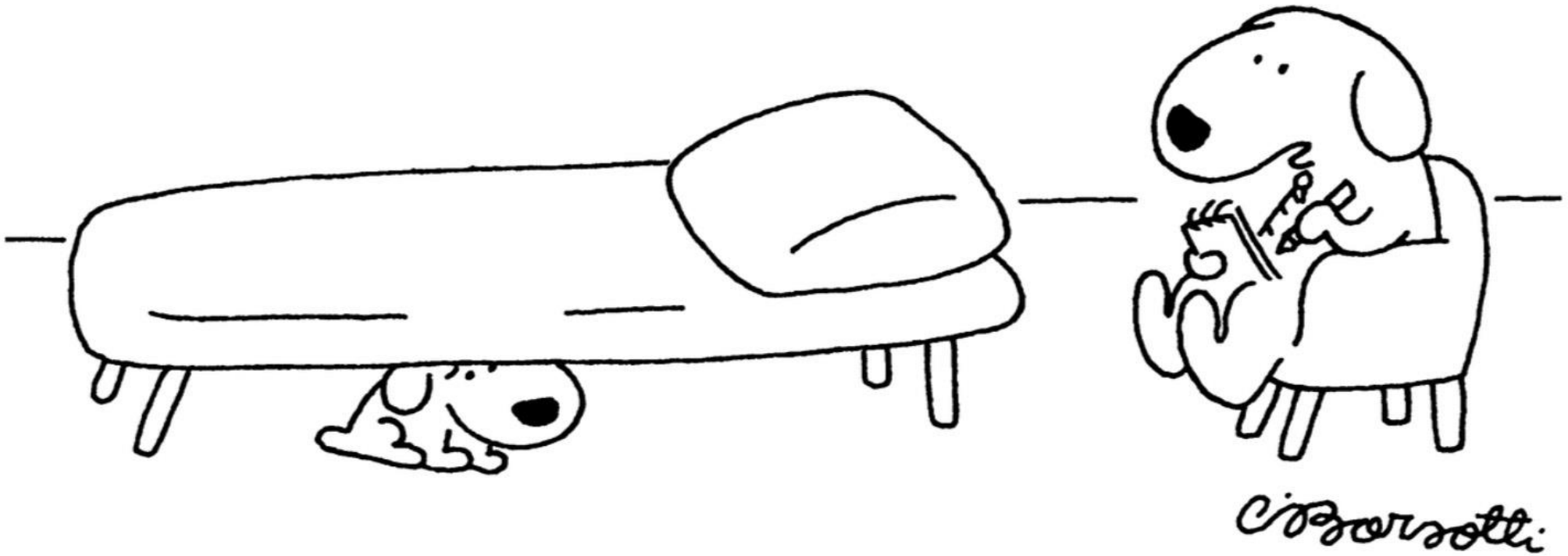
Increasing behavioral complexity and needs of children and youth with neurodevelopmental disorders

Robin Friedlander

December 14th, 2023



"And what do you think will happen if you do get on the couch?"

