

The Early Edition

June 2007

MATRIX PARENT NETWORK AND RESOURCE CENTER

Matrix Parent Network and Resource Center welcomes you to join with many other parents who have found help and support through our services.



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.

Some of the services **Matrix Parent Network** provides are:

- ◆ **HELP Line** – (800) 578-2592 staffed by Parent Advisors for general advice, information, support and referrals
- ◆ **In-depth Consultation** – support from a designated Parent Advisor
- ◆ **Parent Support Groups** – where parents of children with special needs meet and support each other
- ◆ **Trainings and Workshops** – on Individual Education Plans (I.E.P.), transition to preschool/kindergarten and special education processes
- ◆ **Information Packets** – on a variety of topics, such as Individual Education Plans, assessments, behavior, and transition to preschool and kindergarten
- ◆ **The Networker** – bi-annual publication with in-depth information
- ◆ **Networker Express** – monthly e-mail newsletter
- ◆ **Lending Library** – disability related books, magazines, video tapes
- ◆ **Website** – www.matrixparents.org with information and links

Annually, Matrix responds to an average of more than 7,000 requests for information or assistance from over 1,000 families and professionals. By delivering comprehensive support services, Matrix helps families become well-informed and expand their ability to advocate for their children.

Matrix Parent Network and Resource Center

Empowering families of children with special needs to understand and access the systems that serve them.
94 Galli Drive, Suite C, Novato, CA 94949-5739

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DIEGO'S AUTISM

My recollection of Autism was the “Rain Man” character played by Dustin Hoffman in the movie (1988). I never heard of it again until after my son, Diego had an Early Start assessment. He was a healthy boy, 9lb 6.5 oz, full-term and very responsive. Even though my son’s autism did not emerge over night, there were signs along the way. He never crawled, he walked at 15 months old, but he fell a lot. Words came slowly and then when he was about two years old most of them disappeared. His pediatrician stated that he might be getting confused because he lived in a bi-lingual household, so we focused on English only, for a while.



However, the most difficult thing for me, as Diego’s mother, was that he never said *mama* as an infant or toddler, but his father discovered that he did have a name for me. It happened when I was away for a few days; he pointed to my picture and said “pa” (he called his daddy, “da”). He eventually referred to me as “ma”. When prompted, he will make one syllable attempts at words. He *really* tries and loves to be praised for his attempts. He continues to make progress with his speech, but the focus right now is building his vocabulary through the use of PECS (picture exchange communication system).

But more importantly than what he called me or didn’t call me is the bond that we have. He responds very well to affection. He loves to be cuddled and tickled (this is when I get the most eye contact from him; something that is not so typical for children on the Autism Spectrum). Diego has always been drawn to my eyelashes and loves for me to flutter them on his cheeks and lips. Even though his teacher discouraged this, I began calling them “butterfly kisses”. Now, if he wants a butterfly kiss, I prompt him to say it, and he responds with “buh...ly”. We both get such a kick out of it! He gets really ticklish and happy.

Diego is now six years old; he is very loving and affectionate. Fortunately, for me, his delays have allowed me more time to become a better parent. I have a lot more patience, and I have learned to appreciate the little victories such as, his spontaneous communication with the PECS cards and his progress in toilet training. He is a joy, despite the many challenges that we face. I could not love him more, if he were a typical child.

THE DIAGNOSIS

The word diagnosis affects a person, their family and the people around them. What does a diagnosis mean? In the medical world the diagnosis is the process of identifying a medical condition or disease by its signs and symptoms. It's a word that can change life completely.

Sometimes parents want to find the answer to what is causing their child to not be like other children. Others prefer not to know, as they feel a "name" for what is already known is not needed. The moment a diagnosis is received can be a life defining moment. It affects the hopes and dreams for your child and the life that you had envisioned. It affects a marriage, grandparents, siblings and the family. If the condition is genetic, it will be important to share this with other family members.

Whether you have a diagnosis or not, you feel the stares when you walk by with your child that is "different". You hear their hushed comments, which can affect you in a way that people cannot imagine. Some of us remember the moment of the diagnosis as if it were yesterday, for others; it is not a single moment, but a realization. Regardless of the path, one's life is changed in a way never imagined.

One common concern that comes to mind is the future, the child's future and yours. This is accompanied by a multitude of emotions such as denial, fear, blame, grief and confusion. All these feelings are natural and nothing to be ashamed of. Acceptance will finally come.

Receiving a diagnosis is a stark reminder that much of what comes our way can not be planned or chosen. We can choose how to respond to situations that we are given. We can reach out, talk to friends and family or others in similar situations. We can learn all we can about our child's diagnosis. We can take care of ourselves so that we can be strong to take care of our children.

Early Start Services

- ◆ 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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WHAT TO DO WITH RESPITE HOURS?



Once respite hours have been approved by the Regional Center or the school program, what can you do with the time you have available? Respite is there to allow you to have time to rest and relax so that you can continue to care for your child with special needs. There are as many unique ideas of what to do as there are unique families. At first you may not be completely comfortable leaving the house, so there are some things you can do and still be available to help train the respite worker if they have questions. Later, after they know your child better, you may want to leave for longer periods, maybe even for the weekend.

Some suggestions are as follows:

- ◆ Go for a walk
- ◆ Read a book
- ◆ Gardening
- ◆ Get your hair done
- ◆ Favorite hobby
- ◆ Go to the library
- ◆ Go to a restaurant
- ◆ Get a facial
- ◆ Get a massage
- ◆ Feed the birds
- ◆ Take a nap
- ◆ Take a class
- ◆ Listen to music
- ◆ Take a bike ride
- ◆ Meet a friend to talk
- ◆ Go to a Museum
- ◆ Have a latte, coffee or tea
- ◆ Go to a movie
- ◆ Go to counseling
- ◆ Take a long bath
- ◆ Sit in the park
- ◆ Knit or crochet
- ◆ Get away for the weekend
- ◆ Attend a support group
- ◆ Get a manicure
- ◆ Play golf, tennis or other fun sport
- ◆ Workout, yoga or exercise class
- ◆ Go on a date with your partner
- ◆ Go shopping, run errands
- ◆ Play on the computer for fun
- ◆ Have some quiet time
- ◆ Have special time with your other children

Anything you want to do that will help you relax and enjoy yourself will be beneficial. The most important thing is to have respite regularly, so that you can count on having some much needed “time off”. We all love our children, but we also need to have time to rejuvenate ourselves.