



IMPACTING AUTISM THROUGH EARLY INTERVENTION

Suspicion, Diagnosis and "... the power of the tongue":

Why we must start with HOPE!

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Spectrum Possibilities

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THE DRIVING FORCE

We accept that early intervention is critical, but early intervention does not happen if:

- 1) Parents don't believe it is necessary
- 2) Intervention is seen or experienced by parents as a problem, an intrusion and not a positive thing
- 3) Early Intervention resources are not truly available, accessible and affordable
- 4) Parents don't emotionally invest in HOPE for their child's future

Parents are the driving force of Early Intervention!



WHY MUST WE START WITH
HOPE?

**No parent wants to hear anything
bad about their child!**

So how can you convey something potentially
scary and painful in a way that inspires action?



THIS IS NOT EASY

Some possible feelings around the suspicions and diagnosis:

Anger and Resistance – I don't want to believe this

Uncertainty and Fear – What will happen to my child? Will my child fit it?

Grief – This is not how it was supposed to be

Self-doubt and Guilt – Did I do something wrong? Did I cause this?

Shame – What will people say? Will they judge me and my child?

Despair - Why is the happening to me/us and my/our child?

Confusion – What do I do now? Where do I go?

Powerlessness – I do not know what to do to fix this

Relief – I knew something was not right

Overwhelmed – I can't deal with this

SUSPICIONS AND DIAGNOSIS OCCUR WITHIN A CONTEXT

- ❖ The context of a **dynamic family** with life happening, overlapping, negotiating many plans and experiences
- ❖ The context of a **relationship/marriage** between parents
- ❖ Context of **other children** with needs - babies, 11+ exam, teenagers
- ❖ An emotional context of **hopes, dreams, goals and plans** for the child, individuals in the family and the whole family as a unit – e.g. Should we have more children? What about my further studies?
- ❖ A context with **economic and employment considerations – Autism intervention is expensive**
What can we afford? Should I work or not?
- ❖ Context of **culture – intolerance for behavioural differences and actions outside the social norm; invisibility of people with autism**
- ❖ Min of Education has a **three year waiting list** for intervention
- ❖ Medical professionals have **no answers** and **don't agree with parent's feelings or beliefs - TRUST**
- ❖ A context of meaning, values and beliefs – what does it mean to each individual and the family as a whole?



GLOBAL CONTEXT

Parents experience references to autism in a wider global context

For example news reports in USA:

- ❖ Girl with autism and her family removed from a plane;
- ❖ Boy with autism found dead after wandering;
- ❖ School mass shooting suspect thought to have Aspergers/autism
- ❖ Heavy message in media against many parents' views on autism causes



DIFFICULT TO NEGOTIATE THE CONTEXT

Parents have to negotiate the suspicions/diagnosis relative to all those factors in the context of their whole life and that is very stressful, takes time and is difficult to do

Early Intervention often requires a lot of complex decision making about choices and priorities, reorganizing lives and sacrifice



INSPIRING MOVEMENT

**How does a parent move from all those
considerations and emotions
to taking action towards
Early Intervention?**



WE MUST:

- ❖ Think
- ❖ Believe
- ❖ Feel
- ❖ Speak
- ❖ Behave/act

In terms of HOPE!

WHAT IS HOPE?

DEFINITION OF HOPE (dictionary.search.yahoo.com)

Verb: to wish for a particular event that one considers possible

Noun: the longing or desire for something accompanied by the belief in the possibility of its occurrence

WHAT DOES HOPE LOOK AND FEEL LIKE?

Wishing and longing and believing in a possibility. Yearning for something not easily attainable.

So we have to inspire parents to consider the possibilities for their child and to light and fan that fire of HOPE.

WHO INSPIRES PARENTS TO BE HOPEFUL?

- ❖ **Psychologist/psychiatrist** - gives the diagnosis but may only see the child and parent for a maximum of 2 hours in one session or a series of sessions across several months or may not see them for years, if ever again
- ❖ **Therapists (ST, OT, PT etc.)** - see child 45 mins/1-2 hours a week on average
- ❖ **Caregivers** – Aunties at nursery, aides, grandparents spend most time with kids next to parents.

