

NETWORKER

a publication of matrix parent network & resource center • fall 2009

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Building a Team: Finding Resources to Support Your Child

by Ed McManis

Last week a young, single mother called, distraught. She had just received the test results of her 5th grade daughter. In short, her daughter had been struggling in school and was falling further and further behind. One teacher told her, "She'll grow out of it." Another teacher knew her daughter was struggling but she had 24 other students in class and admitted she didn't have enough time to help her daughter.

"I knew there was something wrong." She read in quick bursts from the report: "...auditory processing...does that mean she can't hear? What's this NOS?...I'm not even sure what that means." Then she began to cry. "I'm by myself, what should I do?" What should this mother do and how can others help? How can she find the resources she needs to help her daughter succeed? Where should she begin if she doesn't know what she is looking for? For starters I had her take a deep breath and assured her she wasn't alone; we'd put together a support team. There's nothing tougher than going it alone; not only does it "take a village" with a special needs child, it also takes relatives, friends, professionals, and community groups.

For families just starting their journey, I emphasize the following:

1. Trust your intuition – intuition is based on information you've gathered;
2. Accept the elements (the first rule of survival...);
3. Everyone is busy, so don't get frustrated, be persistent;
4. Many people want to help...surround yourself with these people;
5. Keep it positive – find the positives and strengths in your child's learning.

What does a support team look like? If it helps, think of it as a fantasy football draft or putting together a great orchestral ensemble. Your child's team may include the following

resources: Family/Relatives; Friends; Teachers; Pediatrician; Educational Consultant or Advocate; Psychologist/Counselor; Psychiatrist; and Support Organizations.

FAMILY: Parents and guardians need to be on the same page, from diagnosis to intervention, to education, to graduation. Other siblings need to be involved so they can understand and be supportive (and also to get the attention they need.) A therapist can help a family work through the dynamics when it gets frustrating.

FRIENDS: A great support system can help with advice, commiserating, carpooling, and helping with appointments in a pinch, to name a few. Let them know what (if any) medications your child is taking if they will be helping out with supervision.

TEACHERS: Develop a positive relationship; keep them as allies. Often the homeroom teacher is the first to identify a learning issue. Also, if your child is frustrated in a certain teacher's class, another teacher who has taught your son or daughter can offer guidance. Make sure the teacher understands your child's special needs and more importantly, make sure the school has a program to address those needs.

PEDIATRICIAN: Get a physical; put together a health plan that includes a good diet, exercise, and plenty of sleep. Have your pediatrician discuss possible medication protocols for attention or behavior and the pros and cons. (If necessary, they typically can refer psychiatrists with whom they've worked.)

EDUCATIONAL CONSULTANT: An expert in referring the right educational approach and program for your child, from referrals for assessments to specialized programs, both locally and nationally. They can also serve as a liaison and help maintain a specialized program.

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R E S O U R C E S

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.

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CAHSEE Exemption for Special Ed Students

On July 28, 2009, California law changed the requirement for students with disabilities to take the California High School Exit Exam (CAHSEE) in order to receive their high school diploma. The law added Section 60852.3 to the Education Code which will exempt students with an IEP or a 504 Plan that indicates that the student "is scheduled to receive a high school diploma, and that the pupil has satisfied or will satisfy all other state and local requirements for the receipt of a high school diploma, on or after July 1, 2009."

This exemption will remain until California develops an alternative way for students to demonstrate their academic achievement. This alternative must be available to students by January 2011, although that deadline can be extended by two years.

Finally, schools cannot develop IEPs or 504 Plans just for the purpose of exempting students from the CAHSEE. Students in 10th grade will still be required to take the CAHSEE, even with an exemption, because of the requirements of No Child Left Behind.

When the Cupboard is Bare... A Message from our Director

*Old Mother Hubbard
Went to the cupboard
To fetch her poor dog a bone
But when she got there
The cupboard was bare
And so the poor dog had none*

Sound familiar? A silly nursery rhyme that expresses how we are all feeling these days. The "cupboards" where we used to go for resources and supports for our children are pretty bare and the "bones" we counted on seem to be disappearing before our eyes. We are all wondering how to keep going during these difficult times.

