# When Autism & ADHD Combine with High IQ

Parents are Underutilized in Diagnosis and Treatment

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## Disclosures

## • CEO, ImpactParents.com





## Parents are Underutilized Resource for Diagnosis & Treatment

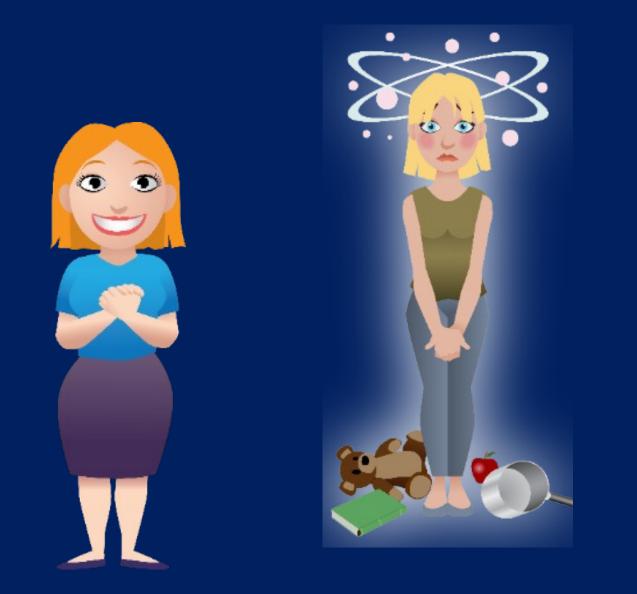
Case Examples for Re-evaluating Diagnosis

What Families Need from Their Providers

## aluating Diagnosis n Their Providers



## WHY am I Here?





**Diagnosis and Treatment** for "Very Complex" kids can more complicated and nuanced than many providers expect





## "I'm DESPERATE."

"I just want some peace in my home."







## Parents' Role in Diagnosis & Treatment





WHY are Parent Interventions Recommended Treatment?







## "No, honey. You're just a mom."







## CASE STUDIES







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Margaret 9 yr old with a typically developing twin and 16 yr old sister with significant anxiety. Dx with GAD at 6 (at Kennedy Krieger), ADHD at 8, Depression at 9. Therapy since 1<sup>st</sup> grade. Hospitalized at 9 at Children's Nat'l Med Center after a series of drastic episodes & a suicide attempt, later saying "I didn't want to die; I just wanted the pain to stop." Local psychiatrist: "I don't' have the capacity to help a kid like her." Emotionally volatile & excessively dependent on mom, who gets no respite.

Parent's & their families have history of mental illness (ADHD, Depr, Anx, Autism)

Multiple diagnoses do not fully explain all of behaviors

Treatment (from early age) focusing on one primary diagnosis (Anxiety)

Sensory & sleep issues, emotionally eruptive & dysregulated from young age

Unusually & highly empathetic. Social connection wanted but difficult

Wanderer – leaving camp, school, classroom without telling adult

Simultaneously aggressive to parents and still extremely emotionally dependent



Carrie is 14. She and younger brother are both adopted. Gifted and Dx with ADHD and in treatment from early age at NYU Cornell. Struggles with social skills, being bullied, emotional dysregulation. Fiercely attached to mom. Won't sleep alone so parents have slept separately for years. Mom walking on eggshells in volatile home environment. Sent home from summer camp; lost placement in competitive Arts HS in NYC. Addition of Prozac calmed irritability. Wilderness Treatment re-evaluation and Dx of ASD, spent 18 months in treatment hospitals.

Parents are high-performers with Anxiety, ADHD, Depression and ?? ASD

Dx didn't explain all behaviors - treated from young for ADHD but not Anxiety

**Emotionally abusive to parent and yet extremely emotionally dependent** 

Disruptive, disrespectful, entitled, emotionally eruptive, sensory issues

Social connection desired but difficult to establish and maintain

Resistant to treatment even when facing expulsion from school she loves

Refuses to do schoolwork or to perform basic tasks for herself (even when wanted)

Sibling is a 'lost child' who is easy-going, compliant, and doesn't make waves.



# Jamie was adopted 12 year old

with 16 yr old adopted brother with classic ADHD. Jamie's Dx included Tourette's, ADHD, Anxiety, OCD, Depression, LD. ASD originally considered but discounted. Therapeutic support began early, parent referred to me by child psychologist. After risking being asked to leave special needs school and attending out-patient summer treatment, Autism finally Dx and has been in-patient placement for 2 years. Teen alternately refuses and engages in therapy.

