



Autism: 10 Lessons for the Course of Life

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





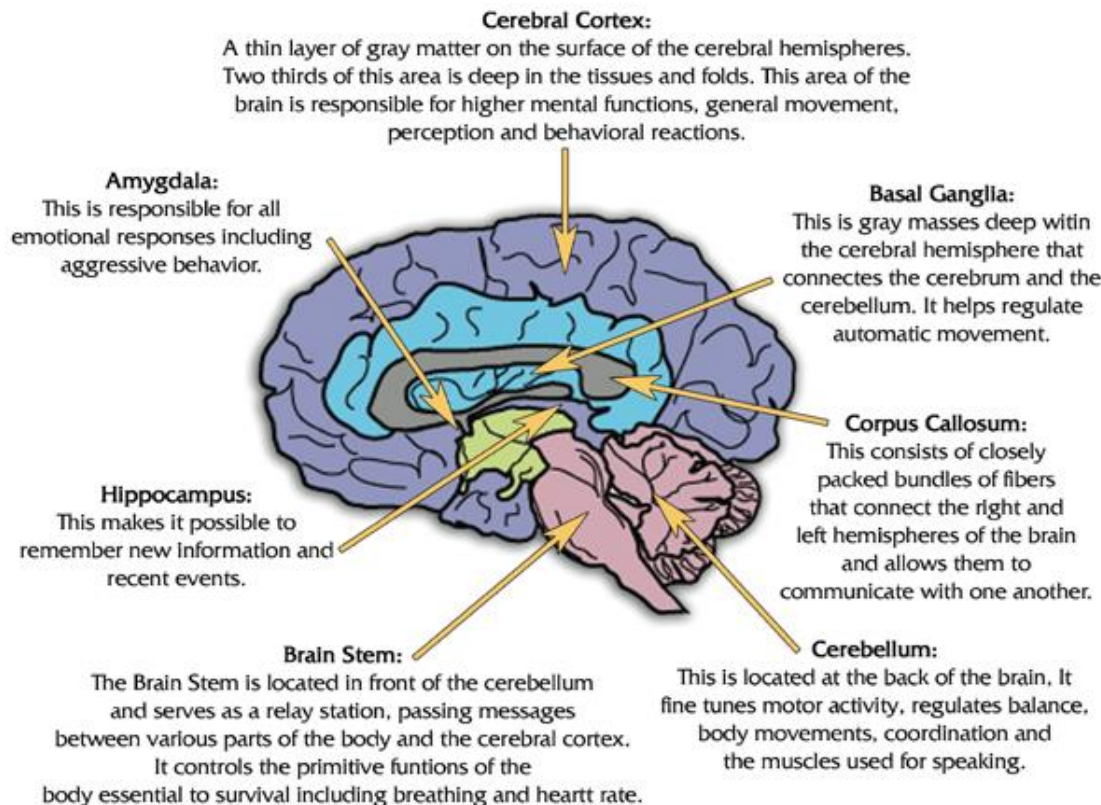
What makes autism autism?

- Genetic condition influenced by the 'under or over connected' neurons.
- Like a loose network of nerves that (especially the social world).
- This creates the tendency of the child to be 'the same'.
- The child with autism tends toward social self absorption and repetition.





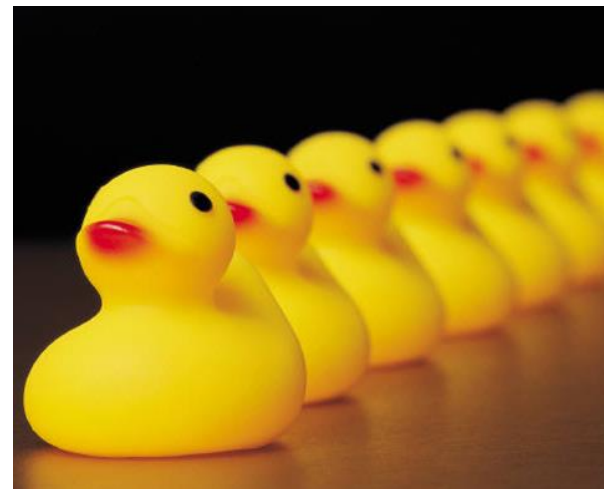
Parts of the Brain Affected by Autism





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.





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



What is a Neurodivergent Individual?



The 5
Characteristics
of Play?



Joyful

Engaging

Social

Meaningful

Iterative



The Nature of Development



- Functional social development follows a natural course described by Greenspan and Weider regardless of age
- The affect diathesis hypothesis
 - **Like a growing flower**
- We should embrace the child's unique profile
- It's all about relationship



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—4 year old)**
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 Levels

6. Emotional Thinking

Builds bridges between ideas
Why, When, & How

5. Symbolic

Leads simple game – dramatizes feelings
pretend play sequences. Who, what, & Where

4. Behavioral Organization & Problem Solving

Continuous flow of engagement
Child leads and adds variations to play. 1 Step commands.

3. Two-way Communication

6 to 10 back-and-forth circles
Does the child initiate when you WANT?
Work of keeping child engaged no longer all on play partner

2. Engagement

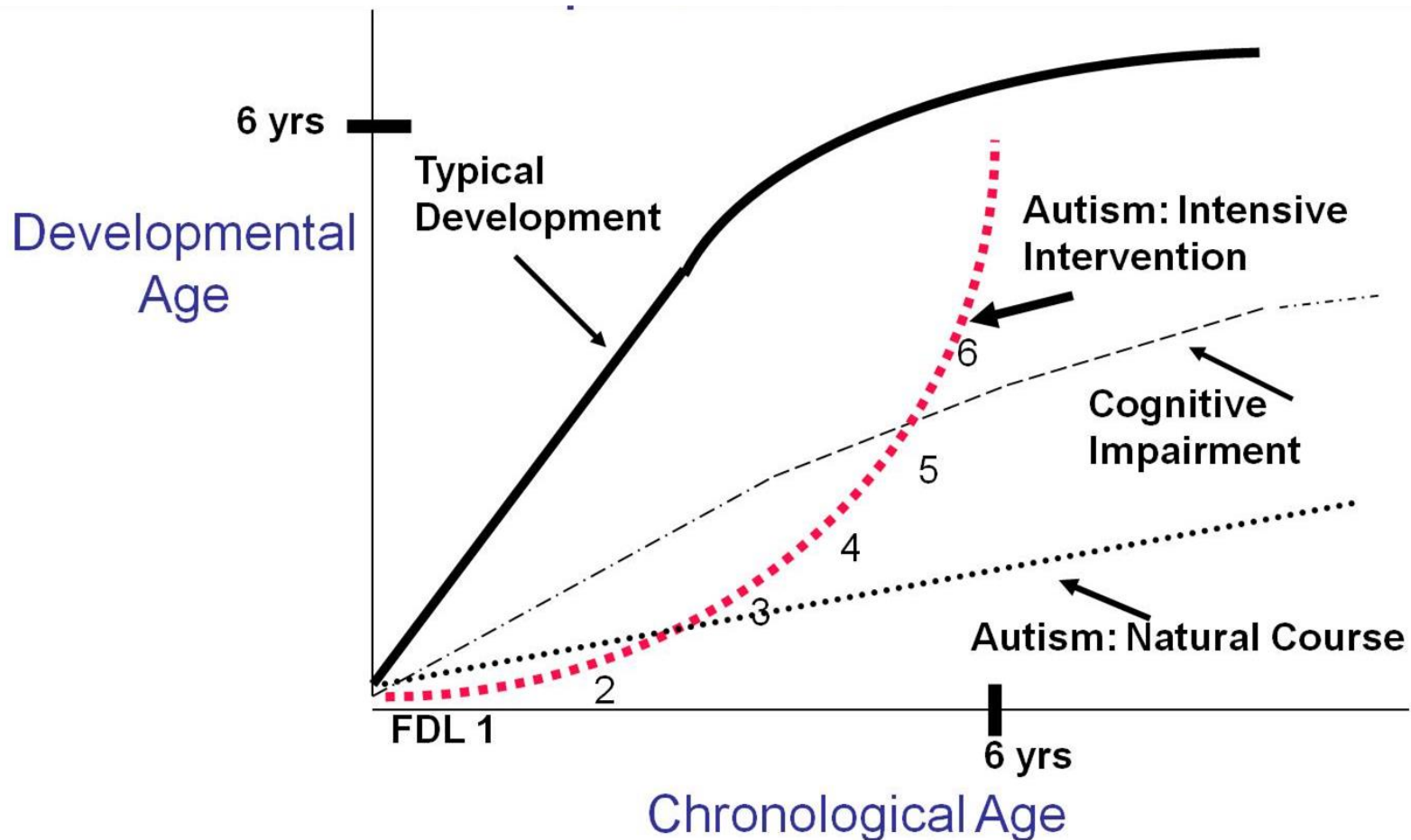
How easy is it to engage child?
Is child having fun, smiling?
SWEAT LEVEL – Play partner doing most work to keep child engaged

1. Regulation & Shared Attention

How much time is child tuning out/spending time in comfort zone?
What sensory supports does child need to stay regulated?