Every professional, doctor, therapist, caregiver the family interacts with should be hopeful for the child's future and inspire parents to seek Early Intervention as the way towards the most positive outcomes in the future.



PLEASE NOTE

Do not argue with parents about their child with autism.

Maternal instincts on overdrive, adrenalin in Mama Bear mode, protective of baby, fight of flight on. This is the energy and power that drives towards a hopeful outcome.

Sometimes what looks like resistance is really strong emotions activated to protect a child or to protect the original hopes for life expectations prior to autism. If you break that or trigger the fight or flight response, early intervention is over.

Or it may be over with you!

Parents need time to work through intense, powerful and complex emotions before thinking about early intervention and making big decisions. Sometimes parents start to act towards intervention while still struggling with difficult and conflicting emotions. They need the opportunity to redirect from the old hopes and dreams to new hopes, but the way forward is not easy to see.



‘NEW HOPE’ REPLACES
OLD HOPES

**You have to encourage a vision of
‘NEW HOPE’
to gradually replace old hopes
before any or all hope is destroyed!**



SIMPLISTIC VIEW “DENIAL” VS “ACCEPTANCE”

Denial

- ❖ Deny that development is not on target
- ❖ Deny the need to see a psychologist/psychiatrist
- ❖ Deny the suspicions
- ❖ Deny the diagnosis

Acceptance

- ❖ Accept that something is not quite right developmentally
- ❖ Accept that professional help is needed
- ❖ Accept the diagnosis

COMPLEX REALITY OF DENIAL AND ACCEPTANCE

Denial

- ❖ An immediate reaction of resistance/ refusal to difficult information or feelings that can become entrenched
- ❖ Denial that your child's life will be very limited
- ❖ Denial that medical issues unrelated
- ❖ Denial of stereotypes about your child when don't see the uniqueness of your child

Acceptance

- ❖ A process that takes time, no need to rush
- ❖ You can question, second opinion, investigate all areas like medical issues beyond diagnosis
- ❖ What are you accepting? Lifelong incurable disorder; limited life, etc. You decide what you will accept and what you will discard

NOT SO SIMPLE

It is not so simple that all denial is bad and all acceptance is good!

Denial

- ❖ You can deny that anything is wrong and do nothing at all
- ❖ You can deny that what you're being told is the whole picture and investigate further
- ❖ You can see the unique capacity in your child and ignore or reject limiting systems

Acceptance

- ❖ You can accept the diagnosis quickly, not question anything and decide there's nothing you can do
- ❖ You can accept the diagnosis, but not allow it to change your life and limit the interventions to operate within your comfort zone
- ❖ You can accept the diagnosis but focus on the person and their potential and decide your child won't be limited by labels and do all you can to advance their development



OR

You can accept the things that make sense and work for you and reject the things that don't, revisiting the issues as time passes while you learn more, understand your child's unique experience of autism and figure out the best approach.

You don't have to accept everything you've been told or reject everything, you can be somewhere in the middle while you chart the course ahead.

But you have to act as soon as possible and facilitate the intervention your child needs.



SETTING-UP FOR A DENIAL RESPONSE

- ❖ If the real experiences of the parents don't match the stereotyped limitations, there may be denial
- ❖ If strengths are not acknowledged but only weaknesses, there may be denial
- ❖ If a negative future is presented rather than a hopeful one, there may be denial
- ❖ If parents can't see how the life they planned and invested in can work with the challenges they are likely to face, or if they have to sacrifice more than they are willing to/capable of, there may be denial
- ❖ If the picture being presented does not match what parents see, believe or want to believe, there will likely be denial
- ❖ If the diagnosis is not presented sensitively and with HOPE, there may be denial



A COMPLEX CONTINUUM

Denial and acceptance are experienced along a continuum which can go back and forth during periods of re-experiencing grief and uncertainty, upon the reminder of losses and expectations at various milestones across a lifetime.

Acceptance is a **PROCESS**

that must begin with **HOPE** if it is to inspire action/intervention.

