

# Copenhagen Psykologisk Ressource Center

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Girls and Women on the Autism Spectrum

Camouflaging and Masking

Stress, Anxiety, Depression and Depression Attacks

Autism, Gender and Identity

# Girls and Women on the Autism Spectrum



# Gender Ratio

- Posserud et al. (2021) *Acta Psychiatrica Scandinavica*
- Norwegian study of 2.5 million children and adults (born before 2011)
- Male to Female ratio for autistic children 4-10 years **4.46:1**
- Male to Female ratio for autistic children 11 to 17 **3.67:1**
- Male to Female ratio for autistic adults is **2.57:1**
- **CDC (2023)** One in 36 eight years olds, ratio **3.8 to 1**

# Characteristics from age 5-12 Years

## Affection and Emotions

- **Indiscriminate and excessive** with affection or **extremely shy** or defensive against affection
- From infancy, extremely intense, **inconsolable despair** that lasts a long time and cannot be distracted



# Characteristics from age 5-12 Years

## Fascination with Symmetry and Order

*“The fun came from setting up and arranging things. Maybe this desire to organize things rather than play with things is the reason I never had any great interest in my peers.”*



# Characteristics from age 5-12 Years

## Social Play

*We create our own world in which to do our own thing*

*Because the other kids didn't like to play the same way I did, and because they would dare to touch my things, I didn't want to play/engage with them*

Playing an **imaginary solitary game** close to, but not engaging with, peers

# Characteristics from age 5-12 Years

## Social Play

- *“Her **self-focus** often gets in the way, as others can feel she doesn’t really care about them and their needs/feelings”*
- *“She enjoys her friends’ company, but does not think of them when they are not around”*
- *I don’t have friends because they don’t like to sit in a corner and read. They would rather run around like **demented rabbits***

8-year-old autistic girl who enjoys reading novels by Charles Dickens

- Social play of girls is relatively simple to grade 4, easy to copy

*We create our own world in which to do our own thing*

*Because the other kids didn't like to play the same way I did, and because they would dare to touch my things, I didn't want to play/engage with them*

*Learning to socialize was painting by numbers*

# Characteristics from age 5-12 Years

## Identify with boys

- *Many stereotypical girls' activities were stupid, boring and inexplicable.*
- *Girls were more **complicated, and unkind** in ways I didn't understand.*
- *Boys are more logical, and accepting, you can **see what to do***

*It was easier to identify with boys because they just wanted to have fun. Girls had more social rules to follow or blunder. They had more gossip and didn't like to get dirty. The guys were fun and I could almost be myself around them.*

- *I don't know how to do girl things.*

# Characteristics from age 5-12 Years

## Gender Specific Toys

- *I loved playing with **Lego** for years and had many thousands as a child. I also loved cardboard boxes, and **drawing/writing**. I always ignored the dolls I was given.*
- *Are model aircraft considered 'toys'? Is there a gender attached to them? I preferred **nature or animals to toys**.*

# Characteristics from age 5-12 Years

## Friendships

- Single friend who provides **guidance and security**.
- Friend a 'teacher aid' in the classroom and playground for friendship
- **Animals as friends**



# Characteristics from age 5-12 Years School

- **Less disruptive** and so less likely to be noticed
- *We think that if we are very, very good, people will like us and all will be well*
- Learn that if you are good, you are left alone
- Learn if you are quiet no one sees you
- *I learned that to fit in and have someone to play with, you have to pretend to be happy*

# Bullying and Teasing



# HOW TO DEAL WITH BULLIES



# Pathways to a Diagnosis for a Teenage Autistic Girl

- Anxiety (all expressions)
- Depression
- Eating disorder
- Situational mutism
- Self-harm
- Borderline Personality Disorder
- Gender Dysphoria



# Teenage Years

## Ultra-feminine or anti-social conventions

- Try to fit in during Primary School by being **ultra-feminine** (pink and frilly)
- In the adolescent years, recognise girls' interests in fashion and make-up, developing expertise in these areas to be included
- When imitation is not working, the pendulum can swing the other way
- **Despise femininity and defy social and gender conventions**
- *I much prefer men's clothes. They are far better made, and they are comfortable, smarter and practical.*

# Social Experiences of Adolescent Autistic Girls

- **Groups:** *'too many opinions'* and disagreement and conflict between peers
- Feeling they needed to act as peacemakers when conflict arose
- May be **more sensitive to conflict between friends**
- Aware peer girls changed their style of dress and interests to focus more on boys
- These were not interests they shared or saw as positive

# Teenage Years

- Difficulty understanding **vindictive behaviour and gossip**
- **Gullible**, easily fooled
- Tendency to **overshare and disclose intimate details**
- Feels she is on **stage and being watched**
- Takes **criticism** to heart
- **Fear of being judged**
- Young-sounding **voice**
- **Writes or draws to relieve anxiety**
- **Vulnerability**



# Teenage Years

- Power of the peer group for **self-esteem**
- *In high school, girls treated me like I was something else, not boy, not girl, just an **it***
- *Even though I had support, I felt very alienated inside. Counsellors chalked this up to teenage angst.*
- *It drains me mentally and physically. I am exhausted after having spent a lot of time with others and I need to recover in solitude.*
- Cinderella at the ball at midnight
- *“I couldn’t send you to your room, because that’s where you always wanted to be anyway!”*

# Screening Questionnaires



# Modified-Questionnaire for Autism Spectrum Conditions (M-Q-ASC)

**Simcoe et al. (2022) *Journal of Autism Dev. Disorders***

**323 children 5-12 years:**

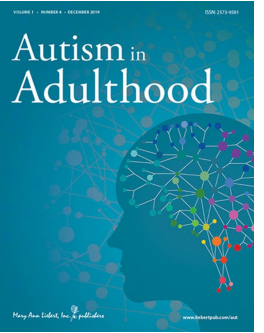
- 111 – Autistic, no language or IQ impairment
- 212 – not autistic
- [www.tonyattwood.com.au](http://www.tonyattwood.com.au)

**36-item** modified version including 7 sub-scales:

1. Imitation
2. Social masking
3. Imagination
4. Friendship and play
5. Sensory sensitivity
6. Gendered behaviour
7. Compliant behaviour

# M-Q-ASC – Autistic Women

Brown, Attwood, Garnett & Stokes (2020), *Autism in Adulthood*, 2(3), 216-226.



