

## ACT's Focus on Research Conference 2023

### Sensory Features and Anxiety in Autism: Implications for Families and Practitioners

A two-day in-person and virtual conference hosted by ACT

Thursday, April 27, 2023

Friday, April 28, 2023

### Distinct Expressions of Anxiety in Autistic Individuals (and Why They Matter)

*Presented by Connor Kerns, PhD*

#### Territorial Acknowledgement

As visitors on this land, ACT - Autism Community Training is grateful for the opportunity to work and learn on the ancestral and unceded territory of the Skwxwú7mesh (Squamish), xʷməθkʷəy̓əm (Musqueam) and səliłwətaʔt (Tsleil-Waututh) people who have lived in this area since before recorded time. These nations are hənqəmiṇəṇ and Skwxwú7mesh speaking peoples. The hənqəmiṇəṇ (Halkomelem) and Skwxwú7mesh (Squamish) languages are part of the Salish Language family, which dates back many millennia. We pay our respects to elders past, and to those present and emerging. As settlers to this land, we are committed to working towards reconciliation.

Simon Fraser University respectfully acknowledges the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh Úxwumixw (Squamish), səliłwətaʔt (Tsleil-Waututh), qícəy̓ (Katzie), kʷikʷəłəm (Kwikwetlem), Qayqayt, Kwantlen, Semiahmoo and Tsawwassen peoples on whose unceded traditional territories their three campuses reside.

#### Event Schedule

*All times are Pacific Daylight Time (PDT)*

Day 1 – Thursday, April 27, 2023

<b>8:15 am</b>	<b>–</b>	<b>9:00 am</b>	Registration / Log on with Zoom Link
<b>9:00 am</b>	<b>–</b>	<b>9:15 am</b>	Introduction by Michelle Schmidt
<b>9:15 am</b>	<b>–</b>	<b>10:15 am</b>	Keynote Presentation by Connor Kerns, PhD
<b>10:15 am</b>	<b>–</b>	<b>10:45 am</b>	Break
<b>10:45 am</b>	<b>–</b>	<b>12:00 pm</b>	Panel: Experiences with Anxiety
<b>12:00 pm</b>	<b>–</b>	<b>1:00 pm</b>	Lunch
<b>1:00 pm</b>	<b>–</b>	<b>3:10 pm</b>	Research Presentations

Day 2 – Friday, April 28, 2023

<b>8:15 am</b>	<b>–</b>	<b>9:00 am</b>	Registration / Log on with Zoom Link
<b>9:00 am</b>	<b>–</b>	<b>10:00 am</b>	Keynote Presentation: Tiffany Woynarski, PhD
<b>10:00 am</b>	<b>–</b>	<b>10:30 am</b>	Break
<b>10:30 am</b>	<b>–</b>	<b>11:45 am</b>	Panel: Early Development & Sensory
<b>11:45 am</b>	<b>–</b>	<b>12:45 pm</b>	Lunch
<b>12:45 pm</b>	<b>–</b>	<b>1:45 pm</b>	Future in Research

### **Accessibility**

ACT is committed to preventing, as well as identifying and removing barriers facing people interacting with our organization. Moving forward, ACT will make every effort to provide real time captioning as well as American Sign Language (ASL) interpreters for all our events.

### **Acknowledgements**

We are grateful to Connor, who will discuss challenges to the detection of anxiety in autistic individuals and provide a rationale for why overcoming these challenges – by recognizing and better understanding the distinct way some autistic individuals experience anxiety – is important for enhancing quality of life for autistic individuals. ACT is thrilled to have Dr. Connor Kerns present on key findings from research to address the challenge of anxiety in autism.

Over the years, those who have attended ACT events know that as we are a small not-for-profit organization, we depend on community collaboration and support to sustain our work. We deeply appreciate the many autistic individuals, parents and caregivers, professionals, and organizations across British Columbia who volunteer their time, donate funds, provide sponsorship, and help spread the word – especially during these challenging times.

Thank you also, to Still Interpreting Inc. for providing ASL Interpretation and Accurate Realtime Inc. for providing communication access realtime translation (CART) services.

**ACT – Autism Community Training**

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## Support evidence-based resources – [Donate to ACT!](#)

### Free Resources from ACT

[Autism Videos @ ACT \(AVA\)](#) – Over 80 quality online videos on diverse topics, including Toilet Training, Sleep, Mental Health, IEP's, Research, and much more – all available free, thanks to our sponsors!

