There’s a parable about accepting children with disabilities that regularly makes the rounds of support-group newsletters and Internet discussion groups. Written by Emily Perl Kingsley, “Welcome to Holland” (Kingsley, 1987) talks about the experience of planning a trip to Italy but accidentally ending up in Holland, which doesn’t have the Coliseum or Michelangelo’s David, but does have lovely tulips and Rembrandt. Holland is different, but it's good in its own way—just like your child with a disability.

While many parents have found this fable comforting, others feel patronized by well-meaning advice and reading material that encourages them to simply accept their lot.

I look at that "Welcome to Holland" pap piece and think, "What the hell do they mean? Try ‘Welcome to Bosnia!’" --Krista, mother of seven-year-old Joshua

When you are encouraged to accept your lot, even to see it as a gift, it can make you think you don't have the right to be mad—but you do. No one deserves to have these disorders, and no one deserves to have their lives turned upside down by caring for someone else who does. On one level, you do have to accept the situation. On another, you cannot, and must not if you are to have the energy and determination to help your child.

To read the rest of this article, click here
Handling children's anger can be puzzling, draining, and distressing for adults. One of the major problems in dealing with anger in children is the angry feeling that is often stirred up in us. We need to remind ourselves that we were not always taught how to deal with anger as a fact of life during our own childhood. We were led to believe that to be angry was to be bad, and we were often made to feel guilty for expressing anger.
It will be easier to deal with children's anger if we get rid of this notion. Our goal is not to repress or destroy angry feelings in children or in ourselves but rather to accept the feelings and to help channel and direct them to constructive ends.
Read the rest of the article here.
TALENTS REQUIRED TO PARENT AN ASD CHILD

Contributed by BBB Members: Lynn, Jen, Khris, Becca, Bernie, Liz, Diana, Sue and Michelle

* Sense of Humor (7)
* Ability to listen to any and all information ever collected about global warming
* A heavy-duty super-capacity washer/drier combo with a very good guarantee
* A fondness for Corel Livingware rather than fine china
* A very well made tough VCR that can withstand constant pause, rewind and fast forward
* Patience by the dump truck load
* The ability to boil your cabbages at least a dozen times! (to repeat yourself time and again)
* The ability to make a schedule and then live by it!
* The ability to plan your life way in advance!
* The ability to love a child unconditionally through all that this disorder will put him through!
* The ability to answer the same question but put 100 different ways.
* The ability to hide in a supermarket after your child has just called a worker an idiot, because they were out of stock.
* Boardroom level skills of negotiation.
* The ability to think ahead or always be 1 step ahead of your child.
* To have to smarts to keep tons of AA batteries in the house.
  · The flexibility to adapt to what your child can not
  · The multitasking capability to do 12 things at once
  · A very large can of Scotchguard
  · A good friend who has been through "the system"
  · A really fast internet connection and a list of sites
  *"Sensory toys"
* Endless financial resources
* A housekeeper that comes daily
* A big bottle of Advil (or something stronger)
* The address to the BBB Autism Club
  · The ability to see and experience imperfection and let that be ok...
  · The ability to accept the world and circumstances as they are but strive onwards without giving into despair...
  · Unconditional Love
* Be able to cook, shop, etc...at a quick pace especially if your child's with you
* Understanding
* Persistence, assertiveness...so that you can advocate for your child.
* ‘A case of beer couldn’t hurt, LOL’
* A hearing aid you can turn off once in awhile, lol
* Hostage Negotiator
Effective Behavior Strategies

*Sandra F. Rief, M.A.*

These strategies are designed to help you better cope with and manage the more challenging behaviors exhibited by children and teens with ADHD. Many can be adapted for all types of kids!

- Establish a few specific, important rules/expectations that are clearly understood by all members of the household.
- Praise and positively reinforce your child for following rules/expectations.
- Establish clear-cut consequences (that are logical, reasonable, and fair) in advance with your child for breaking the rules.
- Enforce with consistency.
- Provide structure, routine, and predictability.
- Set limits and let your child know you mean business.
- Catch your child behaving appropriately (as frequently as possible). Immediately reinforce that good behavior with a positive consequence. This means something your child likes (e.g., praise, smiles, hugs, privileges, activities, points/tokens earned towards a reward). Use the smallest reinforcers necessary. Don't overdo it. Keep rewards reasonable--no big-ticket items.