- Completed by 350 autistic women and 322 non-autistic women
- Age 18-71 years old
- A cut-off of 56
  - correctly identified 80% of autistic women (sensitivity, few false positives)

Conclusion: **A new 22-item screening tool** with a good discriminative capacity between autistic and non-autistic women

**Download** from: [www.tonyattwood.com.au](http://www.tonyattwood.com.au)

# The Autism Spectrum Scale for Females (ASSF)

Being developed and evaluated by Ahmad and Jones (New Zealand)

47 autistic women and 47 NT women

**144 yes/no questions**

Examples of questions:

- I often do not notice when someone is talking to me
- Others find me unaffectionate
- I have sometimes been described as non-emotional or cold or detached

# The Autism Spectrum Scale for Females (ASSF)

## Examples of questions:

- I mostly feel confused about whether to hug someone or not
- If I were to lead a team, I would feel stressed
- I prefer to work on my own
- I often feel different
- I have been in compromised sexual situations
- I would prefer to work with animals rather than to work with people
- I have lots of rules that only I seem to adhere to

# The Autism Spectrum Scale for Females (ASSF)

## Examples of questions:

- I started having romantic relationships much later than my friends did
- I have been seriously deceived more than five times
- I am uncomfortable with direct eye contact



# Gendered Autism Behavioral Scale (GABS)

Clarke et al (2021) *Research in Autism Spectrum Disorders*

- GABS is a coding system to identify non-traditional autism phenotypes using the ADOS Modules 3 and 4
- **Age 9-15 years**
- Observation and questions on:

## **A: Social Adaptation**

- **Camouflaging** (masking)
- **Camouflaging** (compensation) Copying or imitating others so as not to appear different from peers
- **Self-reflection on social behaviour** Awareness of the impact of their behaviour and differences between self and others

# Gendered Autism Behavioral Scale (GABS)

- **Reported Friendships** Reports one or more friendships
- **Understanding of friendships**
- **Quality of reported friendships** Evidence of mutual support and affection via shared interests, regular contact (not a list of names)

## **B: Social Relationships**

- **Age of friends** not markedly older or younger
- **Nature of friendships** Mixture of friendships, one or two intense friendships, being an 'outsider'

# Gendered Autism Behavioral Scale (GABS)

- **Responding to conversational cues** Spontaneous inquiries into the examiners thoughts, feelings and experiences
- **Social interest** Actively seeks and enjoys social activities

## **C: Managing Emotions**

- **Internalizing difficulties** Evidence of **depressive** or anxious symptoms
- **Externalising difficulties** Evidence of aggressive or hyperactive symptoms
- Describes various emotional states in detail and without difficulty or discomfort

# Gendered Autism Behavioral Scale (GABS)

- **Communicating about emotions** Discomfort while discussing emotions with the examiner
- **Influence of social acceptance or rejection of emotions** being emotionally impacted by one or more instances of social acceptance or rejection
- **Violations of sameness or rigidity**

## **D: Interests and hobbies**

- **Reported interests** (frequency/intensity) coding appropriate expressions of interest in topics and hobbies
- **Types of interest** (quality/nature) social or non-social

# Gendered Autism Behavioral Scale (GABS)

- Significant gender differences on several individual items and the **Managing Emotions Subscale**
- Females more likely to report internalizing symptoms and emotional impact due to social acceptance and rejection
- Females have more **relational interests** (people and animals)
- Females demonstrate higher scores on the GABS
- **GABS picks up behaviours not otherwise captured in the ADOS**

# Female Diagnosis Later in Life

- Leedham et al (2020) *Autism* 24 135-146
- 11 autistic females diagnosed over the age of 40 years
- Interpretive Phenomenological Analysis
- 4 themes

## **Theme 1 A hidden condition**

- *I wore different clothes to everything I wore at home. I hated the person that I put on*
- Not being understood by professionals

# Female Diagnosis Later in Life

- *The clinician would say 'you've got borderline personality disorder... I explained to him exactly why I wasn't BPD. I just stopped going*
- Labels were forced on them
- Ongoing confusion about identity

## **Theme 2 The process of acceptance**

- Making sense of their diagnosis
- Grieving and adjusting
- Re-experiencing memories

# The Female Experience of Autism

- Milner et al. (2019) *Journal of Autism and Developmental Disorders* 49 2389-2402
- 18 ASD adult females and four mothers of ASD females in discussion
- Thematic analysis

## **Friendship motivation and experiences**

- The women were able to make friends, but did not feel truly a part of a group or the same as their peers
- *I was with girls that kind of drifted together because they weren't in any other group*

# The Female Experience of Autism

## **Living in a NT world**

- *When she is doing her job, she is a very professional lady, but ordinary things , ordinary life exhausts her*

## **Concept of gender**

- Females are pressured to be more social than males
- *I just don't get gossip. I don't know why it exists, so I always got on with boys or men*
- *Girl peers are less forgiving of other girls*
- Males less pressure to camouflage and females more successful at doing so

# The Female Experience of Autism

- Difficult to adopt the idea of being feminine
- *I'm not good at being a girl*

## **Coping strategies**

- Needing time alone so as not to become overwhelmed
- Need for structure and routine
- *When I am in social situations, I sort of go onto auto-pilot*

