



Thompson Center for
Autism & Neurodevelopment
University of Missouri

THE SCIENCE AND DELICATE ART OF DELIVERING FEEDBACK TO FAMILIES AND PATIENTS

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OBJECTIVES

1. Analyze available research on delivering feedback and having difficult conversations.
2. Identify strategies to promote family-centered, individualized, and digestible feedback for families.
3. Attendees will discuss how to respond when feedback is not received well by families.

SPECIAL THANKS



Connie Brooks, Ph.D.

Xiaotian “Daisy” Hu, MS





WHAT KIND OF FEEDBACK ARE WE TALKING ABOUT?

Feedback can be many things...

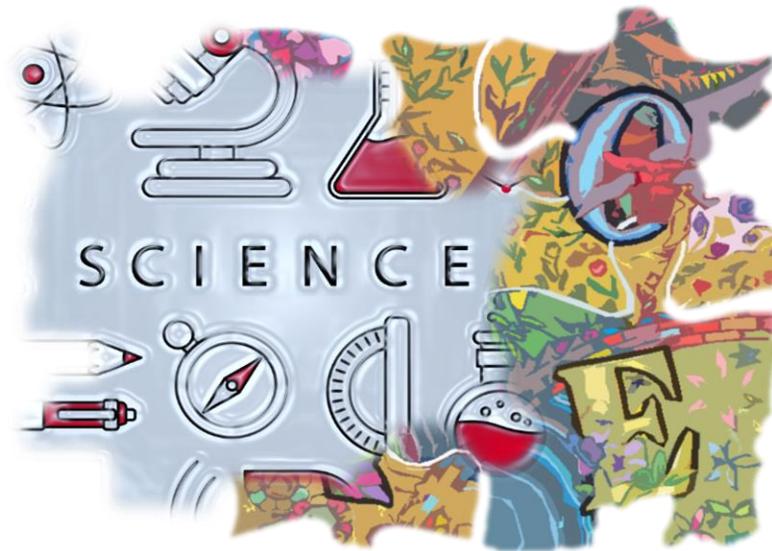
- Correction/encouragement
- Changing/maintaining behaviors
- Quality improvement
- Supervisory
- Sharing information

Today's focus is **diagnostic feedback**, but these strategies can be applied to other situations

"Culmination of communication throughout the assessment process"

- The Psychological Society of Ireland, 2022

ART & SCIENCE IN FEEDBACK



Art & Science

**Family-Centered &
Culturally-Sensitive Care**

THE “WHY”

Aim to provide good-quality care, and increase parent satisfaction

Parents who have positive experience in receiving a diagnosis have better ongoing relationships with providers in the future
(O'Brien and Daggett, 2006)

Feedback can affect parent mental health after the evaluation
(The Psychological Society of Ireland, 2022)

When parents feel heard and they feel confident in the evaluation they are more likely to use and accept the information presented
(The Psychological Society of Ireland, 2022)

When parents are provided with hope, they are more likely to seek care for their child
(Nissenbaum et al. 2002)

VOICES FROM FAMILY EMOTIONS

I just cried all the way home

“I was very nervous before it...shaking when we first went in...although I’d wanted to know for a long time.”

“We were prepared for them to come up with the diagnosis ... I was still upset.”

It was funny really because I expected not to feel much of anything. I thought ‘well we know what’s going to happen’ but really for a week I just felt lost

VOICES FROM FAMILY

INFORMATION/STRUCTURE

There was a lot to take in ... system overload!

I had the feeling of wanting to ask more questions, but not knowing what questions there were to ask