More tips [here](#).

**ADHD Behavior Modification Techniques**

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**Parent Tip**

*by BBB Member Liz*

One of the best tools I've ever used for determining the reasons for some of my son's more difficult behaviors has been the Durand Motivational Assessment Scale (MAS). The scale was developed by [V. Mark Durand, Ph.D., and Daniel B. Crimmins, Ph.D.](#).

"Despite all of our best efforts, a large number of people who have severe disabilities continue to display serious and disruptive behavior problems...". This is a simplified way to carry out a functional analysis.

Quite often, my son's behaviors seem to occur with no apparent antecedent (trigger or reason), this scale helps me to determine whether the behavior is seeking sensory input, attention, escape, or tangible.

The MAS is a sixteen-item questionnaire that assesses the functions or motivations of behavior problems. The sixteen items are organized into four categories of reinforcement (attention, tangible, escape, and sensory). The MAS asks questions about the likelihood of a behavior problem occurring in a variety of situations (e.g., when presented with difficult tasks).

"In addition, using this scale does not involve making behavior problems worse, a feature that has obvious advantages. It is hoped that through the use of the MAS, people with severe behavior problems will have greater access to positive interventions."

To help perform a functional assessment, try this PDF form for A (antecedent) B (behavior) C (consequence).

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**A FOOD TASTING PROGRAM**
by BBB Member Liz (with much help from her team!)

Note: this is best tried on an empty stomach.

The first part is probing for preferred stimuli (preferred foods)

Step one:
Assemble a group (say, 6) of foods you'd like your child two try. Only prepare a small amount of each; then section into very small pieces (i.e.. 1/2 of a pea, tiny shred of carrot, smidge of apple - you get the idea)

Step two:
Set out each of the six foods in separate bowls at the table in front of your child.

Step three:
Determine the most preferred item by noting which food your child reaches for. The first item that s/he reaches for three times is the most preferred item. Set that one aside and determine the order of preferred foods, setting each aside.

Once you have an order (from one to six) of preferred foods, you are ready to start trials.

Step one:
Offer the most preferred item before dinner. Offer small bites ten times (10 trials), keeping data on this. When your child initiates eating this food on his own 80% of the time over three days, it is time to move on to the second preferred item.

Step two:
Follow instructions as above. When successful with 2nd item (80% 3 days in a row), start to rotate that food with 1st preferred item.

Step three:
While still rotating 1 & 2, move on to #3 alone (in isolation). When 3 is successful, rotate with 1 & 2.

Step four:
Continue with each food as above.

NOTE: You may have to prompt the child to take the food.

Scoring:
correct: the child initiates taking the food independently
prompt: you guide the child's hand to take the food.
incorrect: the child throws the food, refuses to be compliant.

Only 'correct' is scored as correct. Mark 'prompt' with a "P", but do not mark as correct. IE, 3 independent tastes, 4 throws and 3 prompts equals a correct score of 3.

Please note: sometimes, you will have no luck with a certain food and you'll have to give that one up for awhile. There is some accounting for taste.
Also, don't start out with all "difficult" foods like spinach, broccoli, cauliflower, onions etc. Try to put in foods that may be agreeable to the child (i.e., bananas, peaches). It is important that the food is not part of his/her usual repertoire.