Charles Barsotti June 10, 1996

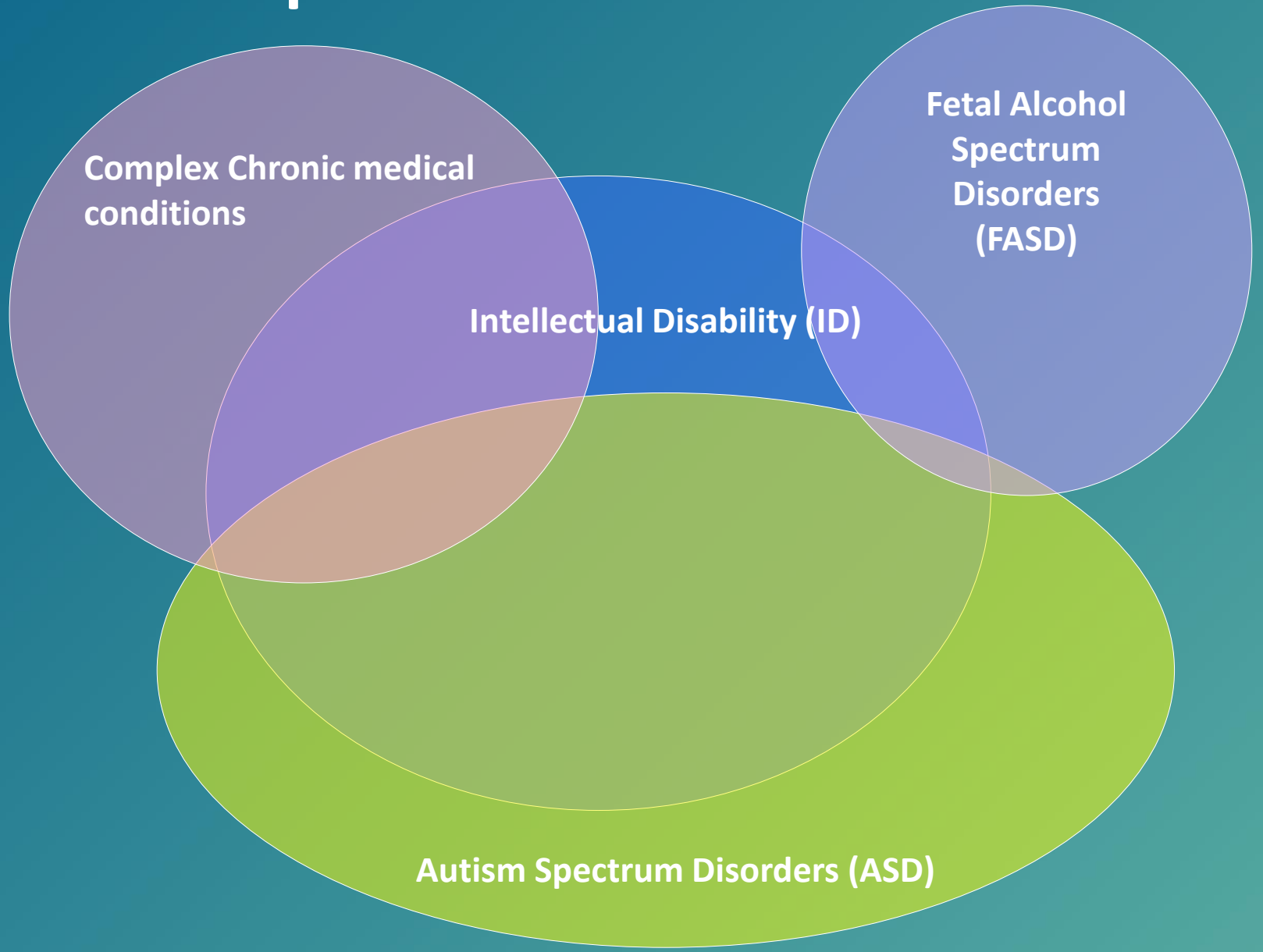
Increasing behavioral complexity and needs of children and youth with neurodevelopmental disorders (NDD's): Talk outline

- The Autism "epidemic"
- Recognize multidisciplinary causes of aggression
- What services do these children/youth MOST need?
- Equitable funding: some ideas about how to support the most needy (= most aggressive children).

The Autism “Epidemic”

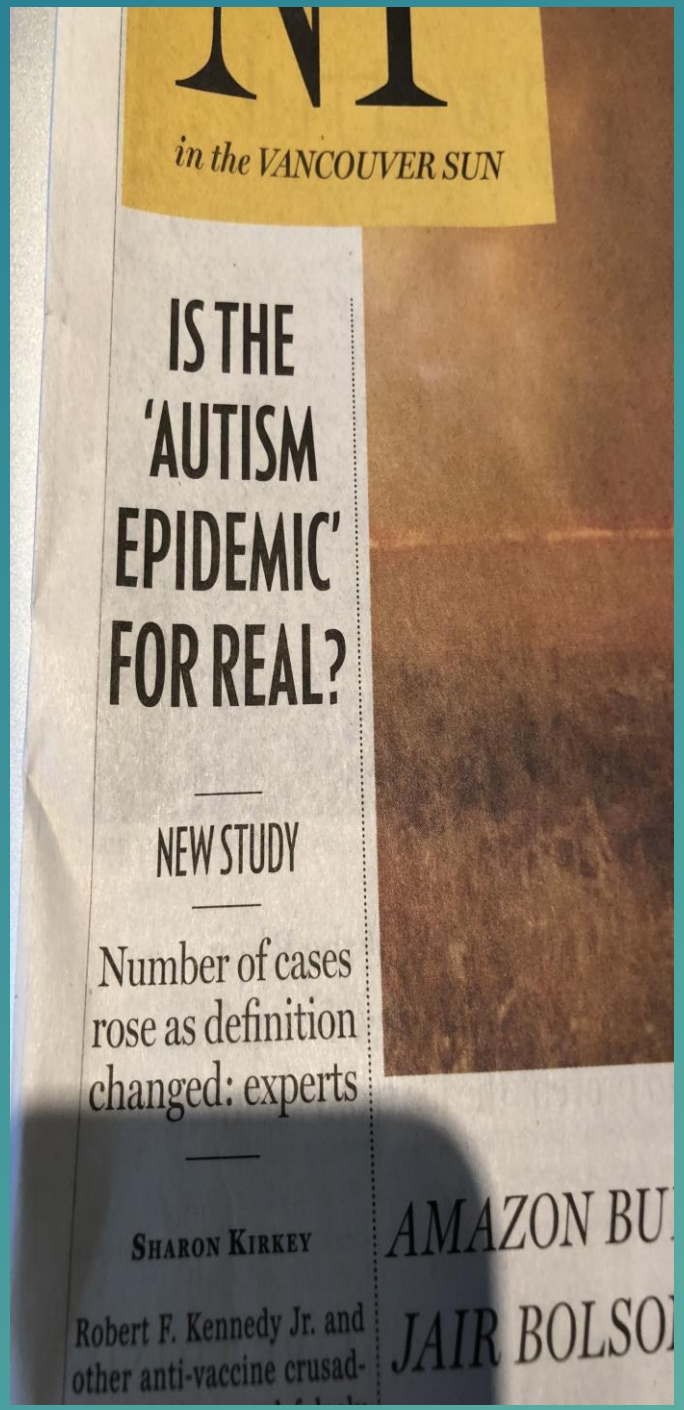
Woodlands institution for the mentally handicapped, BC Canada.