We do not want parents to accept the diagnosis without a sense of **HOPE!**

Sometimes rejecting a diagnosis can be an attempt at remaining hopeful.



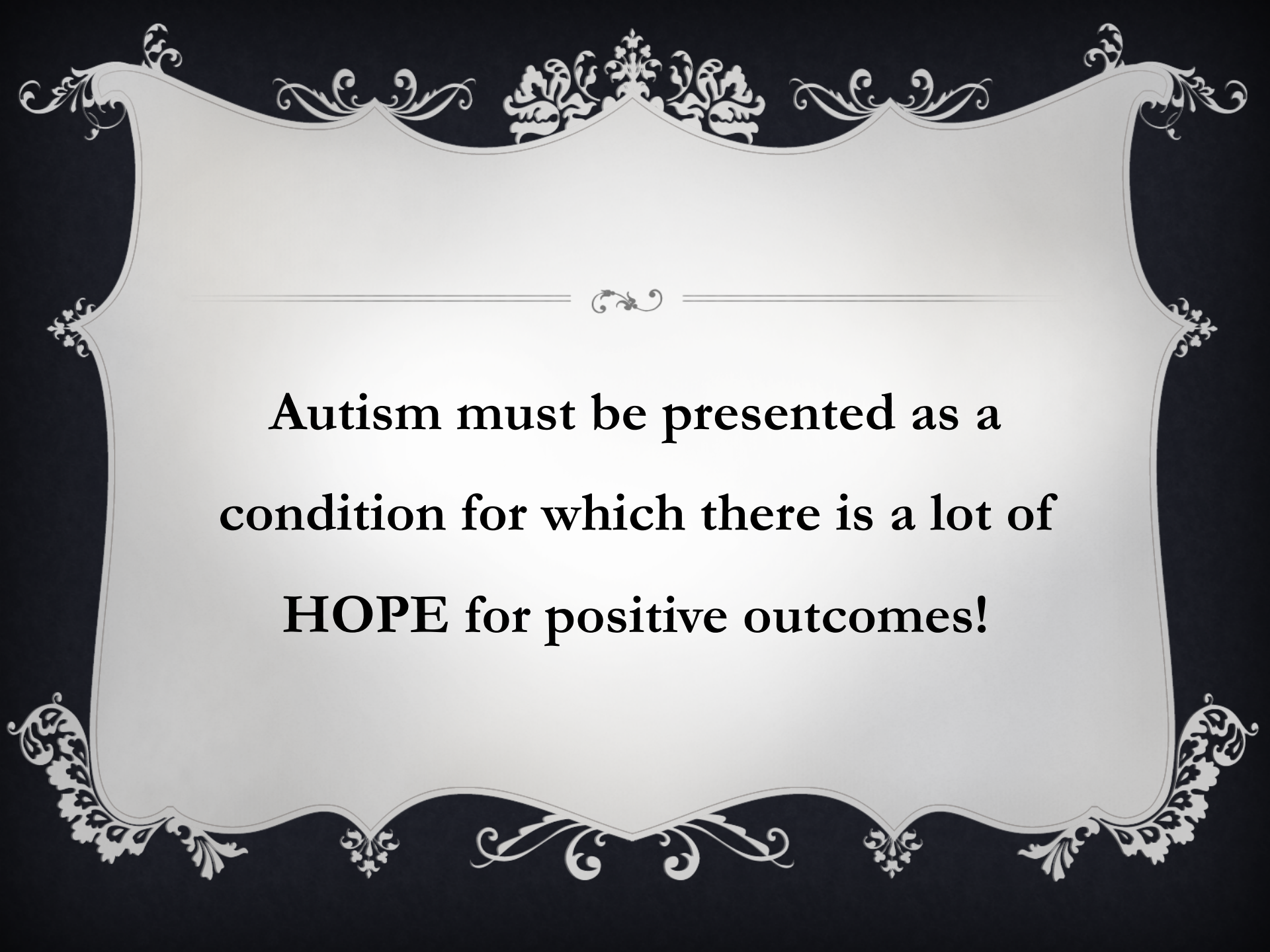
A SPACE FOR NEW HOPE

Parents need a trusted, safe, comforting, patient, non-judgmental and positive space of support while they process all this.