[ACT's Autism & Intellectual Disability \(AID\) Search](#) – Keyword search over 2,000 records containing evidence-based, practical information resources in 36 languages sourced internationally, including B.C.-based community resources useful to families and community professionals.

[ACT in Chinese](#) and [ACT in Punjabi](#) – ACT has been able to both create and identify valuable resources for the Chinese-speaking and Punjabi-speaking communities in British Columbia.

[ACT's Autism Manual for B.C.](#) – A manual for parents and community professionals with 13 chapters, including New Diagnosis Process, Contracting with Professionals, B.C. Education System, Building a Community Group, and more!

[ACT's Event & Training Alerts](#) – Sign-up to keep in touch with our upcoming events and training opportunities.

[ACT's Facebook](#) – ACT carefully sources interesting, insightful stories to inform our community of over 9,000 followers.

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## DISCLOSURES

- Research in this presentation funded by:
  - National Institute of Child Health and Human Development
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  - Autism Science Foundation
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- Other funding received:
  - Canadian Institutes of Health Research (CIHR), National Institute of Mental Health (NIMH), Social Sciences and Humanities Research Council (SSHRC), Kennedy Krieger Innovation Fund
- Disclosures
  - I receive honoraria from published textbook on autism and anxiety published by Elsevier; paid consultation for training researchers in the assessment of anxiety disorders in autistic youth and occasional case consultation on trauma in autism for practicing clinicians and legal teams.
  - **In the future, I will receive a portion of royalties from Oxford University Press related to the sale of the Anxiety Disorders Interview Schedule with Autism Spectrum Addendum (ADIS/ASA) protocols and clinical manual.**

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## LAND ACKNOWLEDGEMENT

- I acknowledge that the land on which I am presenting from today is the traditional, ancestral, and unceded territory of the xwməθkwəyəm (Musqueam), Squamish and Tsleil-Waututh peoples.
- As a department, UBC Psychology is committed to DEI initiatives in an effort to right past wrongs that have been perpetuated by the field of psychology towards Indigenous peoples.



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Anxiety, Stress & Autism Program

## DISTINCT EXPRESSIONS OF ANXIETY IN AUTISM (AND WHY THEY MATTER)

CONNOR M KERNS, PHD  
ASSOCIATIVE PROFESSOR, PSYCHOLOGY  
DIRECTOR, UBC ANXIETY STRESS & AUTISM PROGRAM (ASAP)  
UNIVERSITY OF BRITISH COLUMBIA

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JENNIFER

*“Sometimes, anxiety can build up on itself like a brick on an accelerator pedal - whenever you make a mistake due to anxiety, you become more anxious. It’s just something that keeps being in your head and you can’t get it out and you can’t focus on other things.”*

-described by Jennifer, an autistic adult from Trembath et al. (2012)

Chang et al. (2012), Kerns et al. (2015), Lidstone et al (2014), Mazurek et al. (2013), Mazurek & Petroski (2015), Sukhodolskey et al. (2008), van Steensel et al. (2012)

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## FROM PARENTS & PROVIDERS

*“He shuts himself down, and he goes to bed. He will be in that room for 15 hours”*

- parent of autistic youth from Bearss et al. (2015)

*“I am risk assessing where it is appropriate to go . . . and what is safe. I am a single parent, so I have to really think, where we can go, where we can manage and what’s safe and as part of that risk assessment I think will there be any dogs. So every time I go out, I consider the difficulties that may arise to minimise the anxiety.”*

- Parent of autistic adult with few to no spoken words from Tarver et al., (2021)

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## SUBTLER COSTS

I think I can't.