She (the provider) didn't beat around the bush

They said he's a happy and pleasant little boy

AUTISM FEEDBACK GUIDELINES

Pattison et al., 2021

Title	Year	Publisher
People with Autism Spectrum Disorder: Identification, Understanding, Intervention	2019	Autism Europe (AE; Barthélémy et al., 2019)
Standards of Diagnostic Assessment for Autism Spectrum Disorder	2019	Canadian Paediatric Society (CPS; Brian, Zwaigenbaum & Ip, 2019)
A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia	2018	Cooperative Research Centre for Living with Autism (CRC; Whitehouse et al., 2018)
Autism Spectrum Disorder—Warning signs, Detection, Diagnosis and Assessment in Children and adolescents	2018	Haute Autorité De Santé (HAS; 2018)
Autism Spectrum Disorder under 19 s: Recognition, referral and diagnosis	2017	National Institute for Health and Care Excellence (NICE; 2017)
Clinical Practice Guideline on Assessment and Intervention Services for Young Children (Age 0–3) with Autism Spectrum Disorder	2017	New York State Department of Health and Bureau of Early Intervention (NY; 2017)
New Zealand Autism Spectrum Disorder Guideline	2016	Ministries of Health and Education (2016), New Zealand (NZ)
Assessment, Diagnosis, and Interventions for Autism Spectrum Disorders	2016	Scottish Intercollegiate Guidelines Network (SIGN; 2016)
Practice Parameter for the Assessment and Treatment of Children and Adolescents with Autism Spectrum Disorder	2014	American Academy of Child and Adolescent Psychiatry (AACAP; Volkmar et al., 2014)
Connecticut Guidelines for a Clinical Diagnosis of Autism Spectrum Disorder	2013	University of Connecticut School of Medicine and Dentistry (UC; 2013)
Autism Spectrum Disorders in Pre-School Children: AMD-MOH Clinical Practice Guidelines	2010	Academy of Medicine Singapore (AMS-MOH; 2010)
Best Practice Guidelines for the Assessment and Diagnosis of Autistic Spectrum Disorders for Children and Adolescents (birth to 18 years)	2010	The Psychological Society of Ireland (Autism Spectrum Disorders Special Interest Group [PSI], 2010)
Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment	2010	Thompson Foundation for Autism and the Division of Developmental Disabilities, Missouri Department of Mental Health (MDMH; 2010)
Identification and Evaluation of Children with Autism Spectrum Disorders	2007	American Academy of Pediatrics (AAP; Johnson & Myers, 2007)
National Autism Plan for Children	2003	The National Autistic Society for National Initiative for Autism: Screening and Assessment (NAS; 2003)
Autism Spectrum Disorders: Best Practice for Screening, Diagnosis and Assessment	2002	California Department of Developmental Services (CDDS; 2002)
Practice Parameter: Screening and Diagnosis of Autism	2000	American Academy of Neurology (AAN; Filipek et al., 2000)

SOME COMMON ESSENTIAL COMPONENTS FROM GUIDELINES

Adequate time for feedback

Timeliness from the evaluation

Summary of how the patient's behaviors fit with a diagnosis (or not)

Use of understandable language in family's primary language

Individualized to family's needs

Next steps/interventions

Clear and concise (avoid sugar-coating)

Sensitivity to parent and/or patient's distress/being compassionate and empathic

Privacy (may or may not involve child)

Limited interruptions/distractions

Direct and open conversations with older children/adolescent

Comfort of the space

Information about what we know about ASD

Give hope/discuss strengths



PARENT SATISFACTION — STRUCTURE/INFORMATION

- Parents perceive information to be helpful (Moh & Magiati, 2012) and individualized to the child (Abbott et al., 2013)
- Information given during feedback is also put in writing (Osbourne & Reed, 2008)
- Provider sees child's strengths and recognize them as individuals (Abbott et al., 2013; Braiden et al., 2010; Crane et al., 2016; 2018)
- Parents are more satisfied when given “overwhelming” amount of information as opposed to “adequate” amount (Hasnat & Graves, 2000)

PARENT SATISFACTION — ARTFUL FEEDBACK



Parents are more satisfied with evaluations when:

- Feel as though there is collaboration between the parent and professional
 - Able to ask questions, parents' concerns taken into consideration, professionals are “supportive and empathic” (Moh & Magiati, 2012; Brogan & Knussen, 2003)
- Professionals are “supportive and empathic” (Moh & Magiati, 2012; Brogan & Knussen, 2003) have good interpersonal skills, such as being open-minded, honest, and understanding (Osbourne & Reed, 2008)
- Professionals respond in a way that is tuned-in with the parents and their concerns (The Psychological Society of Ireland, 2022)
- Professionals are more certain about their conclusions (Brogan & Knussen, 2003; Quine & Pahl, 1986)

PARENT DISSATISFACTION

Parents are less satisfied with evaluations when:

- Had to consult more professionals to obtain a diagnosis - jumping through hoops! (Goin-Kochel et al., 2006)
- Waited longer for a diagnosis (Howlin & Moore, 1997)
- Too much or too little information is given (The Psychological Society of Ireland, 2022)
- Information is too technical (Abbott et al., 2013; Hackett et al., 2009)
- Parents are concerned with things outside of the core ASD symptoms (de Alba & Bodfish, 2011)
- Professionals do not provide adequate information about where to go/do not offer help (Braiden et al., 2010; Crane et al., 2016, 2018)



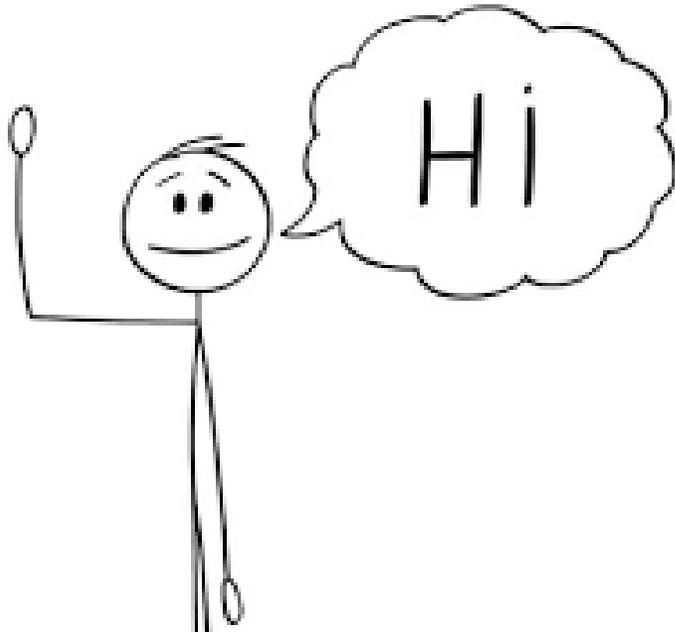
ANDERBERG & SOUTH, 2021

- Some of the only quantitative research on ASD evaluation feedback (rather than focus groups or survey data)
- Key findings:
 - Giving family hope may reduce their anxiety about a diagnosis (which leads to better outcomes for the patient!)
 - Anxious parents are unable to retain as much information from feedback sessions, but the more information shared, the more they feel prepared
 - Helpful to ask parents:
 - about their anxiety about receiving a diagnosis
 - whether they are hoping to receive a diagnosis (or not)
 - how much they believe their child has ASD
 - how much they know about autism and intervention options
 - why they are seeking evaluation (make sure needs are met through the evaluation)
 - When parents are highly emotional or anxious, can be helpful to have follow-up with them



SPECIFIC STRATEGIES (AKA “THE ART”)

AUTISM FEEDBACK STARTS AT “HELLO”



- ❖ FIRST AND FOREMOST: Remember that this is their kid; it's a big deal
- ❖ Begin building rapport
 - ❖ Warm welcome – that fits with you (people can tell when you are artificially “warm”)
 - ❖ “Cadillac Treatment” (©Connie Brooks) – we want them to be comfortable
 - ❖ Acknowledge the time they have waited
- ❖ Establish your expertise/credibility at the start
 - ❖ Introductions – who you are, your expertise/experience
 - ❖ Unflappable
 - ❖ Exude confidence (but not cockiness)
 - ❖ Sometimes we are looking for “subtle” behaviors that most people don't look for
- ❖ Tend to their emotional needs
 - ❖ Acknowledge feelings of frustration, anxiety, sadness, etc.

WHAT ELSE DO YOU DO TO ESTABLISH
TRUST AND RAPPORT?