Developmental Course of Autism





Three Types of Progress

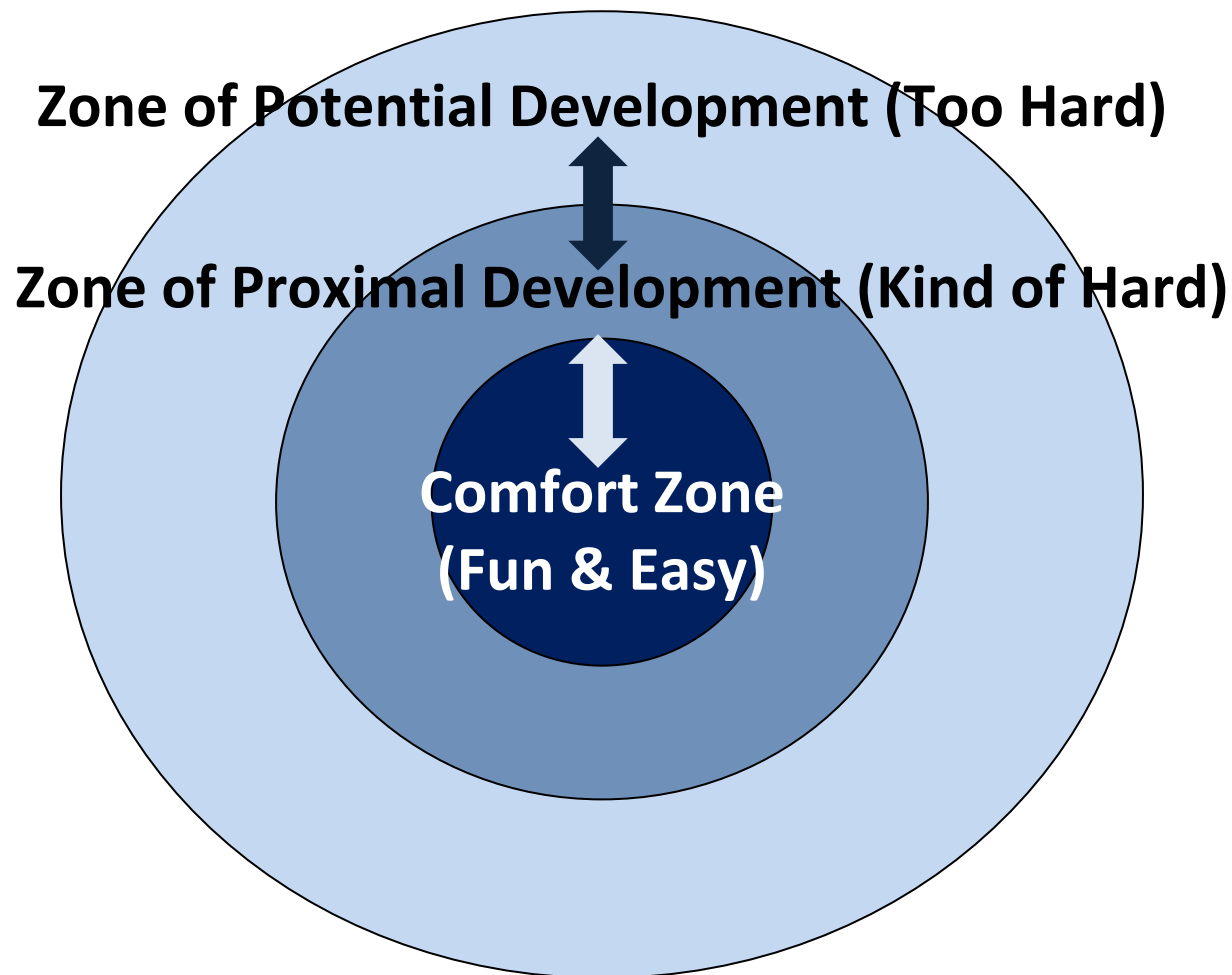
Slow

Medium

Fast



'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 a 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 reliably diagnosed by 14 months 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





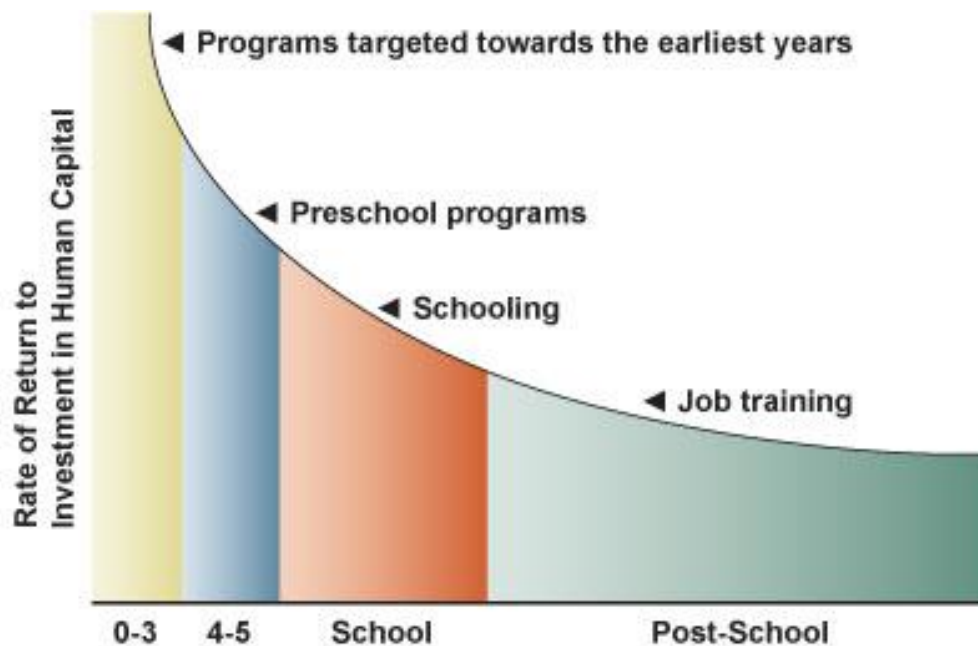
The Paradox and Red Flags

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



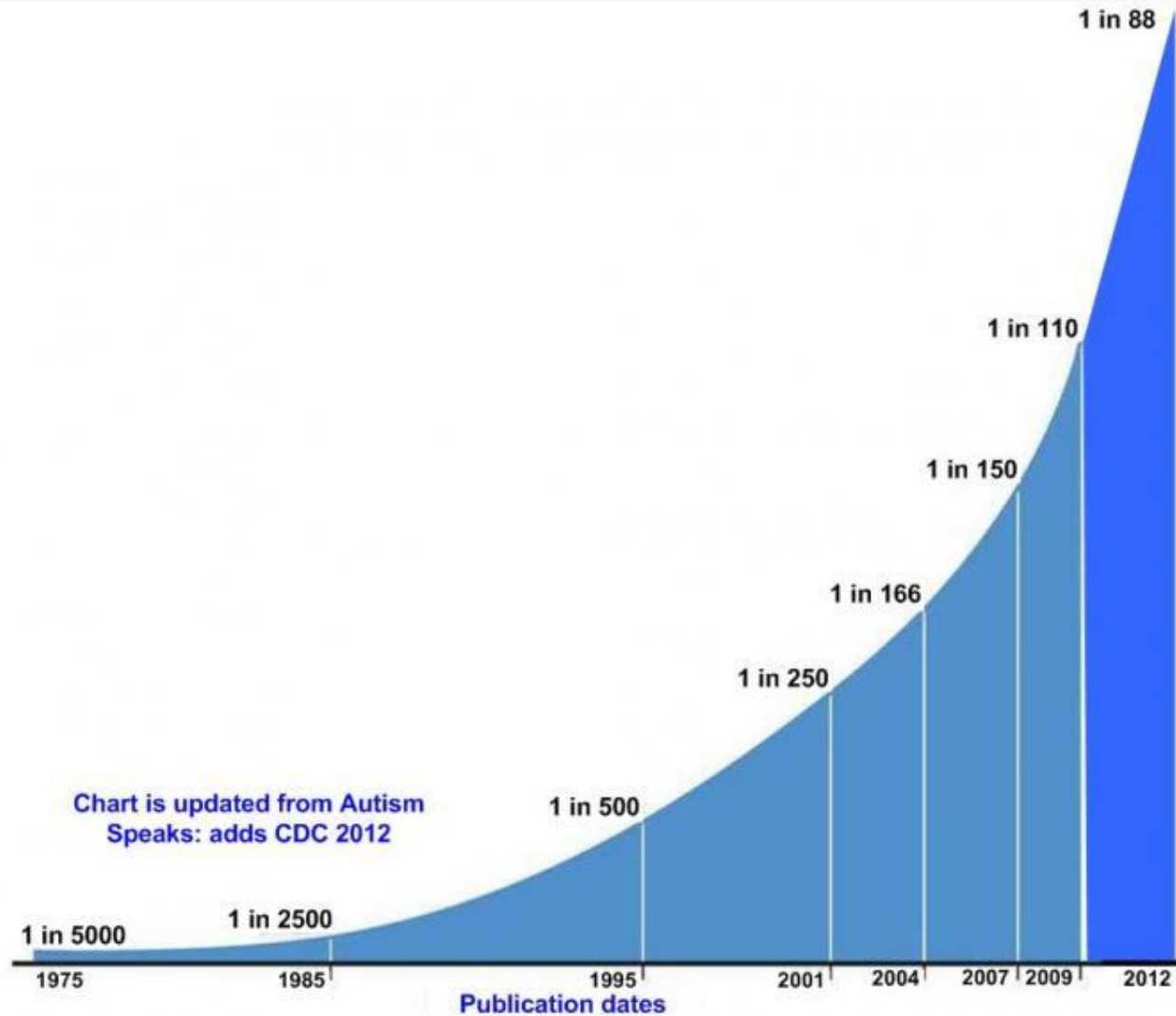
Intervention Options

- 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



* Centers for Disease Control and Prevention (CDC) prevalence estimates are for 4 years prior to the report date (e.g. 2020 figures are from 2016)