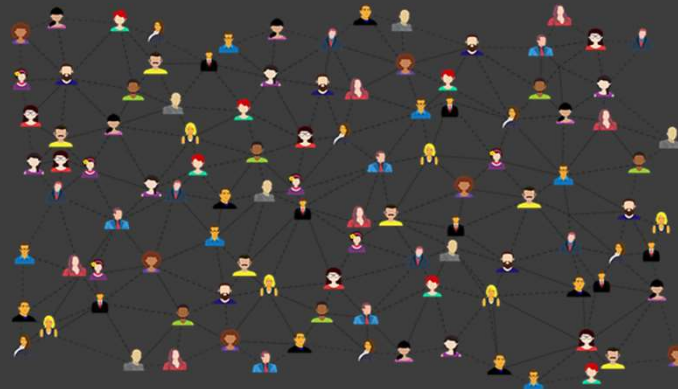


I think I can

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## A PROBLEM WITH PROMISE

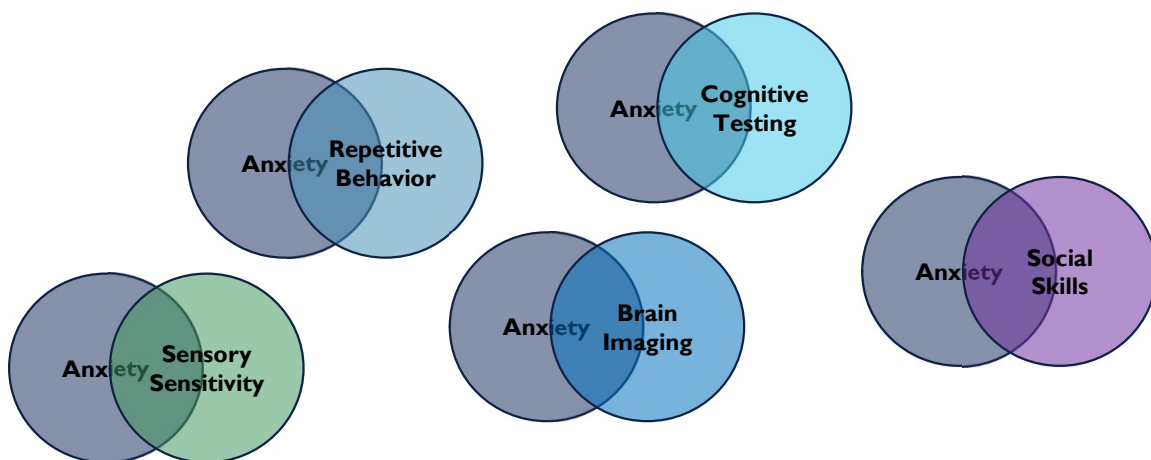
- 58-71% of autistic youth experience remission of primary anxiety disorders after cognitive-behavioral therapy
- Access is expanding



See Hunsche & Kerns, 2019; Wood et al., 2019; Blakeley-Smith et al., 2021; Rosen et al., 2016; Pickard et al., 2012; Storch et al., 2012

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## ANXIETY CONTRIBUTES TO VARIANCE IN AUTISM RESEARCH



(see Andrews et al., 2022; Bellini, 2004; Kerns, Kendall et al., 2015; Kerns & Kendall, 2012; Hopko et al., 2007; Swan & Kendall, 2016; Wigham et al., 2015)

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**To address the challenge of anxiety in autism, we must begin by better recognizing and understanding the diverse ways that anxiety is experienced and expressed by autistic individuals.**

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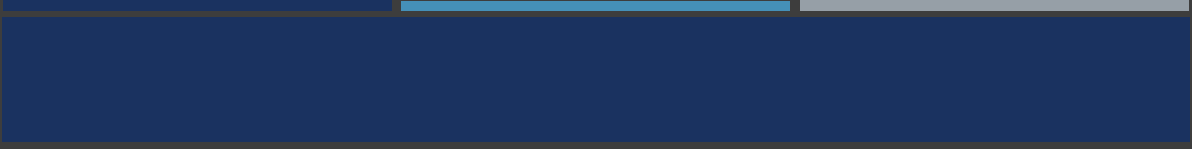
## FROM PARENTS

*“Sometimes it’s very difficult to understand whether it’s an autistic behaviour, or whether it’s behaviour caused by anxiety, or both.”*

- Described by mother of an autistic adult from Tarvor et al. (2021), *Autism*

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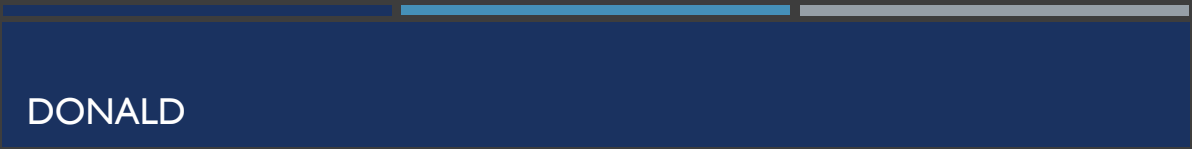


*“Does that person like me?”*

*“Others were not interested in me... the other children ignored me”*

- described by Richard, an autistic adult, from Spain, Yrarar & Happe (2020)