## **Struggle to get a diagnosis**

- Then a sense of relief

# The Female Experience of Autism

- Relieved it was not a problem they had caused and that they were not alone
- *When I got tested I was on auto-pilot and it meant that I got misdiagnosed*

## **Negative aspects of autism**

- Comorbid conditions, such as OCD and depression
- Sensory sensitivities
- *When she was younger, if I had lilies in the house, she'd almost go deaf... it was like the sensory overload made something else shut down*

# The Female Experience of Autism

- *Music: I feel more intensely than other people. To put headphones on is almost euphoric*

## **Meltdowns and shutdowns**

## **Dependence and vulnerability**

- *Jealous of other students who didn't need the help she needed*
- Vulnerability in terms of sexual relationships
- *Sometimes you give out the wrong body signals and people pick it up wrongly*

# The Female Experience of Autism

## **Benefits of autism**

- See the world from a different and unique perspective
- Long attention span and good memory
- Improved sense of empathy
- Greater creativity
- Strong sense of justice



# Guidelines for the Diagnostic Assessment of Autistic Women

Cumin, Pelaez and Mottron (2021) *Autism*

- Interviewed 20 experienced clinicians from 7 countries (including Tony)
- Autism is **best reliably identified by experienced clinicians** who take into account qualitative aspects of autism
- **Standardised assessment tools are not equipped to detect autism in adult women of typical intelligence**
- The ADOS was largely seen as inducing false negatives, particularly in girls and women of normal range IQ
- Created a list of **clinical guidelines** to improve diagnostic specificity and sensitivity

# Guidelines for the Diagnostic Assessment of Autistic Women

## Factors affecting the diagnostic assessment

### Self-diagnosis

Information on autism increasingly available online

Self-diagnosis often correct

Describing their life history, behaviour and abilities through the lens of the research they had done

Asking for **specific personal examples** can help confirm that difficulties are based on lived experience rather than personal research, avoiding 'textbook answers'

# Guidelines for the Diagnostic Assessment of Autistic Women

## **Previous life experiences and diagnoses**

Many women seeking a diagnostic assessment have **complex psychiatric and life histories** and adverse life events

Most women seeking a diagnostic assessment have experienced **trauma** in some form

The **chronology** of difficulties associated with autism is extremely important when making a differential diagnosis such as PTSD

Value of an **external informant**, especially for information on childhood abilities and behaviour

# Guidelines for the Diagnostic Assessment of Autistic Women

Exploration of the amount of mental energy consumed preparing for, during and subsequently **analysing social performance** (intuitive or intellectual)

Autistic women have often not reached **the level of professional/personal achievement** expected considering their intellectual ability

Autistic women are often able **to apply their special interests** and use them as social currency e.g., fashion

# Guidelines for the Diagnostic Assessment of Autistic Women

- History of relationships (**delayed** romantic experiences and **vulnerable**)
- **Gender** may be expressed less conventionally (non-binary) or femininity expertly expressed
- The experienced clinician uses a thorough and reliable assessment combined with a “feeling in the room”

# Female Diagnosis Later in Life

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# Female Diagnosis Later in Life

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## **Theme 2 The process of acceptance**

- Making sense of their diagnosis
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- Re-experiencing memories

# Female Diagnosis Later in Life

- A sense of vindication
- Being allowed to end the arduous search to understand how they experience the world
- Connecting with others with ASD helped to develop self-understanding
- Reliving life through a new lens
- *Your life flashes before your eyes...thousands of memories coming back, constantly of 'oh, I remember when this happened ... that's why I had a meltdown... I couldn't understand why*

# Female Diagnosis Later in Life

## Theme 3 Impact of the diagnosis on others

- Referring to her husband
- *He got really into researching it... it's really improved our relationship because he's realized now that a lot of the arguments that we had were me misunderstanding what he'd said and him misunderstanding how I'd reacted*
- Some family members can be dismissive
- *Anyone who's got to middle age with undiagnosed autism has had to basically do Olympic level training in how to be a normal person*

# Female Diagnosis Later in Life

## **Theme 4 A new identity**

- Life changing relational decisions – ending an abusive relationship
- Newfound confidence to live by their values
- Opportunity to let go of blame
- Engaging in soothing, often practical and enjoyable self-care activities
- Transition from being self-critical to self-compassionate
- Increased sense of agency
- Change of identity

# Autistic Women's Experiences and Well-Being During and After Diagnosis

Harmens, Sedgewick and Hobson (2021) *Autism in Adulthood*

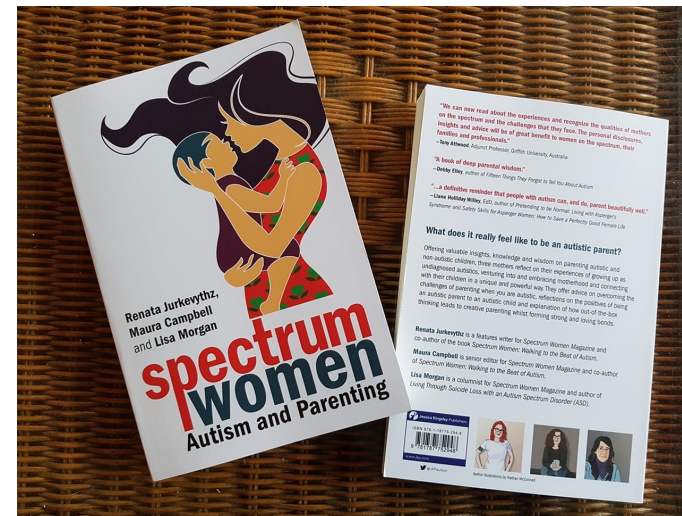
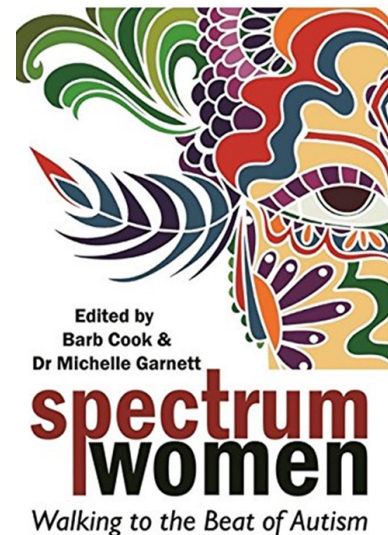
- Data collected from 20 blogsites
- Positive and negative effects on well-being after diagnosis
- **Positive:**
- Being kinder to themselves
- Understanding their needs
- Making sense of the past
- Connection with a community
- Improved relationships