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

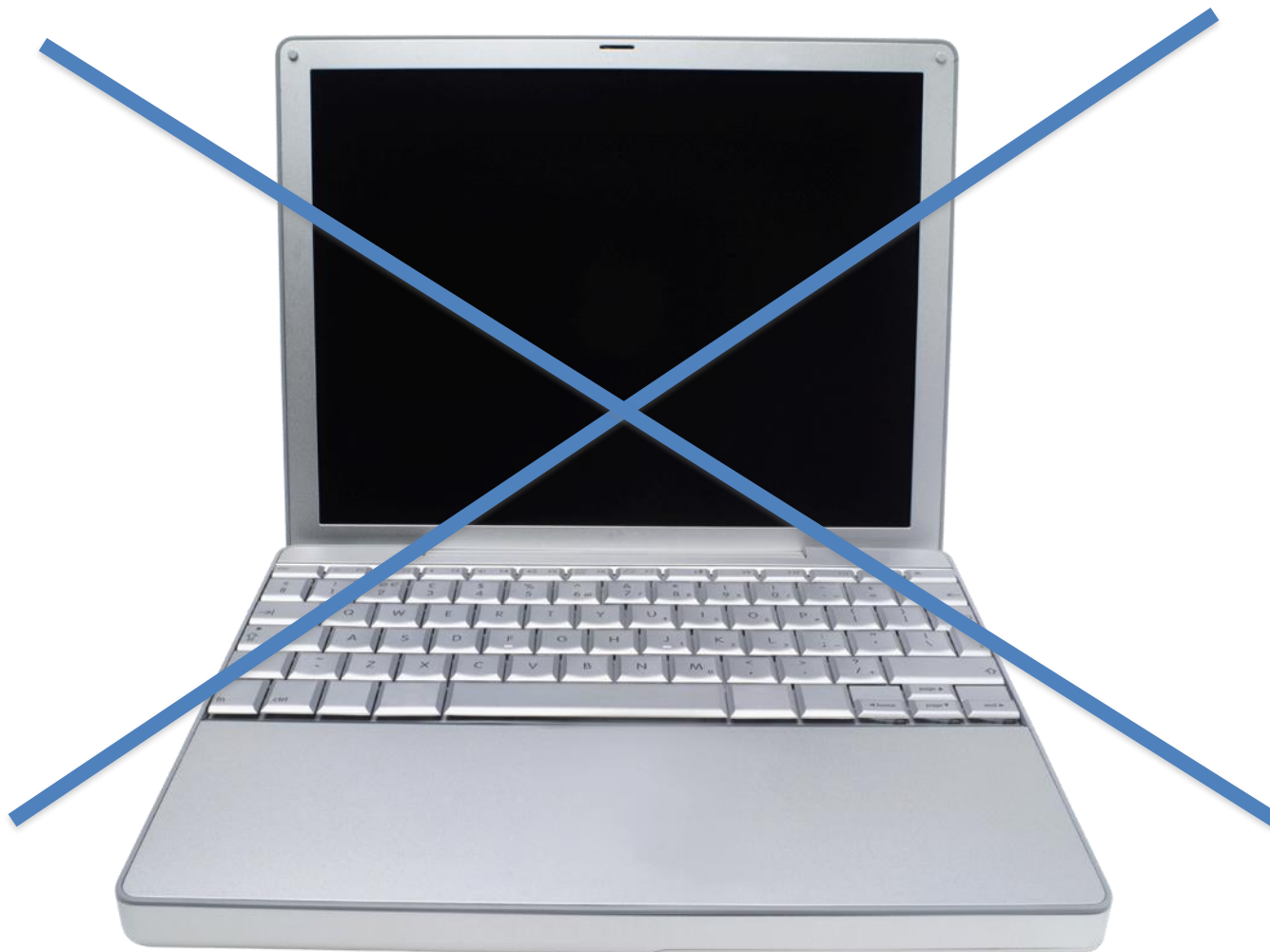
Play based developmental models don't require an official diagnosis

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.



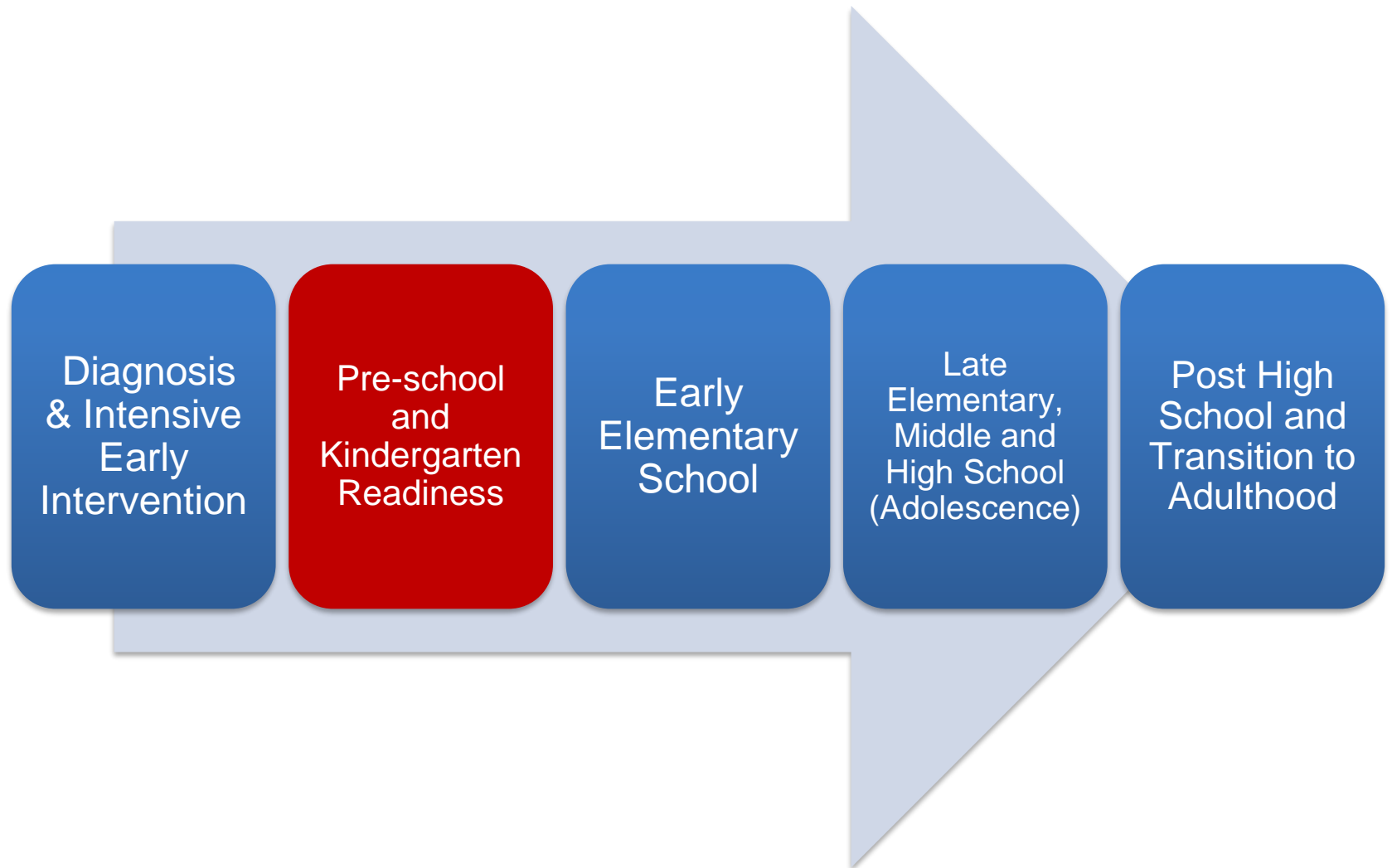
Lesson #2

Parents- Be School Savvy!