Neurodevelopmental disorders



Anatidaephobia: The fear that somewhere, somehow, a duck is watching you.

AUTISM (ASD)


in the VANCOUVER SUN
IS THE 'AUTISM EPIDEMIC' FOR REAL?
NEW STUDY
Number of cases rose as definition changed: experts
SHARON KIRKEY
Robert F. Kennedy Jr. and other anti-vaccine crusad-
AMAZON BU
JAIR BOLSO

Prevalence of Autism

- Reported prevalence of Autism has increased substantially.
- In the 1970's, the condition was considered rare (<0.05%).
- It is now generally agreed that the lifetime prevalence is at least 1% in both young people and adults.
- In 2021, approximately 1 in 39 or 2.6%, of children and youth ages 0 to 18 in B.C. had an open case with the Autism Funding Program (MCFD)

Autism phenotype versus registered diagnosis in Swedish children: prevalence trends over 10 years in general population samples. Lundström et al, BMJ 2015.

Is this a true increase in the core symptoms of Autism?

- Swedish study monitored the annual prevalence of the autism symptom phenotype in 4000 children over 10-year period.
- Over the 10-year period annual prevalence of the autism symptom phenotype was stable.
- Simultaneously the annual prevalence of clinically diagnosed Autism in a service-based register steadily increased.

Autism phenotype versus registered diagnosis in Swedish children: prevalence trends over 10 years in general population samples. Lundström et al, BMJ 2015.

Is this a true increase in the core symptoms of Autism?

- Conclusion:
  - Increased number of children getting services for Autism in Sweden over a 10 year period.
  - But no increased rate of Autism in Swedish children when same symptoms
  - List used to diagnose Autism over this 10 year period.

Autism phenotype versus registered diagnosis in Swedish children: prevalence trends over 10 years in general population samples. Lundström et al, BMJ 2015.

3 reasons why the clinical diagnosis has increased & the autism phenotype rate is unchanged

1. Broadening of diagnostic criteria
2. Diagnostic substitution
3. Availability of services & funding

1. Broadening of diagnostic criteria

- Increased prevalence reported in Lundstrom study was during a period of repeated modifications and often broadening of diagnostic criteria (1993-2002).

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2. Diagnostic substitution

- Increasing awareness of Autism is associated with diagnostic substitution across categories.
- Other Neurodevelopmental disorders, such as Intellectual disability , Language disorder & ADHD may recently have become overshadowed.
- It has been estimated that 1/3 of the increase in prevalence of Autism between 1996 and 2004 can be attributed to diagnostic substitution.