# Autistic Women's Experiences and Well-Being During and After Diagnosis

- **Negative**
- After diagnosis facing **male stereotypes of autism**
- Facing a lack of acceptance from others could impact on women's self-acceptance
- Need guidance in how to manage being **told they do not appear autistic**
- Or fit people's expectations of autism
- **Psychiatry uses a deficit-based model** and 'disordering' can be harmful to an individual's self-esteem

# Pathways to a Diagnosis for Women

- Problems with **employment** or **relationships** lead to a search for an **explanation for being different**
- Having an **autistic child**
- **A friend, employer** recognises autistic characteristics
- **Media**, magazines and documentaries
- **Literature**



Rudy Simone

22



THINGS

*a Woman with*  
**ASPERGER'S SYNDROME**  
*Wants Her Partner*  
*to Know*

FOREWORD BY TONY ATTWOOD  
Illustrated by Emma Rios

# Camouflaging and Masking



# Adaptations to Autism

- The Introvert
- The Extrovert
- **Compensation**
- **Camouflage**



# Compensation

- Creating a **lifestyle** that minimizes the characteristics of autism
- Autistic girl may prefer the company of typical boys whose social dynamics are relatively simpler to decipher than peer girls
- Developing an **interest** and appreciated talent in the arts, sciences and computer games
- **Social eccentricities are accepted** and accommodated due to being valued by peers
- Interest in fictional heroes and superheroes and friendships based on shared interests such as cosplay, Comic Con

# Compensation

- Studying psychology
- Reading books on body language and friendship
- Part time employment and schooling
- A career that does not require much social engagement such as a wildlife ranger



# Camouflage

- Very aware of their difficulties reading non-verbal communication and how to make and keep friends
- Initially detached from their peers
- Keenly **observe social interactions**



# Camouflage

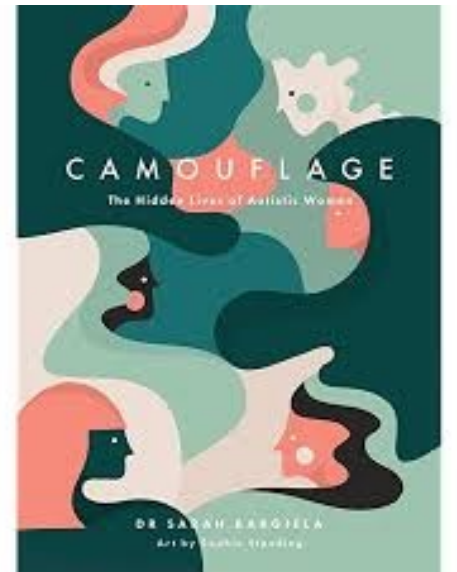
- Seek to learn the **social patterns and systems** to determine, interpret and abide by the **social rules**
- Social abilities achieved by **intellectual analysis** rather than intuition
- Observe, analyse and **imitate**, creating a **social mask**
- Autistic females tend to be better at camouflaging than autistic males and use this adaptation in a wider range of social situations
- ‘Fly under the autism radar’ **delaying a diagnostic assessment**
- *You’re too social to have autism*

# Camouflage

- Everyday should be awarded an Oscar for her **social performance** (Maja Toudal)
- Superficial social ability but **lack of authentic social identity**
- Like 'Cinderella at the Ball at midnight' can maintain the pretence for a while but then be totally **drained of mental energy**
- Recovery in solitude
- **Ruminate** about her social performance
- Creates a high level of social performance anxiety, contributing to an anxiety disorder, self-harm and depression

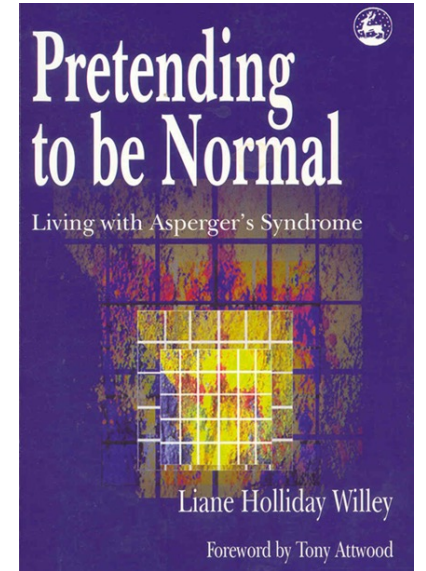
# Camouflage

- Lack of knowledge and acceptance of the **authentic self**
- *I don't know who I really am*
- Low self-esteem and **prolonged self-analysis**
- Worried friendships are based on deceit and a false identity
- Increases feelings of **deep inner loneliness**
- If the true self is revealed, may be **rejected and despised**



# Camouflage

- *I try to be who they want me to be*
- *I have done such a great job at pretending to be normal that nobody really believes I have Asperger's*
- *Emily masks in public and will meltdown the second she is out of the situation.*
- Dr Jekyll and Mr Hyde.
- *I can dance. I can dance with anyone who wants to dance with me, but it is always their choreography.*





# The Camouflaging Autistic Traits Questionnaire (CAT-Q)

Hull, L, Mandy, W, Baron-Cohen, S et al. *JADD 2019* 49 pp 819-833

**The Camouflaging Autistic Traits Questionnaire (CAT-Q)** was developed from autistic adults' experiences of camouflaging

Exploratory factor analysis suggested **three factors**, with the questionnaire comprising **25 items** in total.

