

Powerful Patient #7

Host: Joyce Graff, WebTalkRadio.net

The Gift of Imperfection: Special Needs Children

Holidays are a time of sharing those holiday letters, heavily laden with bragging points about achievements, travel, and of course perfect children.

Families with health issues sometimes feel mute in the face of all this perfect joy. Should they tell people what is REALLY going on in their homes and in their hearts? Or gloss it all over by bragging about the perfect parts and leaving out all the imperfections?

What if one of those imperfections is your child?



A scene from the video “coffee-clash” from YouTube, published by ShutUpAbout.com

Two sisters from Massachusetts, each with an “imperfect” child, have written a book called *Shut Up About Your Perfect Kid!* a humorous book that takes an irreverent look at their lives and challenges, and asks all parents to understand them better, and help to include all children in school activities and play dates.

What if you suspect your child may have a condition that’s more than just variations in the growth curve? As many as 20% of children have some special health or developmental challenges. How can you get help in evaluating your child’s strengths and challenges, and helping maximize full potential? Early intervention can make a great difference in many conditions, including mental health challenges and autism.

Mary Summers from the Family TIES program of the Commonwealth of Massachusetts, herself the parent of a special needs child, shares her own experience and provides some insights into how to get the help you and your child may need.

1) Our guests

Sisters Patty Konjoian and Gina Gallagher each have a child with special needs. Patty’s daughter Jennifer (14) has bipolar disorder. Gina’s daughter Katie (12) has Asperger syndrome a high-functioning form of autism.

They have written a book, *Shut Up About Your Perfect Kid*, to provide support for other families with developmental or mental challenges. They have a website, bumper stickers, and a wealth of humorous support for parents facing similar challenges. See <http://www.shutupabout.com>

Mary Castro Summers is Director of the Family TIES program of the Massachusetts Department of Public Health in Canton. A parent herself of a child with special needs, Mary shares her own story and provides hints to help parents decide whether their child needs to be evaluated for early intervention, and if so how to go about it. And most importantly, as Patty and Gina also know, parents need support from their peers as well as from family and friends.

Supports for Parents of Children with Special Needs

From Mary Castro Summers, Director, Family TIES of Massachusetts 12/11/07

- I. www.massfamilyties.org : Introduction to Family TIES of Massachusetts
- II. www.mchlibrary.info/KnowledgePaths/kp_EPSDT.html : Early and periodic screenings for physical, developmental, and emotional disabilities, as outlined in the Healthy People 2010 principles of the U.S. National Institutes of Health.
 - A. Early and intensive intervention can have a profound impact on the quality of life for both children at risk and their families.
 1. www.aap.org : **AAP Urges Early Autism Screening.** The American Academy of Pediatrics (AAP) is urging early screening for autism spectrum disorders (ASD) for all children. View their reports: "[Identification and Evaluation of Children With Autism Spectrum Disorders](#)" and "[Management of Children With Autism Spectrum Disorders](#)."
 2. www.firstsigns.org offers information, screening guidelines and tools
 3. <http://www.kidsource.com/kidsource/content/early.intervention.html> : Early Intervention system in each state, receiving federal funds to support the infrastructure for the system. Each state has its own criteria for accepting a child for services; referrals generally come from a child's family, pediatrician, or other interested member of their circle of support. General info:
 - B. When a child is deemed to have special needs (physical, developmental, or emotional/behavioral)
http://mchb.hrsa.gov/mchirc/chusa_04/pages/0305cshn.htm , services should be identified to assure that the child reaches their maximum potential, whatever that may be.
- III. Support comes in many forms – important to address the needs of the child, each member of the family, and the family as a unit
 - A. Medical community, through a primary care physician/pediatrician, should become intimately aware of the family's circumstances, the challenges which come with this diagnosis, and resources that will help to alleviate stressors for the family. Ask that physician to serve as the "medical home" for the child, as described by the American Academy of Pediatrics (AAP),

and coordinate care among all specialists who have a role in the life of the child. www.medicalhome.org

- B. Health insurance is essential for children with special needs. Contact your state's Family-to-Family Health Information Center or the state's chapter of Family Voices to learn more about the public insurance programs that may be available for your child, irrespective of the level your family's income. www.medicalhomeinfo.org/tools/F2F.html and www.familyvoices.org
- C. Condition-specific support networks offer information about the diagnosis, current trends for treatment and research, and opportunities to connect with others with the same information needs. It's important to note that there may be only one or many networks available – remember that every group has its own focus and personality, and it's important to find the group that best meets your family's needs – at the time. You are always welcome to expand your horizons, as time goes on. National organizations often have state or local chapters, which can offer opportunities for personal contact with others facing similar challenges. Consider your local phone directory for organizations like United Cerebral Palsy www.ucp.org , Muscular Dystrophy Association www.mda.org , or if your child is affected by a genetic-based disorder, contact the Genetic Alliance to identify an organization for supports www.geneticalliance.org . For very rare conditions, Mothers United for Moral Support offers hope to find families facing similar circumstances. www.netnet.net/mums . Another wonderful resource is Exceptional Parent magazine. www.eparent.com
- D. For Autism resources on a national level, the four best known organizations include:
www.autism.org - diagnosis and therapies information and supports
www.autism.com - research
www.autism-society.org - raise awareness and offer financial supports
www.autismspeaks.org - diagnosis, public awareness, and video glossary
www.aane.org - Asperger's Syndrome diagnosis and therapies info
In Mass., the Mass. Department of Mental Retardation has created its Division for Autism, to develop supports for families of individuals with autism. Regional Autism Support Centers offer information and education, tools for supporting the individual, opportunities for therapies, socialization, and more.
<http://www2.primushost.com/~nsarc/>
- IV. Emotional support is a key component of successful adaptation and parenting for all families, including parents of children with special needs. In all states, there is a statewide program to offer parent-to-parent support, offering parents an opportunity to validate their feelings around their child's diagnosis and the uncertainties that come with special health care needs, and also technical assistance as they make their way along uncharted waters in raising their child. Parent-to-Parent USA can help parents find the program in their

state and offers supports and standards for those programs.
www.p2pusa.org

- V. Special services and supports are available through the state health departments. Contact your Department of Public Health and ask about programs for children with special health care needs, which receive federal funding from the Maternal & Child Health Bureau. www.hrsa.gov/mchb Services may include care coordination, information and referral services, financial supports, connection with the state Medicaid program, Early Intervention services, and programs like Family TIES of Massachusetts.

- VI. When it comes to educational concerns, seek out your state's Parent Training & Information Center www.taalliance.org/centers/index.htm , funded by the US Department of Education www.ed.gov and its Office of Special Education Services www.ed.gov/about/offices/list/osep/index.html . The Center's mission is to obtain appropriate education and services for their children with disabilities; work to improve education results for all children; train and inform parents and professionals on a variety of topics; resolve problems between families and schools or other agencies; and connect children with disabilities to community resources that address their needs. A related resource is www.fape.org/ , where parents can learn about IDEA 2004, a federal law which guides states on providing appropriate education for students with special needs.

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Family TIES: Together in Enhancing Support