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**DONALD**

*“We brought him to a playground slide ..when other children were sliding on it he would not get about it, and when we put him to slide down it he seemed horrorstruck. The next morning when nobody was present; however, he walked out, climbed the ladder and slid down, and has slid on it frequently since, but slides only when no other child is present to join him...”*

– a father’s description of his son, Donald, from Kanner’s (1943) original case series describing autism case series

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## AUDREY & “M”

*“I get anxious in social situations as I don’t see emotions in people until they get to a 10 ...and then it’s an explosion, and I don’t know when it’s going to happen”*

*“a parking lot can be terrifying because of all the headlights...”*

- described by an autistic adult, Audrey, in Hamlon, Richdale & Uljavrevic (2018)

*“At the beginning of term they drop the first period of the first day. M couldn’t sleep that weekend, he has to bring the books in for that period even though he doesn’t have it.”*

- A mother describes her autistic son from Ozsivadjian et al. (2012)

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## DIVERSITY OF EXPRESSION

Anxiety may come in many different varieties in autism, both similar and distinct from the anxieties expressed by allistic youth

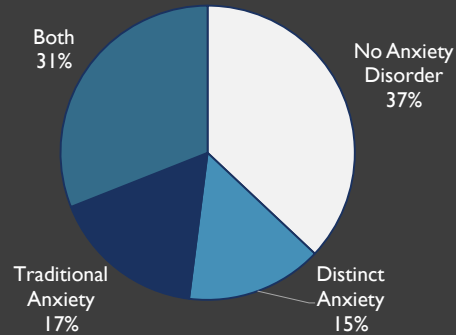


Rose Varieties

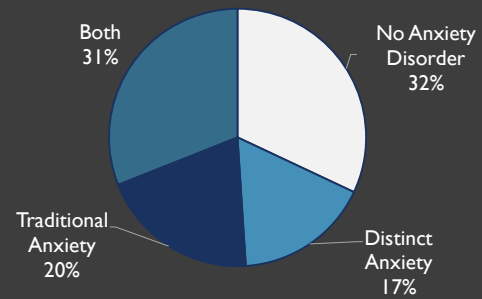
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## HOW WE DEFINE ANXIETY MATTERS

59 Autistic Youth with Minimal to No Intellectual Delays (Kerns et al., 2014, JADD)



75 Autistic Youth with a Wide Range of Intellectual Abilities (Kerns et al., 2020, JCCAP)



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## “TRADITIONAL,” DSM-DEFINED ANXIETY DISORDERS



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## PETER

*“I’ve been unemployed probably for seven years – with the global financial crisis and all that, it’s been hard for a lot of people to get work – not just me. And I hate volunteering – I mean, I need money to survive. So for me, what makes me anxious is just what will happen in the future – the uncertainty of it all, I guess.”*