## **3 subscales**

1. Compensation
2. Masking
3. Assimilation



# Parent Report Camouflaging Measure

- Hannon, Mandy and Hull (2022) *Autism Research*
- *Camouflaging Autistic traits Questionnaire: Parent Report*
- **An adaptation of the CAT-Q** with phrasing changed from “I...” to “**My child...**”
- 25 items scored from 1 to 7
- Scores can range from 25 to 175
- Parents can only report on strategies that they observe their child using or are reported to them by the child

# Self-Reported Camouflaging Behaviours

Julia Cook et al (2021) *autism*

Discovered **38 camouflaging behaviours**

**4 main categories**

## **1: Masking**

- Avoid or limit discussion related to oneself
- Alter or reduce hand or arm movements
- Avoid specific facts and detailed information
- Reduce body movements
- Adjust physical appearance to appear typical

# Self-Reported Camouflaging Behaviours

## **2: Innocuous socializing**

- Maintain eye contact or appearance of eye contact (looking at conversation partner's forehead)
- Mirror another person's speech (accent) and gestures and facial expressions
- Smile at others when speaking or listening
- Verbal encouragers ("oh really", "okay", "yeah")
- Guiding or maintaining the topic of conversation to the interests of the conversation partner

# Self-Reported Camouflaging Behaviours

## **2: Innocuous socializing**

- Apologises or provides excuses for perceived social errors
- Cooperative and avoids confrontation or complaints
- Small talk such as the weather
- Avoid discussion of each other's personal lives
- Avoid appearing knowledgeable
- Avoid jokes

# Self-Reported Camouflaging Behaviours

## **3 Modelling neurotypical communication**

- Increasing use of conventional gestures, body language, facial expressions and speech

## **4 Active self-preservation**

- Ask questions
- Find and discuss points of commonality
- Balance between listening and talking
- Use comfortable topics and scripts

# Aspects of Camouflaging

Cook et al (2021) *autism*

## **Four themes**

- 1: Strong desire for, yet uncertainty in securing social acceptance and connection
- 2: Developed over time to socialize and be valued by others
- 3: Intrapersonal and interpersonal camouflaging consequences such as fatigue, anxieties, friendship difficulties
- 4: Sometimes authentic socializing as an alternative to camouflaging

# Aspects of Camouflaging

- Need for guidance on how to authentically socialize
- With maturity, diminishing desire to camouflage
- *I feel it is more for other people's benefit than for my benefit. I need to be able to switch it off.*
- *I am not ashamed anymore*
- The diagnostic process was central to the development of self-awareness and self-acceptance

# Adolescent Experiences of Camouflaging

- Bernardin et al. (2021) JADD 51, 4422-4435
- Qualitative study of 76 adolescents (23 female) ages 13-18 years
- **Motivations for camouflaging**
- Acceptance
- Avoiding negative **experiences**
- Avoiding negative **perceptions**

# Adolescent Experiences of Camouflaging

- **Positive consequences**
- Avoiding negative consequence
- Friends
- Being perceived positively
- Positive interactions with others
- **Negative consequences**
- Feeling bad (drained, negative emotions, to be alone after camouflaging)
- Feeling inauthentic

# Adolescent Experiences of Camouflaging

- **Perceived ease of camouflaging**
- All autistic males reporting camouflaging to be easy
- Only one autistic female reported camouflaging to be easy

# The Relationship Between Masking and Wellbeing

- Cage et al (2022) *Autism in Adulthood* 4, 247-253
- Explored whether autistic community connectedness (ACC) can protect against the negative effects of masking
- 196 participants completed an online survey
- **Higher ACC related to more positive wellbeing**
- However, there was no interaction effect; **ACC did not moderate the relationship between masking and wellbeing**

# The Relationship Between Masking and Wellbeing

- **Those with greater attachment to the autistic community may also be more aware of discrimination against their community**
- Tackling prejudice toward autistic people is critical in helping reduce the negative effects associated with masking
- **We must change perceptions and increase the inclusion of autistic people**

# Camouflaging and Mental Health

- Bradley et al (2021) Autism in Adulthood 3
- Camouflaging often referred to as masking
- Online survey, 277 diagnosed autistic adults (128 female and 78 male) or self-identified as autistic (56 female and 15 male)
- Thematic analysis indicated three themes

# Camouflaging and Mental Health

- **Theme 1; Dangers of camouflaging**
- **Exhausting**
- Leads to mental ill health- **depression and anxiety**, suicidal thoughts
- Others not accepting my autistic self
- Creates **unreal perceptions and expectations**
- Camouflaging to fit in, avoid being bullied or abused, to be accepted
- *People sense 'different' and withdraw from it*
- *Lost the real me - grief*

# Camouflaging and Mental Health

- *Little of me left*
- *Being a patchwork of acts*
- *Easy to slip up and make a mistake and when the mask slips the consequences are massive*
- Others are offended, shocked and rejecting
- **Theme 2 Positive aspects of camouflaging**
- *Allows me access to the social world*
- *To be accepted*
- *To meet people, find work, friendships, partners and have children*
- **Surviving or thriving?**

# Camouflaging and Mental Health

- **Theme 3 Why I don't need to camouflage like I used to**
- *Not since being diagnosed*
- Too exhausting
- *Friends were accepting*
- *Employer wants to make reasonable adjustments*
- *I can't see the point anymore*
- **Not needing to camouflage when with people who understand or accept autism**