EXPECTATIONS AND EDUCATION

Setting up/clarifying expectations

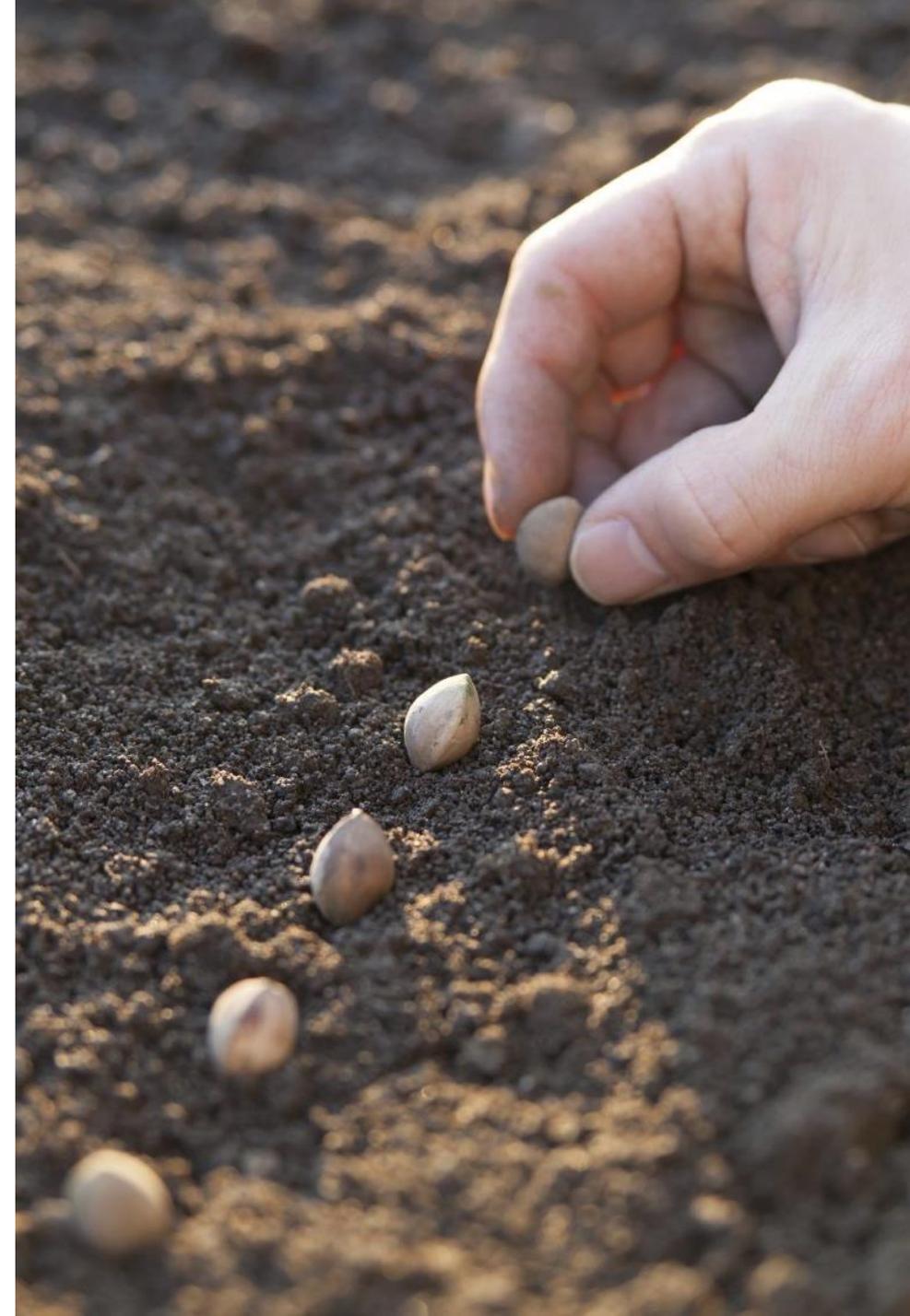
- Ease worry by setting an agenda for the day
- Make sure we are meeting the family's needs – what are they looking for? What is their goal? How can we help?
- May not have ALL the answers
- When is feedback happening?

Plant seeds, educate, be transparent with kindness

- Say “autism” early and often
- Don't wait until the feedback to talk about the criteria or how a decision is made
- What are the possible outcomes of the evaluation – and how would they feel about them?

PLANTING THE SEEDS

- When asking questions, link them to behaviors you've observed
 - “I noticed he lined up his dinosaurs in the room, does he do that at home too?”
- Pointing out symptoms reported that fit or don't fit after the interview
 - “I'm hearing some things that may be related to autism”
 - “After seeing him for a little bit, and hearing what you're seeing at home, I have some concerns for autism, but our other testing will tell us more”
- Pointing out behaviors as they are happening during ADOS and observational measures
 - Often easiest for younger patients
 - Sometimes helpful to have someone else in the room with you if possible
 - “Notice how I held my hands out to the side to see where he was looking while he made a request for more bubbles? He often looks at the object instead of me”



ONGOING BEHAVIORS THAT LEAD UP TO FEEDBACK

- Actively listening – don't rush through just to get done quicker
- Clarifying for understanding
 - Ok so when you say he does repetitive things with his hands, what does that look like?
 - Repeat back
- Communicating
 - Where are you “leaning” – but only do this when you have a strong sense or when you are worried that a diagnosis could be shocking
- Not over-promising or speaking from experience you don't have
- Trust/maintenance of rapport
 - Praising efforts
 - Building confidence in their instincts

THE FINALE — THE WHOLE SHEBANG...