Professionals and therapists in this field need to allow parents the time to work through these complex deeply personal, emotional and spiritual issues and experiences and maintain a flexible, non-judgmental approach while focusing on how to help the child as soon as possible.

The goal is to get that child help as soon as possible, do not make yourself an enemy of the parent, as they struggle with that continuum of denial and acceptance.

Give them that space while putting things in place to help.



**Autism must be presented as a
condition for which there is a lot of
HOPE for positive outcomes!**



HOW DO WE START WITH HOPE?

- ❖ LISTEN TO PARENTS!! - Much of what parents are told about autism does not match the reality they are experiencing with their child. E.g. not loving and affectionate. You must respond to their unique experience with their child. Do not speak from stereotypes.
- ❖ Eliminate judgment and be sensitive to how challenging it is to accept and figure out what to do about an autism suspicion/diagnosis
- ❖ Be understanding, compassionate and hopeful yourself, believing that things can get better



HOW DO WE START WITH HOPE?

- ❖ Speak from a place of hope and not despair
- ❖ Believe that each child can improve
- ❖ Don't set any limits on the outcome
- ❖ You have to connect with and touch the heart of a parent so they can move from a place of hearing a diagnosis and feeling overwhelmed to seeing possibilities
- ❖ You need to be informed of the current understanding of autism and not the traditional views, as parents will be reading information online. There is new research all the time - new understanding, new approaches, new therapies and interventions



PROVERBS 18 VS 21

“Death and life are in the power of the tongue.”

WHAT YOU SAY MATTERS!

Your words can make the difference between
activity and inactivity

(both in an immediate and long-term sense)



WATCH WHAT YOU SAY!

- ❖ Our kids with autism hear your words and are influenced by them in how they perceive themselves
- ❖ Your words influence how other kids interpret and interact with the child on the spectrum
- ❖ Things you say to other parents can encourage or discourage them from supporting parents coping with a child on the spectrum



RECOGNIZE EVERYTHING AS IMPORTANT AND RELEVANT

A number of medical conditions often accompany autism and are often related to the autism biochemistry

- ❖ Allergies – food and environmental
- ❖ Asthma
- ❖ Eczema
- ❖ Gastrointestinal problems
- ❖ Seizures
- ❖ Mitochondrial disorders
- ❖ Metabolic disorders

DIAGNOSIS IS NOT PROGNOSIS

Diagnosis: identification of the characteristics meeting certain criteria

Prognosis: forecast of the likely outcome

We know right now it looks like this,
but we don't know what will happen in the future

Diagnosis

INTERVENTION

Prognosis

(Between diagnosis and prognosis is intervention)

What you do makes the difference in the developmental trajectory



BIGGEST OBSTACLE TO EARLY INTERVENTION

Parents must have the capacity for HOPE

- ❖ A VISION of what is possible for their child
- ❖ A pioneering spirit to do new things you/they never expected they'd have to do
- ❖ Access to models, success stories and examples of HOPE
- ❖ Access to therapeutic resources
- ❖ Starting from or getting to a place in life where they can see a way forward
- ❖ A belief system that supports hope and supporters who are also hopeful
- ❖ Parents need support adjusting what they're doing as their understanding of what is needed changes



FOR NURSERY PROFESSIONALS FIRST RESPONDERS


Determine the Procedure for addressing suspicions

- ❖ Bringing signs you've noticed to the attention of superiors
- ❖ Note taking and observations with examples - this will be important to help parents gather info for assessments
- ❖ Determine who is responsible for managing the child's case
- ❖ Determine who speaks to the parents. Please choose a sensitive, compassionate person



DELICATE SITUATION

- ❖ Some parents need confirmation of suspicions
- ❖ Some parents don't want to believe anything is wrong
- ❖ We don't know what is wrong until it is assessed by a qualified professional
- ❖ Who is qualified to diagnose?
- ❖ When formal assessment does not occur, and suspicions remain, what then?
- ❖ What is your responsibility?



What do you believe?

