

# Autism Spectrum Disorder

Diagnosis  
Treatment  
Impact

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## What is Autism:

- ▶ Autism is a pervasive neuro-developmental condition which effects a person's ability to communicate and interact with others.
- ▶ People with autism may have a difficult time understanding 'typical' social cues and social behaviors.
- ▶ They may face challenges engaging with those around them – either by using words or non-verbal behaviors.

# BUT: that is just the formal definition..... IN REAL LIFE ..... AUTISM IS

- ▶ A baby that NEVER sleeps well
- ▶ Exhausted parents who BLAME each other for “what is wrong with our child”
- ▶ A toddler who melts down in tantrum for no explicable reason
- ▶ A 2-year-old that doesn’t learn to speak as expected.
- ▶ A 3-year old with no fear... who wanders.... frequently seeks water and often drowns
- ▶ A 4-year-old who just WILL NOT toilet train
- ▶ A 5-year old that will not separate from his parents, so parents can never go “out”
- ▶ A 6-year-old who can’t interact with peers, just sits alone, in his own world
- ▶ An 8-year-old with no friends, doesn’t understand the “ joke” or that she is the brunt of it

# In Real Life ..... Autism Is

- ▶ Parents MISSING work, MISSING social interaction and frequently divorcing.
- ▶ Its Schools hiring extra one on one aides because they can not control the child in the classroom
- ▶ It the young adult who can not transition to life on his own.
- ▶ It's the police responding to an out of control person who doesn't respond to their orders, cant seem to understand, .....And tragedy can follow .
- ▶ Its that person who every one in our small town knows about but doesn't know how to help

# In Real Life ..... Autism Is

- ▶ Contradictions... Confusions...chaos
- ▶ Many of the parents of Kids on Spectrum say their child is their biggest challenge but also their greatest joy
- ▶ It is a spectrum

# Prevalence

- ▶ Autism is one of the fastest growing neurological conditions in the world
- ▶ in the United States is 1 in every 68 people
- ▶ 1 in 42 boys and 1 in 189 girls

## Why so many Diagnosis now?

- ▶ More people are aware of Autism and recognizing the symptoms
- ▶ Better training of Medical Professionals
- ▶ The diagnosis is more exact today
- ▶ It includes conditions that were excluded in the past.

## Diagnosis....

- ▶ Parents are often the first to notice that their child is showing unusual behaviors
- ▶ failing to make eye contact
- ▶ Not responding to his or her name
- ▶ Playing with toys in unusual, repetitive ways.
- ▶ Spinning, flapping, echoing
- ▶ No recognition of personal space



## Lack of Diagnosis

- ▶ Parents frequently ask their PCP what is wrong. However, PCP awareness may be lacking and often the parents are told that nothing is wrong or the child will outgrow this “phase”
- ▶ Many PCP’s are aware of the BIG signs but unaware of subtle signs

# How SHOULD the PCP screen for Autism

THERE ARE SEVERAL EASY TOOLS

- ▶ Modified Checklist for Autism in Toddlers (MCHAT) at 18-24 months
- ▶ Ages and Stages Questionnaire (ASQ) birth to 60 months
- ▶ Communication and Symbolic Behavior Scales (CSBS) to 24 months
- ▶ These can be done at Well Child Visits

## M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)	Yes	No
5. Does your child make <u>unusual</u> finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Yes	No
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Yes	No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11. When you smile at your child, does he or she smile back at you?	Yes	No
12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13. Does your child walk?	Yes	No
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Yes	No
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Yes	No

# TIME!!!!!!

- ▶ Many PCP's do not have capacity or can not stretch their day to include an additional hour for Autism diagnosis

## BUT

- ▶ they CAN and SHOULD screen and refer.
- ▶ Screening tools can be handed out at front desk
- ▶ MA staff can score them
- ▶ Pre-screening allows the PCP to be better informed of the developmental levels before s/he goes into the room.

## Screening tools

- ▶ The MCHAT and ASQ are both **billable** to HCA
- ▶ CPT 96110 can be billed 5 times between 0 - 3 years
- ▶ MCHAT is a free download.
- ▶ ASQ is a one-time purchase that can be used without limits .
- ▶ If your clinic is not yet using MCHAT and AGEs and Stages screenings at well child exams, you are encouraged to add these very powerful yet easy to use tools to your providers library.