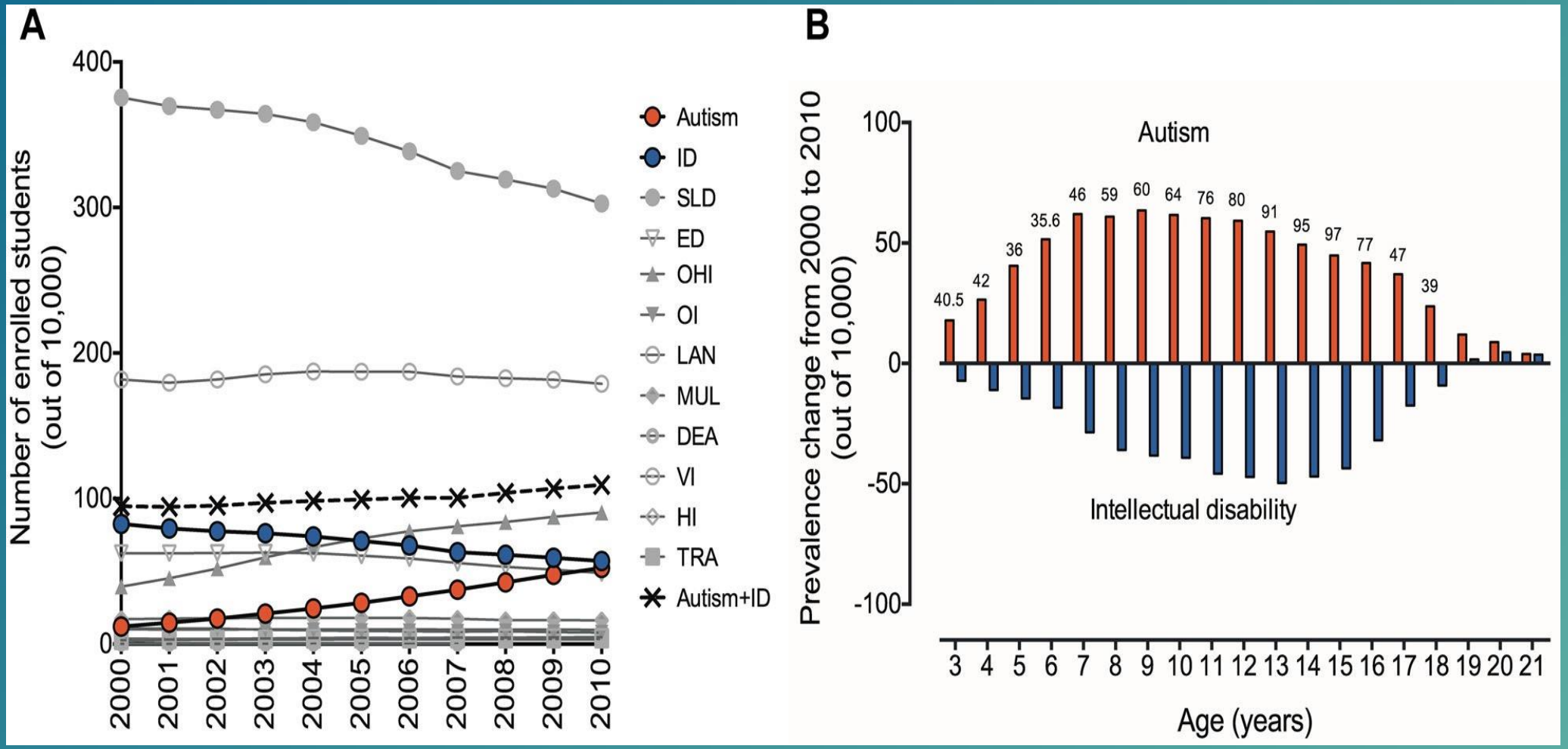
Autism phenotype versus registered diagnosis in Swedish children: prevalence trends over 10 years in general population samples. Lundström et al, BMJ 2015.

Diagnostic substitution: an example

- Prevalence of diagnoses in special education in USA from years 2000 to 2010.
- As rate of clinically diagnosed Autism increased, there was a concomitant reduction in the prevalence of Specific Learning Disorders & Intellectual Disability.

Comorbidity of Intellectual Disability Confounds Ascertainment of Autism: Implications for Genetic Diagnosis, Polyak,et al. Am J Med Genet, 2015.

Diagnostic substitution



"The real question is, where'd you get all these pictures of my mother?"

Pat Byrnes June 28, 2021

Aggression

Recognize multidisciplinary causes of aggression

Children with complex NDD's present with behavioral problems

- Aggression
- Self injury
- Oppositional defiance
- Sleep
- Wandering

Id, eval & management of children with Autism (AAP, 2020)

Normal temper tantrums

- Temper tantrums normal part of development.
- Children 18-60 months
- 2 components: anger (screaming & occasional kicking) followed by distress (whining & crying)
- Median duration 3 minutes
- Frequency (less than daily)
- Bad temper tantrums last 5-20 minutes

Rage outbursts (emotional dysregulation)

- 1-2% of 6-year-olds
- Endure & regulatory attempts ineffective
- Inappropriate to the trigger (short fuse)
- Quick start and slow recovery
- Destroy property, throw ,spit, kick, threaten, may need restraint.
- Resemble a bad temper tantrum, but last 30 – 60 minutes

Nick

- 5 year old with Autism.
- Severe aggressive outbursts.
- Recent outburst was shouting and stomping feet; hitting mom and shouting that his mom was a liar because she wouldn’t let him have ice cream, Said he hated her & was going to stab her.
- Minor triggers such as not allowed to go on iPad before school or sister goes in car before him.
- Outbursts last 15-30 minutes.

Consequences of aggressive behavior

- Parental burnout
- Family isolation
- Restricted access to schools.
- Restricted access to community-based programs.
- Placement out of family home

Causes multifactorial

- Poor frustration tolerance
- Inability to communicate distress/needs
- Inability to deal with overwhelming emotions
- Exaggerated fear of threat
- ADHD
- Anxiety
- Depression
- PTSD

"Guess you're right—I do internalize criticism."

David Borchart January 2, 2023

What do children with NDD's & complex behaviors need?

- Support
- Treatment
- Recognition that needs may change over time

Support & treatment needs

1. Assisted communication/ Behavioral/OT
2. Parent behavioral management training
3. Treatment of comorbid mental health conditions
4. Respite
5. Residential treatment &/or placement
6. Case manager for complex cases

1. Assisted communication/ Behavioral/OT

- Have the family describe in detail a few incidents
- Clarify precipitants to aggression
- Assist with emotional regulation/ learning distress tolerance.
- Does child need AAC (augmented alternative communication)?

