

What Interventions and Supports Does My Child with Autism Need and How can I Determine if They are Effective:

Making Decisions That Make a Difference

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Pre- Diagnosis

- “What’s going on with my child? How can I help?”
- “I don’t want there to be anything ‘wrong’.”



Is it Autism?

- How is the topic introduced to the family?
- What reactions may be elicited?
- What support/s will need to be provided to the family during the evaluation stage?





After the diagnosis...

- Behavioral Therapies
- Medical Treatments
- Biomedical Treatments
- Sensory Dietary
- Alphabet of agencies

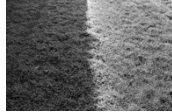
Reality is....

- Sleep deprivation
- Family discord
- Medical bills
- Friends don't speak the same language
- Extended family may not be supportive
- Genetic blame game
- Overwhelming amount of paperwork

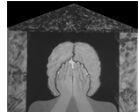




Who am I?



HALF frozen



Nobody's home

Who We Think We
"Should" Be



Why wouldn't ALL parents do
ANYTHING?!



- EVERY treatment
- EVERY therapy
- NEVER miss a day
- WHOLE LIFE is autism
- Just where is that going to get us?

We...

...love our children
...are trying
...will make mistakes
...CANNOT CURE
AUTISM
...need understanding,
compassion and
HELP!



Obstacle Removal

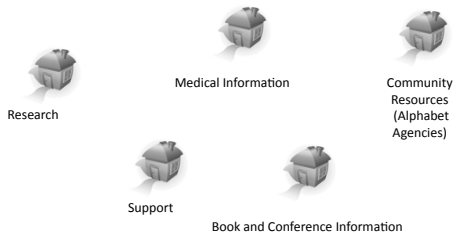
"I finally came to the realization that you fix things that are broken and my children were not "broken." They had obstacles that I could try and help them overcome."

Eric Blackwell



What We Found

A village to help us in raising our children...



How to Choose the Right Village

- Similar circumstances
- Similar philosophies
- Relevant resources



There is a SPECTRUM of support communities just like there is an Autism Spectrum!

The “right “ village will FEEL right.

How to Know if Intervention is Working

- Immediate measure: Is my child doing well (eat, sleep, meltdowns)?
- Long-term measure: assessments, formal and information (feedback from others)
- Consider the implications for the whole family: Is it working for ALL of us?



For Example:
Social Stories made a big difference!

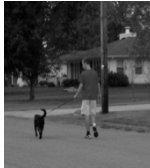


Finding Balance

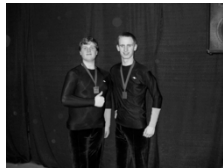
- Every family is unique
- Not everything has to be about autism
- You're required to have fun and laugh sometimes
- Relationships are the most important thing



Daily Activities



Band



Autism Awareness Fair 2009
A Boy Scouts of America Eagle Project by Cameron Blackwell

My name is Cameron Blackwell, I am 17 years old and beginning my senior year at Jeffersonville H.S. in southeastern Indiana. I am currently working on my Eagle Scout Project and would like to invite you to participate.

For my project, I am holding an Autism Awareness Fair and raising donations for the Resource Library at the Southern Indiana Autism Resource Center. The autism fair will be held Saturday, August 8, 2009 at The Church of Jesus Christ of Latter-day Saints, 1534 State Road 86, New Albany Indiana from 9am to Noon. At the same time as the Awareness Fair is going on inside the church, my friend, Lindsey Smith will be holding an Awareness Walk in the parking lot for her Girl Scout Gold Award so you can support BOTH projects by coming out that day. These projects are really close to my heart as I am diagnosed with Asperger Syndrome, an Autism Spectrum Disorder and my youngest brother is diagnosed with autism. We along with our family, spend around the county at Autism conferences to help raise awareness and I am hoping that these projects will help many who live in our community to better understand those with ASD.

