



What Families Have Taught Me

- Over 25 years of caring for families as a developmental and behavioral pediatrician
- It has been an honor to share in the life course of thousands of families who have a child on the autism spectrum
- This talk will summarize what I have learned in 10 fundamental lessons that span the course of life
 - From initial diagnosis to early adulthood
 - To help the child reach their full potential
 - Goal: Happiness & a meaningful life
- Key 'touchpoints' or turning points in the life & educations of the child and family
- Let's set the stage with a discussion of neurodiversity and the developmental urge to grow toward one's potential



What is a Neurodivergent Individual?

- Neurodivergence is the term for when someone's brain processes, learns, and/or behaves differently from what is considered "typical"
- 'Person first' or 'Identity first' language?
- The 'Neurodiversity Movement' embraces differences and promotes a path to the potential within each person
- I hope to describe that path common to all children and adolescents



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What It All Starts With...

It all starts
with...
The
Acceptance
Paradox

By accepting the child <u>exactly</u> where they're at developmentally, that is the best way to help the child make progress toward their full social potential!



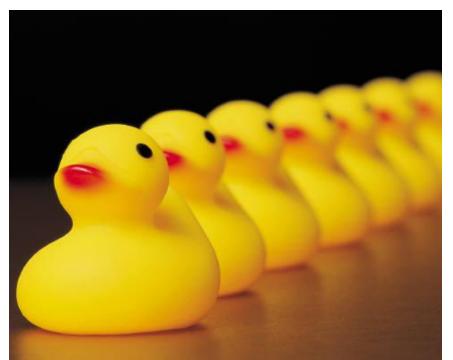
What makes autism autism?

- Genetic condition influenced by the environment that causes the brain to have 'under or over connected' neurons
- Like a loose network of nerves that can't capture the complexity of the world (especially the social world).

 This creates the tendency of the child toward repetition and the need to 'keep the world

the same'.

 The child with autism tends toward social self absorption and repetition.

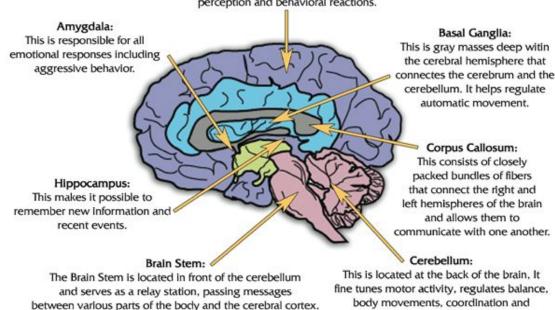




Parts of the Brain Affected by Autism

Cerebral Cortex:

A thin layer of gray matter on the surface of the cerebral hemispheres. Two thirds of this area is deep in the tissues and folds. This area of the brain is responsible for higher mental functions, general movement, perception and behavioral reactions.

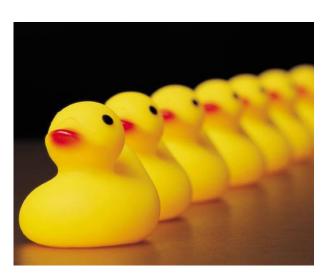


It controls the primitive funtions of the body essential to survival including breathing and heartt rate. the muscles used for speaking.



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What makes autism autism?

Difficulties & Strengths

Difficulties

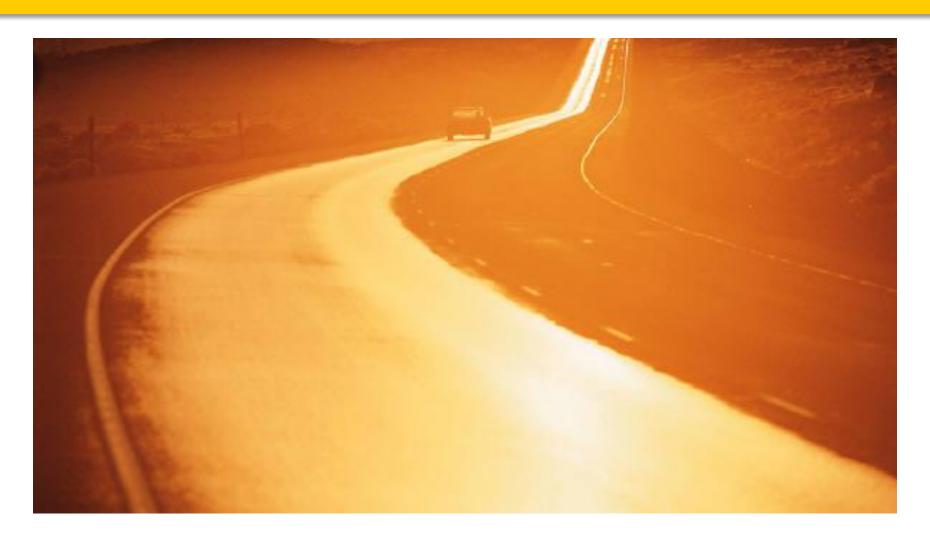
- Dominated by sensations
- Trouble with transitions: Keep the world the same
- Difficulties with social interactions
- Anxious, easily overwhelmed by demands