# Stress, Anxiety, Depression and Depression Attacks



# Stress

- Moseley et al (2021) *Health Psychology* 40, 556-568
- 127 autistic and 104 non-autistic adults
- Autistic adults experienced **more lifetime stressors** and generally perceived **stressors as being more severe**
- Greater perceived stressor severity was related to **poorer physical and mental health, greater loneliness and lower social support**
- **Loneliness** mediated the relationship between autism and poor mental health

# Maja Toudal: Energy Accounting



- Concept of an **energy bank account**
- Energy **withdrawals and deposits**
- Energy depletion contributes to **depression**
- **Physical and mental health**

# Energy Bank Account: Withdrawals and Deposits

## Withdrawal

- Socializing
- Change
- Making a mistake
- **Sensory sensitivity**
- Daily living skills
- Coping with anxiety
- Over analysing social performance
- **Sensitivity to other people's moods**
- Being teased or excluded
- Crowds
- Government agencies
- Body shape
- Family gatherings
- Perceived injustice
- Certain people

## Deposit

- Solitude
- Special interest
- Physical activity
- Animals and nature
- Computer games
- Meditation
- Caring for others
- Nutrition
- Sleep
- Reading Harry Potter books
- Mental health vacation day
- Information on the Internet
- Being with pets
- Certain people

# Energy Accounting

- **currency:** numerical measure or value of how much an activity or experience is energy draining or refreshing from day to day.
- **energy range** rated from one to 100 for each activity or experience in the withdrawal or deposit columns.
- On some days, socializing can drain energy at a value of around 20 but on other days could be 100



# Energy Accounting

Add all the numerical values in each of the two columns to see if the energy bank balance at the end of the day is in **debit or credit**

If needed, **schedule more energy-infusing activities** for the next day/week

## Colour coding system

- Neutral
- Recharging
- Physical
- Social
- Draining
- Other

August / September 2015				Uge 36			
	Morning	8-12	12-15	15-18	18-20	Evening →	
31 Mandag	Make lunch Walk dog	Classes/ School	Classes/ School	Homework Dance/yoga		Walk dog Tv/Gaming	Steak & potatoes
1 Tirsdag	—    —	—    —	—    —	Homework Work out		Walk dog Tv/Gaming	Spaghetti & meatsauce
2 Onsdag	—    —	—    —	—    —	Homework Dance/yoga		Walk dog Tv/Gaming	Chicken & curry
3 Torsdag	—    —	—    —	—    —	Shop for party Work out	Homework Homework (catch up)	Walk dog Tv/Gaming	Veggie lasagne
4 Fredag	—    —	—    —	—    —	Shop for party Work out	Home work/ write assignment	Walk dog Tv/Gaming	Tuna salad
5 Lørdag	Sleep in	Walk dog	Start cooking	Walk dog Get ready	Birthday party	Birthday party	29!  Danmarks udsendte Big dinner Cheesecake
6 Søndag	Sleep in	Walk dog	Time off	Walk dog Dance/yoga	Time off	Time off	Noodles

# Energy Accounting: Balancing the Books

- Knowing when to **stop 'spending'**
- New sources of **energy 'income'**
- Having enough **energy reserve** in the account
- **Risk of energy depression**



# Autistic Burnout

- Mantzalas et al (2022) *Autism in Adulthood* 4 52-65
- Data scraping to extract public posts about autistic burnout from 2 online platforms
- Used reflexive thematic analysis
- 8 primary themes and 3 subthemes
- Themes
- **1: Systematic and pervasive lack of autism awareness**
- Negative experiences within health care, education, employment and family systems

# Autistic Burnout

- *How do I survive autistic burnout if neither my doctor, nor University, nor psychologist allow me to take the rest I need in order to function?*
- **1.1 Discrimination and stigma**
- Not being accepted
- Direct and indirect discrimination in the workplace
- Employers deliberately altered their working conditions to make it harder for them to cope, forcing them to resign

# Autistic Burnout

- **Theme 2: A chronic or recurrent condition**
- Many first experienced autistic burnout during childhood or adolescence
- Recurred during adulthood
- Build up of demands that exceeded their coping abilities
- Increased at developmental transitions such as to and from high school
- After stressful life events
- Many described burnout lasting months or years
- Recovery protracted or never fully achieved

# Autistic Burnout

- **Theme 3: Direct impact on health and well-being**
- Affected mental health and cognitive abilities – executive function
- Overwhelming exhaustion and inability to function
- Can affect the ability to produce and process speech and heightened sensory sensitivity
- Loss of self-care skills
- Becoming more autistic
- Higher incidence of meltdowns and shutdowns

# Autistic Burnout

- Led to suicidal ideation
- Needing a break from life
- *...experiencing burnout so severe for so long that you wish you could just not be here anymore*
- **Theme 4: a life unlived**
- Altered the trajectory of their lives
- Limiting education and employment, relationship difficulties

# Autistic Burnout

- **Theme 5: blessing in disguise?**
- Burnout was a catalyst for a diagnosis of autism
- Diagnosis providing a new perspective for re-evaluating their lives
- Improved self-awareness, self-care, self-esteem, confidence
- Becoming a self-advocate
- Finding the autistic community
- Connecting with others who have shared the same experiences
- Lifestyle and career changes
- *A massive autistic burnout has probably saved my life*

# Autistic Burnout

- **Theme 6: self-awareness and personal control influence risk**
- Self-awareness and control over stressors affected the risk of developing autistic burnout
- Ability to recognize the build up of pressures and change environmental stressors
- Benefits of rest and social and sensory avoidance
- **Theme 7: Masking: damned if you do, damned if you don't**
- Masking a leading factor for autistic burnout
- Masking leading to identity confusion, support needs unrecognized or disbelieved

# Autistic Burnout

- **Theme 8: ask the experts**
- *Like so much else about autism, I've learnt everything I know about autistic burnout from insightful descriptions and selfless honesty of autistic people*
- Stronger together, with support and advice
- Online compassion and understanding
- The Twitter hashtag #Actually-Autistic widely used to claim an autistic identity