Cuts, reductions, and freezes are the words we have come to dread. These are not little things – they are the services and supports we have counted on for our families and our children with special needs in order to function. We watch, in shock, as services and provisions such as in-home supports, access to medical and dental services, diapers, and respite are reduced or evaporate.

So how do we Mother and Father Hubbards proceed? Are there steps we can take to make sure our children are cared for? Are there strategies you can use to weather this mess?

Yes, there are things that you can do to minimize the impact.

1. Get organized – the more organized you are, the more prepared you can be to advocate on behalf of your child.
 - a. Get all your paperwork together in one place, sort it into categories, and include all the most recent reports and documents –these can show eligibility and assessments showing the need and justification for the services.
 - b. If you are missing pieces, contact the appropriate agencies and ask for copies. You may have to make the request in writing, but it is certainly worth it.
2. Find out the chain of command for each of the agencies with whom you are working. Who is your contact person, do you have their most recent phone number, email, etc.?
 - a. Who is their supervisor, what is their contact information? And so on up the chain of command.
 - b. Do the agencies have a governing

board? Who are they and how do you reach them?

3. Learn your rights and what, if any, appeal processes are in place.
4. Be prepared to make a concise, compelling case; verbally and in writing.
5. Document all your attempts to seek services; write down who you spoke to and when.
6. Please remember, the folks at the agencies are human beings and have feelings; they don't enjoy being the bearer of bad news, so be polite but firm.
7. Understand that sometimes the best advocacy just does not work and the most compelling story does not work. The pie has simply gotten smaller and what we need is no longer there.
8. Get to know your legislators – they need to hear the stories from the families.
9. Get creative. Do you know any families you can partner with or perhaps share or swap things with? Join the Matrix Parents Yahoo! Group to post resources you are looking for or want to share. The diapers that don't fit your child anymore perhaps can be used by someone else. Brainstorm ideas of creative re-use or trading of resources.
10. There is strength in numbers and this is a critical time to expand your network of families with children like yours, as well as with the professionals, teachers, therapists, and others who care for your child. This network can then be used to make more positive changes in the future. I firmly believe these cuts will not stay permanent and a solution will be sought that has a more positive impact
11. Finally, take care of yourself. Remember to breathe. You are not alone.

Nora Thompson



The Deepest Cut: Historic Reductions in Health & Human Service Programs

Due to California's recent budget crisis, major changes have been made to all programs under the Health and Human Services Agency. For many families of children with special needs who depend upon such resources to meet the needs of their children these changes and reductions in services are not just discouraging, they are devastating. As your Parent Training and Information Center we are committed to keeping you informed and updated on current news and events – even if the news isn't always good – because we believe that information is essential for effective advocacy. Understanding the challenges we as a community are facing is important, for it is from here that we will be able to set a clear and compelling direction to weather these difficult times and continue to create positive futures for all our children.

Below is a summary of key changes that may affect families with children with disabilities:

Medi-Cal: In most cases, the following services for adults (age 21+) were eliminated effective July 1, 2009: acupuncture services, adult dental, chiropractic services, incontinence creams and washes, optician/optical lab services, optometry services, podiatry services, psychology services, speech therapy and audiology services.

CalWORKS: Cost of living adjustments have been suspended and CalWORKS grants were reduced 4 percent, reducing the maximum monthly cash grant from \$723 to \$694. Significant changes in work requirements for adults will be initiated in July 2011.

SSI/SSP: Cost-of-Living Adjustments (COLA) for this year were suspended and permanently eliminated. SSI/SSP grants were reduced by 2.3 percent effective July 1, 2009, reducing grants from \$870 to \$850 for individuals, with another .6 percent reduction going into effect November 1, 2009.

Developmental Services: Funding reductions for Regional Centers through the Department of Developmental Services have resulted in significant changes to the Lanterman Act which eliminate, change and reduce services for infants and toddlers (See *Changes to Early Start* on page 5), school age children as well as adults who are clients of the Regional Centers.