Strengths/Potential

- Neuroplasticity
- Experts
- Great memories
- Learn facts
- Mechanically inclined



The Course of Life Is A Path





10 Lessons: The Framework

- Playfulness
- Developmental
- Relationships
- Types of progress
- Touchpoints/turning points in the course of life



The Definition of 'Play'



The 5
Characteristics
of Play?



Joyful

Engaging

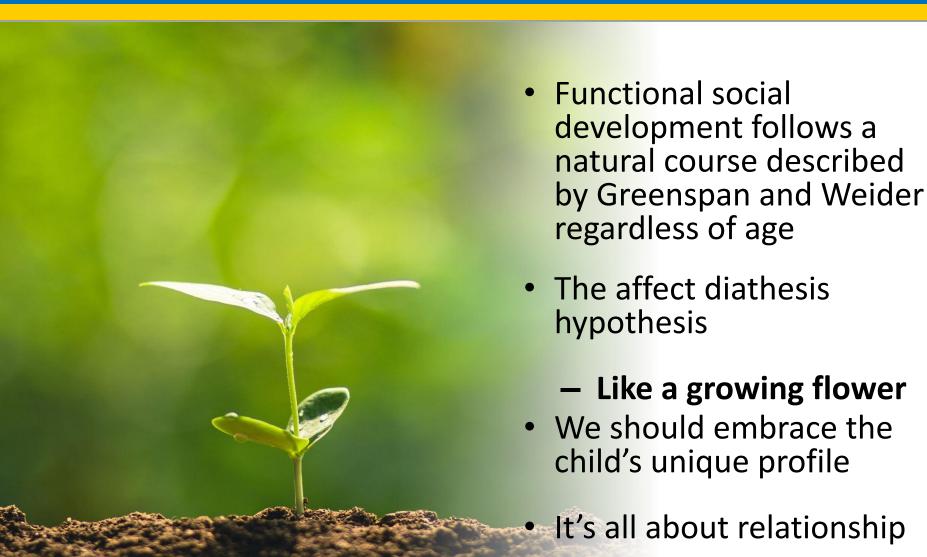
Social

Meaningful

Iterative



The Nature of Development





Relationships

- Drive development
- Individualize interaction
- Lead to engagement and interaction

When you do what the child loves the child will love to be with you and others!







9 Functional Developmental Levels*

- 1. Self regulation and shared attention (FDL 1)
- 2. Engagement (FDL 2)
- 3. Two-way Communication (FDL 3)
- 4. Complex two-way Communication (FDL 4) (18m)
- 5. Shared Meanings & Symbolic Play (FDL 5—2y)
- 6. Emotional Thinking (FDL 6—3-5 year olds)
- 7. Multi-causal Thinking (FDL 7—5-7 years old)
- 8. Shades of Gray Thinking (FDL 8—8-12 year old)
- 9. Thinking off an Internal Standard (FDL 9—13+ year old)

^{*}Greenspan and Weider



The All Important FDL 6!

- Talking in short to long sentences
- 'Why' and 'when' questions.
 - Understands cause and effect; Builds bridges between ideas
 - Two ideas connected logically
 - Lives in time. Can recall the immediate past (what did you eat for breakfast?)
- Identifies own and others' feelings
- Recognizes relationship between feeling, behavior, and consequences
- Two thematic play
- Can carry on simple conversations
- Can play with peers
- Misbehavior as developmental accomplishment



FDL 6: Who's Turn





The Definition of 'Play'