Autism: 10 Lessons



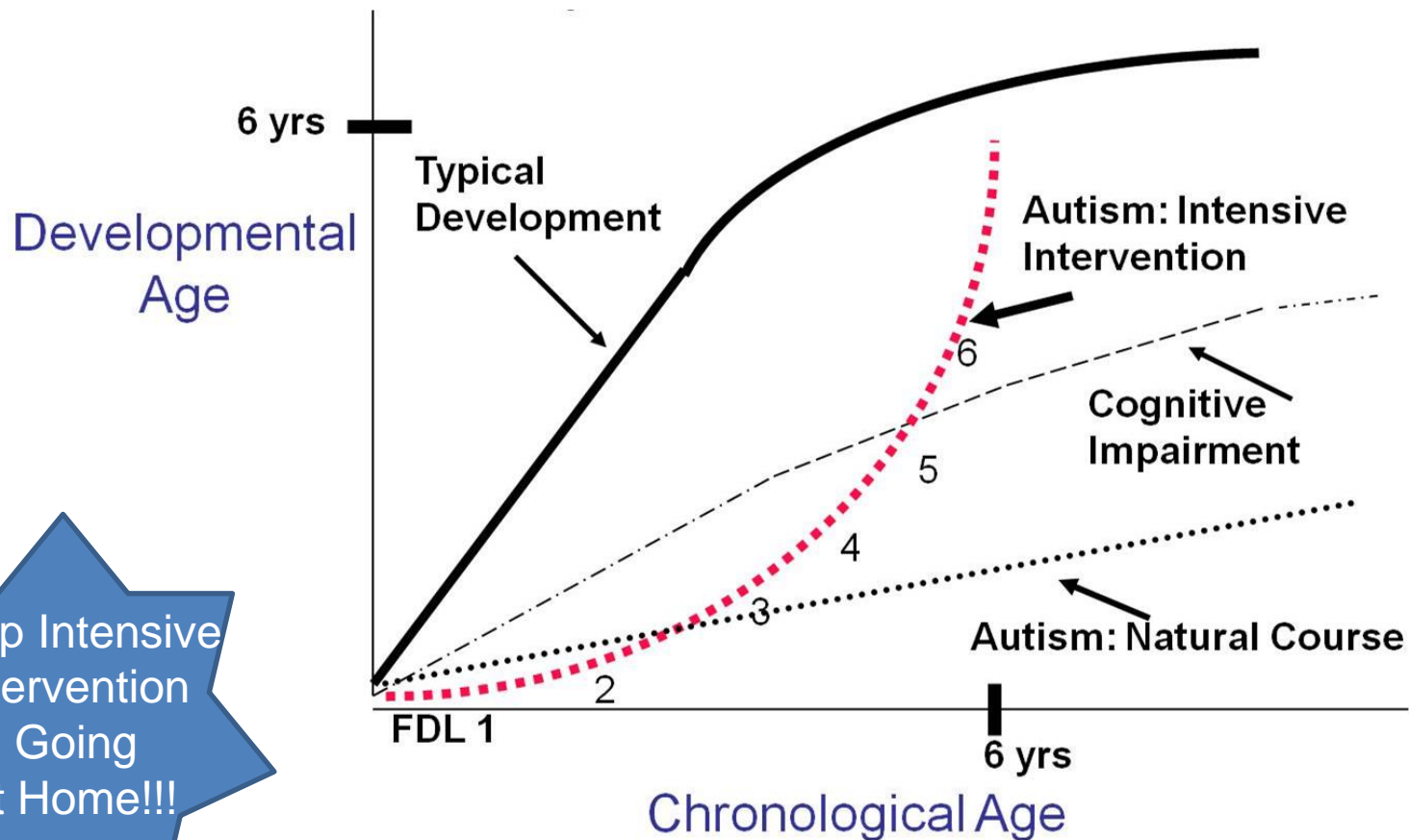


Lesson #2: Parents—Be School Savvy

- 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



Keep Intensive
Intervention
Going
At Home!!!



9 Functional Developmental Levels*

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



Conversations

**Expressive:
Sentences**

**Expressive:
Single Words**

**Receptive:
Give/Get Commands,
Routines**

**Expressive:
Gestural
Communication**

**Two Way Back and
Forth Communication**

Engagement

Shared Attention

Early Intensive
Intervention is
working
on these FDLs



Lesson #2: Parents—Be School Savvy

- The initial period of 1-2 years of intensive intervention hopefully helps the child move up to FDL 4-5.
- 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 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 **Appropriate**), LRE (**Least Restrictive Environment**)
- In Ohio all pre-school are integrated; in Michigan few are





Least Restrictive (More inclusive) Environment (LRE)

General Ed with peers
+ Push in or Go out
for (SLP, OT, MSW,
Special Ed Teacher)



Gen Ed + Resource
Room + Push in/Go
Out



General Ed + a **Part-
time Aide/Parapro** +
push in/go out



Gen Ed + **Full Time
Aide/Para** + push
in/go out



Self contained class
with peers with mixed
disabilities with
mainstreaming for
gym, recess, music,
art (noisy)



Small self-contained
class with all children
on the spectrum and
little mainstreaming



"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

Belonging



School & IEPs

- The **teacher** is **THE** most important factor:
Structured and Nurturing
(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



Get it in WRITING!





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 **Demands** of pre-school for compliance and routines are good





Most autistic children
love pre-school!



The more inclusive the better



Lesson #2 Summary

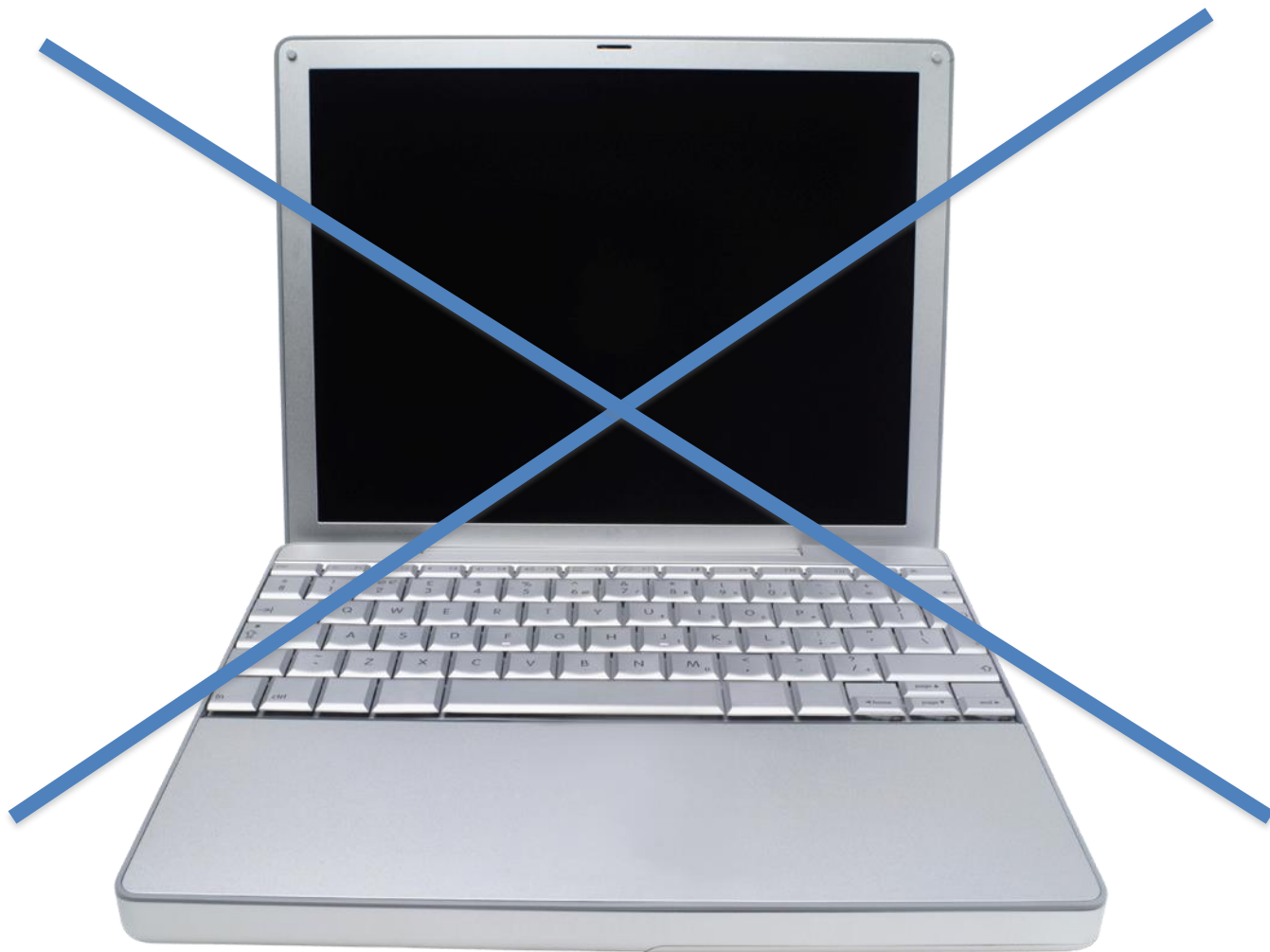


#2: Be School Savvy

- 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). . .





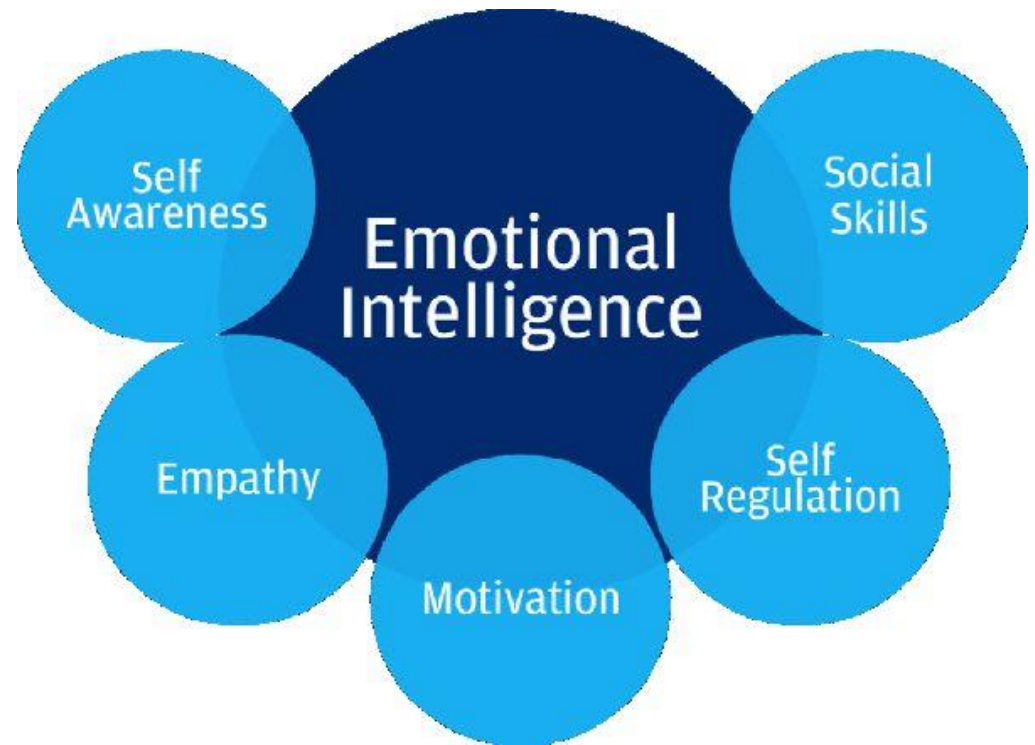
PPS.