Group training for parents in lieu of individual ABA must be considered; camp, social recreation, and non-medical therapies are suspended; respite is limited to 90 hours per quarter. For more detail see www.disabilityrightsca.org.

IHSS: IHSS services are eliminated for individuals with the lowest needs. The neediest individuals will continue to receive domestic and related services. Additionally, IHSS will no longer pay the difference between the lower IHSS share of cost and the higher Medi-Cal share of cost applied to each recipient whose income is over the SSI maximum amounts. Both recipients and service providers must be fingerprinted and providers will be subject to background checks.

Healthy Families: Reductions in funding for the Healthy Families program will result in disenrolling thousands of children beginning as soon as October 2009, with tens of thousands of children continuing to be removed from the program on a monthly basis through June 2010. Efforts are being made to offset some of these reductions through collaborative efforts with First Five of California as well as other entities.

Mental Health: Reductions will eliminate state support in the Mental Health Managed Care program for services other than federally reimbursed services; reducing EPSDT program funding; and deferring AB 3632 payments for mandated mental health services to qualifying Special Education students.

Child Welfare and Foster Care: Significant reductions in child welfare services and foster care services will result in 10% cuts in rates for group homes, foster care agencies and seriously emotionally disturbed children. Funding for transitional housing assistance for foster youth who are emancipating will also be reduced. Adoption Assistance Program funding for families who adopt will no longer receive automatic increases.

The special needs community has faced many challenges in our history and the present economic situation and the resulting reduction in services is no different. As a parent-run organization Matrix understands your concerns about the future and we are here to help families understand and face these challenges so we can all hit the ground running once we are on the other side of this downturn.

Links for Low-Cost Medical or Dental Care

For families who may be struggling with the cost of medical or dental care, we offer some low cost options that you may be able to locate in your area:

Primary Care Services

To search for low cost primary care clinics in your city: www.cpga.org/resources/findclinic/

For help with problems with your managed health care plan: www.hmohelp.ca.gov/

Dental Services

To search for low cost dental services in your zip code: www.cda.org/clinics

To search for dental providers who may accept Denti-Cal in your county: www.denti-cal.ca.gov/

For information on reduced cost services available through University of the Pacific School of Dentistry at clinics located in San Francisco, Stockton, Oakland and Union City: www.dental.pacific.edu/Dental_Services/Clinics.html

Where to Look for the Resources You Need

Finding and accessing resources is an important part of your journey as a parent/guardian of a child with special needs. Utilizing different systems and service providers is a key component of advocating and providing for your child, particularly given their more complex needs. Gathering information and educating yourself is essential because learning about what is available and pursuing these opportunities may make a significant difference for your child. Unfortunately, sorting through all of the readily available information on the internet, in the community, and from friends, colleagues and others may find you “playing detective” as you search for information and referrals. For many families the sheer volume of information may be overwhelming. Matrix can help.



Matrix as a Resource Center

Matrix is a Parent Network and *Resource Center*. True to our name, we provide resources through our libraries, our website, newsletters, support groups, trainings, handouts, and phone consultations – all of these services are provided free of charge. Maybe you’re looking for detailed information on your child’s special needs or diagnosis, or you need a referral for a tutor, a psychologist, a dentist, an afterschool program, or financial planning. Sometimes you may not be sure what it is you’re looking for. We can help you identify what may be helpful for you and your child and point you in the right direction. It is important to note that while you may not know exactly what you are looking for, it is usually helpful to have an understanding of why you want services for your child. What currently isn’t working? What additional help would they benefit from?

Matrix as a Parent Center

As a Parent Training and Information Center (PTI) Matrix is here to assist you in networking with other parents. Utilizing our Yahoo group (visit www.matrixparents.org to join) is an easy way to interact with local parents about resources. Our support groups also facilitate networking. By connecting with other parents/guardians who may be experiencing similar

challenges as yours, you not only find needed support, but also valuable feedback on available resources. Matrix can also connect you with other groups/agencies serving your specific need.