The 5
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Joyful

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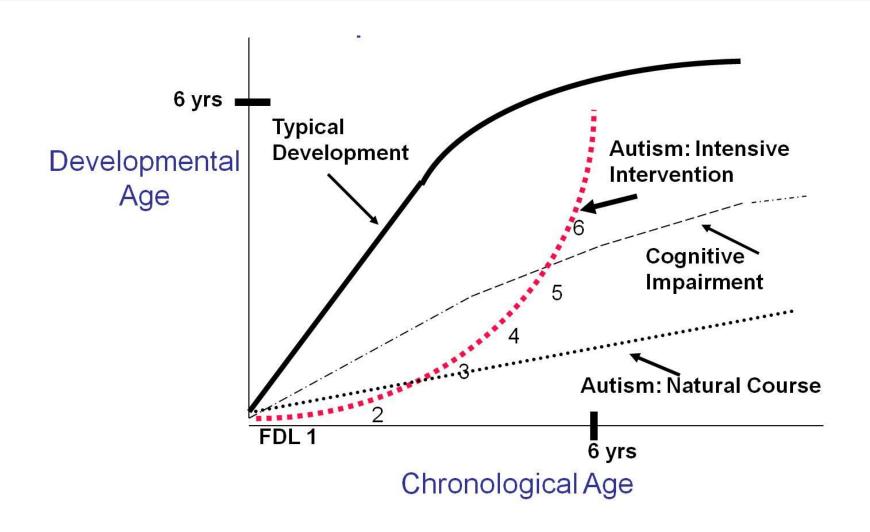
Social

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Developmental Course of Autism





Three Types of Progress





'Setting the Bar' at the Right Level





The Values Families Hold Dear

- For faster movers, the path leads to high school diploma and a college education.
- For middle movers, the path leads to self sufficiency with or without full time work (work is over-rated!)
- For slower movers, the path leads to reaching for one's fullest potential along the lines that I will describe:
 - Marked by continuous developmental progress
 - Improved social connectedness
 - A life that is playful, fun, meaningful, happy and growth oriented,
 - All families want a better relationship with their child and they want their child to reach their full potential



Principle #1: Fun With People

"When you do what the child loves, the child will love to be with you."

—Dr. Rick

Lesson #1

Intensive Early
Intervention Matters!









Autism: 10 Lessons

Early
Diagnosis &
Intensive
Early
Intervention

Pre-school and Kindergarten Readiness

Early
Elementary
School

Late
Elementary
Middle and
High School
(Adolescence)

Post High School and Transition to Adulthood



Lesson #1

Start as early as possible

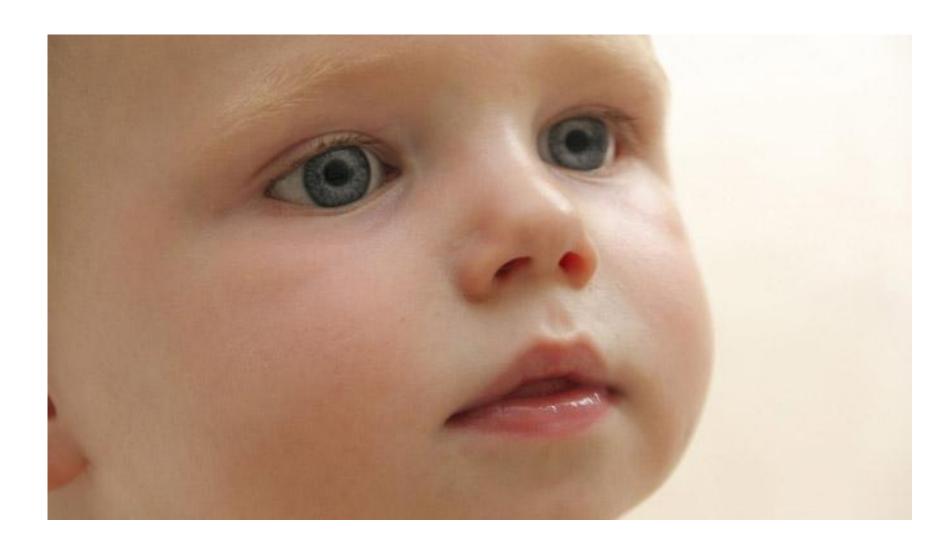
- 14 months
- 6 months? 'Red flags' will do

New research on early identification is growing

- Genes
- Blood markers
- Eye tracking
- Siblings at risk



6 Month-old Babies with Autism Prefer Objects to People





Screening and Early Diagnosis

- Symptoms can manifest as early as 6 months
- Can be reliable diagnosed by 14 month in most children
- Pediatricians are screening for ASD at 18 and 24 months
- The M-Chat is the best screening tool
- Gold Standard Diagnosis: An experienced clinician
- ADOS (Autism Diagnostic Observation Schedule) + Clinical evaluation
- Early dx leads to early intervention
 - Time is ticking





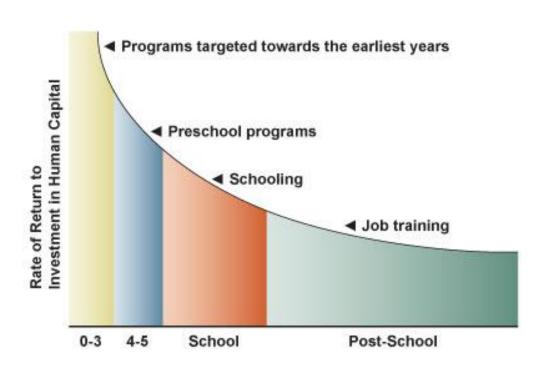
The Paradox and Red Flags

The Diagnosis
Paradox

- But you don't need an official diagnosis!
- Red flags are enough
- Problems with responding, sustaining engagement, being in their own world, doing their own thing. . . are enough
- To get insurance coverage you need a diagnosis
- But to begin early intervention you don't
- Start with play!