2. Parent behavioral management training

- 180 children aged 3-7, with Autism and moderate or greater behavioral problems.
- Offered either Parent Training or Parent Education
- Both treatments led to improvements.
- Parent training was superior to parent education on parent ratings of disruptive and noncompliant behavior and a measure of overall improvement rated by a blinded clinician.

Effect of Parent Training vs Parent Education on Behavioral Problems in Children With Autism. A Randomized Clinical Trial. Bearss et al, JAMA, 2015

3. Treatment of comorbid mental health conditions

- Most psychiatric disorders are treatable
- Beware diagnostic overshadowing (it’s probably not the NDD driving the aggression)
- Medication & psychological treatments
- Need access to psychiatry and psychology/counseling

Comorbid mental health conditions with Autism

- ADHD (50%)
- Anxiety (50%)
- Depression (20%)
- Catatonia (15%)
- Bipolar (14%)
- OCD (12%)

ID, Eva & Management of children with Autism (AAP, 2020)

Ethan

- 7-year-old boy with FASD.
- School report that he is restless & impulsive & can’t stay at his desk. He runs out the classroom.
- No awareness of danger.
- Touches and takes pencils from other students.
- Thinks this is hilarious.
- When teachers intervene he gets angry and hits out.
- Pediatrician diagnoses ADHD & treats with clonidine.
- His restless & impulsive behavior improve & he is now able to stay in the classroom and learn

Jonnie

- Jonnie is 6 years old and has Autism.
- He cannot fall asleep until midnight & then in a bad mood next day.
- Good sleep routines in place.
- Goes to his pediatrician who puts him on melatonin with significant improvement in his sleep.
- Daytime behavior also improves
- Parents are sleeping & feeling better too.

Nick

- The 5-year-old with Autism.
- Severe aggressive outbursts.
- Diagnosed and treated underlying ADHD with clonidine.
- Rage outbursts significantly improved

Mark

- Mark is a 12yr old who has unspecified intellectual disability & autism
- Limited verbal capacity (occasional “no” or “mom”).
- Crying episodes for about 1.5 years.
- Prior to this, Mark was generally doing well.
- Also stopped wanting to eat (lost weight), developed poor sleep, lost energy and interest and wanted to be in a dark room covered by a blanket.
- Started to be aggressive & self injure (SIB) - hitting himself hard in the leg, groin, head.

Mark

- Mark is seen by pediatrician.
- No medical cause for his presentation.
- Diagnosed with Major Depression
- Treated with fluoxetine with good response.
- Smiling more, eating more, sleeps better, wants to go out.
- Much less aggression & self injury.

4. Respite

- More funding for the most needy families
- No point offering funding if the child’s behavior such that family can't find respite caregivers
- Need dedicated respite homes, which families can access for planned respite.

Jake

- 8-year-old boy with unspecified intellectual disability & autism.
- Nonverbal.
- severe aggression to mom and self.
- At night, up for 2- 4 hours and insists that mom or dad drive him around.
- If not driven around he bangs his head and is aggressive and wakes everyone up.
- Cannot attend school.
- Recently admitted to hospital because of aggression.

Jake

- Family provided with overnight respite funding.
- But they cannot find anyone prepared and with skills to do this.
- MCFD recommended mom try and get a nursing student for help
- (Mom has reached out to her own nursing program without success).