Parents are educated with ADHD, Depression, and/or Alcoholism

Challenging behaviors from early age, often attributed to attachment & TS

Multiple diagnoses. Exposure therapy for OCD, art therapy, social skills, etc

Simultaneously abusive to parent and extremely emotionally dependent

Disruptive, disrespectful, entitled, emotionally eruptive, sensory issues

Social connection desired but difficult to establish and maintain

Resistant to therapy and school agreements, tends to leave classroom

Refuses to do schoolwork even though she wants to stay at the school



Commonalities of "VERY" complex kids with ADHD and Anxiety who were reevaluated and Diagnosed with Autism Multiple diagnoses do not fully explain all behaviors

Extreme attachment to (at least) one parent

Sleep issues prevent typical sleeping patterns for child and family members

Treatment (from early age) focused on one diagnosis to exclusion of others

**Emotionally eruptive and extremely emotionally dependent** 

Sensory issues; dysregulated from young age; may be 'wanderer' or 'fighter'

Social connection wanted but difficult

Likely to have history of being bullied



Commonalities of parents of "very" complex kids with ADHD and Anxiety who were re-evaluated and Diagnosed with Autism.

One or both parents have often received extensive therapy with limited results

**Coaching and expanded understanding has guided parent to return to therapy**  Families/parents have history of mental health differences and/or adoption

Parents sought support for child's challenges at very early age

Parents have seen multiple providers, typical approaches ineffective

Parents feel on the edge of breakdown or burnout

Parents continue to seek clarity because they know something's missing

Parents are tolerating extremely disrespectful behaviors

Parents can't get respite because the child is obsessively attached

Parents have reached the point of setting little or no expectations for the child



Diagnosis in complex cases could be better informed by exploration of parents' experience.





Medication without skills for parents to learn conscious management is an incomplete protocol.





Support for parents is insurance.

recommended by providers.

# generally not covered by

# **Referrals are generally not**

Recommended Treatment for Children is 'Behavior Parent Training' (BPT) or 'Behavior Therapy' and Should Include:

### **Understanding child's behavioral issues**

Skills to strengthen positive behaviors and minimize unwanted behaviors

How to set appropriate expectations

How to use rewards & consequences effectively

**Opportunity to practice specific strategies and get feedback to adjust** 

Participation in a community for peer support and to end isolation



In a 2020 survey of 180 parents to explore factors that underlie barriers and compliance for parents regarding Behavior Management Training... > Less than 30% of Parents received Recommendations for Behavioral Management Training (BMT)

> Parents did not understand distinction between free information and Behavioral Management Training (BMT)

> Parents did not see themselves as part of treatment and expected treatment to focus exclusively on child



What Do Parents Need MOST from Providers in Diagnosis & Treatment? Look for signs of 'very' complex kids and a need for more nuanced diagnosis

Ask questions about parenting challenges & look for outliers

Set appropriate expectations: there's no easy fix and they're not alone

**Encourage Parent BMT in treatment for ALL complex kids including teens** 

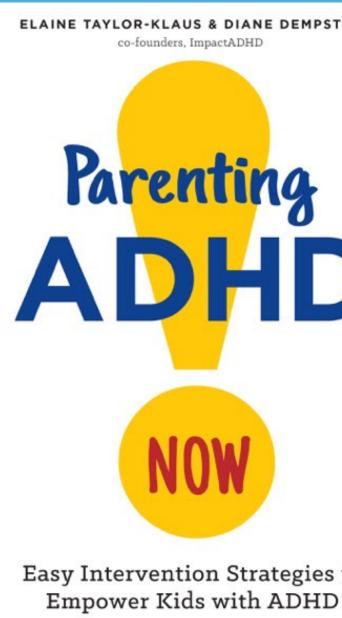
Explain that parents need more than info; reinforce value of parent support

Stop worrying about offending parents by strongly encouraging parent training



### Books by Elaine Taylor-Klaus, PCC Get a sample chapter of "The Essential Guide":

Download at: ImpactParents.com/APSARD



**ELAINE TAYLOR-KLAUS & DIANE DEMPSTER** co-founders, ImpactADHD

Parenting

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The Essential Guide to Raising Complex Kids with ADHD, and More

ELAINE TAYLOR-KLAUS, ret, over ED-FOUNDER OF INDIRCHPRINE CETL CHIEDER OF SHIT IS SECOND FOR PRIMER & INSCIDENT. Freeword by Edward H. Helland, M.D.