HAVE FUN



Lesson #3:

*EQ is More Important
Than IQ*





Autism: Lesson #3

Diagnosis
& Intensive
Early
Intervention

Pre-school
and
Kindergarten
Readiness

Early
Elementary
School

Middle and
High School
(Adolescence)

Post High
School and
Transition to
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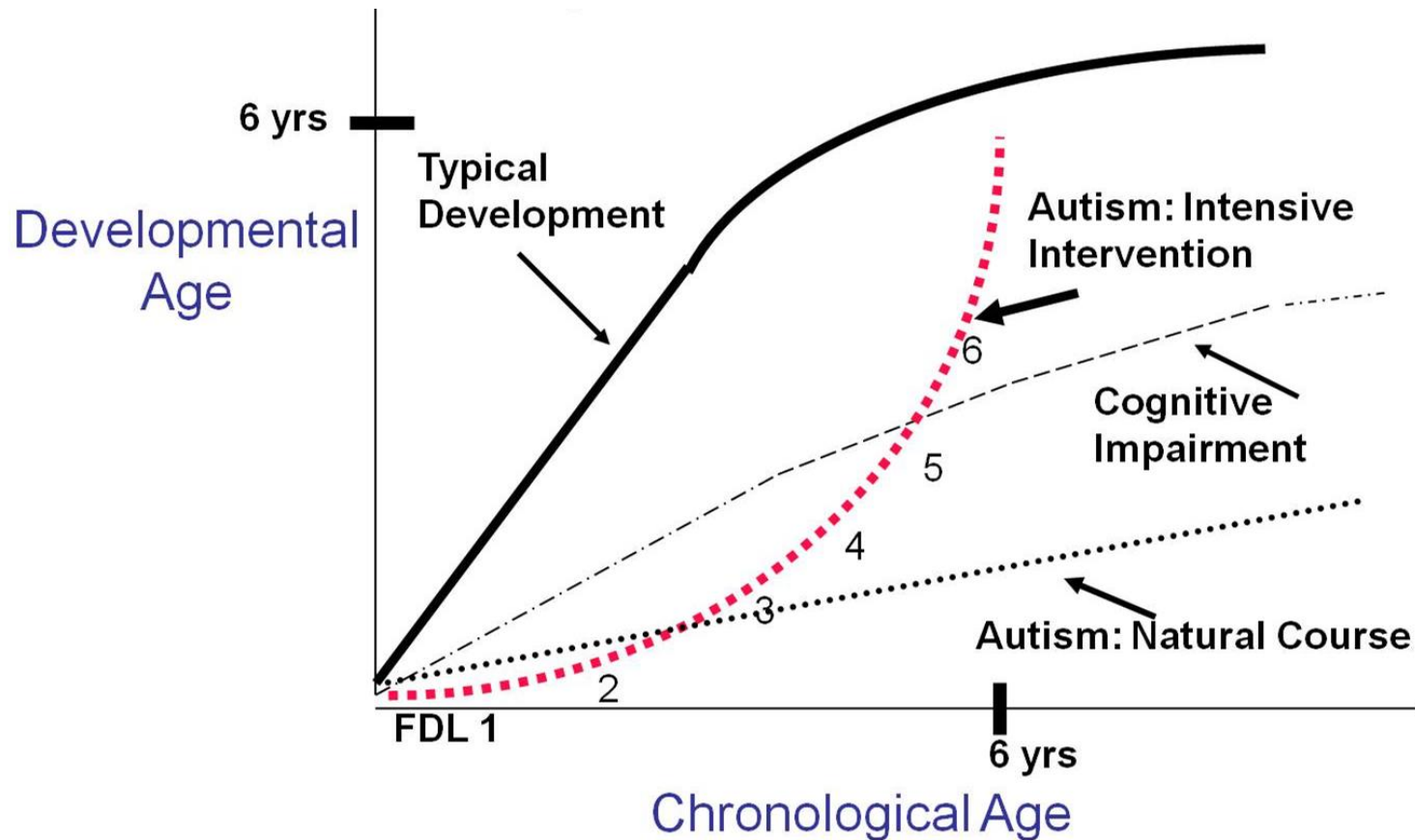
Lesson #3: EQ is More Important than IQ

- As the child progresses to FDL 4-5 and turns 4-5 yrs old
- The Big 3 Developmental Domains:
 - **Interaction**
 - **Imagination**
 - **Emotions**
- Imagination
 - Pretend
 - 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

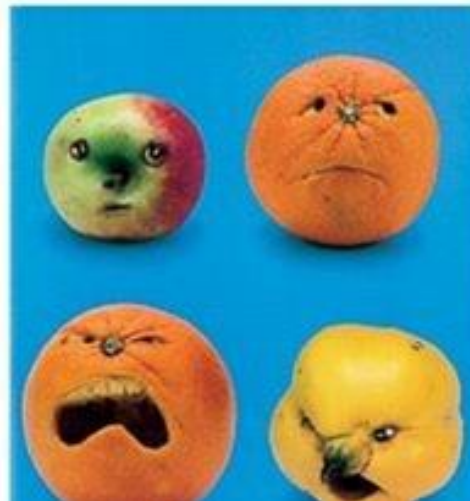
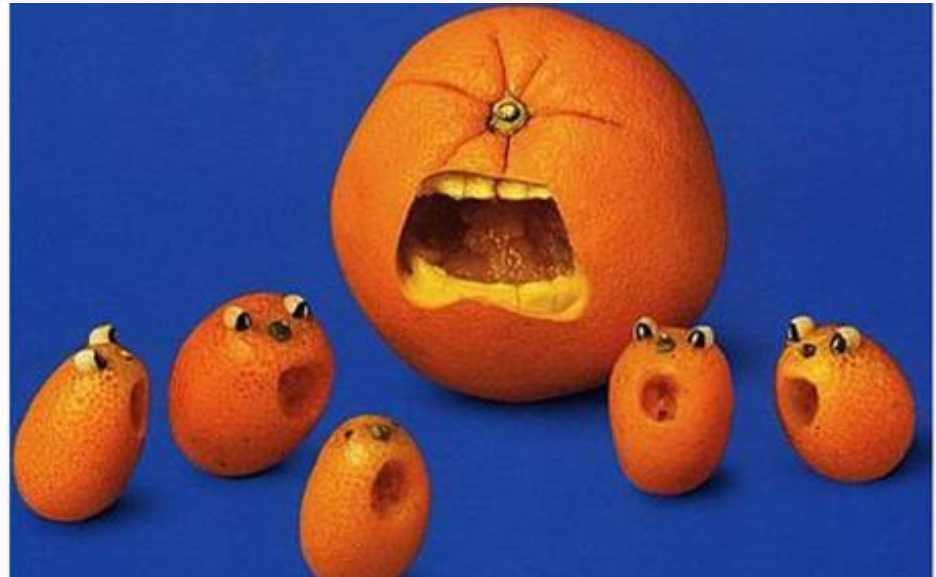
- Role playing
- Doctor
- Teacher
- Good guys and bad guys
- Taking care of babies





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"