Programs by Age



Lesson #1

The Definition of 'Intensive Early Intervention'

National Research Council (2001)

- Begin early: 14 months-3 years
- 15-20 hours/week (2 hours/day)
- 1:1 or 1:2 adult to child ratio to start
- Engaging
- Strategic Direction
- Comprehensive programs address ASD



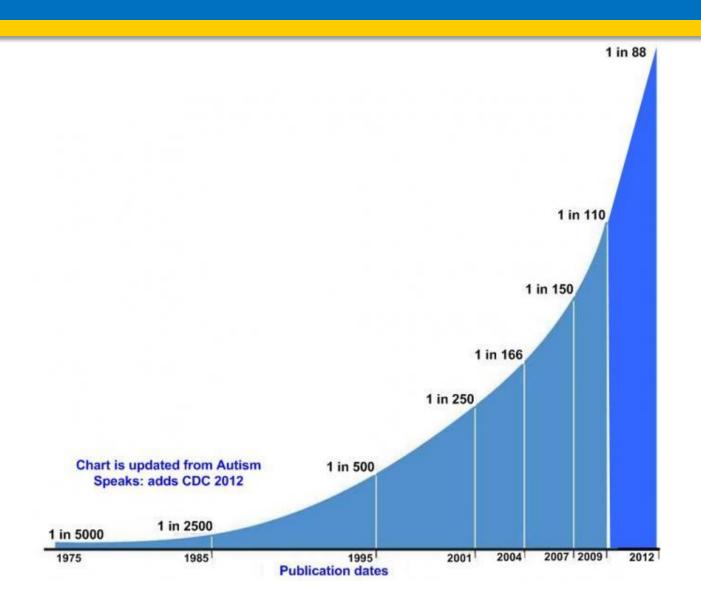
Intervention Options

- Developmental, Relationship-based Intervention
 - See Binns & Oram Cardy and NCAEP
- Applied Behavioral Analysis
- Combined: Early Start Denver, Project Impact
- Speech and Language
- Occupational Therapy
- Special Education
- Parent implemented vs. Professionally delivered
- Parents feel like they have been left hanging



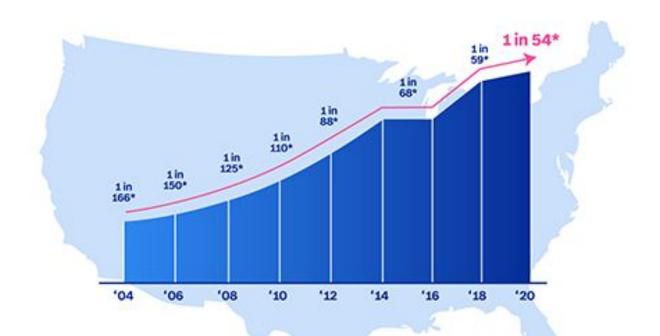


Autism Prevalence 1975-2012





Estimated Autism Prevalence 2020





Lesson #1

- With the dramatic increase in recognition of ASD, therapist delivered services can't meet the need
- Training parents is the best way to reach the most children
- More insurance companies are covering parent coaching models.
- See your references (Binns & Oram Cardy)



Good Prognostic Factors

- Early diagnosis
- Early intensive intervention
- Any words before age 2.5
- Splinter skills/special abilities early on
- High parental expectations
- Good response to intervention
- No hypotonia or motor delays
- No genetic findings
- Experienced guidance



Lesson #1 Summary

Start intensive early intervention as soon as possible

Diagnosis is not essential if the signs of ASD are present

Play based developmental models don't require an official diagnosis

For ABA in the USA a diagnosis is usually necessary

'Empowering parents through parent coaching models' is smart public policy



P.S. Limit Screens (1-2 hours max). . .



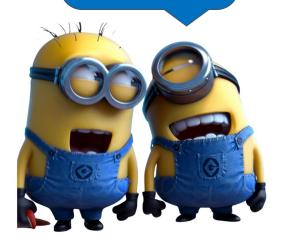


PPS

Why did the cookie go the doctor?