THE FEEDBACK

- ❖ Have tissues available – but don't come waltzing in with a box of tissues..
- ❖ Are they trying to take notes? Do they have support they need?
 - ❖ Allow for recording, if consistent with your policy
 - ❖ If both parents couldn't be there – can you call the other parent?
- ❖ Set the expectations for feedback
 - ❖ “First I'm going to talk about autism – because that's what brought you in!”
 - ❖ Ask as many questions or as few as you need
 - ❖ This is FOR YOU
- ❖ Don't dawdle – deliver the news right away with permission
 - ❖ “I'm going to jump right in with the diagnosis, if that's ok?”

FEEDBACK STRATEGIES CONT'D

- ❖ Allow “space” for the family to react and process a bit
 - ❖ And periodically check in!
- ❖ Check in on their emotions
 - ❖ Even when you think you know what’s going on – or they told you they wouldn’t be surprised!
- ❖ Be genuine with your own emotional reactions (to a degree)
- ❖ “What questions do you have?” versus “Do you have any questions?”
- ❖ Give resources, written information, and how to contact if they have questions
- ❖ Ask questions about what they need in the feedback session
 - ❖ “Would it be helpful to go through why he meets criteria for ASD?”

FEEDBACK SHEET EXAMPLE

UNIVERSITY *of* MISSOURI THOMPSON CENTER FOR AUTISM & NEURODEVELOPMENT

Clinical Assessment Team

205 Portland Street
Columbia, MO 65211
(573)884-8052

<http://thompsoncenter.missouri.edu>

Patient's Name: Betty Boop|
Hospital #: 55-55-55-55-5
Date of Birth: 10/29/1933
Referred by: Parent referral
Provider: Rose M. O'Donnell, Ph.D.
Graduate Clinician: Daisy Hu, M.S.
Psychometrist: Peyton Matthews, BS
Date of Evaluation: 10/13/2022

Diagnoses:

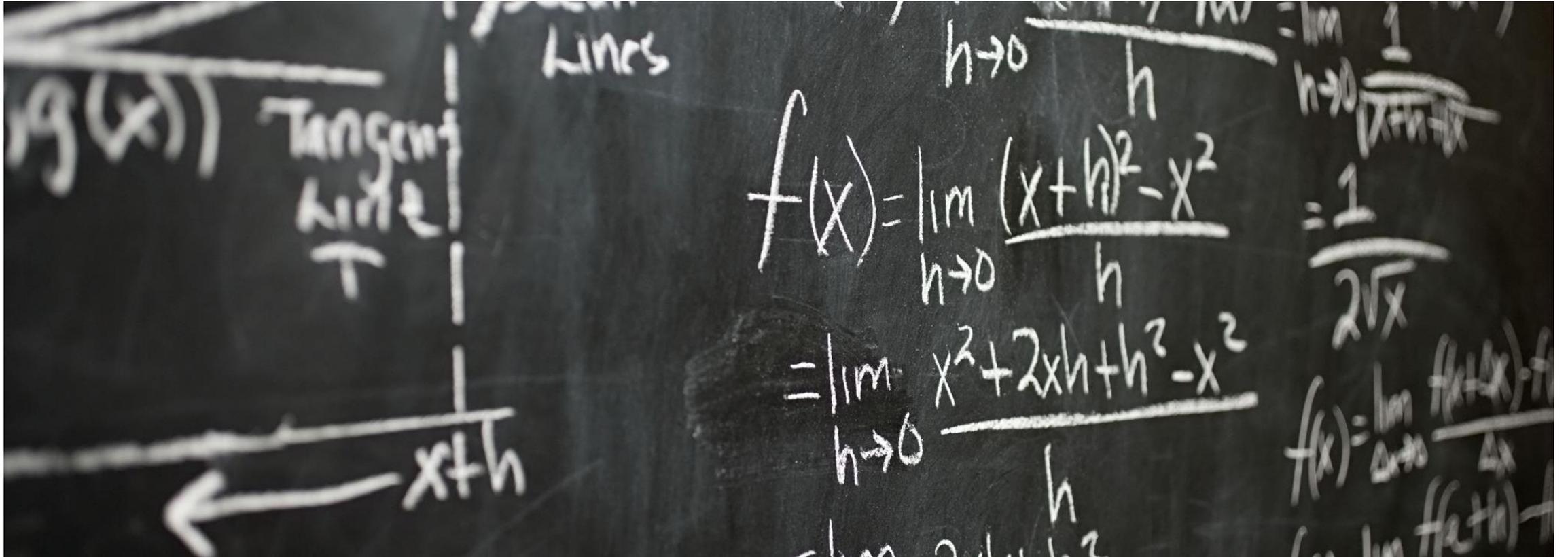
Autism Spectrum Disorder
Attention-Deficit/Hyperactivity Disorder, by report