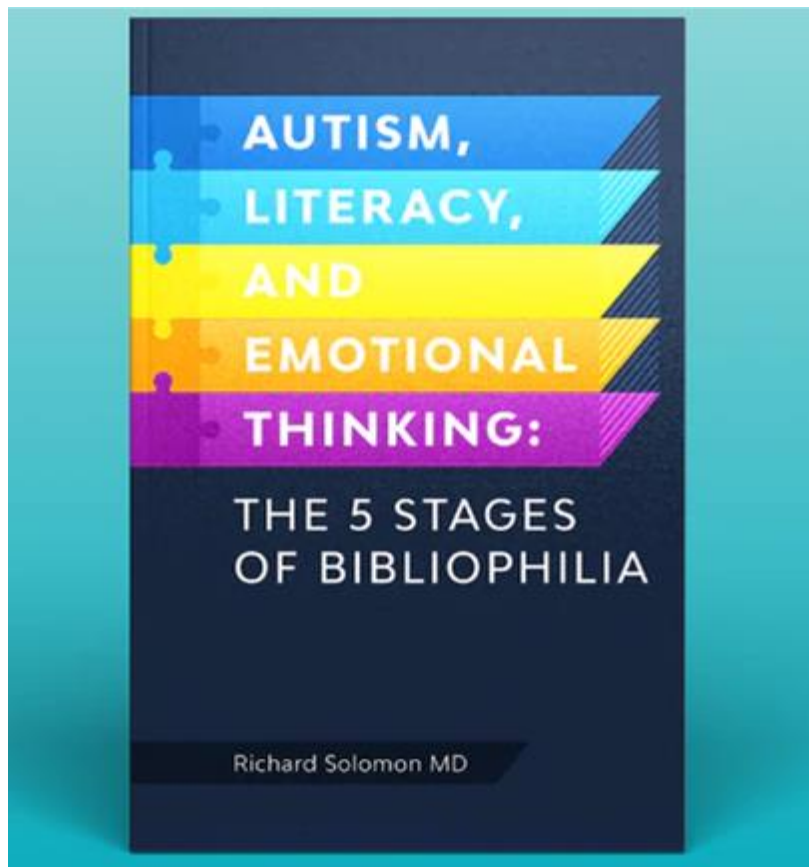


Over Time EQ Evolves with IQ

- 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



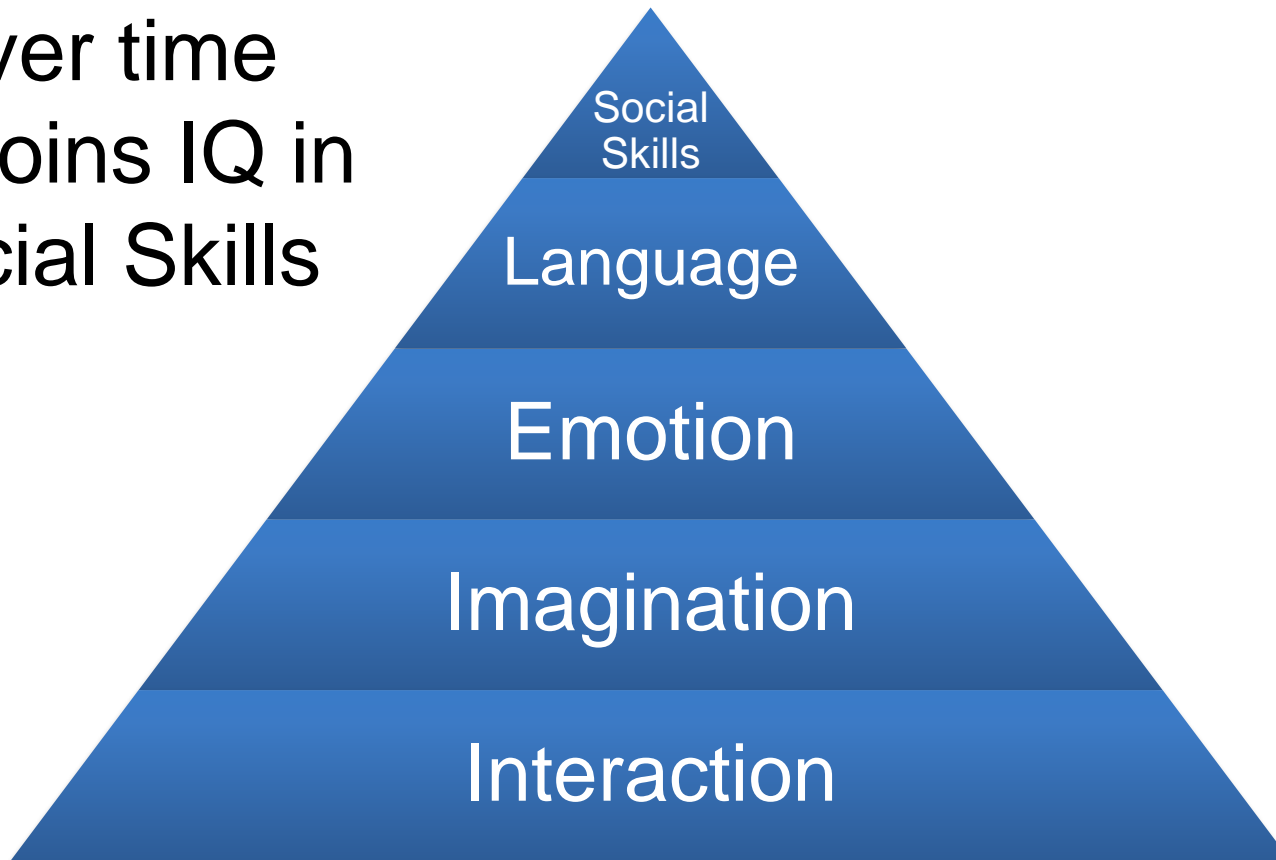
It's free and
only 25
pages!

- 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



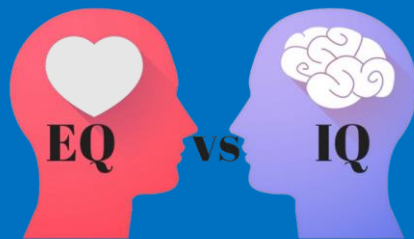
Development of Social Skills

Over time
EQ joins IQ in
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.
..

IQ



Lesson #4:



*Delay
Kindergarten?*

Lesson #4:



*Delay Kindergarten**

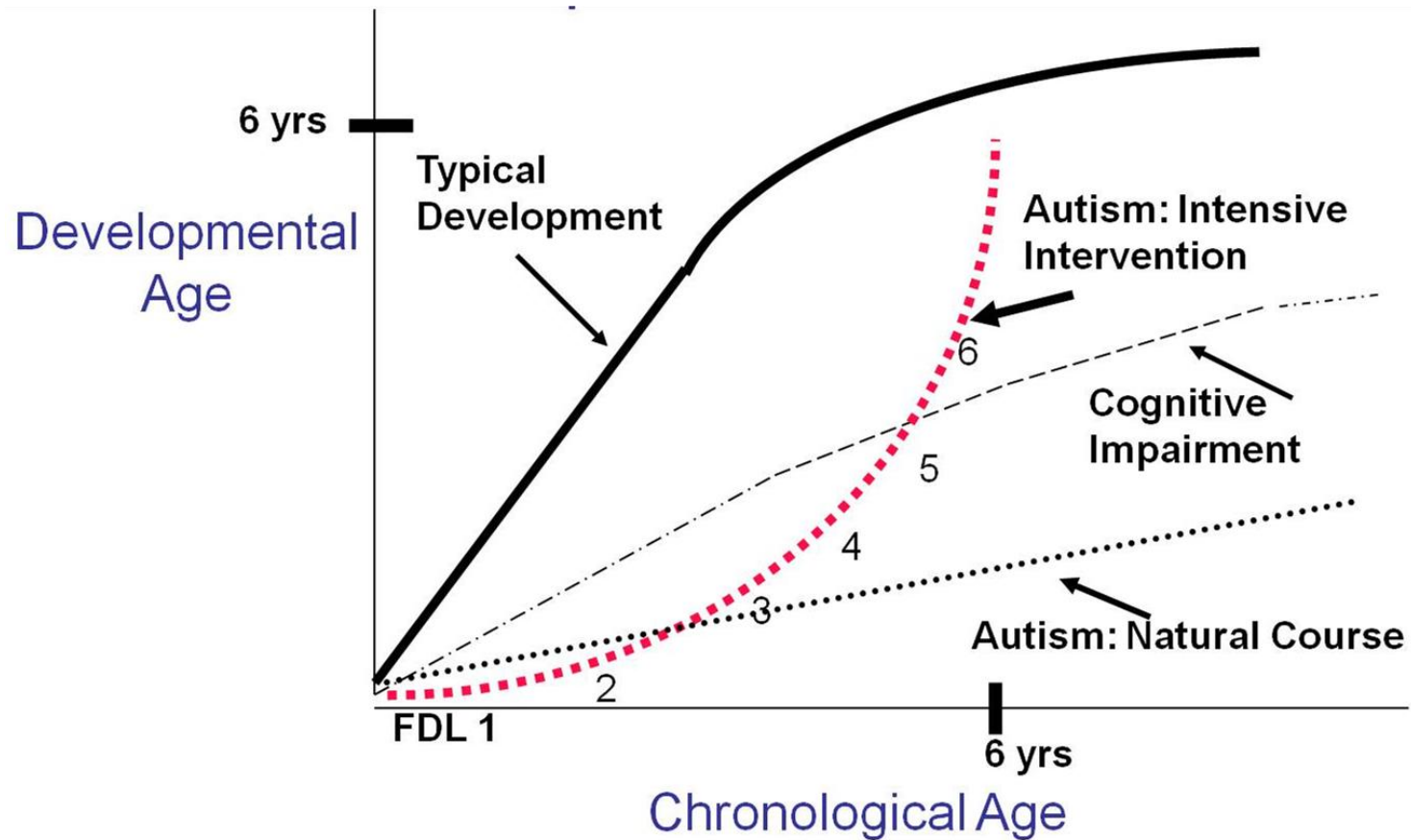
***Age doesn't matter!!**

- The child is getting older and moving toward kindergarten.
- Hopefully, they are moving up developmentally to FDL 5-6 like Julian
- 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

$\frac{3}{4}$



Developmental Course of Autism





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Climbing the Language Mountain



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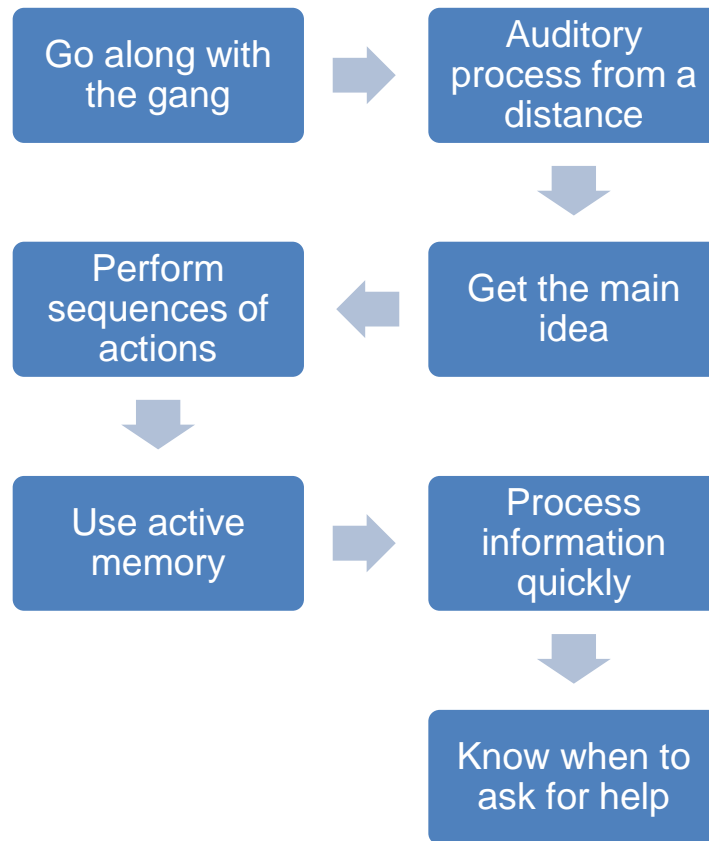
Engagement

Shared Attention

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



The 7 Habits are Daunting



Lesson #4:



*Delay Kindergarten**

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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 6? 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?