*- Description by Peter, an autistic adult, from Trembath et al., 2012*

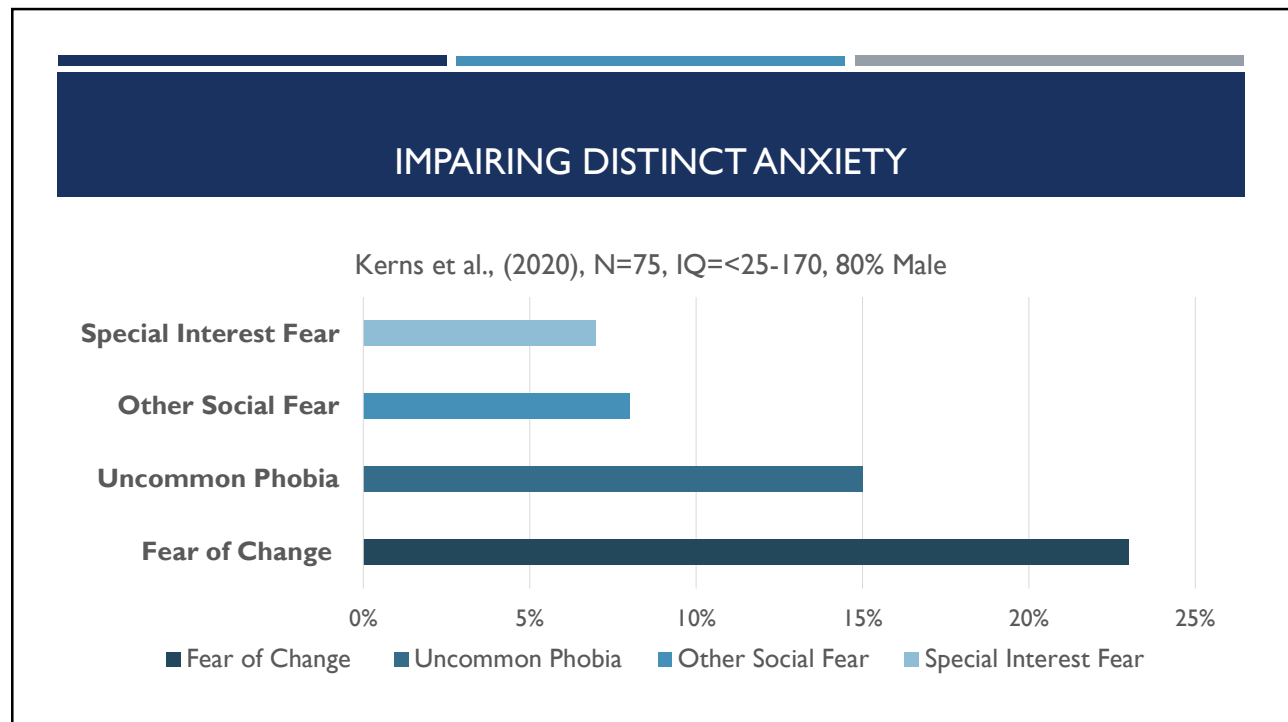
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## VICTORIA DESCRIBES HER SON

*“[He is] concerned about people smoking in that he is worried for their health because I’ve had to stop him saying ‘Smoking is a health hazard’ to them all the time. You know, because he was concerned. In fact, he lost a job because he was so upset that other people were smoking near him.”*

*- a mother, Victoria, describes the anxieties of her autistic adult son from Trembath et al. (2012)*

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### UNCOMMON PHOBIAS V. SENSORY SENSITIVITIES

*"I have a fear of mushrooms...if you whip one out, I start the physical sensations of fear but it wouldn't bother me [lack of accompanying anxious thoughts], I wouldn't be like 'oh no mushroom is dangerous.' It's just making me feel pain."*

- description by an autistic adult, Kathy, from Hamlon, Richdale & Uljavrevic (2018)

*"H becomes extremely anxious when he hears a baby cry...he's got a radar from 700 miles..."*

*"If she moved the cucumber near H, he's heaving, panicking..."*

- a description of H's anxiety by his parent from Ozsivadjian et al. (2012)

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## ANXIETY DISORDERS INTERVIEW SCHEDULE WITH AUTISM SPECTRUM ADDENDUM (ADIS/ASA)

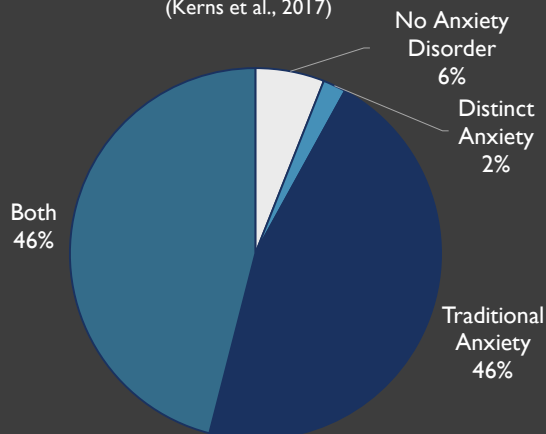
- Semi-structured diagnostic interview for child anxiety disorders adapted for autistic youth
- Conducted with parents by trained clinician
- ASA includes guidelines and additional prompts to
  - Differentiate overlapping autism and anxiety symptoms (e.g. social avoidance, sensory sensitivity, perseveration)
  - Query for distinct expressions of anxiety
  - Emphasis on behavioral examples for youth with limited language skills
- Inter-rater and retest reliability high across studies (preschoolers - teens)
- Evidence for discriminant validity and convergent validity of DSM anxiety