Initial Recommendations:

1. A **full report** is forthcoming that will discuss these findings in more detail. A number of specific recommendations will also be included in the full report.
2. Betty may be eligible for supports through Columbia Public Schools to help improve her social interactions within the school setting. Additionally, should behavioral problems increase within the school setting, supports to help with rigidity may be beneficial.
3. Betty would benefit from the Thompson Center's social language group and a referral will be made on her behalf.
4. Betty's symptoms of anxiety should be monitored over time. While her symptoms are not currently at the level to provide a diagnosis, she is exhibiting some mild symptoms at this time, which may worsen over time.

Thank you for the opportunity to participate in Betty's care. If you have any questions, feel free to contact the Thompson Center at (573) 884-8052.

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Licensed Psychologist
Assistant Clinical Professor



**DOES THE ART & SCIENCE ALWAYS
WORK?**

Absolutely not

WHAT ARE BARRIERS TO ESTABLISHING TRUST?

Individual factors?

Cultural factors?

Structural factors?

Historical factors?

How do our biases affect establishing trust?



Not everyone views a diagnosis of ASD the same way... this may impact your feedback

- Korean community tends to experience more discomfort, stigma, and discrimination related to ASD (Kang-Yi et al., 2018)
- Kenyan families have a range beliefs about what causes ASD (evil spirits, witchcraft, curses, infection, drug abuse, birth complications, malnutrition, genetic problems) and how to intervene and support (spiritual health to “modern treatment in health facilities”) (Gona et al., 2015)
- Latino families tend to receive limited info about ASD and are more likely to interpret red flags as typical behavior or attribute them to family dysfunction; when delays are present it tends to be associated with feelings of embarrassment, rejection, and family burden (Zuckerman et al., 2014)

CULTURAL CONSIDERATIONS



WHAT ARE SOME BARRIERS TO DELIVERING OUR “IDEAL” FEEDBACK?

- We're talking about really hard stuff
- Language
- Differing views
- Lack of trust
- Previous bad experiences
- Cultural differences
- Denial
- Mental health
- Feelings of guilt or shame
- Bias
- Nerves/emotions
- Time
- Experience
- Not on our “A” game

GIVING SENSITIVE/DIFFICULT INFORMATION

- ❖ Remember, this isn't about you
 - ❖ Check your ego at the door
- ❖ Be CLEAR
 - ❖ Don't use vague language or metaphors – say what you mean
 - ❖ You might be nervous, but avoid weakening language with “kind of” or “sort of”
- ❖ Be empathetic
 - ❖ “I know you said you would be surprised earlier, how are you feeling now?”
 - ❖ “I know that information was probably hard to hear, how are you doing?”

**BUT WHAT IF
YOU USE ALL
THE ART AND
SCIENCE AND
FEEDBACK IS
STILL ROUGH?**

- ❖ Align with the parent – THIS IS SO HARD TO DO SOMETIMES!
- ❖ Give next steps – can they get another opinion? A follow up down the road?
- ❖ Can they choose not to accept/share the results?
- ❖ Other options
- ❖ Focus on the end outcome/goals

SOME EXAMPLES

The “explainer-awayer”

- Sometimes people aren't ready to hear the diagnosis, do all you can to get them there

“YOU’VE MISSED SOMETHING!”

- Sometimes what people say their reaction will be, doesn't match their actual reaction

A feedback that lasted nearly as long as the evaluation

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QUESTIONS AND THOUGHTS?