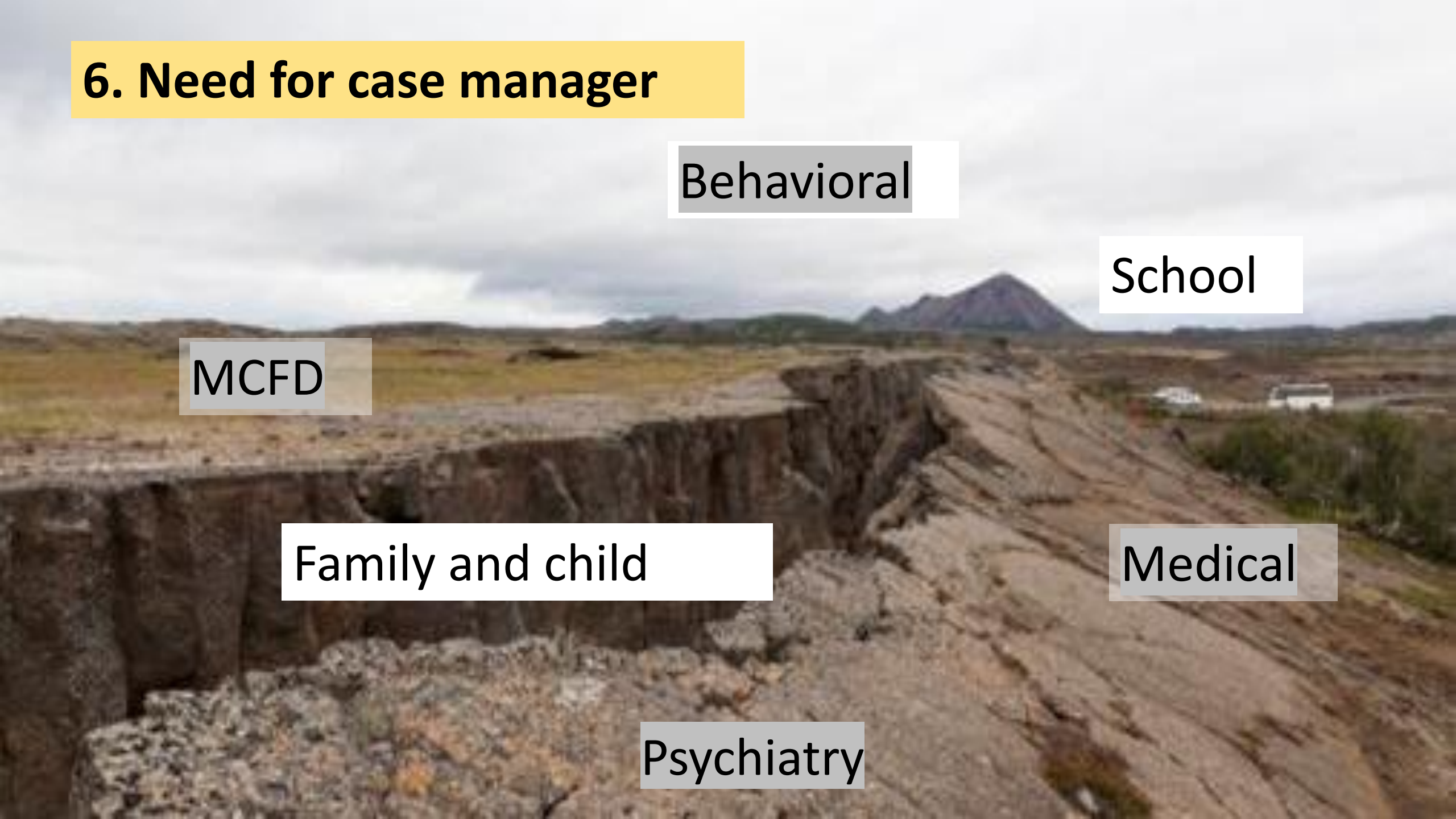
Emergency respite

- If there is a 6- bed planned respite home with skilled staff, then 2/6 beds can be set aside for children and youth who need emergency respite because of their behavior.
- MCFD cannot rely solely on hospitals to address behavioral emergencies.
- A shared care model could be negotiated with Health for psychiatric medical and nursing support.

5. Residential treatment &/or placement

- Recognition that some families will be unable to continue to look after their children in the family home because of their behavioral complexity.
- May need 6-month treatment home or permanent placement
- Plan ahead to ensure that when this happens, MCFD isn’t scrambling to find a suitable resource.