FAVORITE LINKS

Children's Stress in Childhood

How Parents' Stress Affects Children

How to Know When Your Family Needs Therapy

Family Medical Checklist

Medication Checklist

Babysitters' Checklists

Positive Behavior Checklist

7-Day Food Diary (to check against possible food allergies)

RECOMMENDED READING

Asperger Syndrome and Difficult Moments Practical Solutions for Tantrums, Rage and Meltdown by Brenda Smith Myles and Jack Southwick

Growing Up Severely Autistic They Call Me Gabriel by Kate Rankin

Learning To Listen: Positive Approaches and People with Difficult Behaviour by Herbert Lovett

Disabilities by Karin Melberg Schwier and Dave Hingsburger
ADDRESSING THOSE TOUGH BEHAVIORS

"My Potty Checklist"

Bully Advice for Kids

Bully Advice for Parents and Teachers

Stereotypic (Self-Stimulatory) Behavior

Brief Report: The Effects of Exercise on the Self-Stimulatory Behaviors and Positive Responding of Adolescents with Autism

School Discipline and the Student with Disabilities

Autism Society of America "Challenging Behaviors"

Avoiding Unfortunate Situations: Law Enforcement and Autism

Treatment of Destructive Behaviors in Persons with Developmental Disabilities

Autism Proof Your Home

Parenting Tips for Better Sleep plus Sleep Log

Law Enforcement and the Autism/PDD Issue

Group Homes and Other Alternatives

Information Written for Law Enforcement

Tic Severity Checklist
GENERAL ARTICLES

The Ostrich Syndrome

The Dark Side; Loving Every Minute of it - addressing negative feelings of motherhood

What is Encopresis?

HARD TO TALK ABOUT - IMPOSSIBLE TO IGNORE

People with Mental Retardation and Sexual Abuse

Family Violence Against Women with Disabilities

A SPOONFUL OF HUMOR... HELPS THE MEDICINE GO DOWN

SURVIVOR: WELCOME TO MY WORLD
By Lain Chroust Ehmann

I don't know what the big deal about Survivor is. What's so tough about getting along on a remote tropical island, anyway? For most of the parents I know, a few weeks of solitude—or a few weeks surrounded by other adults without a nose to be wiped, a bottom to be cleaned, or a toddler to discipline—sounds like pure heaven. Heck, forget about the million dollars in prize money; I'd pay to get sent to Pulau Tigua. Somehow, the hardships these participants face don't seem so bad.

I hear the show's producers are already planning next year's Survivor: 2001 in Australia. Maybe instead they should consider a sequel that really tests the limits of human endurance: isolate team members in a secluded house with several members of the under-six set and let 'em battle it out.

I can just see it now: MTV's The Real World meets Romper Room. Ratings will skyrocket as parents everywhere take time from reading "Hop on Pop" to tune in.

The first episode, warring Tribes (Pampers vs. Huggies) compete in a relay race Reward Challenge. Which team can be first to unload the groceries from the minivan in sub-zero temperatures while the three-year-old is clamoring for a Popsicle, the toddler is eating cat food, and the newborn is sleeping peacefully in the car? The Pampers Tribe is rewarded with a Baby
Bjorn pack, suitable for keeping colicky infants quiet while still allowing "Mom" or "Dad" some limited freedom to do the dishes and clean the house.

At the Tribal Council, the Huggies Tribe votes the former Navy SEAL out because he inadvertently wakes the baby with his cursing when he drops a grocery bag containing a dozen eggs on the icy front steps as he attempts to keep the Golden Retriever from mauling the cookie-selling Girl Scouts who appear at the door at an inopportune moment. His errors compound when he fails to rekindle the oven's pilot light after the preschooler extinguishes it by dumping the entire contents of the flour canister on the stove.

The next week, contestants face their first real crisis as all three children are hit with a simultaneous case of the stomach flu at the same time the house is invaded by swarms of unexpected visiting relatives, wanting to be fed and housed for "just a few days." The mail also brings a few unpleasant surprises, and the teams must band together to make important decisions, such as whether to pay the furnace repairman or get a new transmission put in the minivan.

The Reward Challenge of the week—the Bath and Bed relay—goes to the Huggies Tribe, who successfully bathe, diaper, pajama and put all three kids to sleep in record time. They walk away with a stack of Barney videos and a VCR for the family room TV set.

At Tribal Council, in an unprecedented move, all participants under the age of 25 on both teams are kicked out for dissension (the final straw was when the younger contestants, fed up with the steady diet of macaroni and cheese, tater tots and Teletubbies use the money set aside for a family outing to Chuck E. Cheese's to order in sushi and the Bare Naked Ladies Pay-Per-View concert special).