**You must believe that a difference can be made by your actions in order to
inspire HOPE.**

Your goal is to accelerate action in an environment that can easily stall it.

When you speak and act from a place of

HOPE

all things are possible!



WHAT IS YOUR HOPE FOR THIS CHILD?



Let's look at some of the possibilities:

COMMUNICATION

- ❖ Movement from non-verbal to pre-verbal to verbal and echolalic to conversational
- ❖ Acquisition of speech, language and communication
- ❖ May need the support of technology to communicate

SOCIAL INTERACTION

- ❖ Gains social skills – eye contact, flexibility, interaction
- ❖ Makes and maintains friendships
- ❖ Live and included and fulfilling life

BEHAVIOURAL MANAGEMENT

- ❖ Sensory integration and emotional regulation
- ❖ Dynamic and spontaneous interaction

DEVELOPMENT OF COGNITIVE AND ACADEMIC SKILLS

MAXIMIZED POTENTIAL

WHAT CAN YOU SAY?

What to say

I have attended some seminars/courses and been doing some reading on developmental challenges.

I have noticed a few things I think we might want to keep an eye on.

It is best to check these things out early in case there is something that needs to be addressed.

If something is found then we can all address it early together to ensure the best possible future.

Here is some information you can read and some resource persons you can contact.

We are here to help so don't feel you're on your own

We're willing to learn with you and support you.

What not to say

- ❖ Something is wrong with your child
- ❖ Your child has a problem
- ❖ You need to do something fast
- ❖ You are in denial
- ❖ Do not say words like disorder, retarded, slow, delayed, etc.
- ❖ Your child has autism

WHO IS QUALIFIED TO DIAGNOSE?

- ❖ Developmental pediatrician
- ❖ Pediatric neurologist
- ❖ Child psychologist
- ❖ Child psychiatrist

Who from professional experience can suggest likely possibilities and recommend referrals above?

- ❖ Speech therapists
- ❖ Occupational therapists

They can also begin to work with your child prior to confirmation of any diagnosis. This is Early Intervention



PLEASE NOTE

Many (but not all) parents prefer to hear and say their child HAS AUTISM and not their child “is autistic”.

- ❖ To have autism means there is potentially something you can do to lose it and some children can lose their diagnosis
- ❖ More importantly it does not label them and limit them to being a one-dimensional person
- ❖ Never met a parent who has a problem with “has autism” but met many who have a problem with autistic

Please try not to turn off parents

HOPEFUL SUGGESTIONS

Create a hopeful atmosphere:

- ❖ Collect a library of books about autism, autism therapeutic interventions, and Biomedical treatment
- ❖ Maintain a list of websites and FB pages on autism and autism treatment e.g. TACA Talk About Curing Autism; ARI Autism Research Institute; Autism Treatment Center of America; AutismOne; Nourishing Hope for Autism; Autism File; Generation Rescue; Spectrum Possibilities etc.
- ❖ Post notices of upcoming webinars and courses on autism e.g. ICDL Floortime courses
- ❖ Maintain a list of local contact persons, autism groups and charities and be in contact with them



HOPEFUL SUGGESTIONS

- ❖ Recommend a support person/mentor or support group
- ❖ Facilitate presentations at PTA meetings or in small groups with invited therapists and support persons
- ❖ Keep an open door for parents to talk when they are ready or feel the need
- ❖ Become aware of dietary intervention for autism and provide allergen friendly foods at school events (no foods that may escalate problematic behaviours like food dyes, artificial sweeteners, sugary foods, etc.)



PROVIDE DEVELOPMENTAL CHARTS FOR PARENTS

- ❖ Parents have to have the capacity to acknowledge and recognise that something is not developing as expected
- ❖ Parents need to know the signs of typical development and developmental problems
- ❖ Parents need support to identify the problems and what to do
- ❖ Parents have to understand why they need to seek help ASAP