Matrix’s Resource List

Matrix has a comprehensive list of referrals. This list primarily focuses on resources in the four counties we serve, but we can also direct you to greater Bay Area and State links for resources. The resource list is accessible through our Helpline (1-800-578-2592). As a clearinghouse of information Matrix does not make recommendations (you are your child’s expert, not us), but we instead provide three names of agencies or individuals that will hopefully meet your needs. Contact information, including websites (if available) and specifics about services offered are provided so that you can go on to explore these options on your own and find the best match to meet your needs. -- see questions to ask below. Both family members and professionals are welcome to give us a call.

Questions to Ask the Agency or Professional You are Contacting

- Please describe the specifics of your service(s)?
- What is your experience with my child’s disability? What is your credential – any specialty?
- Do you have a brochure to send or download?
- What are your fees, do you have any scholarships, sliding scale rates?
- What are your hours?
- What ages do you serve?
- Do you use evidence-based practices (if yes, what are they?) or do you have data around outcomes of your service?
- Do you have references?
- What is the likely length of this service, what are the realistic outcomes or benefits to my child?
- Are you willing to work with the other agencies/individuals providing for my child. Will you come to an IEP meeting?
- How often can we communicate and in which way (phone, email, etc.)?

Note: Websites (if available) are a great way to learn about what an agency/individual is offering, however, this doesn’t necessarily replace dialoguing with the professional around your specific concerns and needs before choosing them as a service provider.

A Very Special Awards Program

The Council for Exceptional Children (CEC) is proud to announce their annual *Yes I Can! Awards*, through which students with disabilities – some for the first time in their lives – are recognized for their accomplishments in nine categories: Academics, Arts, Athletics, Community Service, Employment, Extracurricular Activities, Independent Living Skills, Self-Advocacy, and Technology. Students may be nominated by a parent, teacher, principal, or other adult. All 2010 winners will be acknowledged at the CEC Convention & Expo, April 21-24 in Nashville. And every child nominated receives a certificate of accomplishment. Nominations must be postmarked by Oct. 9, 2009. Please visit CEC’s Web site at www.cec.sped.org for more information, including eligibility guidelines and the nomination form.



The Early Edition

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

The Early Edition is a publication of the Matrix Family Resource Center (FRC) program as part of California's interagency system of early intervention services for children, birth to 36 months. Our FRC staff is here to provide information and support to help you care for your baby. Useful information and additional resources are also provided in a designated Early Start section on our website at www.matrixparents.org

Because all babies are different,

they rarely do the same thing at exactly the same age. You may wonder: Why isn't my son sitting up? Why isn't my daughter crawling? Is my child's hearing (or vision) normal? If you are concerned about your baby or toddler's development, it is important to follow your instincts and talk to your child's doctor about this. You can also call the Matrix Help Line at 1-800-578-2592 or California's Early Start referral line at 1-800-515-BABY for information on early intervention services in your area.

The first step is to have your child referred for evaluation and assessment if your baby's development really does appear to be delayed. Even though some services for infants and toddlers are being changed in California, many children will continue to receive a variety of services and other children will be assessed and referred to generic services. YOU can make a difference in your child's life with accurate information about your child's development and the resources that are available.

FREE KIT FOR NEW PARENTS

First 5 California has a free kit for new parents that is available by calling 1-800-KIDS-025. It is also available in Spanish by calling 1-800-50-NIÑOS. This kit contains a DVD (or VHS tape) on a variety of topics from oral health to child care to safety and discipline. There is a new parents booklet that is divided by "ages and stages" that helps parents track their baby's development. The Kit includes information on what to do when your child gets sick, planning your child's first visit to the dentist, a number of other resources and a copy of *Puppy and Friends (Baby's First Book)*.

Changes in Early Start Services

There have been significant changes in the laws regarding Early Start services. However, implementing regulations and policies, which are still being written, may mean those changes have an impact which is less dramatic. We are providing parents with the following information on the changes in the law that was put into effect in July 2009.