## Diagnosis: No medical test

- ▶ specially trained physicians and psychologists administer autism-specific behavioral evaluations.
- ▶ A VALIDATED TOOL is used to establish the presence (or absence) of autism; ( examples)
- ▶ Autism Diagnosis Interview (ADI) revised (85 questions)
- ▶ Autism Diagnostic Observation Schedule (ADOS).
- ▶ Evaluations typically take about 2 - 3 hours of the professional's time ( we usually do one new evaluation each week)

## Impact: Financial

- ▶ In rural area, for a healthy child, with no issues the cost is about \$10,000-12,000 a year. For a cost of about \$250,000 through the age of 17.
- ▶ For a child diagnosed with ASD, but WITHOUT an intellectual disability, costs were between \$50,000 to \$60,000 per year to age 17. For a total cost of about \$950,000 to age 17.
- ▶ ASD had higher costs for doctor visits and prescriptions -- an extra \$3,000 a year (average)
- ▶ "Non-health care" services averaged \$14,000 per child, and special education at school accounted for more than 60 percent of those costs.

## Impact: Financial

- ▶ **PARENTAL PRODUCTIVITY LOSS:** mothers of children with autism earn, 56 percent less than mothers of children without health limitations
- ▶ Many parents of autistic children reduce their work hours, or quit their jobs to care for their child full-time
- ▶ **TOTAL ECONOMIC COSTS** for autism in 2015 was approximately \$268 billion in the U.S.
- ▶ ASD costs are equal to diabetes costs and far exceeds the costs of stroke and hypertension.
- ▶ The societal costs to support a single person with autism is \$3.2 million over his or her lifetime, and as a group, upwards of \$35 BILLION EACH YEAR in direct (both medical and nonmedical) and indirect costs.



## Impact: Family Stresses

- ▶ Some parents said a child with Autism led to divorce. "Husband took off due to stress,"
- ▶ "The incredible needs posed by this child cause[d] my marriage to fail,"
- ▶ Older studies suggested 80% divorce rate, but that is no longer substantiated. Parents of Children with ASD divorce at about the same rate as other couples.
- ▶ One father summed it up: "Autism does one of two things, it drives families apart, or makes them stronger."

## Isolation

- ▶ Impact on friendships and social networks, nearly 60% of mothers and fathers reported Isolation.
- ▶ One said "My husband experiences cycles where he actually avoids us and our home."
- ▶ Another parent seemed too harried to put thoughts into complete sentences, saying "[Our son] needs constant supervision, we do not have a normal life - marriage is strained - no time together as a couple, need respite care."
- ▶ As with any chronic disease, having a child on the autism spectrum had a negative impact overall on the parents ability to maintain social interactions and friendships

Stigma .. Parents of a child with autism tend to be judged.....

This is the Scene:

- ▶ The child is screaming, spinning or making noises, and the Parents are on the receiving end of disapproving stares or outright hostility from The Annoyed.
- ▶ "Control your child," The Annoyed says coldly.
- ▶ Maybe he assumes the child lacks discipline;
- ▶ maybe he recognizes the disability but blames the parent for not controlling the behaviors
- ▶ The Annoyed can be anyone: a stranger....  
an acquaintance....or even your family.

## Collateral stress










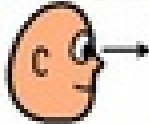



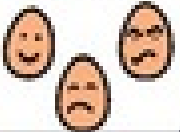










- ▶ Kami is in kindergarten and meets for the first time her classmate. Johnny doesn't sit in his chair. He stands in the corner and spins. He throws himself on the floor and tantrums.
- ▶ He spits, bites and pinches. Johnny has a one on one aide, but his tantrums disrupt the entire class. Kami knows tantrums are not acceptable, why is Johnny allowed to do those things?
- ▶ We are now in the 3<sup>rd</sup> grade. Johnny still tantrums. But the class room is used to him. It may disrupt the lesson, but we have learned to adapt. What is the impact of Johnny's behavior on Kami?
- ▶ What is the cost in time and attention for the entire class
- ▶ It teaches understanding and it causes stress

## Treatment

- ▶ For years, there was no real treatment of Autism .
- ▶ People were thought to be mentally retarded,
  - ▶ shut away and ignored
- ▶ Behavioral Sciences began to study Autism and the first programs were developed in the late 1970.
- ▶ Now the Behavioral Science and Applied Behavior Analysis (ABA) is an effective, evidence based treatment for Autism Spectrum Disorder.
- ▶ Each person with autism is unique. Each intervention plan must be as unique to address their individual needs. Intervention can involve behavioral treatments, medications or both.