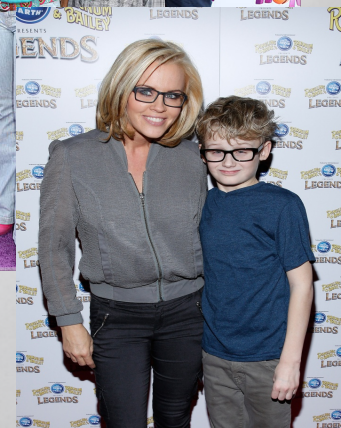
EXAMPLES OF HOPE

Celebrities

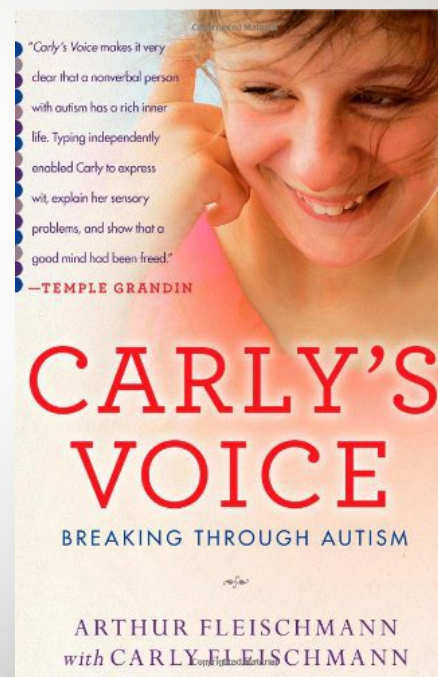
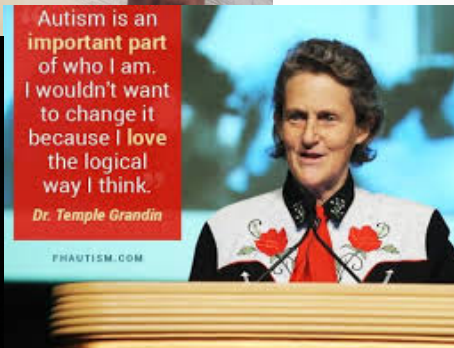
- ❖ Toni Braxton
- ❖ Holly Robinson-Peete
- ❖ Jenny McCarthy

Local Mums

- ❖ Sen. Patricia Inniss
- ❖ Tracey Knight
- ❖ Deborah Thompson-Smith



EXAMPLES OF HOPE



TREATMENT SPECIALISTS

Check out their websites, Facebook pages, email, telephone and ask questions, watch their webinars

Skype consultations possible

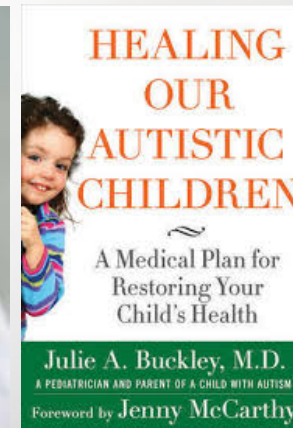
Seizures – Dr. Richard Frye

GI Disorders - Dr. Arthur Krigsman

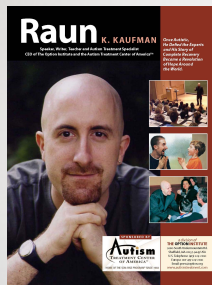
MAPS doctors - Medical Academy of Pediatrics for SN

Biomedical Pediatrician - Dr. Julie Buckley

- ❖ Dr. Buckley has been to Barbados and will be back
- ❖ She presented on Biomedical treatment to doctors
- ❖ Several doctors have her book on biomedical treatment and it was donated to the QEH
- ❖ Her office is in Florida and approximately 6 local families are already in contact with her and/or being treated by her



STORIES OF RECOVERY



Not everyone will totally “recover”. Recovery does not mean perfection, but it is a process through multiple (sometimes few) interventions of gradually and sometimes rapidly regaining lost skills and learning new ones till functioning reaches the level where you can no longer identify symptoms of autism.

The possibility of recovery means that there is HOPE!



HOPE IS THE FOUNDATION!

**Parents' HOPE is the driving force and thread/cord/rope
gently pulling, stretching and connecting
the progressive steps in the child's development
across their lifetime**

**Starting with HOPE lays the foundation
to continue with HOPE.**

THANK YOU



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