He needed a diagnosis.



I'm feeling kind of crummy.



Lesson #2

Parents- Be School Savvy!





Autism: 10 Lessons

Diagnosis & Intensive Early Intervention Pre-school and Kindergarten Readiness

Early
Elementary
School

Late
Elementary,
Middle and
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Post High School and Transition to Adulthood

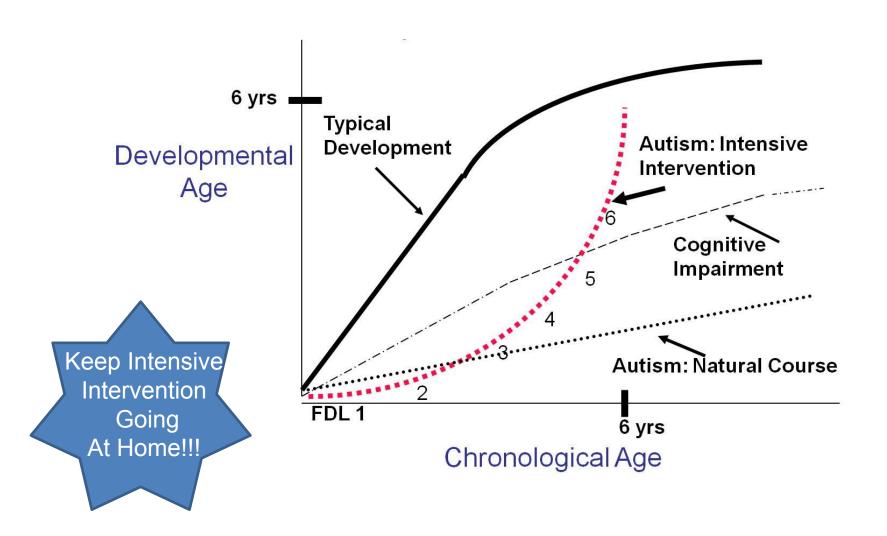


Lesson #2: Parents—Be School Savvy

- The initial period of 1-2 years of intensive intervention hopefully has helped the child move up to FDL 4-5 by age 3. Like Finn.
- The child is more connected socially, but receptive and expressive language are still developing
- As the child leaves early intervention and the child turns 3 years old, parents are considering pre-school.
- Special education services now include an IEP, Individualized Education
 Plan
- Parents encounter the school system.



Developmental Course of Autism





9 Functional Developmental Levels*

- 1. Self regulation and shared attention (FDL 1)
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Climbing the Language Mountain



Early Intensive Intervention is working on these FDLs



Lesson #2: Parents—Be School Savvy

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- The child is more connected socially but receptive and expressive language are still developing
- As the child leaves early intervention and the child turns 3 years old, parents are considering pre-school.
- Special education services now include an <u>IEP, Individualized Education</u>
 <u>Plan</u>
- Parents encounter with the school system begins.



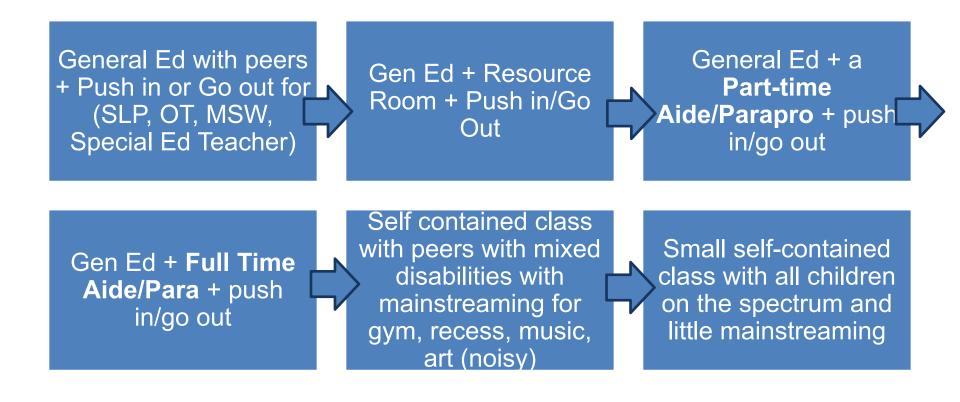
School & IEPs

- IEPs give parents a lot of power to determine their child's service profile. Know your rights!
 - Think of the IEP as a menu of options (restaurant analogy)
 - You can get whatever you want (within reason)
- Parents rarely feel empowered by the school systems
- The IEP offers a range of supports for the child from the least restrictive to more restrictive services
 - IEP, FAPE (Free and <u>Appropriate</u>),
 LRE (<u>Least Restrictive</u>
 <u>Environment</u>)
- In Ohio all pre-school are integrated; in Michigan few are





Least Restrictive (More inclusive) Environment (LRE)





"Thou Shalt Not Be The Highest Functioning Child In Thy Classroom!"