6. Need for case manager

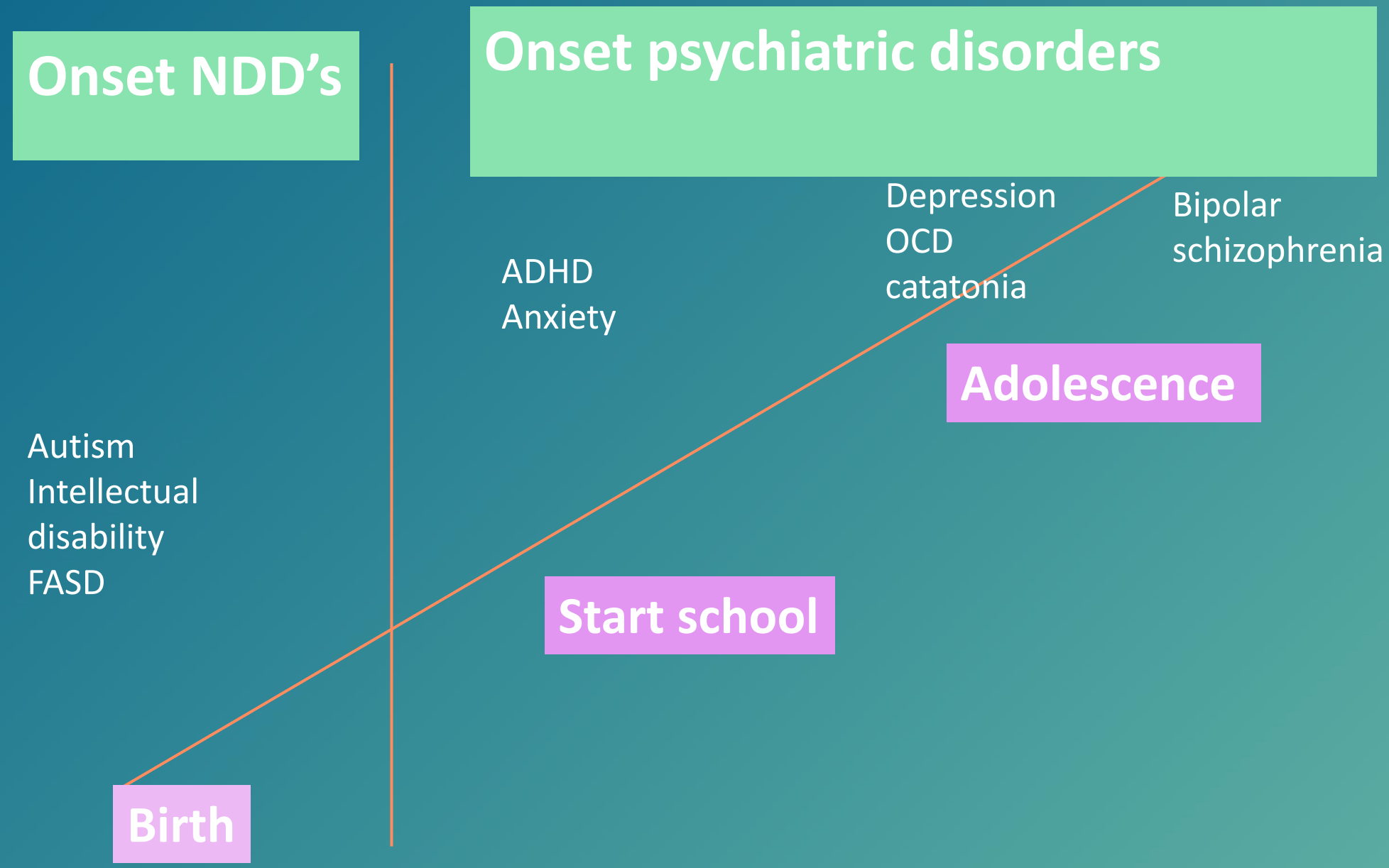


Some ideas about equitable funding (my ideas)

1. Diagnosis based funding not useful.
2. Funding according to need is the holy grail.
3. Helping deal with aggression is the biggest need
4. If funding most needed for children with aggression, then need data to evaluate degree and impact of the aggression

Developmental timeline

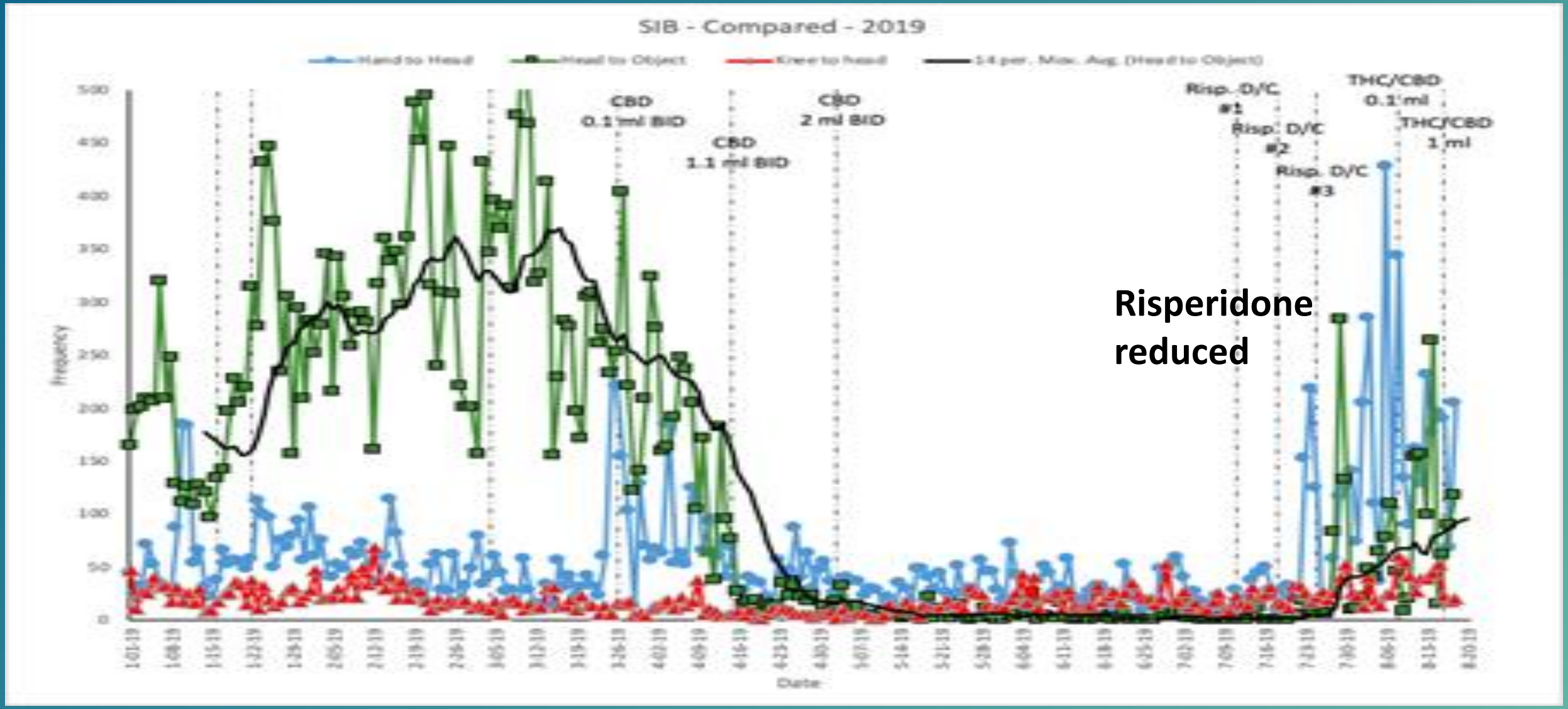
- As the child gets older, significant comorbid behavioral and mental health challenges emerge
- And the child gets bigger and stronger
- More services needed as child gets older


