Special Occasions with Children with Special Needs

Making family gatherings good, not ghastly

Family get-togethers are the worst. Too many people. Too much noise. Too much food. Too many opinions on the ways you're raising your children. Never mind the fact that kids with special needs often go crazy during big family events -- they're often not exactly a shining hour for us as parents, either. How can you make it through the meal without chewing someone out, putting your foot in your mouth, or eating your words? If a quiet dinner at McDonald's is out of the question, here are some ways to get through these gatherings without going crazy.

Make an escape plan.
Better to leave before things go bad than stick it out and live to regret it. If you're spending the holiday at a home other than your own, arrange a time limit or a signal ahead of time and if your child seems to be coping better than expected, you can always extend the deadline, but be ready to split at a moment's notice. If at all possible, when your holiday travels involve such a distance that you'll have to stay overnight, get a hotel room. Your child (and you) will need someplace quiet and chaos-free to decompress after so much family exposure. Then again, if everybody's coming over to your house for dinner, make your child's room off-limits to everybody but him or her, and encourage your child to make it through the meal without chewing someone out, putting your foot in your mouth, or eating your words? If a quiet dinner at McDonald's is out of the question, here are some ways to get through these gatherings without going crazy.

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Kaaren receives the Ann Royal Special Recognition for Lifetime Achievement Award

Kaaren Hayes, Director of the Family Support of the High Country, received the Ann Royal Special Recognition for Lifetime Achievement Award.

Kaaren joins a special group of individuals who have received this award for their dedication, commitment, talent, passion, and tireless effort.

The Foundation promotes education in developmental disabilities through an annual conference held in Raleigh on December 5th & 6th for parents and providers (typically over 600 individuals attend the conference) as well as through the granting of scholarships for continuing education. The Foundation also honors individuals who have made distinguished contributions in the field of developmental disabilities.

Congratulations, Kaaren!
to use it as a refuge when things get overwhelming.

Clothes don't make the kid. If your child has sensitivities to certain types of clothes, or just stubbornly insists on wearing something you (or, you suspect, your mother) will find inappropriate, don't pick a battle today. Eyebrows may raise if your kid's in sweats while every other little cousin is dressed to the nines, but you want to start your child out with as low a stress level as possible. Fussing over clothes, or putting him or her in clothes that you know will cause anxiety, is a bad way to start. And this way, when the inevitable spills occur, you'll be the only parent at the table who's not worrying about ruined outfits.

Augment the menu. Whether you're bringing a little something to somebody else's party or planning your own repast, make sure there's something your child will enjoy eating. And then don't comment if that's all he or she will eat. The goal of the day isn't cleaning your plate or trying new foods or pleasing the cook. It's getting through the meal with a minimum of trauma. And, more importantly, it's about giving thanks for the good things in our lives. If your child only wants to give thanks for macaroni and cheese, so be it.

Be the one who watches the kids. Keeping a close personal eye on your little one has a number of benefits. You can intervene in inter-child squabbles. You can assess your child's level of overstimulation and act accordingly. You can play with your child if no one else will, or lead the other children in a game your child can participate in. And, perhaps most importantly during these events when you feel every judgmental eye is on you and your family, you can avoid conversations with grown-ups. You'd sure like to discuss your child-rearing flaws with Aunt Gertrude, but -- oh, honey, do you need some help with that? Why don't we sit down here on the floor and do it together.

Bring supplies. Fill a backpack with things your child finds reliably comforting or fun to play with -- toy cars, a stuffed animal, a tape and tape player, a few books. Having them available, even if he or she doesn't actually play with them much, may give your child a sense of familiarity that will be relaxing. If he or she gets overstimulated, find a quiet corner or a back room in which to spend a little time with the toys. If nothing else, toting the toy bag around and making it available when necessary gives you something to do that does not involve long conversations with unpleasant relatives.

Beware of bribes. You may be tempted to offer some big reward for your child's good behavior at a family get-together, but that can backfire. The fear of losing that much-wanted thing may add to your child's stress overload and actually bring on even worse behavior. Some kids may talk themselves out of wanting the reward because they feel so incapable of providing the required self-discipline. And once you've lost that incentive, things can go downhill very quickly. Small spontaneous rewards during the course of the event are often more effective, because they reduce stress and improve mood. Then, if your child does pull it off, you can always give the big reward later with much praise and encouragement.

