

# *The Early Edition*

MATRIX PARENT NETWORK AND RESOURCE CENTER 800-578-2592

Matrix Parent Network and Resource Center welcomes you to contact us on the Matrix HELP Line at **800-578-2592**. Matrix parents can assist you with parent support, resources, information, referrals, education and the lending library.



**Matrix Early Start Parent Advisors are parents of children with special needs that 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 trained parent advisors will answer the majority of parents' questions, providing support and education, support group and training schedules and referrals to other resources
- **Parent Advisors** – individual consultation and support for parents
- **Parent Support Groups** – support groups where parents of children with special needs meet and find support
- **Trainings and Workshops** – helps parents better understand the IEP, transitions to preschool/kindergarten and special education process
- **Information Packets**- questions answered on topics such as IEP, assessments, behaviors, and transition to preschool and kindergarten
- **The Networker**- mailed newsletter with in-depth information
- **Networker Express** - e-mail newsletter
- **Lending Library** - books, magazines, articles, video/audio tapes
- **Website**-[www.matrixparents.org](http://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 better able to advocate for their children and enrich their lives.

## What is Respite? Does my Family Need it?

I don't remember ever hearing the word **Respite**, until it was something I needed. I have to say that I had no idea what respite was. Another parent told me about it, so I asked the regional center about respite. The dictionary describes respite as "usually a short interval of rest or relief". This definition seems to appropriately describe what respite services are for families that have children with special needs. Respite allows parents or caregivers to have someone else provide care for their child with special needs so that they can take a much needed break. Respite is one of many services provided in the Early Start Program for families of children birth to 3 years old. The regional center representative or the school representative can provide this service when requested.

When my husband and I first got respite services, we took naps in the house while the respite provider took care of our child. We were so exhausted that sleeping was what sounded the most exciting to us at the time. The next step we made was to do something else in the house, while the respite worker was taking care of our child. This allowed us to be available to the respite provider for questions about our child as they might arise. Eventually, we became comfortable with the idea that someone else was able to care for our child and we ventured out of the house. We went a few blocks away with our cell phone and then dropped in on them to see how it was going. It did take some time, but now we are able to go to another city and see a movie. We actually take our time and escape for a few hours. It has made such a difference in our relationship. Parenting a child with special needs does take a toll on relationships. It has also made a difference in the quality of care that we are able to give our child. It seems to work best if we have a set time every week for respite. Otherwise, we find excuses not to go; most often we are just too tired to go. It seems if we have regularly scheduled times for respite, we force ourselves to go, even when we are tired. We feel much better when we return home. Our spirits are lifted; we appreciate our children more and feel like we can handle the difficult daily tasks of parenting once again.

Taking some time for yourself when you are parenting a child with special needs is so important. It can be helpful to write a list of things you like to do. Sometimes we get so involved in taking care of others that we forget to take care of ourselves. Some fun ideas are: taking a walk, getting a latte, sitting in the sun, taking a nap, going to a Matrix support group or workshop, reading a book, going to the park, seeing a movie, getting a haircut, spending special time with your other child, spending time with your spouse, exercising, visiting a friend, taking a bath or just spending time alone. Whatever helps to make you feel relaxed is great!

## Can This be Happening?

There are times in life when you stop and ask yourself, “Can this be happening?” Is this really what we have to deal with? Can this be happening to my child, someone so young and innocent? I thought these situations were only on TV doctor shows or in movies. I don’t think I am strong enough to handle this. I know I am not informed enough to be asked to make these decisions. Well, sometimes there are no choices, things just happen. You have to do what is necessary; you put one foot in front of the other and keep on going.

Sometimes things happen to families and their children that are very frightening. You may have to learn about new medical procedures that you know nothing about. You may find you need to learn about them quickly to be able to make informed decisions about your child’s health and well being. Will this make things better? What are the risks? What else can be done? Fortunately, Matrix Parent Network is here to listen and support you. **You are not alone.**

Matrix staff does not have all the answers, but we do know where to find information to support you. We also may know what others parents have done in similar situations, but most of all **We Listen**. We are parents of children with special needs. We have children with developmental, physical, medical, emotional and/or learning disabilities. We have children with speech delays, Autism, rare syndromes, seizures, cerebral palsy, Down syndrome and diabetes. We understand what it is like to find out there are challenges your child needs to deal with. It can be devastating to learn that your child is developmentally delayed. As parents, we always want the best for our children. We work at protecting them and teaching them to be the best they can be. We have an idea of what we think they will be like when they grow up. When we find out that our child has delays, often we feel sadness that they have to face challenges in life. We grieve the loss of the child we imagined and have to work on finding acceptance while getting services for the child we have. Many parents have these feelings and they love their child very much. It is part of the grieving process that we experience. Some parents experience this right away, for others it takes years and some never experience it at all. We all cope with stress in different ways. We need reassurance that we are doing the right thing. We do the best we can with what we know at the time.

The most important lesson to learn is that parents need to be their child’s case manager. Parents know their child best, because they are with them in all types of situations over long periods of time. The pediatricians, speech therapists, physical therapists and early interventionists have many other children they work with. Parents are the only ones who see the whole picture; professionals only have a snapshot and parents have the video.

## KITCHEN TABLE WORDS OF WISDOM

### Tips for Parents of Children with Special Needs From Experienced Parents

1. Enjoy your child.
2. Enjoy being a parent.
3. Learn to trust your gut feelings and your intuition.
4. Ask other parents.
5. Ask for help when you need it.
6. You don't have to do therapy with your child all the time.
7. Play with your child.
8. Make a connection with another parent.
9. Enjoy your child just the way they are.
10. Keep copies of all records.
11. Sometimes the expert is you!
12. Ask for explanations when you need them.
13. Take time for yourself - and others in your family.
14. You are often your child's best advocate.
15. Professionals only have a "snap shot", you have the whole video.
16. Take care of yourself and nurture your marriage.
17. Remember to laugh.
18. Notice the small stuff.
19. Find a strength that your child has as a result of their "special need".
20. Nurture the siblings and give them special time.
21. Take SPECIAL time for yourself and family. (spouse, friends)
22. REST, as often as you need to.
23. This too shall pass - enjoy the moment.
24. Nobody's perfect, just do what you can.
25. Stuff happens that you can't control.
26. It is not your fault.
27. Record "interesting" things about your child to help describe them.
28. Learn all you can about your child's disability.
29. Learn to accept - it is what it is.
30. Each child is unique and your child's path will be their own.