A Stinko-saurus!



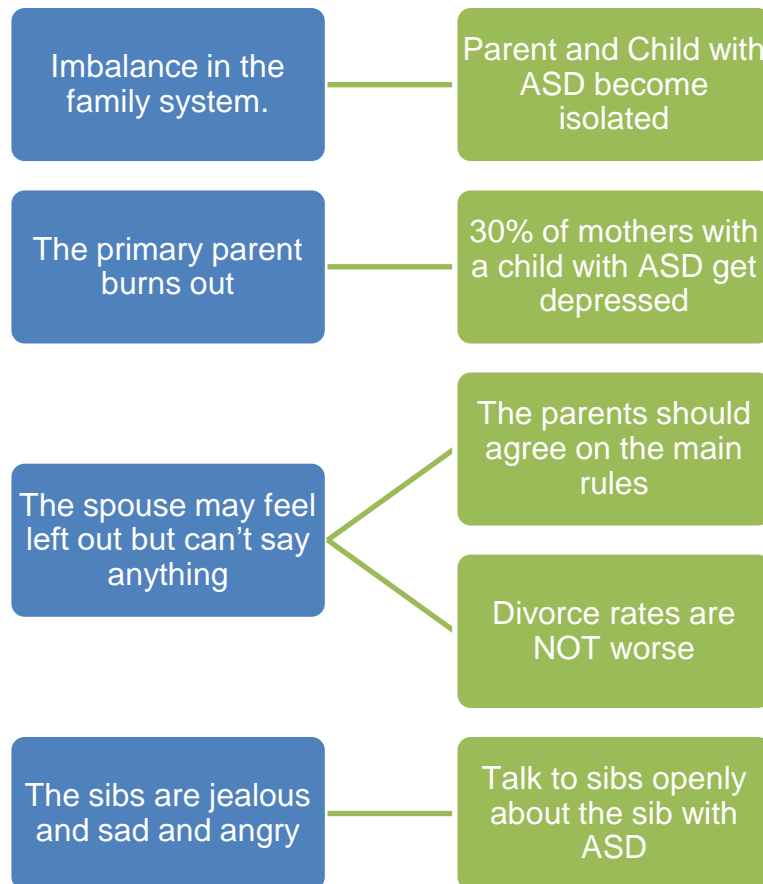
Lesson #5:

*Take good care of your
family system!*





4 Dangers of the Path: The Family





Take Care of Your Family

- **The Self Care paradox:**
When mom's and dad's take care of themselves, they take better care of the family!
- **The Guilt Paradox:** Doing the 'best' for the autistic child in not necessarily the best for the child (especially if the family or marriage falls apart!)

We must take care of
our families wherever
we find them.

Elizabeth Gilbert





The Mom is Usually The Team Leader





The Competent Child



- Parents with high expectations have children who achieve high levels of success
- Very good parents hurt their child's feelings—by saying 'No'.
- By making appropriate demands you give your child a 'message of competence'.
- By not expecting them to do what they can—the philosophy of can—they internalize weakness and often become tyrants. They **MUST** have what they want or they fall apart (secretly feel weak).
- Poor frustration tolerance, lowered self efficacy (esteem) are the result of too much tenderheartedness

Lesson #5

Summary



- Take good care of your family system and it will take care of everyone including the child on the spectrum
- Siblings will be more supportive
- A strong family system promotes the child's competence by making appropriate demands



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PPS.



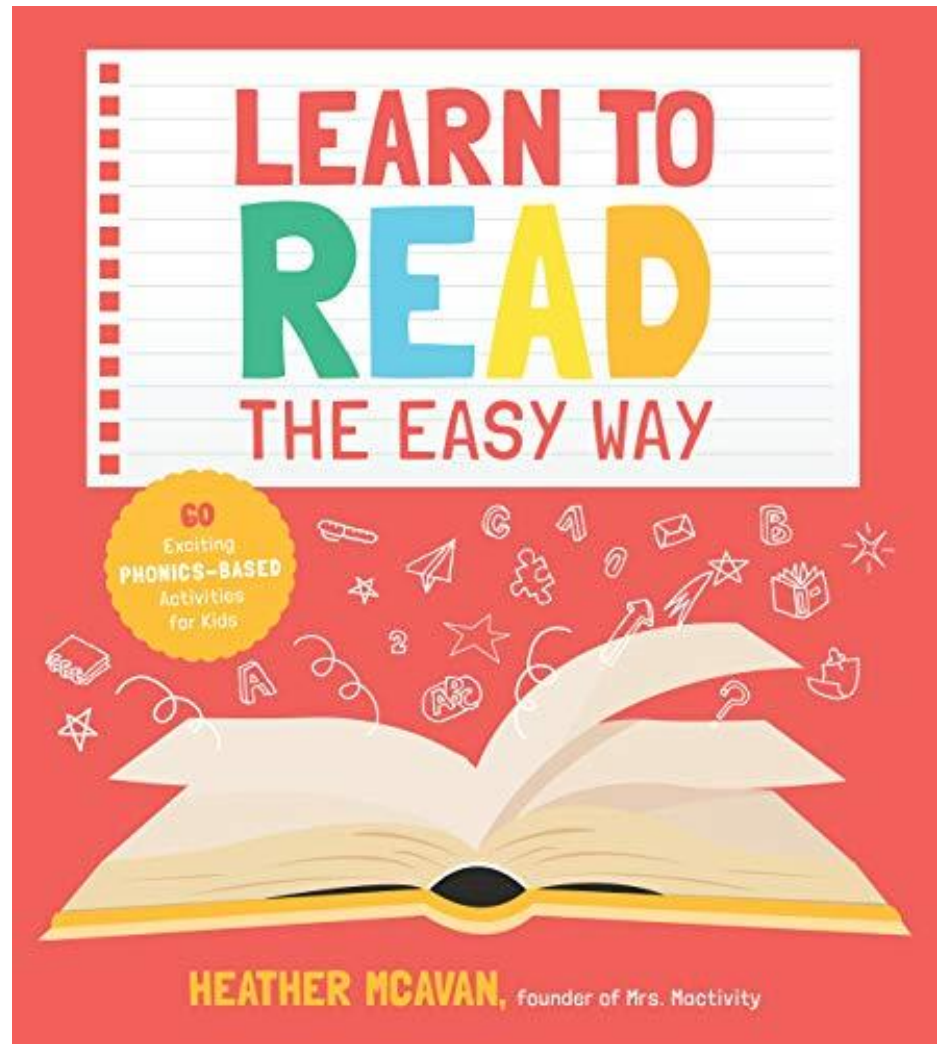
I shook my family tree and a bunch of nuts fell out!

That's insane!