In upcoming installments, watch breathlessly as teams deal with issues such as chronic diaper rash (Will the chemist, Ramona, be able to concoct a solution to cure the condition, or will the team have to resort to cloth diapers?), sibling rivalry (Who really flushed the Cabbage Patch Kid down the toilet?), and parenting philosophies (What exactly is "Attachment Parenting," anyway?).

See them dump members for transgressions such as giving the kids nightmares by allowing them to view Bride of Chuckie ("I thought it was a 'Rug Rats' movie," says the ousted contestant). Watch the tribes vie in Challenges such as the Potty Parade and the Supermarket Scurry for creature comforts like a Peapod grocery delivery account, a subscription to Parents magazine and renowned pediatrician Dr. T. Barry Brazelton's home phone number.

Who will survive the changing emotional weather of life with three kids? Who will prove hardy enough to withstand the ups and downs of parental life? Who will walk away with the big prize? Tune in and find out.

Now that's entertainment!

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Past Issues

(to request, email liz@deaknet.com and indicate which volume/issue(s) you prefer)

Volume 1; Issue 1 WELCOME ISSUE!

Volume 1; Issue 2 SUMMER CRISIS ISSUE

Volume 1; Issue 3 SPOUSAL CONCERNS ISSUE
How to Defuse an Angry Outburst
Say Good Bye to an Angry Outburst

Here’s How:

1. Do not respond with anger or threats.
2. Put on soft music.
3. Sing a silly song.
4. Put on headphones and dance around the room.
5. Speak softly, so the child has to pay close attention to what you're saying.
6. Try to redirect the child to a positive activity.
7. Have a snowball fight with cotton balls.
8. Set a timer and give the child a specific amount of time to stop.
9. Count out loud, ask your child to count with you.
10. Sit near the child and begin reading an age appropriate book to the child.
11. If necessary, remove the child from the area or remove yourself.

Tips:

1. Stay consistent each time that an outburst occurs.
2. Do not give into the child's demands, or you will reinforce the value of outbursts.

Restricted Repertoires in Autism and What We Can Do About It

Revised by Cathy Pratt

This is a summary of a presentation by Tony Attwood, Ph.D., from Brisbane, Australia. Dr. Attwood described the developmental sequence followed by typical children. Children with autism spectrum disorder follow the same developmental sequence, but in an exaggerated fashion. For example, children with autism spectrum disorder may collect the same type of objects as other children, but to a point of excess. Another example is the intense need for symmetry, or for information on a certain subject. These exaggerated behaviors are identified as a restricted repertoire of activities and interests.

Many individuals with autism spectrum disorder engage in simple, repetitive actions such as rocking or spinning objects. What to do about repetitive actions depends on the reason the individual is performing the activity or the function of the behavior. The following are possible reasons for repetitive actions and programming ideas specific to these reasons.

To read more, check out BBB Autism's PDF Files.

ALSO

Check out our PDF files for great printable articles on challenging behavior. Look for:

- Generic Habit Training (Toilet Training)
- Dealing with Tantrums
- Visual Supports
• Discipline and the ASD Child
• Social Skills Training in School
• Behavioral Issues and the use of Social Stories
• The Messages of Behavior

....and many more!
How to Build Self-Esteem  
Boosting Self-Esteem is Essential to Good Health.

Here's How:

1. Applause, applause.
2. Happy notes tucked in their lunch or under their pillow.
3. One-on-one attention.
4. Hugs.
5. Praise.
6. Attending their school activities.
7. A favorite meal or treat.
8. Telling your child how proud you are of him or her.
9. Saying "I love you."
10. Celebrate their accomplishments.

Tips:

1. It will always be in the best interest of your children to nurture a healthy self-esteem.
2. Avoid negative power plays and accentuate the positive behaviors.

Teaching Play skills to a Child with ASD

"This is a selection of notes from over two years of behavioral intervention sessions with a young child who ultimately recovered completely from autism. It includes many curricula ("drill sheets"), therapists' notes, and parents' notes, covering (in part) his development from no pretend play skills all the way to fully independent, spontaneous, creative play. The notes are by the parents, Megan and Jim Sumlin (pseudonyms), who feel strongly that this information should be freely available to all who might benefit from it. They ask only that these drills belong in the public domain, and are not to be claimed or copy written by any person who is or will in the future be seeking monetary gain for wide distribution of same. Feel free to re-distribute this document, but please include this entire preface.