You can be involved many ways, you can donate any amount towards purchasing books for the resource library or you can purchase a book yourself and donate it. I can personally accept donations, my contact information will be elsewhere on this site or you can do it electronically by clicking on the Credit button. If you would prefer to donate a book, the good people at Autism Apperger Publishing Company have set it up so you can order online and type "Eagle Project" in the special instructions and you will not pay shipping, the books will be gathered at the publishing company and shipped together. Just click on the AAPC link to donate that way. Any books are welcome, we'll post a wish list on this site as well.

There is a link to download the registration form to have a booth at the Fair. If you have repeat information for Autism related services in this area and would like to participate, please contact me if you have any questions.

www.autismawarenessnow.com

CAMERON BLACKWELL
Phone: 812-786-4402
Email: CameronBlackwellPaper@gmail.com

DONATE BOOKS TO THE CENTER
Don't forget to put the word EAGLE in your order (YES! When you CHECKOUT it is the "Special Instructions Field". AAPC will take care of the rest.)

CLICK HERE
APC
Autism Apperger Publishing Company

BOOKS REGISTRATION
To download a booth registration form, all you need to do is CLICK HERE


TO BUY BOOKS FOR MY PROJECT!
A special thank you to the good folks at AAPC for their support with this project! They have already donated MANY books at no cost for my project.

DONATE MONEY FOR AUTISM BOOKS
Cameron's Eagle Project
\$0 \$100
100% 15%
Total of \$1,000
4 contributions 1 each \$250
I am able to make my books support the Southern Indiana Autism Resource Center

Inexpensive Good Times


- Walks (even teens if you reward them)
- Craft projects
- Library
- Reading or books on CD
- Add on stories
- Cooking
- Creative messes

The ball of string



Let Them Express Their Passion

- The mess...is to be expected, which teaches another life skill
- Generalize skills to other practical uses
- Creating memories
- Positive feelings about home being where they are understood



Home repairs
Classroom repairs
Buried treasure



Obstacle Removal

Removing obstacles takes teamwork. Each member of the team plays a critical role. We bring our strengths and weaknesses to the situation and through working together we hopefully help lift not only the person on the Spectrum but also the whole team.

Obstacle Removal

- Sometimes an obstacle cannot be totally removed. It may be a person involved. It may be a physical or environmental issue.
- At that point we need to look for ways to remove the obstacle as a factor in success.

Skills not Gadgets



Behavior Tells Us a Story...

- I can't express my needs verbally
- I feel anxious
- I am coping the best I can
- This relaxes me (stress reliever)
- I'm not aware of how others perceive me
- I don't understand!
- **You** don't understand **me**: I give up!

It's Not about Managing Our Kids' Behavior

Instead of asking yourself 'What's it going to take to motivate this kid to behave differently?' ask 'Why is this so hard for this child? What's getting in his way? How can I help?'

Dr. Ross Greene, The Explosive Child

Prudent Flexibility

- What is the goal?
- Is a current meltdown worth the cost of the long-term goal?
- Risk assessment
- Pick your battles



Know When to SHUT UP
(and Wait)



Transitions

Why are
transitions
so difficult
for our kids?
It's basic Physics...



An object in motion tends to stay in motion
An object at rest tends to stay at rest

Meltdown Prevention



Self-Management Tools



- Priming
- Predicting
- Count-down
- Wrap-up
- Reward

Priming:

This is what we expect will happen

- Explanation
- Schedule
- Visual Aide
- Reward



- What is going to happen?
- What typically happens?
- Be brief yet thorough

Priming: Explanation

- Get the child's attention
But, do not force eye contact
- Tell the child what is going to happen
- Be brief yet thorough
- Get verbal confirmation
- Show no panic or fear!



