a child with special needs and wisdom from 2 professionals on marriage.

After the Tears by Robin Simons

The Elephant in the Playroom by Denise Brodey

You Will Dream New Dreams by Stanley Klein Ph.D and Kim Schive

Married with Special Needs Children: A Couples' Guide to Keeping Connected by Laura Marshak, Ph.D and Fran Prezant, M.Ed.

All of these books are available in the Matrix Library – call 415.884.3535 and come visit us!

CALIFORNIA EARLY START MATERIALS

California Early Start is a valuable resource with many helpful materials. You can download these at www.dds.ca.gov/earlystart or call us at 800.578.2592 and we'll be happy to send you copies.

Early Start Services

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- † Assistive Technology
 - † Audiology
 - † Family Training, counseling
 - † Health services
 - † Medical services, diagnosis only
 - † Nursing services
 - † Nutrition services
 - † Occupational therapy
 - † Physical therapy
 - † Psychological services
 - † Respite services
 - † Service coordination
 - † Social work services
 - † Special instruction
 - † Speech and language services
 - † Transportation necessary to receive services
 - † Vision services
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Empowering families of children with special needs to understand and access the systems that serve them.