



Managing It All: *IDEAS* for Parents

By Melanie G. Snyder

IDEA usually means “Individuals with Disabilities Education Act.” But here’s another IDEA: Inform, Document, Enjoy and Accept - four keys to success in “managing it all” when you have a child with special needs.

Inform

“Lots of our stress as parents comes from the unknown,” says Cherie Takemoto, Executive Director of the Parent Educational Advocacy & Training Center (PEATC). “If you’re well-informed and can put things into perspective - that alone can help.”

“Learn everything you possibly can about your child’s disability and rights under various laws,” advises Suzanne Hill, special needs advocate and former manager of the US Marine Corps’ Exceptional Family Member Program in Virginia.

PEATC offers numerous ways for parents to become informed, including training classes, resource materials and a toll-free information line offering “a chance to talk with and ask questions of another caring person who has probably walked a lot of the same journey,” says Takemoto. “They help callers to break things down into more manageable pieces, and figure out how to get what they’re looking for, in ways they might not have thought of.”

The PEATC website is also full of information because, as Takemoto says, “Many of us at PEATC have been there at 3 a.m., lying awake worrying about some issue with our child and we understand that need for reliable information that’s accessible even in the middle of the night.” A good starting point is the PEATC publication *Beginning With Families* (see Resources).

Document

Managing all the details of your child’s health history, specialists, and insurance can seem overwhelming. Create a well-organized filing system, document critical information (Beginning With Families has easy-to-use forms) and make sure your spouse and child’s caregivers know where to find it. Keep frequently requested information in your wallet to save time and frustration whenever schools, doctors and others require it.

“Writing things down can help to keep everything in perspective and seem more manageable,” says Takemoto. Documenting conversations with your child’s teachers, caregivers, doctors and other support providers, and putting your concerns, ideas and requests to them in writing can save time and prevent stressful misunderstandings.

Another common stressor is worries about what would happen to your child if something happens to you. Create an estate plan and work with a professional with special needs estate planning expertise (see Resources).

“I have worked with many families who have said, ‘Oh, I’ll get to doing that eventually’, but I encourage families to get this done as soon as possible,” Hill suggests. Documenting these essential provisions for your child’s care can alleviate lots of worries.

Enjoy

“Remember that your child is a child, first,” says Takemoto. “Don’t look at your child as something that needs to get fixed. Enjoy your child.”

Friends with twin sons, one of whom (Owen) has spina bifida, build fun into every day, whether telling jokes around the dinner table (Owen’s

a master at “Knock-Knocks”), dancing to loud music in the living room, playing games or watching movies together.

Focus on your child’s abilities and possibilities, rather than limitations. The “Hopes & Dreams Exercise” in Beginning With Families is a great starting point.

Owen’s parents have even found creative ways to take him biking, hiking and kayaking by considering all that he can do.

If you have other children, it can be challenging to find one-on-one time to spend with them. Try reserving a specific time each day to connect with them, even if only for a few minutes. Put it on your calendar and give it the same priority you’d give a doctor’s appointment. Another option is “TLC Time,” Takemoto explains, “Tell your kids they can come to you any time they need TLC Time and ask for it. When they do, stop what you’re doing and spend a few moments focused only on them.”

Schedule regular dates with your spouse or partner to enjoy time as a couple. Caring for a child with special needs can take a heavy toll on a marriage and divorce rates among parents of children with special needs are about six percent higher, according to a 2004 study.

Finally, take care of yourself. A psychologist once told me people are like rubber bands. If we’re constantly stretched to the limit, we lose our ability to bounce back. We need to relax the tension regularly to maintain our resilience.

“Most days you’re going to end the day with leftovers on the ‘To Do’ list and you just have to be ok with that,” says Takemoto.

"Make time for yourself and don't feel guilty," Hill advises. "Relish the moments of normalcy in your life."

Give yourself a daily time-out, locking yourself in your bedroom or bathroom for a few minutes of peace and quiet. One friend keeps an egg timer on her nightstand and uses it to grant herself three minutes of silence and deep breathing daily.

"Mommy time-outs" can also help when you feel yourself losing it, says Takemoto. "It gives you a chance to get your act back together. Then, when you're ready to come back and face the world, come on out." Hill adds, "The world won't stop revolving. When you open the door and come out, your life will still be there."

