

#### UW AUTISM CENTER CENTER ON HUMAN DEVELOPMENT & DISABILITY

UNIVERSITY of WASHINGTON

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#### **Could I Be Autistic?**

A Free Workshop for the Self-Diagnosed and Wondering

Lucas Harrington, PsyD Zack Siddeek, MSW Katya Downey April 28, 2021



## Lucas Harrington, PsyD

- Dr. Lucas Harrington, Psy.D.
- Currently working at the UW Autism Center, previously a UW LEND fellow at the Child Development Clinic
- Autistic, involved with the neurodiversity/autism acceptance movement since college



## Lucas Harrington, PsyD

- Formally diagnosed at the age of 29
- Many additional or incorrect diagnoses
  - Depression
  - Anxiety
  - ADHD
  - PTSD
  - Bipolar Disorder
  - Eating disorder not otherwise specified
  - Possible seizures
  - "Silent migraines"



#### Lucas Harrington, PsyD

Initially mis-evaluated due to stereotypes

- Too good at perspective taking
- Showing emotion
- Laughing at neurotypical humor



### Zack Siddeek

- Grew up in Western Colorado.
- Heavy drinker of Shirley Temples starting from age 3.
- Mix of Italian, Iraqi, and German.
- Diagnosed with PDD-NOS at 11.
- MSW from UW in 2018.
- Disability Systems Navigation Coordinator, Arc of King County & Organizer of the Square Pegs





## Katya Downey

- MSW Student at the University of Washington
- No formal diagnosis of autism, but
  - Identified by other autistic social workers
  - Autistic therapist suggested sub-clinical/unlikely to show up much on an evaluation
  - Worked with neurotypical clinician who expressed visible doubt about possibility of autism
  - In retrospect, many "classic" female autism signs



## Who Are You?

- If you are interested in connecting with other webinar participants, you can share about yourself in the chat. You could share your name, your pronouns, your area of the country or world, and your interests. All of these are optional.
- You can use private chat to exchange contact information with people you want to connect with more.
- Please use caution in connecting with strangers. Participants have not been screened.



## Notes for Today

- Feel free to ask questions and make comments in the chat box. We will probably wait and try to answer most of the questions at the end.
- Please make sure your microphone is muted. There are a lot of people in this webinar so we cannot have people ask questions or make comments out loud.
- Please do not ask questions about whether we think you are autistic or should get an evaluation. We are here with resources to help you make your own decisions; we cannot give an opinion in these areas.



#### WHAT IS AUTISM?



## What Is Autism?

- Autism is a *neurotype*, a way in which the brain can be structured (The Neurodiversity Movement/Section 1: The Basics, n.d.). It is also a developmental disability.
- Autistic and neurotypical brains each have their own set of advantages and disadvantages.
- Autism is known to be extremely genetic (Tick,

Bolton, Happé, Rutter, & Rijsdijk, 2016).



## How Is Autism Diagnosed?

#### **DSM-V** Criteria

- Impairment in social/emotional reciprocity
- Impairment in nonverbal communication
- Impairment in interpersonal relationships (American Psychiatric Association, 2013)

#### **Alternate Perspective**

- Difficulty with typical expectations of reciprocity
- Reduced or atypical nonverbal communication
- Atypical approach to social relationships, difficulty understanding typical interpersonal expectations



## How Is Autism Diagnosed?

#### **DSM-V Criteria**

- At least two of the following:
- Repetitive or stereotyped behavior or language use
- Patterns of rigidity or ritual
- Unusual interests or unusually intense interests
- Atypical responses to sensory input (American Psychiatric Association, 2013)



## ASAN's "About Autism"

- Sensory differences
- Differences in learning and thinking
- Narrow and intense interests
- Differences in movement
- Need for predictability
- Challenges in typical communication
- Challenges with typical social expectations (ASAN, n.d.)



## Neuroclastic's "Communal Definition of Autism"

- Reduced subconscious filtering of social information
- Differences in understanding abstract cultural concepts/status symbols
- "Autistic inertia"
- Sensory differences
- Interaction focused around knowledge
- Motivation for acceptance, truth, and recognition
- Exhaustion from masking (Bettin, n.d.)