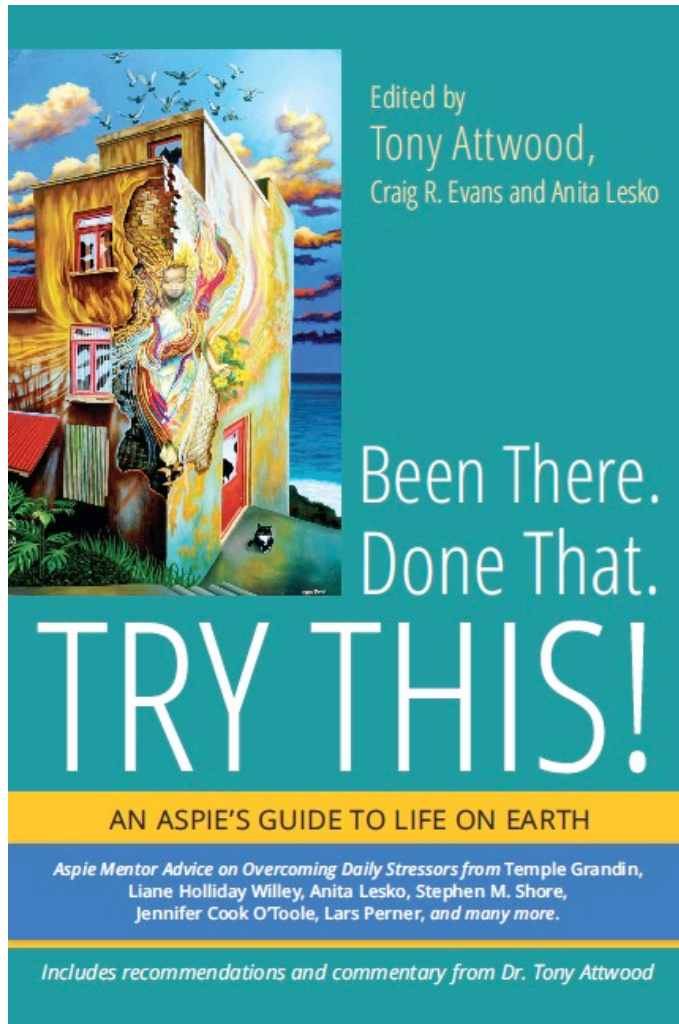
# Defining Autistic Burnout

- Higgins et al (2021) Autism 25, 2356-2369
- Used the grounded Delphi method with 23 autistic adults
- Definition intended for clinicians and the autistic community
- Autistic burnout defined as a highly debilitating condition characterized by:
  - **Exhaustion**
  - **Withdrawal**
  - **Executive function problems**

# Defining Autistic Burnout

- **Generally reduced functioning**
- **Increased manifestation of autistic traits**
- Autistic burnout is **distinct from depression** and non-autistic burnout
- Can include complete social isolation
- **Need for withdrawal and downtime for recovery**
- With cognitive overload, **CBT could be counterproductive**
- **Need to address social issues and sensory environments** to reduce stressors that can lead to autistic burnout or suicidal ideation

# Anxiety



86% of over 300 autistic adults reported having daily problems with **anxiety**

# Anxiety

- Richard Maguire explained, *“I call anxiety the permanent emotional state for autistic people... anxiety is my constant companion. Much of my life and strength have been used up on anxiety.”*



# Genetics and Neurology

**Genetics** - family history of depressive and anxiety disorders – inherited and infectious

## **Neurology**

Amygdala – size, function, and connectivity

Andrews et al (2022) *Biological Psychiatry* 91, 977-987

Less connectivity between the amygdala and frontal lobes



# Anxiety and the Fight, Flight, Freeze Response

## **Fight**

- Threatening language and actions
- 'Attack' mode for self-protection

## **Flight**

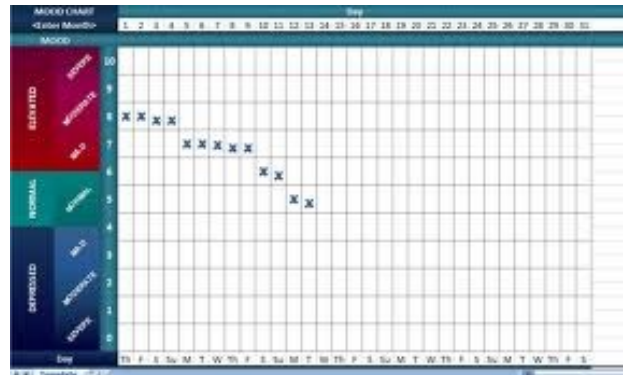
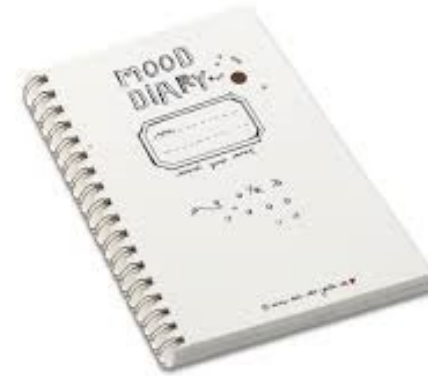
- Escape the situation
- Escape into imagination and fantasy