## Early treatment is Best

- ▶ Autism is a communication disability, and as with other disabilities such as hearing loss or visual impairment , the longer the child is without those tools, the less chance they have of full integration of those skills into their daily life. The earlier treatment is instituted, the better the outcome.
- ▶ Visual impairment = Glasses ,surgery
- ▶ Hearing loss = hearing aids, implants
- ▶ Communication Disability = Picture exchange boards all the way to speech generative computers.
- ▶ APPS for I-pads and tablets

I, me, my 	what 	where 	when 	good 	bad 
he/she/they 	want 	like 	look/see 	stop 	more 
you/your 	feel 	play 	eat 	drink 	time 
don't/not 	get 	go 	read 	finished 	turn 

## ABA Therapy ..... step by step

- ▶ behavioral intervention teaches the child social and communication skills
- ▶ It teaches life skills
- ▶ It prepares the child for the **neurotypical** classroom.
- ▶ It can dramatically change the educational experience of the ASD child and the other children in the class room.



## HCA coverage of ABA Therapy

- ▶ In Jan 2013, in the settlement of a lawsuit by Washington Autism Alliance and Advocacy, the Washington state HCA approved payment for ABA therapy for Children with Autism Spectrum Disorder . The HCA approved Early intensive behavioral intervention in the 24 thru 59-month ages, and individual therapy thru age 21years.

# Early intensive behavioral intervention

- ▶ Is a 12 week, 4 days a week, 3 hours a day program.
- ▶ Individualized treatment plan designed by a board certified behavior analyst(BCBA) and implemented by a certified behavior technician(CBT) for the NEEDS of the individual child.
- ▶ The BCBA does an initial intake to analyze the behaviors of the child. Then the program reinforces desired behaviors, teaches replacement behaviors and extinguishes undesired behaviors.

## Parent and family training are INTEGRAL to the program

- ▶ Just like any other skill, Practice is imperative
- ▶ What is learned in therapy must be practiced in home and school
- ▶ As the child with Autism enters school, they are taught targeted social skills training.
- ▶ Adolescents with autism can benefit from transition services that promote a successful maturation into independence and employment opportunities of adulthood.

## Becoming A Center Of Excellence for the Health Care Authority

- ▶ To Diagnose Autism Spectrum Disorder and Order ABA therapy for children on the Autism Spectrum, you must be a Center of Excellence per the HCA.
- ▶ COE can be: Neurologist, Psychiatrist, Psychologist, Developmental Pediatrician OR Other qualified medical providers who are prequalified by the agency
- ▶ COES must use a Validated Tool, Observe behaviors, and Interview families.

## COE Training from HCA

- ▶ Medical providers who wish to be COE's may attend COE training with HCA personnel.
- ▶ The clinic or the Provider can be designated as a Center of Excellence (COE) and do internal diagnosis and write the WA state required order for ABA.
- ▶ The COE is a Consultant. WE do not replace the PCP in the care of the child.

## Then What????

- ▶ A HCA covered child diagnosed with Autism Spectrum Disorder for whom ABA therapy has been ordered is referred to a State recognized ABA Therapy Provider. HCA has a list on its web site.
- ▶ The ABA Provider coordinates with the MCO and insurance to get approval for treatment.
- ▶ The BCBA performs functional behavioral assessments and formulates the treatment plan
- ▶ Child enters therapy. The journey has begun.

## Developmental Disabilities Administration eligibility is Different from HCA

- ▶ If the family wishes to have their child listed as eligible for DDA assistance, they must comply with the WAC that governs the diagnosis of Autism Spectrum Disorder for DDA and the COE is not included in that WAC.

Thank you

▶ Questions?