Remain calm. Memorize this phrase, and repeat it over and over in your head whenever you feel yourself losing your cool: I do not have to apologize for being a good parent to my child. We may struggle under the weight of "advice" or disapproval from family members, but our kids don't care about that: They need what they need. You know best what your child needs, and providing it is your most important responsibility, no arguments. Since most children with special needs react badly to stress in their environment, particularly stressed-out parents, staying relaxed and low-key is one of the best things you can do to keep your child's behavior in line. You can always throw a tantrum when you get home.

Don't overbook. Hold the festivities down to one event per holiday.

By Terri Mauro, www.specialchildren.about.com
Supporting FSN-HC

The funding for Family Support Network of the High County is very tight this year. We have cut back staff hours and are operating on a skeleton budget. As a Holiday Gift or a New Year’s commitment/resolution, please help us meet our basic needs.

- $10.00 will cover the cost of 10 Parent to Parent FSN-HC packets for families new to Early Intervention
- $15.00 will cover the cost of copying 100 copies of our Newsletter
- $35.00 will provide postage to mail 20 area schools “People First: an Elementary, Youth and Adult guide to Understanding Disabilities
- $40.00 will mail out one issue of our quarterly Newsletter (Most go by email!)
- $50.00 will purchase a video for our Lending Library
- $150.00 will provide part-time office help for 1 month
- $250 will cover office supplies for the rest of the year
- $500 will provide 47 hours of staff time to develop our program in outlying counties

A donation of ANY amount will be gratefully accepted.

Checks can be made out to:
Parent to Parent FSN-HC
150 Den-Mac Drive
Boone, NC 28607

A tax receipt will happily be provided upon request.

Assistive Technology Ideas

Tots n Tech has an amazing website which features assistive technology ideas for communication, eating, play, and mobility/positioning.

Here are some ideas for communication:

- Bubbles and BIG Mack Switch Encourage Interaction
  It can be challenging to find fun ways for siblings to interact when one child can not talk. The message “Blow bubbles” was recorded on a BIGMack switch and the switch was positioned on the child’s lawn chair. Whenever the child touched the switch, he was able to tell his brother to blow more bubbles which provided great opportunities for both children to pop them!

- Velcro Choice Board

Need an easy board for pictures or symbols? Try using a scrap of carpet. Laminate the photos or picture symbols of favorite toys, family members or food items to be used. Place the hook side Velcro on the back of each picture/symbol. The Velcro attaches easily to the carpet and can be taken anywhere. Pictures could also be placed in different rooms or on the cupboards where the desired pictured object can be found. If sign is being used, a picture of the sign next to the card could help the parents remember the sign.

- Communication Can
  Pringles Torengos (the potato chips) come in a triangular shaped can. After eating the tortilla chips and cleaning the can, take the label off. Cut a piece of self-stick felt (available at Michaels or AC Moore) to cover the outside of the can. You now have a communication device or choice board. Attach 2” communication symbols with the Velcro (male side) on the back of the pictures and they will stick to the can. Because the can has 3 sides, you can have three sets of messages ready to view or choose from. The can has a lid and the symbols can be stored inside the can until ready to use.

For more ideas, check out Tots n Tech’s website at: www.asu.edu/clas/tnt
**Q & A**

**What are the changes in the Early Intervention Program?**

North Carolina has entered the second year of the redesign of the early intervention system. Eighteen CDSAs have been created, each with an associated provider network to deliver intervention services and a regional council involved in the planning and monitoring of early intervention services. The CDSA is the local lead agency for early intervention in each region of the state.

Statewide, an unprecedented number of referrals has created severe challenges for the CDSAs. For the fiscal year, 2005, the system received over 17,000 referrals, an increase of over 12,000 from the average under the old system. It is thought that the increase is a result of several factors:

- a new federal requirement that all children adjudicated as abused or neglected be referred to early intervention;
- the new simpler single portal of entry to early intervention through the CDSAs; and
- the publicity surrounding the new early intervention system

As a result of the significant increase in referrals and a shortage of resources (despite a $5,000,000 increase in legislative appropriation this year), the Early Intervention Branch has pursued several initiatives to help align resources available to demand. Among these are:

- individual expectations of performance for each CDSA in relation to meeting the 45 day timeline from referral to development of the Individualized Family Service Plan and the timely delivery of intervention services and following ITP guidelines for transition from the Infant Toddler Program.
- requiring CDSAs to discontinue services to preschool age children. The rate of the transition dependent upon the CDSAs ability to meet its ITP requirements.
- Proposing a change in eligibility guidelines to limit the number of children enrolled in the program. The public comment period ended on December 12, 2005. Following the public comment period permission to implement the new definition must come from the Office of Special Education Programs in Washington, DC and the NC Commission on Public Health.