Lesson #2:

Inclusion is ...

- The less restrictive the better
- The child will model after other children
- Being with a range of children helps all children
- There is a growing sense of acceptance of differences and a feeling of belonging





School & IEPs

- The teacher is <u>THE</u> most important factor:
 <u>Structured and Nurturing</u> (can't pick)
- Parents: Trust your intuitions when checking out schools
- The most important thing:
 Put all requests in writing!
- Keep working on functional social development





School & IEPs

- Think about what you want your child to achieve
 - Interaction
 - Imagination
 - Emotion
 - Developmental
 - Social
 - Academic
- Write out what you want and give it to the school at the beginning of the school year
- The <u>Demands</u> of pre-school for compliance and routines are good









The more inclusive the better



Lesson #2 Summary



#2: Be School Savvy

- Keep working on the child's functional development by being savvy about the IEP process!
- Teacher: Nurturing and structured
- School as a restaurant. Know your menu of IEP rights.
 - LRE: Least restrictive
 - FAPE: Appropriate—IEPs that fit your child
 - What are YOUR IEP goals?
- Real inclusion leads to a feeling of belonging!
- "Thou shalt not be the highest functioning child in thy classroom."
- Put everything in writing



P.S. Limit Screens (1-2 hours max). . .





PPS.







Lesson #3:

EQ is More Important
Than IQ





Autism: Lesson #3

Diagnosis & Intensive Early Intervention

Pre-school and Kinder-garten Readiness

Early
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School

Middle and High School (Adolescence) Post High School and Transition to Adulthood



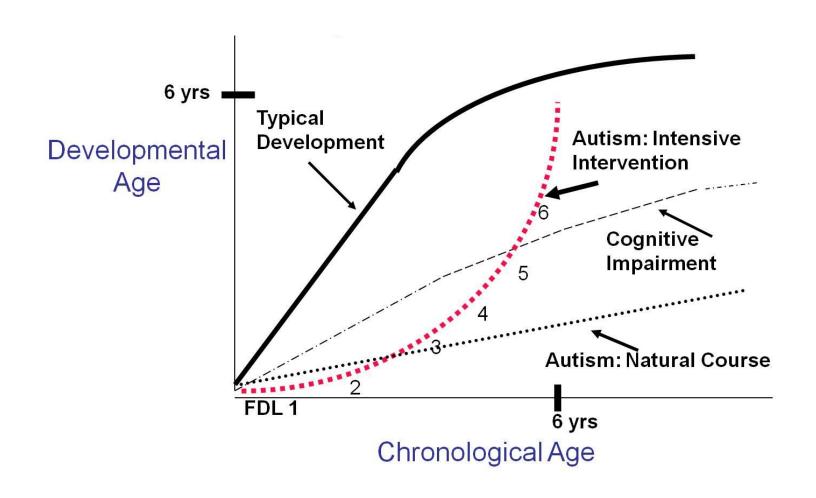
Lesson #3: EQ is More Important than IQ

- As the child progresses to FDL
 4-5 and turns 4-5 yrs old
- The Big 3 Developmental Domains:
 - Interaction
 - Imagination
 - Emotions
- Imagination
 - Pretend/Make believe
 - Sense of humor
 - Imagining the past and future
 - Imagining how others feel





Developmental Course of Autism





Simple Play



Simple (One Idea) Imaginative Play



- Everything come alive
- Trains that make train noises
- Animal sounds and pretending to be an animal
- Babies that eat
- Swords
- Monster chase
- Puppets with big mouths that talk and eat
- Doctor shots



Imaginative Play

More Complex (Two Idea) Imaginative Play

- Role playing
- Doctor
- Teacher
- Good guys and bad guys
- Taking care of babies





9 Functional Developmental Levels*

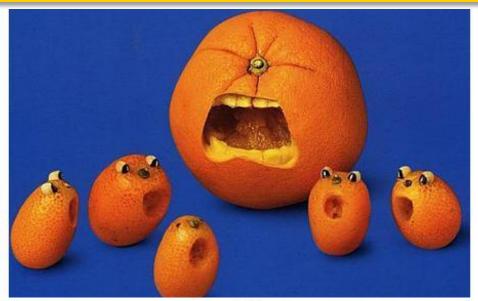
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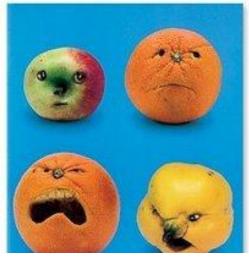
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Feelings