ELIGIBILITY: "High risk" infants and toddlers will no longer be eligible for Early Start. The State will develop a new Prevention program which will be available at Regional Centers with very limited services and a capped budget. According to the Department of Developmental Services, these changes are effective October 1, 2009.

To qualify for Early Start under "developmental delay" children are assessed in 5 areas of development: Cognitive, Physical, Communication, Social/Emotional and Adaptive/Self-help. Children assessed for eligibility who are over 24 months of age now must have a 50% delay in one area or 33% delay in two areas, compared to children with typical development. Children assessed for eligibility from birth to 24 months of age will continue to be eligible if they show a delay of 33% in one developmental area, compared to typically developing peers.

Eligibility will continue for children with conditions which are an "established risk," which means a child has a high probability of having a developmental delay or they have what is considered a "low incidence disability" (e.g. blindness or deafness).

FUNDED SERVICES: For children under age three, Regional Centers will no longer fund services which are not required by the federal government including day care, diapers, respite,

interpreters/translators, genetic counseling, and most medical services, except durable medical equipment. This is effective October 1, 2009.

NEIGHBORHOOD PRESCHOOLS: Priority will be given to funding neighborhood preschools with Regional Center funded supports rather than specialized infant development programs. The Governor cut an additional \$50 million from Early Start expecting that First Five will cover it. These neighborhood programs are to be used if available.

USE OF PRIVATE INSURANCE: Except for services related to evaluation and assessment of their child, parents will have to use private insurance to pay for Early Start services that are covered under their insurance plan. Parents will be responsible for any deductibles or co-payments when they use their private insurance. If parents are unable to get a decision from their insurance plan regarding approval or denial of a claim this will not result in a denial or delay of those services to their child by the Regional Center.

To learn about the latest developments in implementing these changes we recommend that you look at two pertinent websites: California's Infant Development Association or IDA www.idaofcal.org/ and the Early Start page of the California Department of Developmental Services or DDS www.dds.ca.gov/EarlyStart

We at MATRIX are here for you as you navigate through these challenging economic times. If you are interested in being part of a support group for families of children under age 3 or have any questions or need assistance, call us at 1-800-578-2592.

Thanks to our Contributors (July 1, 2008 to June 30, 2009)

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Trevor Gallagher	Nora Thompson & the Matrix Staff
<i>Kathleen Connelly</i>	<i>Norman & Cathie Bryan</i>
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<i>Brenda Gates-Monasch & Walter Monasch</i>	<i>Raquel Gonzales</i>
	<i>Candace Gratto</i>
	<i>Madeline Kellner</i>

In Memory of:

John I. Arena
<i>Anna Arena of Academic Therapy Publications, Inc.</i>
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<i>Daniel Akst</i>
<i>Susan Barnes</i>
<i>Bethany Bentley</i>
<i>California Travel & Tourism Commission</i>
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<i>City Pass</i>
<i>June Cooperman & Larry Litvak</i>
<i>Nancy Daniels</i>
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<i>Randy McDonald</i>
<i>Navy Comprehensive Dentistry</i>
<i>David Perazzo</i>
<i>Pier 39 Limited Partnership</i>
<i>Mary Lou Ramsey</i>
<i>San Mateo Co. Convention & Visitors Bureau</i>
<i>Linda Schreiber</i>
<i>Scoma's Restaurant, Inc.</i>
<i>Tucker Short</i>
<i>Society of American Travel Writers</i>
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<i>The S.F. Newspaper Company, LLC</i>
<i>Henry Trainor</i>
<i>VIA Magazine of California AAA</i>
Steven R. Douglas
<i>Raymond F. & Ning Douglas</i>
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Richard Abraham
McElwain
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Lou, Joe & Prish Nannery
<i>David Chicoine</i>
Katie Rose Thompson
<i>Team of Advocates for Special Kids</i>
<i>Jerry Thompson & Sons</i>
<i>Painting</i>
<i>Tom & Doreen Thompson</i>

Our thanks to the following 2008-09 volunteers, whose skills, time, energy, & enthusiasm made a world of difference.

