

# Late Diagnosed Autistics: Unmet Needs and Resource Gaps

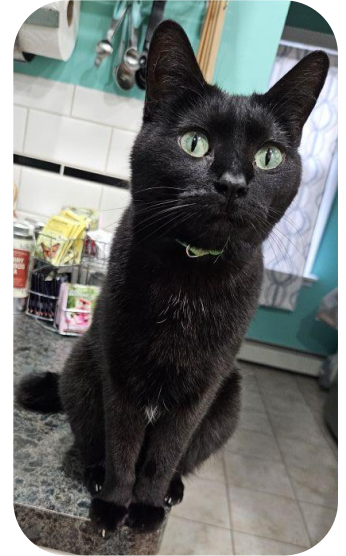


**Jessica Humiston LPC (she/her)**



## Hi, I'm Jessica!

- **Licensed Professional Counselor (LPC)**
- **Experience: Outpatient, non-profit, and agency settings.**
- **Provide Neurodiversity Affirmative Therapy, focusing on late diagnosed Autistic and/or ADHD teens and adults.**
- **I am also late diagnosed Autistic, ADHD, OCD.**
- **Special Interests: Doctor Who, cats, baking, video and board games, Halloween.**
- ***I am hard of hearing and use hearing aids.***



# A Note on Vocabulary

- **Identity First Language**
- **Diagnosed vs. Identified**
- **Neurodiversity/Neurodivergence**
- **Neurotypical/allistic**





# What is Late Diagnosis?

**University of Virginia puts the age of late diagnosis at 12 or older, stating that women, gender-queer and LTBQ+ folks are often diagnosed much later. (2022)**

**University of North Carolina literature review put the average age of late diagnosis at 11.5 years old.**

**Several studies of late diagnosed individuals focused on children diagnosed after age 6.**

**Field generally agrees that late childhood to early adolescence means late diagnosis.**



# Diagnosis

- **Diagnosis is usually the first major hurdle for late identified folks.**
- **Without diagnosis, it is difficult get supports, accommodations, additional services, etc.**
- **Some hurdles to diagnosis include diagnostic criteria, perceptions of autism, cost, insurance coverage, and finding an assessor that works with adults.**



# Diagnosis

- **The diagnostic profile of Autism in the Diagnostic and Statistical Manual (DSM) best fits the typical profile of children, particularly young, white males.**
  - **One study by Robert McCrossin (2022) showed that 80% of autistic females in the study remained undiagnosed at age 18.**
  - **Study from Durkin et. al (2017) found that white children were 19% more likely to receive a diagnosis than black children, and 65% more likely to receive a diagnosis than Latinx children.**
- **Diagnostic criteria are written in terms of deficits - this is negative and stigmatizing, but also these traits tend to show up more frequently during distress.**



# Diagnosis

## Criteria includes:

- **Marked impairment in use of non-verbal communication (ie: eye contact).**
- **Failure to develop peer relationships appropriate to developmental level.**
- **Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people.**
- **Lack of social or emotional reciprocity.**
- **Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.**
- **Stereotyped and repetitive motor manners (ie: hand flapping)**
- **Stereotyped and repetitive use of language or idiosyncratic language.**

*Please note: this is not all of the criteria, and an individual does not need to have all of these characteristics for diagnosis.*



# Diagnosis

- **Perceptions of Autism:**
  - **The widespread stereotypes are based on more 'obvious' instances of autism that are identified earlier in childhood.**
  - **This leads to a lot of missed opportunities for assessment in folks who do not fit this profile, or bias of assessors.**
  - **For example: low or non-speaking, interest in trains, hand flapping/head hitting/rocking, no emotional expression, no social concern/little interest in others, overly assertive/rude.**



# Diagnosis



- **Access**
  - **High Cost**
  - **Insurance**
    - **Medicaid - pays in full, few options**
    - **Deductible applying to testing for commercial insurance**
  - **Accepting or Specializing in Adults**
    - **The main focus of diagnosis and services is on children.**



# Diagnosis

- **Re-examine diagnostic criteria.**
- **Assessors of lived experience.**
- **Further development of tools to use on adults.**
  - **MIGDAS, RAADS-R**
- **Research focused on adult traits.**





# Vocational Concerns



- **Accommodations**
  - Often employers want documentation from healthcare provider of a diagnosis.
  - Need more education for individuals surrounding acquiring accommodations.
- **Job hopping**
  - Often have multiple jobs over shorter periods of time due to difficulties with jobs (job loss, boredom with work, intolerance to work environment, etc.).
  - This looks undesirable on a resume.
- **Communication**
  - Crompton et. al (2025) found few communication differences when teaching between autistic and allistic persons.

# Social



- **Masking**
  - **Often becomes more difficult with age.**
  - **High amounts of masking in youth compared to lowered amounts in adulthood often results in ridicule from support systems, feelings of inadequacy, and shame.**
- **Friendships**
- **Dating**
- **It is important to remember that Autistic folks communicate differently than allistic folks!**



# Medical

- **Difficulty with communicating with medical professionals.**
- **Common physical health diagnoses that occur with autism:**
  - **Hypermobility/Ehlers-Danlos, POTS, GI disturbances and conditions, epilepsy and seizures, insomnia, migraines.**
- **Cost and health insurance.**
- **Medications.**
  - **Differences in side effects, processing in the body.**
- **Time and executive functioning.**
- **Dental visits.**
  - **Sensory, lack of understanding in the field.**



# Medical

- **More education of medical professionals.**
- **Opportunities to rehearse for appointments.**
- **Development of coping skills for appointments.**
  - **Writing down concerns, asking for communication accommodations, informing medical staff of concerns and Autism, assertiveness skill development.**

# Mental Health and Therapy



- **Jadav and Bal (2022) conducted a study in which those diagnosed in adulthood were more likely to receive diagnoses of anxiety or depression than those diagnosed in childhood.**
  - **Adult women were more likely to have anxiety, depressive, or eating disorders than adult men.**
- **Other commonly occurring mental health diagnoses include:**
  - **ADHD, Bipolar, OCD, ARFID, PTSD/Trauma related disorders, auditory processing differences, suicidal ideation and attempts.**
  - **Continued research and education on how these present in autistic individuals.**

# Mental Health and Therapy



- **Often other mental health diagnoses will lead providers to missing Autism.**
  - **I most often see misdiagnosis of Bipolar or Borderline Personality Disorder where there is actually Autism present.**
    - **These things can and do co-occur, but presentations of distress in an autistic person can often look like either of these diagnoses.**
  - **Better education across the board for all mental health professionals (therapists, psychiatrists/prescribers, assessors) on when to seek out additional assessment to rule in or out autism.**
  - **How do mental health concerns present in autistic people.**

# Mental Health and Therapy



- **Burnout**
  - **Autistic burnout from living in a neuronormative society as an autistic person.**
    - **Masking to meet behavioral expectations that look neurotypical.**
    - **Overwhelm from managing multiple areas of life (work, home, finances, etc).**
    - **Inability to take adequate breaks, both in day to day tasks and large breaks like vacations, time off work, etc.**
  - **Self-Accommodation!**

# Diagnosis Loop and Burnout



This loop continues with every new diagnosis, and often contributes to burnout.





# Grief

- **There is often a grief response when Autism is discovered later on.**
  - **This can be caused by feeling a loss of being 'normal', due to ableism.**
  - **Loss of potential to have made earlier life easier.**
- **When we share this information with others, they may have similar grief response which can lead to denial, dismissal, doubt, or having to shoulder the emotional response of our support system.**



# Thank You!

If you would like to contact me for further information:

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