- When we recognize the autistic child's feelings
- By 'mirroring' back to them what they are feeling
- They learn to put words on their feelings
- Recent studies show that the amygdala which is the seat of strong feelings is less regulated in children with ASD
- They can be overwhelmed with impulses
- This leads to misbehavior
- "How to Talk So Kids Will Listen and Listen So Kids Will Talk"







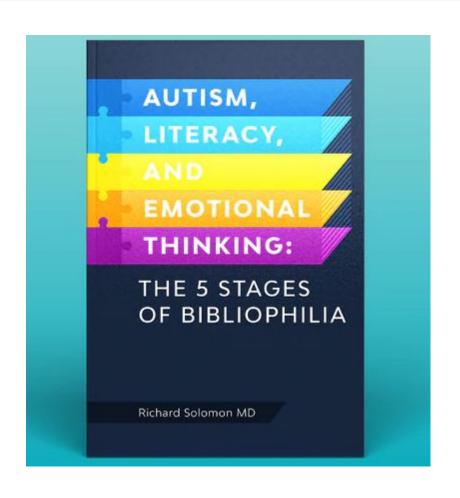


Over Time EQ Evolves with IQ

- Emotional intelligence requires the ability to live in time, connect ideas, and read other people's feelings
- IQ helps and should be nurtured
- Many children on the spectrum do well with letters, numbers, colors, shapes—the basic IQ of pre-school
 - The problem comes with true IQ—abstract thinking and problem solving—putting two ideas together logically
- Interaction, imagination, and emotional thinking pave the way
- Eventually the child understands books and develops reading comprehension (see Lessons 4-10)



Books & Reading Comprehension



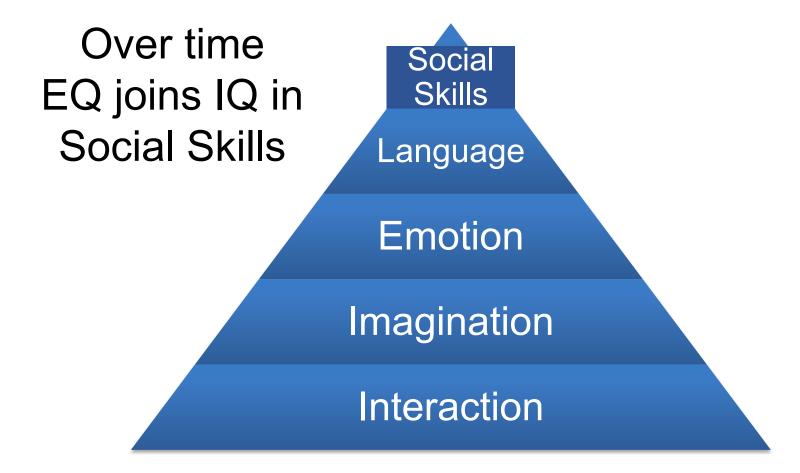


It's free and only 25 pages!

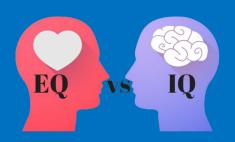
- See my new eBook:
 Autism, Literacy and
 Emotional Thinking
- Bibliophilia:
- The book (tastes good)
- The picture on the page
- The story on the page
- The story in the book



Development of Social Skills



Lesson #3 Summary



- EQ is more important than IQ
- So, promote emotional thinking through. . .
- Interaction, Imagination, and Emotions/Feelings to lead to social skills and better IQ
- Recognize and mirror back feelings
- Promote pretend play and imagination
 - One idea pretend
 - Two idea pretend
- Use books to promote EQ



P.S. Limit Screens (1-2 hours max). . .





PPS.











EQ is more important than.







Autism: 10 Lessons

Diagnosis & Intensive Early Intervention

Pre-school and Kindergarten Readiness Early Elementary School Late
Elementary,
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Post High School and Transition to Adulthood

Delay Kindergarten*

*Age doesn't matter!!