Priming: Schedule

- Use a timeline and Stick to it
- No last minute changes
- Consider this step as a trust-builder
- Write it down or create a visual



Priming: Visual Aids



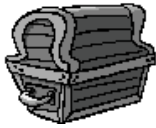
- Oh great! One more thing I have to do!
 - *Ounce of prevention is worth a pound of cure*
 - Developing a routine
 - You can use basics again and again
 - Once a routine is established, you may find you no longer need detailed visuals
 - Even adults use visual reminders: calendar, datebook, palm pilot, grocery list

Rewards: Why And How They Work

- Children respond to extrinsic motivation
- They respond to positive reinforcement, especially when using a special interest
- It creates a more self-motivated atmosphere
- It creates a cooperative environment



Priming: Reward



- Tell or negotiate
- **Reasonable** compliance
- “Going with the program”

Predicting: Think Ahead

- Examine all variables
- What has happened in the past
- With the child, think of possible alternatives ... just in case



Countdown



- Time needed varies by activity and location
- Be prepared
- Do not use seconds
- Don't say “just a minute” unless you mean 60 seconds



Rewards

- Balance difficult or distasteful activities with rewards:
 - No meltdowns = ??
 - Penny rewards
 - Stop at Video Store
 - Stop for ice cream



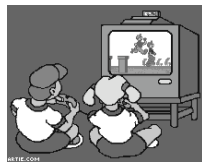
Rewards: Why and How They Work



- It teaches valuable lessons that may help your child to realize the benefits of other types of compensation
- It creates a habit that often leads to increasingly greater motivation

Rewards-Daily

- Computer or electronic games
LIMIT TIME
- Candy
- Collectable cards
- Activity with an adult
- Key is consistency...
- And, finding new rewards as the child gets older

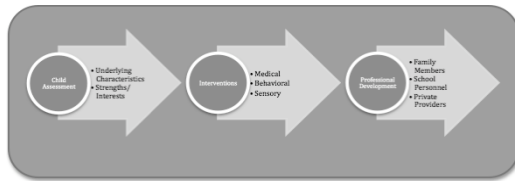


Wrap-Up

- Present the facts
 - Not a time for scolding or making judgments
 - A play-by-play listing of what occurred
- Make sure the child is calm before you wrap-up



Pathway to Professional Development



The Underlying Characteristics Checklist (UCC)

- Social
- Restricted Patterns of Behavior, Interests and Activities
- Communication
- Sensory Differences
- Motor Differences
- Cognitive Differences
- Emotional Vulnerability
- Medical/Biological



Collaboration on Program Development

- Prioritizing areas on which to focus through assessment
- Identifying and celebrating strengths, special interests
- Developing easy-to-use interventions
- Supporting implementation of interventions
- Evaluating
- Celebrating successes



Prioritizing Areas

- What is the short and long term vision for the child?
 - All voices should be heard!
- More doesn't always mean better!



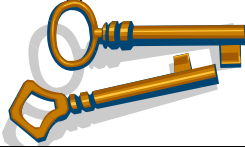
Developing Interventions

- Stay away from the cookie cutter approach!



Keys to Implementation

- Interventions link to specific underlying needs
- Everyone is on board
- Consistency across people and environments
- Open, honest communication
- A shoulder to lean on for support



Allie

•Priorities:

- Develop communication and language skills to increase social relationships with peers
- Increase independence with self-help skills
- Interact with siblings
- Increase food selections



Allie's Strengths and Special Interests

• Strengths

- Follows routine well
- Likes to follow task to completion
- Follows 3 step work systems and schedules


















• Special Interests

- Dora the Explorer
- Music
- Fuzzy things
- Motor activities



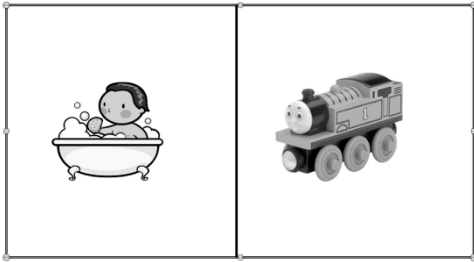
Examples of Supports

Work Calendar: Library
Employee: Jacob

Month: MAY	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
					1		3
4		5	6		7	8	
						16	17
18		19	20		22		24
25		26	27		29		31

Examples of Supports

First-Then



Examples of Supports

Dora the Explorer wants you to remember these things about taking turns on the swing:

1. If there is only one swing at the playground, it is important to take turns with the other children who want to swing.
2. If you are waiting for your turn to swing, you can play on the other fun playground equipment, like the slide, merry-go-round or the teeter-totter.
3. It is important that everyone has fun swinging on the swing.