To read the Sumlins' program, please click here.
Some Behaviors Associated with Autism
Social Behavior

Socially Avoidant

- May avoid many forms of social interaction
- When interaction occurs, the most common response is tantruming/ running away
- Infants arch their back to avoid contact
- Caused possibly by hypersensitivity to certain sensory stimuli

Socially Indifferent

- Some individuals will not seek social interaction; avoid social situations
- Seems to prefer being alone; indifferent to the company of others
- Caused possibly by not obtaining "biochemical" pleasure by being with people

Socially Awkward

- May try hard to have friends, but can not keep them
- Do not learn social skills and social taboos by observing others
- Lack common sense when making social decision
- Caused possibly by the lack of reciprocity in their interactions, since conversations revolve around themselves

Self-Stimulatory Behavior

Visual

- Hand flapping
- Staring at lights
- Repetitive blinking
- Moving fingers in front of eyes
- Watching things out of the corner of his/her eye

Auditory

- Tapping ears
- Snapping fingers
- Making Vocal Sounds
- Placing hands over ears

Tactile

- Scratching
- Rubbing the skin with one's hands or with another object
- Sometimes tactile defensive; i.e. some fabrics can be painful to feel
- Can have a high tolerance to pain
Vestibular

- Rocking front to back
- Rocking side to side
- Turning in circles

Taste

- Placing body parts or objects in one’s mouth
- Licking objects

Smell

- Smelling objects
- Sniffing people

Self-Injurious Behavior

This type of behavior can be characterized by any behavior, which causes bodily harm to him/herself. The most common observed self-injurious behavior would include head banging, hand biting, and excessive scratching or rubbing. Problems can occur due to some ASD individuals having a high tolerance to pain.

There are two main sets of theories as to why people engage in self-injurious behaviors social and physiological.

Social Theories

- Self-injurious behavior occurs to gain attention from other people
- Self-injurious behavior occurs in an attempt to avoid or escape a task

Physiological Theories

- Behaviors release beta-endorphins in the brain, which provides an internal pleasure
- Self-injury may be caused by sub-clinical seizures
- Head-banging or ear hitting may be caused by an ear infection
- Behavior may occur as a result of over stimulation, a release
UPCOMING CHATS:

**APRAXIA** - Thursday, August 16th at 2pm and 9pm est  
Convert to your time zone here.

PLEASE NOTE: TRANSCRIPTS FROM APRAXIA CHAT AVAILABLE UPON REQUEST liz@deaknet.com

**AUTISM AND ENZYMES** - Monday, August 20 at 9pm est

**AUTISM AND CHALLENGING BEHAVIORS (SELF INJURY AND VIOLENCE)**
- Wed Aug 29 2:00pm est
- Thurs Aug 30 2:00 pm est
  - Back to school
- Thurs Aug 23 9:00pm
- Tues Aug 28 2:00pm

COMING SOON: "How to Set Up a Home IBI Program", "Autism and Essential Fatty Acids"

Regular chats take place Mon-Fri at 1pm and 8:30 pm daily. If no one is in the chat room when you get there...give it a chance. You never know who might drop in!

For chat instructions, please email the chat(s) you wish to attend to liz@deaknet.com

COMING SOON:

For an upcoming issue, I am asking for your favorite links, plus stories and articles you have written yourself on the following topic:

* Home programs: this includes anything you have on ABA/IBI, OT, SLP, Floortime, Miller method, Options, gfcf diet, sensory diet, swim therapy, music therapy and anything you can think of. Hints for hiring (and firing) employees...anything of that nature.
  * Acceptance/Denial
  * Nutrition and ASD
  * Asperger Syndrome
  Thanks for all your support,
  Liz

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A notice to our readers...

The founders of this newsletter and the BBB Autism support network are not physicians.

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or statuesque_f@yahoo.com
Your help is appreciated!