Although our CDSA has been able to respond to over 345 referrals this past year without creating a waiting list and initiating services promptly, the impact of the discontinuation of preschool services and the change in eligibility definition will be significant.

Historically the CDSA (formerly the DEC) has evaluated over 500 preschool age children per year. Most of these evaluations were done to determine eligibility for the preschool program. As the CDSA transitions to become a 0-3 year old program only, the local school systems will need to develop their own resources to meet this need. The CDSA will offer support through education and mentoring but the schools will still need to find individuals to perform these evaluations.

The proposed change in eligibility definition is designed to keep the number of children enrolled constant. However since our CDSA does not have a waiting list, we will
need to pursue a more concerted child find effort to ensure that all potentially eligible children in our service region are identified and referred to the CDSA. We will also need to strongly support the Health Department CSC programs, Parents as Teachers, and other related programs to ensure children that do not meet our eligibility guidelines are appropriately monitored and supportive services are made available. A potential positive outcome of a more restricted eligibility definition is that the CDSA may be better able to provide the full array of required services to each enrolled child. Of course, this outcome could only be achieved in sufficient resources are available to make those same options available throughout the state.

By Douglas Galke, Director
Children’s Developmental Services of the Blue Ridge

Schwab Learning

Schwab Learning, found online at SchwabLearning.org, is a nonprofit program of the Charles and Helen Schwab Foundation, a private foundation. Their mission is to provide information and inspiration for families whose children struggle with learning and attention problems. Schwab Learning’s goal is to help transform, for good, the lives of a significant share of American children who struggle with learning and attention. Given accurate information and support, parents and kids can bring about positive and dramatic changes in their lives. By focusing on a child’s strengths while addressing his challenges, every child can experience success in learning and life. By providing information and peer support to kids in a safe and interactive environment, SparkTop.org is designed to help them gain confidence and insight about their challenges and strengths.

Offering Families Help and Hope

Their philosophy conveys great hope for kids who struggle with learning and attention problems. In serving those children — and their parents — they aspire to help kids lead satisfying and productive lives.

From SchwabLearning.org
Upcoming Events

**Challenging Behaviors & Medically Fragile Share Groups** meet the second Friday of each month at the Boone Unitarian Universalist Church (381 E. King St, beside the Playhouse). Dinner provided & Child Care provided if a space is reserved in advance.

**Assistive Technology Library Open House** on Friday, January 27th from 1:00- 4:00 pm at Children’s Developmental Services Agency of the Blue Ridge, 150 Den-Mac Drive in Boone. (Snow date: Friday, February 10th 1:00 – 4:00 pm)

   Enjoy:
   - Suggestions for make it and take it activities
   - How to’s for purchasing equipment through the CSHS or AT Funds
   - AT catalogs
   - Equipment available for check out
     - Equipment demonstrations:
       - Augmentative Communication devices
       - Adapted Learning
       - Positioning and Mobility
   - Environmental Control
   - Literacy kits and adapted books
   - Computer access and software

   Toddler Training Credits will be awarded.

HATS OFF!

Welcome to Norma Buchard, our new Outreach Coordinator! We all are so thrilled to have her at FSN-HC!

Thank you to the ASU’s ACT, the student team who organized the Dance Marathon and all the dancers for their good energy and incredible spirit! Thank you for raising money for FSN-HC! Your donations are keeping us going!

Thanks to ASU student Andrew Baird for producing a video about our program. Look for it on the web site soon!

Thanks to ASU student Michelle Cole who has worked faithfully for our program for 4 years!

Thank you to our Board Members for a wonderful year! Your work and dedication is very much appreciated!

Happy Holidays everyone!

We wish you a healthy and happy new year!

Please support our projects so that we can continue to serve our parents and the community. Detach this form and send donations to the address below and help continue this much needed program. All donations are tax-deductible.

Name ________________________________

Address ________________________________

City __________________ State _________

Zip Code __________ Amount $___________

Name of Honoree(s) ____________________________

__________________________________________

Thank you for your valuable contribution.

FSN-HC
150 Den Mac Dr.
Boone, NC 28607