Examples of Supports

WAIT

MY TURN

HELP

Examples of Supports

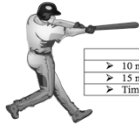
Schedule



Examples of Supports



Examples of Supports



School Reinforcer Menu for Michael

MY REWARDS	
>	10 minutes of reviewing baseball statistics in personal magazines/books
>	15 minutes to research on the internet on baseball/sports statistics/events
>	Time to browse books in the school library

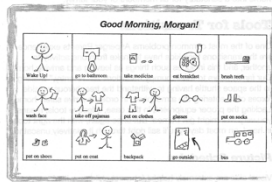
Home Reinforcer Menu for Michael

MY REWARDS	
◆	30 minutes of time to browse the web
◆	Trip to local baseball cards store
◆	30 minutes of video games



Visual Strategies

- Many ways to use this as a tool
- Allows processing time
- Allows for review
- It's the schedule telling him, not you



Do2learn.com

Daily Schedule

Time	Activity	Class	Class	Notes
8:15-8:30	Reading			
8:30-8:45	Math	1	1	2
8:45-9:20	Spelling			
9:20-9:40	Science			
9:40-11:00	Workshop			
11:00-11:30	P.E.			
11:30-12:00	Spells			
12:00-12:45	Lunch			
12:45-1:10	Science			
1:10-2:10	Special Studies			
2:10-2:30	Reading			
2:30-3:00	Art			

Importance of Home-School-Community Communication

- Provides means to share information regarding changes in student's underlying characteristics/interventions
- Provides consistency of programming across environments and people
- Allows student success to be celebrated by ALL



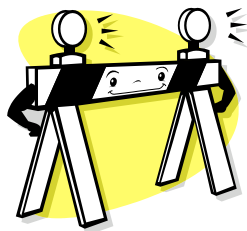
Parents



"We're afraid of parents!"

- We need to:
- Watch our tone
 - Being angry doesn't give us the right to be MEAN
 - Pick our battles
 - Look for opportunities to praise what they are doing right
 - Remember relationships build with time and trust

Communication Barriers



- Time
- Appreciation
- Trust
- Confidentiality
- Honesty
- Feedback
- Positives vs. Negatives

Caution....Keep in Mind...

- Tone of voice
- Facial expressions
- “Old baggage”
- Finger pointing
- “Meeting before the meeting”
- “Internal alarm clock”



Home-School-Community Communication

- Communication notebook
- Communication checklist
- Email listserv
- Blogs
- Wikis
- Quickie Phone calls
- Quickie Face-to-face check-in's



School to Home Meltdowns

- Work to identify the problem
- Always take underlying characteristics into consideration
 - too busy of a day
 - what happened on the way home?
 - what does the child need to transition?



Parents' Unreasonable Requests or Staff Roadblocks?

Parents' Unreasonable Requests or Staff Roadblocks?

Create a NEW vision

- Reality check
 - Think about the future
 - Talk to adults with same DX or their parents
 - But KEEP IN MIND: things are better now & constantly improving

It's a Long Road

Our Kids Grow Up

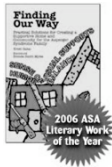


Remember...



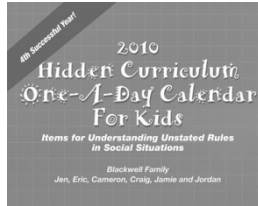
In the long run it is the family who is surrounded by an accepting, supportive community that will have a better outcome...and the community itself benefits too!

www.kristisakai.net



kristisakai@hotmail.com

www.autismnotes.com





Please visit our website for resources on ASD, AT and low incidence disabilities:
<http://www.ocali.org>
amy_bixler@ocali.org

Some of Our Favorites