- The child is getting older and moving toward kindergarten.
- Hopefully, they are moving up developmentally to FDL 5-6
- Most kindergarteners are at FDL 6-7
- Sound-letter phonics is FDL 6
- Beware the 7 Habits of Highly Effective Kindergarteners
- It is here that parents have to make an important decision.
- Do I send my 5 year old to kindergarten?
 - I have advised parents to wait and have never heard a parent regret the decision. Wait until 6 or even 6 ¾



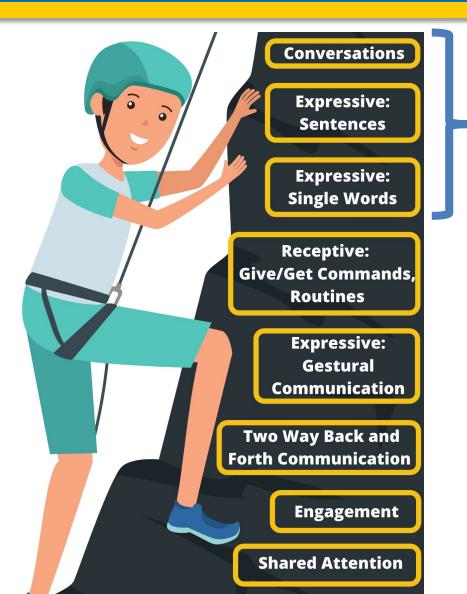
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Climbing the Language Mountain



Faster movers in Kindergarten & First Grade Need to get to FDL 6

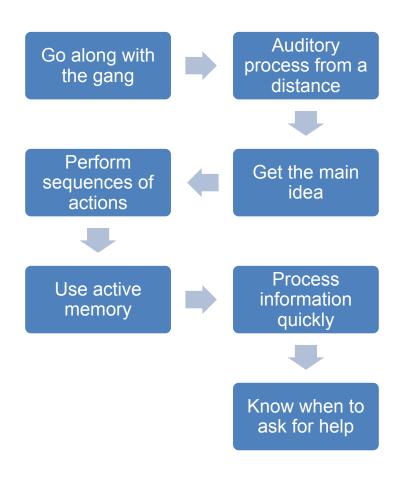
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The 7 Habits are Daunting



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Ageism and School

- The Big Lesson is that this is a rare opportunity to give your child a whole year to mature and catch up
 - Never again
- To have time to move from FDL 5, FDL 6, or FDL 7 is a gift
- Luckily, if you do send your 5 year old to kindergarten, the schools usually do a good job of adapting the curriculum to accommodate the child.



The Philosophy of 'Can'

- This year before kindergarten is a big growth year
- This is a time to work in that Zone of Proximal Development
- Here's some guidance: "Ask yourself: 'Can my child do this?' If they can, then they should.
- THIS IS THE PHILOSOPHY OF 'CAN'
- It helps parents understand their child's potential.



Faster Movers: IEP Goals

- Kindergarten at age 6+.
 - Reason, reasons, reasons!!
 - Getting to 'Why' and 'When'
 - Focus on early literacy, math, writing
- Get the right amount of help—IEP. Be school savvy.
- Use your summers for academics
- Get tutoring



Slower Movers

- Gaining a year is great for slower movers too!
- The 'just right challenge'. Set the bar right and hit the nail on the head
- Keep working on the FDLs!
- If they do go to kindergarten
- Consider more support:
 - Part time aide
 - Full time aide
- Be strength's oriented and
- Go for the 'Philosophy of CAN'

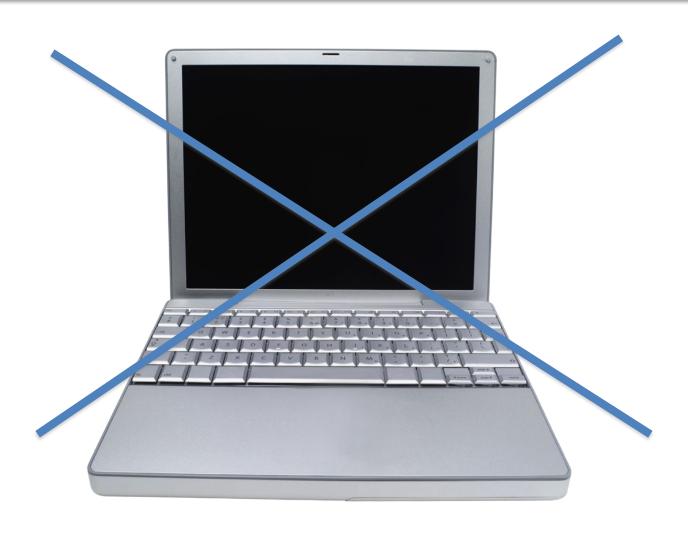


Lesson #4 Summary

- Delay Kindergarten
- One year at this age is huge!
- Never again will you have this opportunity
- Keep working on FDL 4 □ 5 □ 6
- Once in kindergarten, if the child stands out socially, talk to the class about 'Autism'
- Keep being school savvy
- Aim for the 7 Habits



P.S. Limit Screens (1-2 hours max). . .





PPS.











What do you call a dinosaur that doesn't take a bath?