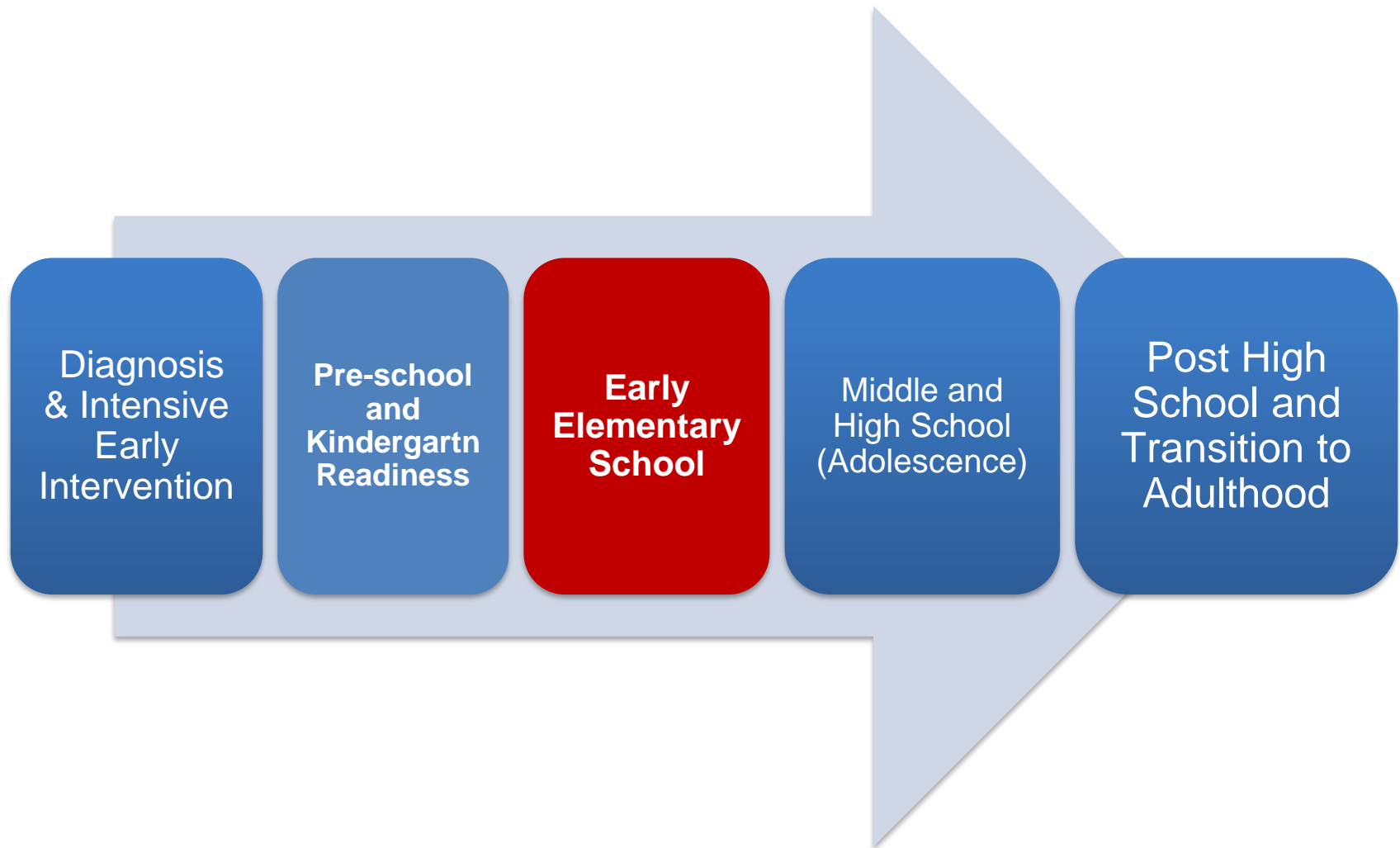
Lesson #6:

*Learn to Read
Then Read to Learn
2nd ? 3rd Grade*





Autism: Lesson #6





Reading 1st, 2nd and 3rd Grade



- Phonics is an FDL 6 skill learned in 1st grade
- By end of second grade most students are fluent readers. Many children with ASD are fluent too.
 - They've learned to read
- But, by third grade, **can they read to learn** and make sense of the stories/books? i.e. Do they have reading comprehension?
 - Are they at Greenspan FDL 7?
- Many autistic students will not be ready to read and will need a more adapted curriculum to enjoy school (be school savvy—set the bar right)



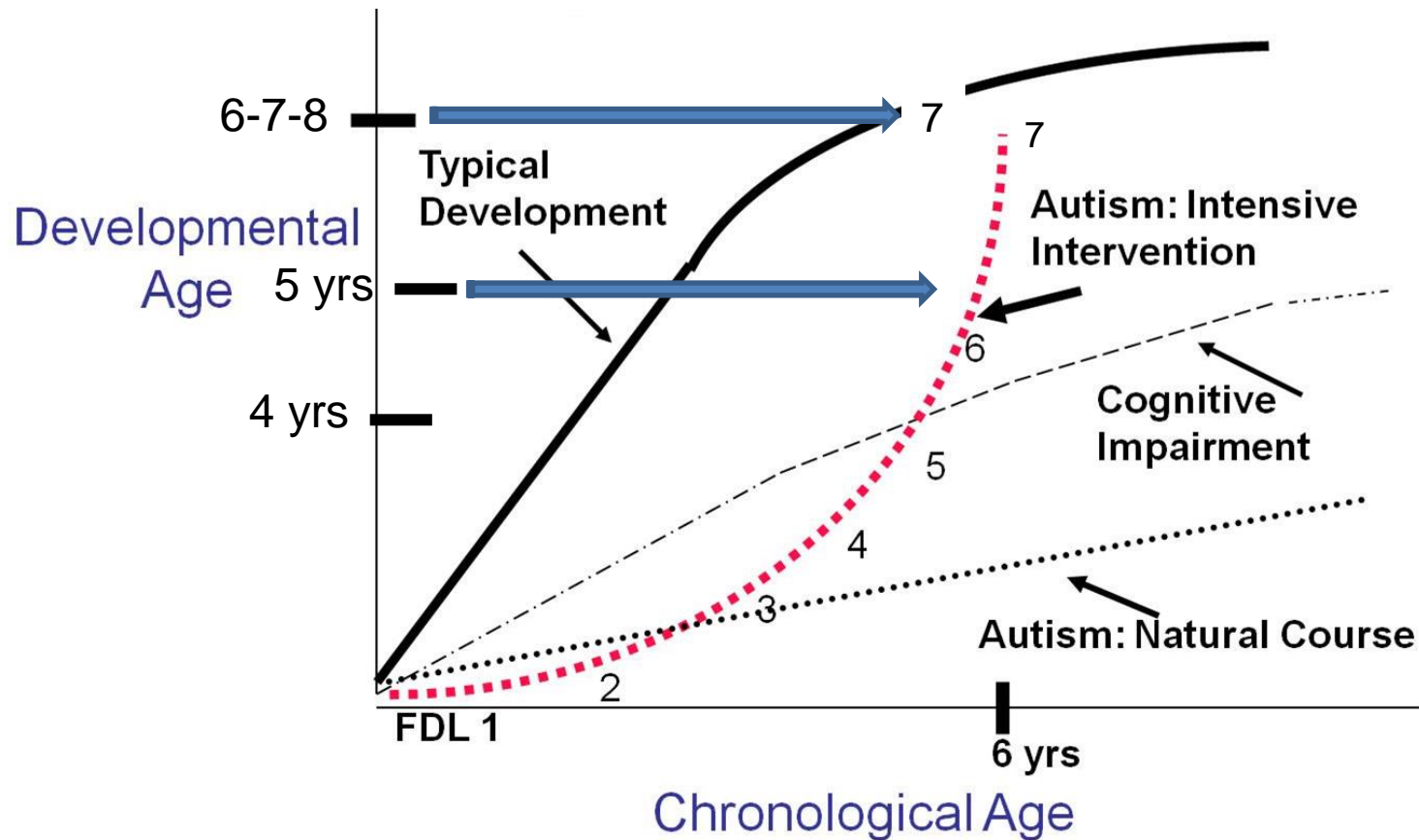
9 Functional Developmental Levels*

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)***
5. ***Shared Meanings & Symbolic Play (FDL 5—2y)***
6. **Emotional Thinking (FDL 6—4 year old)**
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

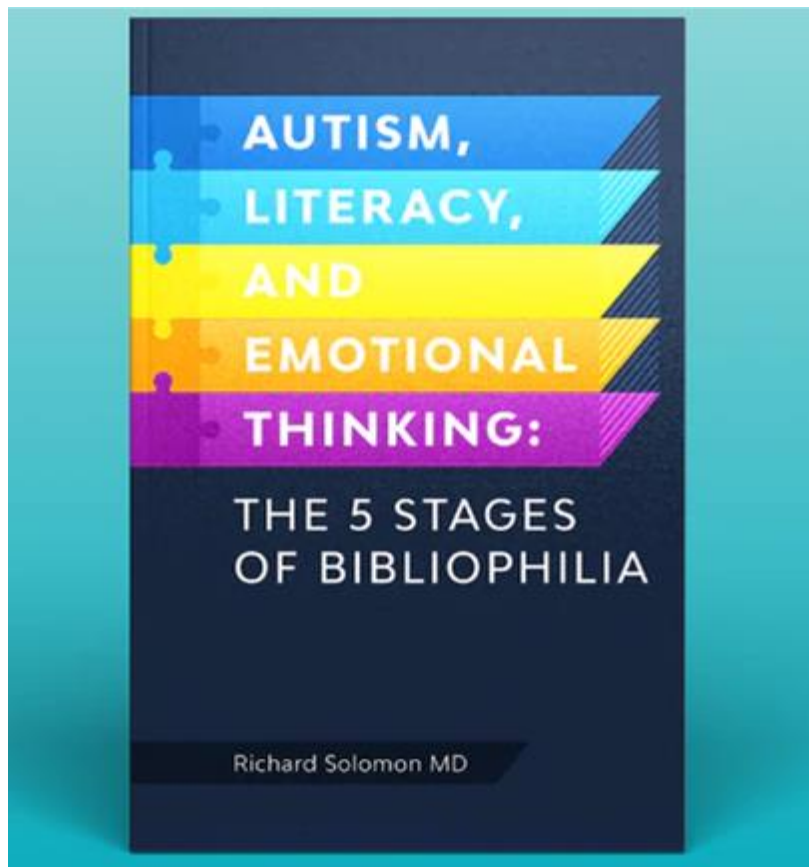


Developmental Course of Autism





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



Learning to Read, Reading to Learn

- Literacy and the love of reading—leads to success in school
- Get a dictionary. Love words. Read books
- Use your summers to learn!!
- **Getting reading, math, and writing tutors (The 3 Rs)**
- Use OTs for help with fine motor coordination
- Speech and language therapists and ABA for higher level language skills
- Continue to give m&m's
- Use 'The Stone in the Pond' approach
- Take jokes seriously!





Give them M&M's

- Meaning and motivation
- IEPs should be built around the child's interests
- Be project oriented and playful
- Make learning/reading fun
- Learning is a lifetime of joy or a school career of misery and boredom