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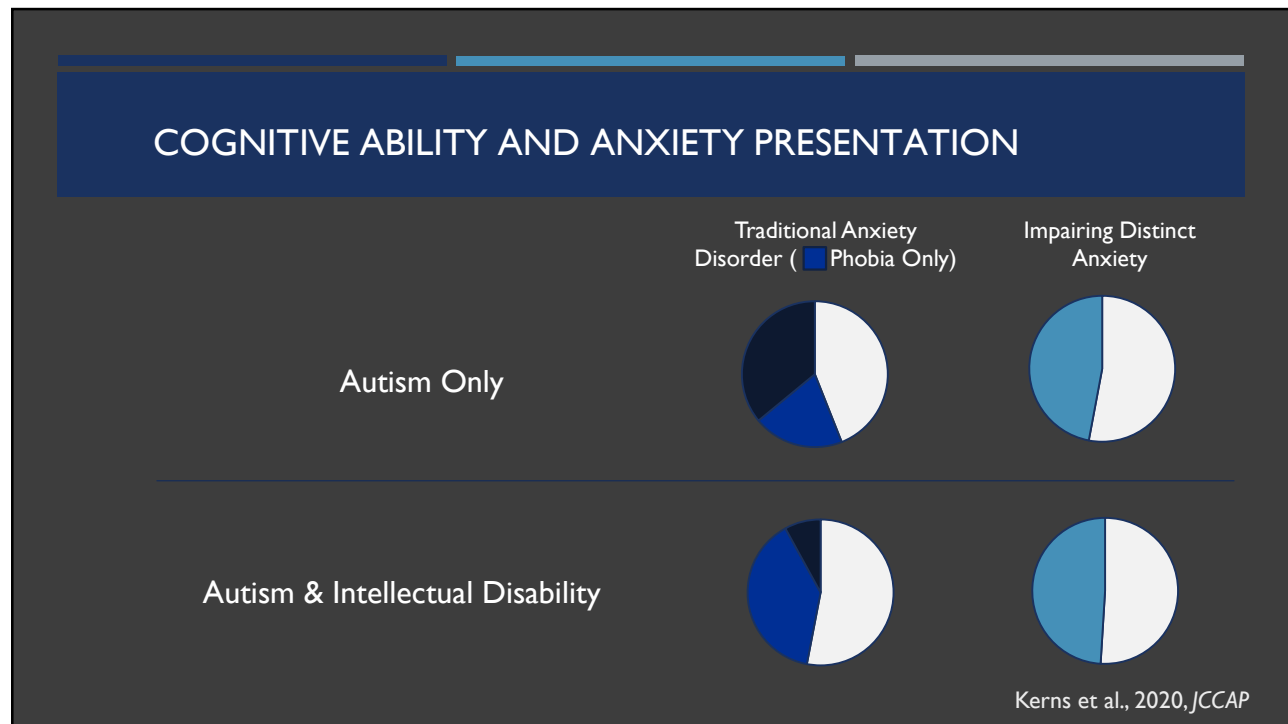
## WHO GETS REFERRED FOR ANXIETY TREATMENT?