Barbara Alexander	Ray Douglas	David Kessler	Jasmine Ochoa	Sandy Strang
Jim Askim	Dusty Dutton	Megan McKeon	Orange Sherbet, Jill Pierce & Adrian Libertini	Liz Sturgis
Megan Askim	Elizabeth Ferris	John McKeon	George Paloglou	Virginia Thibeaux
Madeleine Bludeau	Dave Fichman	Ryan McKeon	Nancy Petranto	Bud Thompson
MaryAnn Bowman	Rachel Fichman	Marin Harley Owners' Group	Colleen Revill	Lynne Wasley
Jeanne Bowman	Rebecca Foust	Paul Miles	Alan Rosenthal	Barbara Watson
Sheena Brevig	Talya Gates-Monasch	Janet Miller	Joan Ryan	Jack Watson
Jenny Calloway	Elliot Hollings	Tammy Mobley	SiSi Semple	Jon Wheeldin
Joan Capurro	Jenny Huff	Walter Monasch	Ted Simon	Joanna Wheeldin
Bill Cox	Celeste Lee	LeighAnn Moore	Sonoma Valley High School Students	Chuyuan (Jason) Zeng
Kristin Douglas	Doug Lipinski	Joel Neecke		
Ning Douglas	Joan Lubamersky			

We want to acknowledge all of our donors. If we inadvertently left you out of our Fall 2008 and Spring 2009 Networker, and you're not included here despite having contributed between July 1, 2008 and June 30, 2009, we apologize! Please call Brenda at 415-475-2118 so that she can make the necessary correction.

Building a Team: Finding Resources to Support Your Child -- continued from page 1

PSYCHOLOGIST: There are a wide range of psychologists and services they provide. Clinical Psychologists typically provide individual and family counseling and psychotherapy. Educational Psychologists can help you with assessment and testing procedures and in designing an educational plan.

PSYCHIATRIST: Trained to perform diagnostic evaluations, provide psychotherapy, prescribe medication and brain imaging procedures. It's ideal when the psychiatrist works in tandem with the psychologist, parents and teachers to keep a good flow of information and feedback.

SUPPORT ORGANIZATIONS: Such as Matrix. (Also Parents Education Network, PEN, and Support for Families in San Francisco). Matrix provides a wealth of information, support and direction to families. They facilitate parents

(and children) connecting with other families who have similar circumstances and also link them with resources in the professional community.

The order of putting together a team varies for each family and their particular circumstance. If you get stuck along the way, reach out to Matrix. Especially in these difficult financial times, creativity is needed.

Ed McManis is the Head of School at Sterne School in San Francisco. Sterne is a small, co-educational private school for students with learning differences. He can be contacted at 415-922-6081, emcmanis@sterneschool.org. Sterne School is located at 2690 Jackson St. SE, CA 94115.

parent network
+ resource center



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SAVE THE DATE:
3rd Annual Author's Luncheon featuring:
TEMPLE GRANDIN
April 19, 2010

Extraordinary observer, teacher, speaker, and author TEMPLE GRANDIN will speak at our 3rd Annual Author Luncheon to benefit Matrix. Among her many published works are: *The Way I See It: A Personal Look at Autism and Asperger's* (2009) and *Thinking in Pictures and Other Reports From My Life With Autism* (1995). Matrix supporters and clients, Becky Foust Pilcher and Tammy Moble, will co-chair the luncheon. For more information or to be involved in planning, please contact Brenda at 415-475-2118 or brendagm@matrixparents.org

MATRIX ONLINE AUCTION

Our Fall auction, beginning Thanksgiving Day, offers you a chance to buy holiday gifts the easy way -- and have them delivered to your door! Donate or secure a donation worth at least \$100 and you'll get a \$10 credit towards your own auction purchases. Want to help Matrix client & supporter Debbie Ward assure that you'll have spectacular gift choices? Call Brenda at 415-475-2118 or e-mail brendagm@matrixparents.org

Networker • RESOURCES Issue
Fall 2009

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

The Networker is printed through funds from the Marin Community Foundation.



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