

CHS Community News

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TIPS & STRATEGIES: Assisting Your Family Member With Disabilities

Parenting a child with disabilities is a family, school and community affair. Information and advice given to parents needs to take care not to add to the stress level already experienced by the family. All guides need to be considered relative to each family's own unique set of circumstances. The school, extended family members, health care providers, educators, clinicians and community members all share a key role in helping each family to cope by supporting and assisting the parenting process.

As difficult as it is, most families are able to come to terms with the addition of a child with special needs into their family. They emerge from an initial state of shock, grief, confusion and uncertainty, not only with acceptance of their situation, but a healthy desire to move forward, focused on the positive aspects of their lives. Some families need professional help as they traverse this initial phase of coping or they may find the support they need from other families with a child with disabilities, clergy, friends, extended family members or their health care providers. The tips and strategies reviewed are only suggestions based on first hand experience of family members. All suggestions need to be considered in relation to each individual/family's specific and unique situation.

Tips for Family Members...

- ◇ Build alliances, partnerships and friendships.
- ◇ Remember to plan - work on today's issues but remember long term needs too.
- ◇ Keep notes - maintain lifelong records.
- ◇ Seek outside assessments, clinical team reviews and always ask for written follow up.
- ◇ Remember to express appreciation - 'thank you's' go a long way (and you'd be surprised how seldom teachers, caregivers and helpers get thanked).
- ◇ Family members and friends may not be able to help you today, but may be in a position to help down the road.
- ◇ Remember that things change over time - list out non-negotiable items for the future as well as flexible items.
- ◇ STAY HEALTHY - THIS IS A LIFELONG JOURNEY!
- ◇ Find a technology partner and ally to support you with assistive technology and other communication systems.

"The most important things are safety and security — they are the foundation of all care and services."

*Kevin J. Leahy
Executive Director
Cooperative for Human Services, Inc.*



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Serving adults with disabilities and their families since 1981



"It has helped me understand that true love is meeting someone, child or adult, special needs or not, exactly where he or she is -- no matter how they stack up against what "should be." Raising a special needs child shatters all the "should be's" that we idolize and build our lives around, and puts something else at the core: love and understanding."

Maria Lin, Parent



STRATEGY # 1 — MAINTAIN A POSITIVE ATTITUDE

While no one is positive all the time about life and life's circumstances, the truth of the matter is that positivity is one of the best coping strategies known. Life can be especially challenging for families with a child with special needs. How parents and siblings feel and think about these challenges can profoundly affect their ability to successfully address issues and maintain well being among all family members.

STRATEGY # 2 - THE FAMILY RULES Never Underestimate the Power of Family

Your child with special needs makes an impact on every family member, not just the parents. Tips to bring family cohesiveness can be championed in many different ways — here are some suggestions:

- * Have regular family meetings where everyone can express their feelings, opinions and give input for family decision making.
- * Assign chores, teach independent living skills and give responsibilities to ALL family members — Remember, this is a team effort, first and foremost!

STRATEGY # 3 - GET HELP FROM EVERYONE The More the Merrier!

Develop your own network of support and don't be afraid to ask for help.

- * Educators, health care providers and respite workers are paid to help and most want to be asked for help.
- * Other family members, friends, neighbors, church and community members are also willing to help, but often need to be asked specifically. Make a list of activities that you need help with and share it with everyone.
- * Seek counseling, therapy or peer support through professional help, parent support groups, parent education, parent to parent programs.

STRATEGY # 4 - TAKE CARE OF YOURSELF So you can take care of everyone else.

Parents must take care of themselves so they have the stamina, energy and motivation to care for their family member with special needs and their brothers and sisters too. In her article "Survival Tips for Parents," Jan Baumel, M.S., Licensed Educational Psychologist, gives these outstanding suggestions:

- * Change your standards for nonessential tasks such as perfect housekeeping.
- * Find a healthy physical outlet. Discover a sport or exercise you really enjoy, and do it regularly.
- * Get enough rest and eat healthy foods.
- * Take pleasure from music, movies, magazines, museums, and even favorite television programs. It's OK to take time for yourself to escape every once in a while.
- * Give yourself permission to say no. Remember "Super Parent" can't be all things to all people at all times.
- * Find someone you trust — relatives, friends, sitters — to take care of your child so you can get away.



Resources for Families

ADVOCACY, RESEARCH & INFORMATION

Federation for Children with Special Needs: <http://fcsn.org/>

National Center for Learning Disabilities: www.ndd.org

Positive Parenting Resource Center: www.unitedarc.org/positiveparenting.html

The Arc of Massachusetts: www.arcmass.org

Mass. Families Organizing for Change: www.mfofc.org

Center for Parent Information and Resources: www.parentcenterhub.org

MA Disability Information Index website: www.disabilityinfo.org

Easter Seals: <http://www.easterseals.com/ma/>

Aspergers Association of New England: www.aane.org

Autism Consortium: www.autismconsortium.org

The Beach Center on Family and Disability: www.beachcenter.org

Family Ties: www.massfamilyties.org

National Alliance on Mental Illness (NAMI) of MA: www.namimass.org

Disability Law Center, Inc.: <http://www.dlc-ma.org/>

MA Down Syndrome Congress (MDSC): www.mdsc.org



GOVERNMENT RESOURCES

Department of Public Health: <http://www.mass.gov/eohhs/gov/departments/dph/>

Department of Developmental Services: <http://www.mass.gov/eohhs/gov/departments/dds>

Department of Elementary and Secondary Education: www.doe.mass.edu/

MA Special Education Parent Information: <http://www.doe.mass.edu/sped/parents.html>

Mass Health Services: <http://www.mass.gov/eohhs/gov/departments/masshealth/>

Mass. Rehabilitation Commission (MRC): <http://www.mass.gov/eohhs/gov/departments/mrc/>

Social Security Disability: <http://www.ssa.gov/disabilityfacts/>

MA Commission for the Deaf and Hard of Hearing: <http://www.mass.gov/eohhs/gov/departments/mcdhh/>

MA Commission for the Blind: <http://www.mass.gov/eohhs/gov/departments/mcb/>

Need more information?

Call Cooperative for Human Services, Inc. at 781-538-4626

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Executive Director

Michelle MacEachern
Director, Support Service

Janice Ellis-Ballerini, LMHC
Director, Clinical Support Service

Felicia Smith
Director, Individual and Family Supports

More Family Resources

“Emergency Readiness Toolkit for Parents of Children with Disabilities and Special Health Care Needs,” a comprehensive guide with checklists and forms for emergency preparedness published by University of Massachusetts Medical School, Eunice Kennedy Shriver Center, October, 2010. Free download available at: http://www.umassmed.edu/uploadedFiles/shriver/service/Emergency_Preparedness_Initiative/ToolkitPart1.pdf

“Directory of Resources for Families of Children and Youth with Special Needs,” Mass. Families Ties, 2013. Free download available at: www.massfamilyties.org/pdf/2013_fties_directory.pdf



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