69 Autistic Youth seeking CBT for Anxiety  
(Kerns et al., 2017)

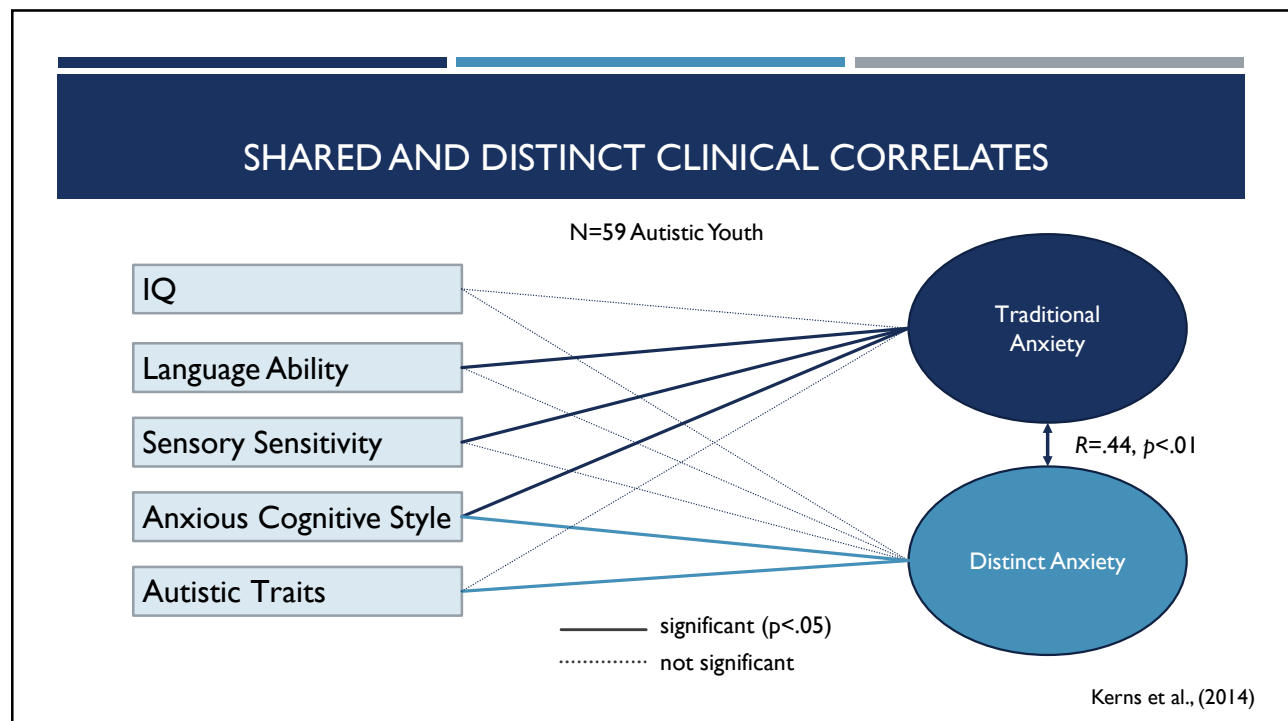


- Mostly kids with traditional anxiety disorders, but 50% also have problematic distinct anxieties

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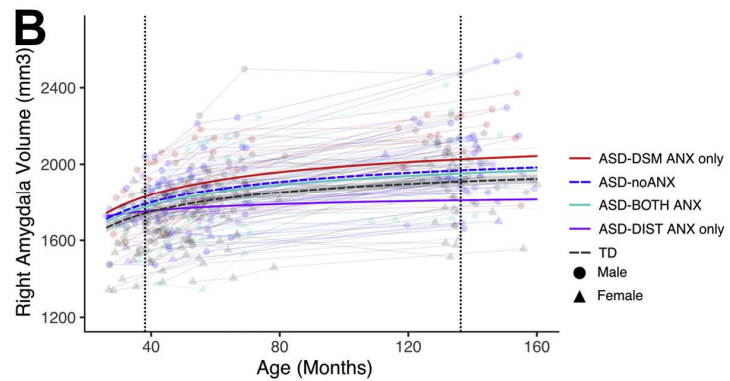
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## DISTINCT NEUROBIOLOGY

Traditional and distinct anxiety disorders are associated with different patterns of amygdala volume and growth (Andrews et al., 2022, *Biological Psychiatry*)



N=71 Autistic Youth (8-12 yrs) & 52 Controls

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## LIMITATIONS & FUTURE STUDIES



- Samples limited to children, mostly White & male
- Parent v. combined parent/youth interviews
- Response to intervention
- Underlying mechanisms
  - The role of sensory processing differences
  - The role of adversity and traumatic experiences
- Dissemination & implementation

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## ALFRED

*“He had a good deal of worrying....”*

*“He frets when the bread is put in the oven to be made into toast, and is afraid it will get burned and be hurt. He is upset when the sun sets. He is upset because the moon does not always appear in the sky at night.”*

*- A mother's description of her son, Alfred, age 3 years, from Kanner's (1943) original case series describing autism*

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Questions?

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## ANXIETY STRESS AND AUTISM PROGRAM (ASAP) LAB



- **Mission:**
  - To improve understanding, assessment and treatment of anxiety and stress-related disorders in autistic individuals, particularly youth
  - In so doing, to enhance quality of life and functioning of autistic individuals
- **Language:**
  - Identity-first v. person-first

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## MEET OUR TEAM



Michelle Hunsche  
PhD 3 student  
Theory of Mind & Mental Health



Elise Ng-Cordell  
PhD 1 student  
Cognition, emotion, & behavior



Victoria Wardell  
MA 2 student  
Traumatic Memory



Charlotte Stewardson  
MA 1 student  
Gaps in mental health services



Em Mittertreiner  
Lab Manager  
Gender diversity

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## ASAP LAB RESOURCES

- AUTISM EVIDENCE ASAP COMMUNITY TALK SERIES
- ASAP RESOURCE GUIDES
  - Anxiety,
  - Transition to adulthood,
  - Traumatic reactions
  - Suicidality
- MORE TO COME...

