Autism and the Family Connection
The Critical Role of Family

Participants will...
• Understand why family (immediate and extended) plays a significant role in the health and well-being of a child with autism.
• Understand some of the neurological underpinnings of the responses and actions of individuals with autism.
• Gain an understanding of some practical ways that family members can help the family of a child with autism.
• Learn some of the ways that they can be unhelpful or counterproductive in their responses to autism and decisions around raising the child with autism.
• Be inspired and motivated to be the best they can be for their families.

E + R = O
Event + Response = Outcome
What are the EVENTS?

Treatment decisions  Family response

Autism Diagnosis
Waiting lists  School
Behaviour  Decisions

The only thing we can control...

Event +
Response = Outcome

Autism Taught Me...

We can choose:
• Our thoughts
• Our behaviour
• Our dreams and images
You must take personal responsibility. You cannot change the circumstances, the seasons, or the wind, but you can change yourself.

Jim Rohn

The potential you hold is life changing

Changing what you can...

Find the Gift

Maintain Optimism

Build relationships

Build your knowledge, credibility and skills
Find the gifts of autism:

A child with autism taught me to:

- Reach beyond what I thought I was capable of doing
- Live in the present
- Re-evaluate my meaning of success
- Celebrate life’s small gifts
- Build relationships
- Value differences

Maintain Optimism

Adversity is temporary
Can be overcome by a “can do” attitude and strong persistence
Leave all negativity, self defeat and resentment at the door
Optimism is learned

What attitude are you modeling?

Anger? Hostility? Resentment?
Fear? Blame?

OR

Hope? Persistence? Faith?
Optimism? Collaboration?
Build Relationships

“The way a team plays as a whole determines its success. You may have the greatest stars in the world, but if they don’t play together, the club won’t be worth a dime.”

Babe Ruth
The Role of family:

- Roots to a child - a past and a future
- Nurture emotional health and well being in children with autism and their siblings
- Role model
- Physical presence

“Grandparents can be role models about areas that may not be significant to young children directly but that can teach them about patience and courage when we are ill, or handicapped by problems of aging. Our attitudes toward retirement, marriage, recreation, even our feelings about death and dying may make much more of an impression than we realize.”

Eda LeShan

What Does NOT Help?

- Questioning the diagnosis and insisting on getting a second opinion
- Ignoring attempts to explain the diagnosis and behaviour
- Dismissing the explanation provided by parents or doctors
- Blame
- Insisting on certain treatments or therapy
What Does NOT Help?

- Information overload
- Concentrating your attention on the child that does not have autism
- Emotional distance
- Overstepping boundaries
- Playing non-interference: “We do not want to meddle.”

“BEING THERE”

- Affirm and love the parents
- Listening to what is said and what is not said
- Accepting the child “as is”
- Keep the disability in perspective
- Listening
- Be positive and hopeful
- Adhere to the limits and schedules established

Are you really listening?

Listening means:

- Hear someone out and try to comprehend another point of view
- See the world through someone else’s eyes
- Not always having the answers and solutions
- Hear the offhand remarks and what is not said
- Focus on the emotion behind the words
“Doing”
- Provide respite opportunities
- Spend time with the siblings of the exceptional child
- Play
- Read with the child
- Share special interests
- Encourage the child’s independence

“If we make our goal to live a life of compassion and unconditional love, then the world will indeed become a garden where all kinds of flowers can bloom and grow.”

Elizabeth Kubler-Ross

Build your knowledge, credibility and skills
WHY is he doing that?

Processing Problems
Executive Dysfunction
Sensory Problems
Imitation Deficits
Weak Central Coherence
Mind Blindedness
Repetitive and Restrictive Behaviors
Social Communication and Language Difficulties
Anxiety
Executive Dysfunction
Weak Central Coherence
Mind Blindedness
Repetitive and Restrictive Behaviors
Communication and Language

Expressive difficulties:
• A lot of words but no meaning
• What happened at recess?
• Can we talk about something else?
• Why are you talking like that?
• More dialogue please!

Communication and Language

Receptive difficulties:
• It was just a joke!!
• I read it but I don’t get it!
• I heard you but I don’t get it!
• I heard you but I don’t know what you said
• Do you want me to look at you or hear you?

Don’t assume that a verbal individual understands you and that a non-verbal individual lacks understanding!
Autistic thinking

Repetitive Routines, Behaviours and Movements

- What do you mean we aren’t going to library today???
- Inflexible thinking and behavior (brainstorming, problem solving, multiple meanings…)
- Why does he keep doing that?

What you might see...

- Continue using an ineffective strategy
- “Why isn’t it working?”
- Less likely to learn from mistakes
**Problem Solving**

**My way!**

**Socializing and relationships**

- Misunderstanding of or inattention to facial expressions in others
- Perimeter walkers
- Prefer to be alone OR does not know HOW to “be” with others
- Lack social thinking: inappropriate comments or responses

**Problems with Play**

- Seems to not know HOW to play with toys or children
- Lacks a soundtrack
- May play by himself
- Intense reaction if play does not go his way (rules)
- Extreme difficulty sharing toys
- Lacks imaginative play (sticks are swords)
Emotional Difficulties

Communication Impairment

Hardwired for Sameness

Sensory Issues

Overactive Amygdala

Cognitive Inflexibility

Problems with Abstract thinking

Emotional Hijacking

Hypersensitivity:

Overly reactive to sounds, lights, fabrics, food textures, smells

“One of my sensory problems was hearing sensitivity, where certain loud noises, such as a school bell, hurt my ears. It sounded like a dentist drill going through my ears.”

Temple Grandin
Hypo sensitivity

- May seek deep pressure (bang into things and people, hug really hard)
- Unaware of clothes “falling off”
- Oblivious to smells
- Unaware of where his body is in space (movements are big and all over the place)

“Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life.” — Therese Jolliffe

Is it any wonder that our children with autism OVER REACT?
Behaviour is Communication

I need your attention.
I need something tangible.
I need to change something.
I need to escape or avoid something.
I need to self regulate.

Surviving Meltdowns and Tantrums

Weathering the Storm

1. Stay completely calm.
2. Nix any notion that the child is a brat.
3. No discussion.
5. Remind yourself that your own competence is not in question.
6. Calmly and safely remove him from the environment.
To sum up... A student with autism may struggle in these areas:
Communication and Language
Cognitive deficits and patterns of thinking
Social Interaction
Emotional regulation
Anxiety
Motor Issues
Visual differences

Thriving Day by Day
• Stop talking so much!
• Reframe questions into statements
• The gift of rituals
• Routines and schedules
• Use pictures, diagrams and written word to “show” what you are saying

Thriving Day by Day
• Transition tools
• Checklists and Rules
• Organization support
• Choices
Through it all, REMEMBER...

What are we working towards?

**Autonomy**
Every task, every skill needs to be taught so that the student will complete it as independently as possible.

What happens when we...

- Fail to fade prompts
- Rescue individuals from struggle
- Play helicopter parent
- Avoid personal responsibility
Putting it in Perspective...

Child to Mom in response to whether to disclose his autism diagnosis:

“You know mom, I am so much MORE than my autism.”

The potential you hold is life changing

I wish you joy on the journey!

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