Sometimes, you may need a longer break than an egg timer can provide. At those times, respite may help, whether for a few hours, a week, or more. The National Dissemination Center for Children with Disabilities (NICHCY) offers a comprehensive article on when to consider respite and how to find providers (see Resources). Mental health or social service agencies, PEATC and disability support organizations can help you locate qualified, medically trained respite providers or try the ARCH National Respite Network and Resource Center's online, searchable database.

Accept

Accepting help may be one of the hardest things for us to do as parents. Yet, it's also one of the wisest.

"Before I was a parent of a child with disabilities, I didn't have a need for any outside help," Takemoto confesses. "I've had to learn that asking for and accepting help from others is the best way for me to be successful and stay strong, and it's been the best thing for my child."

Family members, neighbors and friends may be willing to help, but might not know what to do. If you make a list of tasks that need to be done, it's much easier to ask others to help. You can even coordinate care for your child through an online tool from the National Alliance for

Caregiving (<http://nac.lotsahelping-hands.com/>) where you can define tasks that need to be done, invite others to view and sign up for tasks, and track their commitments. Those who sign up to help receive automatic email reminders. Best of all, it's private, secure and free.

Support groups, online parenting networks and parent to parent organizations can offer emotional and moral support.

"Networking with other parents whose children also have special needs can make you feel less alone and help you to put your own situation in perspective," says Takemoto. She suggests connecting with parents whose children have similar challenges and are a bit older than your own; their experience can provide a window into future phases of your child's life.

"Not all support groups will work for you," says Hill. She suggests attending at least two meetings before deciding. Look for groups with a professional leader or regular professional speakers. "The leader should moderate the discussion, provide structure, encourage participation and demonstrate acceptance for everyone in the group." Though disability-specific groups can be helpful, Hill suggests trying mixed or non-specific support groups as well.

If you don't have time for support group meetings, online parent discussion forums, listservs, blogs or chatrooms may be helpful. However, quality and usefulness vary widely, depending on who participates and whether it is moderated. National disability organizations are a good place to start when seeking a credible online network.

Parent to Parent offers a unique form of support for parents, through a one-to-one match with an experienced, trained Parent Partner whose child has similar special needs.

"A Parent Partner's primary role is to listen and offer a shoulder to cry on, and a hand to hold," says Dana Yarbrough, Executive Director of Parent to Parent Virginia. Parent Partners do not provide therapeutic

consultation, or medical or legal advice. Instead, they offer, "unbiased information on the choices they have made for their child and family, and can assist the family with moving through the grief cycle towards full acceptance of the gifts and talents a child with a disability brings . . ." - perhaps the most important kind of acceptance of all.

Inform, Document, Enjoy, Accept - a different IDEA for parents of children with special needs, and an IDEA whose time has come. ■

Melanie G. Snyder has written for over 25 parenting magazines across the US and Canada, children's magazines Cricket, Calliope and Guideposts for Kids, education publishers Harcourt, Scholastic, and SIRS, and others. See her website at www.MelanieGSnyder.com.

Organizations:

PEATC

100 N Washington St., Suite 234
Falls Church, VA 22046-4523
703-923-0010 (Voice/TTY)
800-869-6782 • www.peatc.org

Parent to Parent of Virginia
P.O. Box 38341 • Richmond, VA 23231
804-795-1481 • www.ptpofva.com

Publications:

Beginning With Families: A Parent's Guide to Early Intervention -
www.peatc.org/Fact%20Sheets/BeginningwithFamilies-English.pdf

Putting Life in Perspective - tips on maintaining balance, care for caregivers, dealing with guilt and related topics:
www.peatc.org/base.cgim?menu_sub_nav=spec_ed&template=spec_ed.life_in_perspective

Put It In Writing -
www.peatc.org/Fact%20Sheets/Put%20it%20in%20Writing.pdf

Estate Planning:

www.snapinfo.org/our_special.html

Respite:

ARCH National Respite Network and Resource Center (ARCH)
800 Eastowne Dr., Suite 105
Chapel Hill, NC 27514
919.490-5577 x 222
<http://chttop.org/ARCH.html>