#### Where are you at in your exploration process?



#### **TALKING ABOUT SELF-DIAGNOSIS**



## Self-Diagnosis

- The University of Washington Autism Center and the Arc of King County supports selfdiagnosis
- Much of the autistic community supports selfdiagnosis
- The University of Washington Autism Center is generally not taking new adult evaluation clients at this time



- Financial barriers
- Logistical barriers
- Anxiety and distrust
- Communication challenges
- Lack of interest in formal diagnosis
- Stigma (Lewis, 2017)



Possible concerns about:

- Legal proceedings
- Military
- Security clearance
- Insurance
- Foster parenting/adoption



Female and AFAB people often don't fit stereotypes:

- Relatively strong imaginations
- Studying and imitating others (masking/camouflaging) (Kirkovski, Enticott, & Fitzgerald, 2013)
- More typical interests (Lai & Baron-Cohen, 2015)



- Racial bias in diagnosis is commonly reported but under-researched
- Children of color have been diagnosed at a later age than white children (Mandell, Listerud, Levy, & Pinto-Martin, 2002).
- Black children have been more likely than white children to be diagnosed with an emotional/behavioral disorder before autism (Mandell, Ittenbach, Levy, & Pinto-Martin, 2010)





#### What barriers or concerns are you experiencing?





(Nzphotonz, 2017)

# WHAT IF YOU WANT AN EVALUATION?



## What to Expect from Testing

- Interview (history and current characteristics)
- Input from a second person
- Cognitive testing
- Autism Diagnostic Observation Schedule-2 (ADOS-2) activities
- Questionnaires
- Final meeting to explain diagnoses and recommendations



## What to Expect from Testing

- Full cost with no insurance is usually a few thousand dollars
- Private insurance varies heavily by company call the number on your insurance card for questions
- Medicaid usually pays for 100% of services
- Division of Vocational Rehabilitation (DVR) may pay for an evaluation





#### WHAT IF YOU DON'T WANT OR CAN'T GET AN EVALUATION?

## **Online Self-Reflection Resources**

- Autism Quotient (AQ) and Ritvo (RAADS-R), available at <u>www.aspietests.org</u>
- Efforts to capture a "female profile" at <u>https://tinyurl.com/samcraftchecklist</u> and <u>https://tinyurl.com/TaniaMarshallChecklist</u> (overlap with anxiety, trauma, high cognitive scores, and ADHD)
- An Autism Self-Diagnosis Masterpost at <u>https://tinyurl.com/selfdiagnosispost</u>



## Receiving Accommodations with Other Diagnoses

- Depression
- Anxiety
- PTSD
- ADHD
- OCD

- Extensions on tests and assignments
- Quiet break space
- Flexible schedule
- Permission to bring fidget items or sensory protection
- Additional coaching (<u>https://askjan.org/</u>)



## Self-Diagnosis-Friendly Resources and Communities

#### **Online Resources**

- Autistic Self-Advocacy Network (<u>https://autisticadvocacy.org/resources/</u>)
- Autastic (<u>https://www.autastic.com/</u>)
- Autistic Women and Nonbinary Network (<u>https://awnnetwork.org/</u>)
- Autistic People of Color Fund (<u>https://autismandrace.com/</u>)
- AASPIRE Health Toolkit (<u>https://www.autismandhealth.org</u>)
- The Arc (<u>https://thearc.org/</u>)



Self-Diagnosis-Friendly Resources and Communities

#### Facebook Groups

- Ask Me, I'm Autistic
- Autism Late Diagnosis Support and Education
- Autistic Families of Color (WA)
- Groups listed on Autastic.com



## Self-Diagnosis-Friendly Resources and Communities

#### Local Resources

- Square Pegs (<u>https://www.meetup.com/Squarepegs/</u>)
- Arc of King County (<u>https://arcofkingcounty.org/</u>)
- DVR: Department of Vocational Rehabilitation (<u>https://www.dshs.wa.gov/dvr</u>)
- Alliance of People with Disabilities (<u>http://disabilitypride.org/wordpress/</u>)
- Disability Rights Washington (<u>https://www.disabilityrightswa.org/</u>)
- NW ADA Center

(Northwest ADA Center | ADANW (nwadacenter.org))





## How likely are you to pursue a formal evaluation?





## How much would you want a formal evaluation if there were no barriers?



- The University of Washington Autism Center and the Arc of King County support selfdiagnosis
- Much of the autistic community supports selfdiagnosis
- You may want or need a formal diagnosis for various reasons



An evaluation costs a few thousand dollars without insurance, can be anywhere from free (with Medicaid or DVR approval) to full price depending on your insurance situation.



It is possible to receive accommodations and services under a more obtainable (accurate) diagnosis, such as depression, anxiety, or ADHD. Primary care providers, psychiatrists, and therapists/counselors may be able to diagnose these.



## It is possible to participate in the autistic community without a diagnosis of any kind.



## It is okay to participate in the community if you don't have a diagnosis.

## It is okay to participate in the community if you aren't sure.

It is okay to begin exploring the question and then realize it's not the right fit after all.



#### Self-discovery is a journey. I hope this has been helpful in figuring out what steps may be right for you.



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#### **Questions?**

## Thank you for attending!



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