Onset NDD's
Onset psychiatric disorders
Depression
OCD
catatonia
Bipolar
schizophrenia
ADHD
Anxiety
Adolescence
Autism
Intellectual
disability
FASD
Start school
Birth

Getting hard data to document aggression

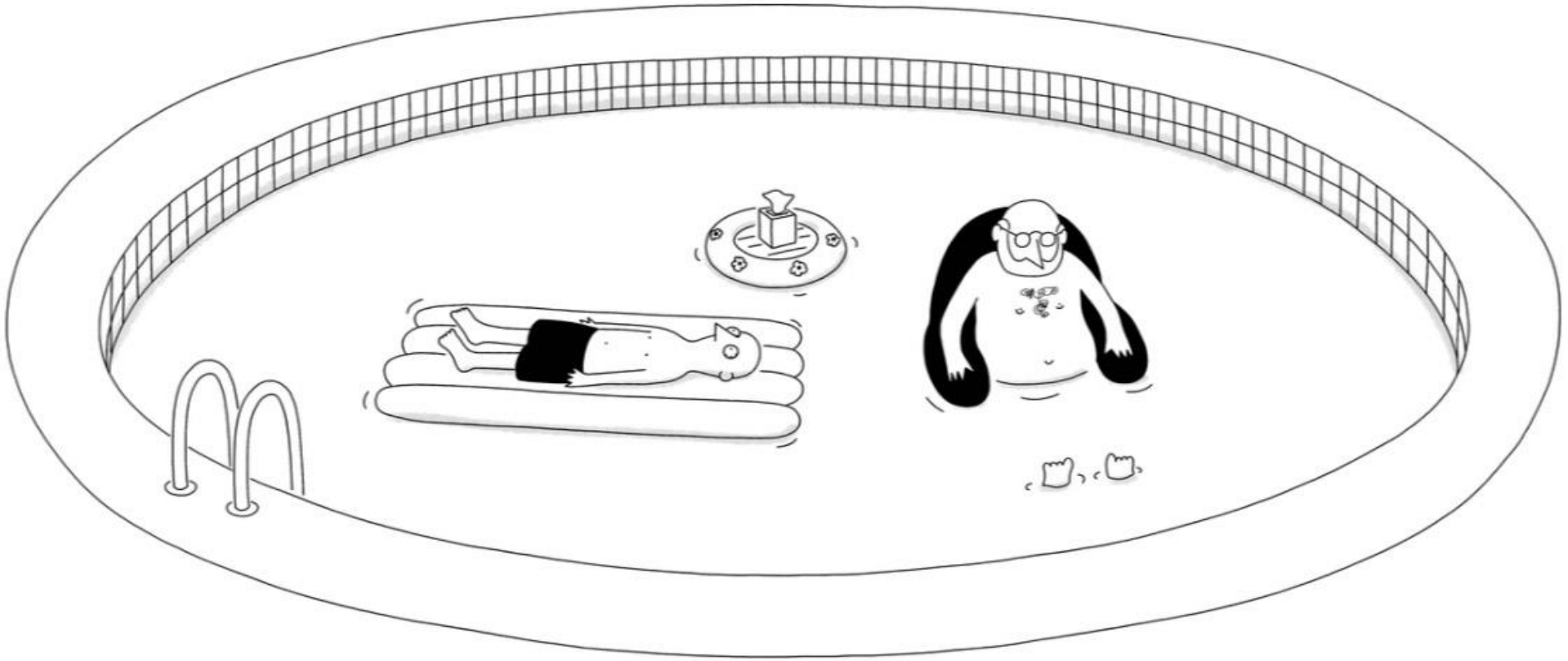
- Child suspended from school and/or day care or only able to attend for a restricted time?
- Number of critical incident reports at school or in community.
- Do caregivers (parents, teachers respite, daycare) show visible injuries (bruises)?
- Measure the severity of aggression using a standardized rating scale.
- Number of diagnoses (NDD's & psychiatric).
- Measurement of parental stress and capacity.

SIB frequency (0 – 500 hits/day)



Summary: increasing behavioral complexity and needs of children and youth with neurodevelopmental disorders

- The Autism “epidemic”
- Multidisciplinary causes of aggression
- Algorithm to understand causes of irritability
- MOST needed services are for aggression
- Some ideas about equitable funding



AQUA THERAPY

Seth Fleishman September 13, 2021