## **'Freeze'**

- Shutdown
- Situational muteness

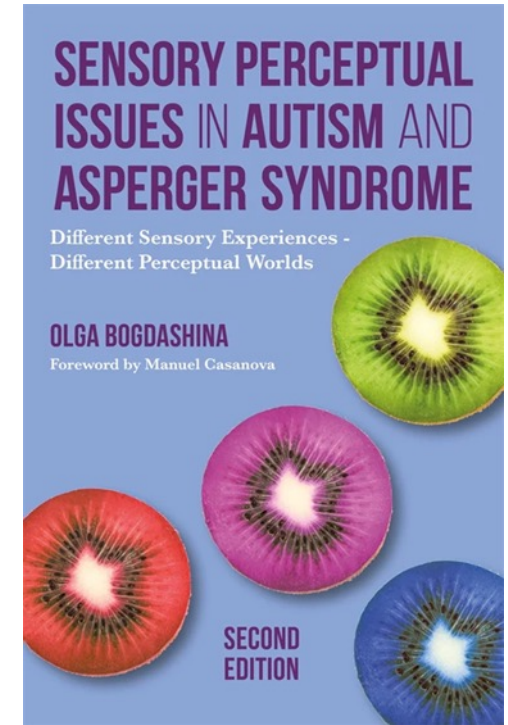
# Tides of Anxiety

Mood diary



# Sensory Sensitivity

- Sounds
- Lighting
- Aromas
- Clothing
- Food



# The Assessment of Anxiety

## **Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD)**

Jacqui Rodgers et al (2016) *Autism Research* 9, 1205-1213

24-item scale, self, and parent report, **children 8-16 years**

Never, sometimes, often, always

4 subscales

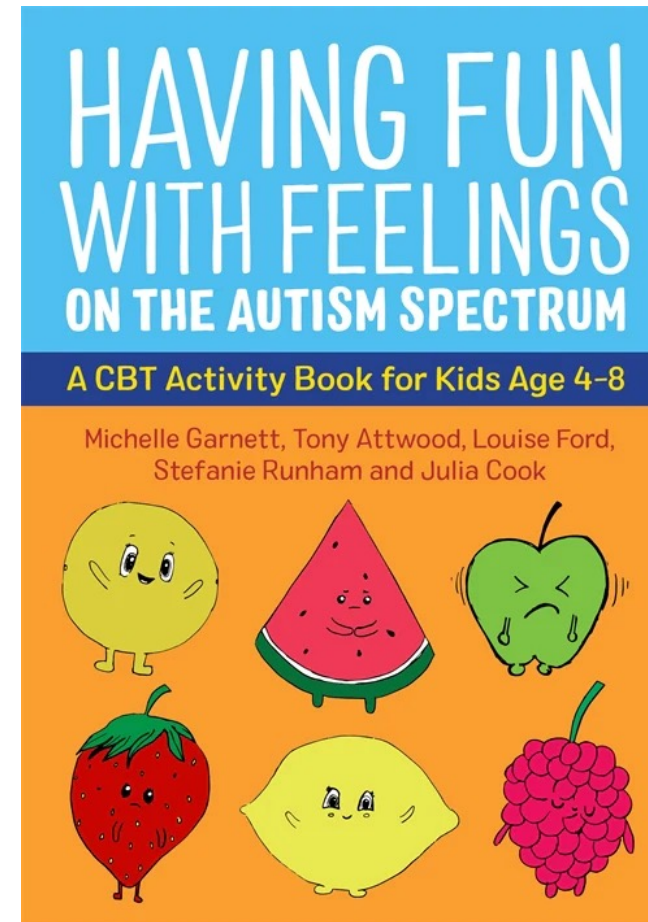
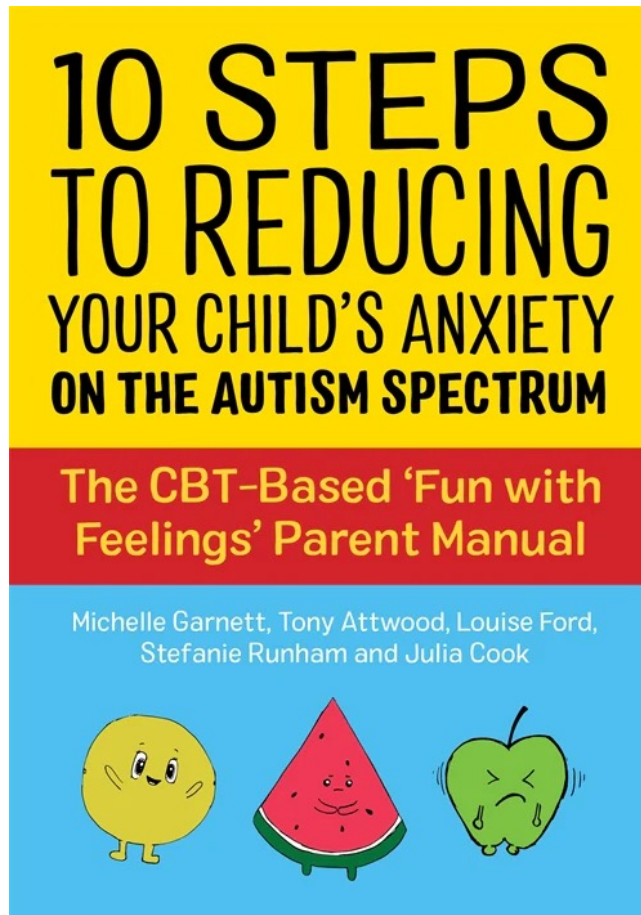
- 1. Performance anxiety**
- 2. Uncertainty**
- 3. Anxious arousal**
- 4. Separation anxiety**

# Anxiety Scale for Autistic Adults

- Rodgers et al (2020) *Autism in Adulthood 2*, 24-33
- The ASC-ASD was designed to measure anxiety in ASD children (Rodgers et al 2016)
- This was modified to become the **ASA-A** as a self-report anxiety questionnaire for autistic adults
- 20 items rated on a 4-point Likert scale from 0 ("never") to 3 ("always")
- General Anxiety factor and 3 group factors - social anxiety, uncertainty, anxious arousal
- **A score of 28 a clinical cutoff**

# Resources for Reducing Anxiety

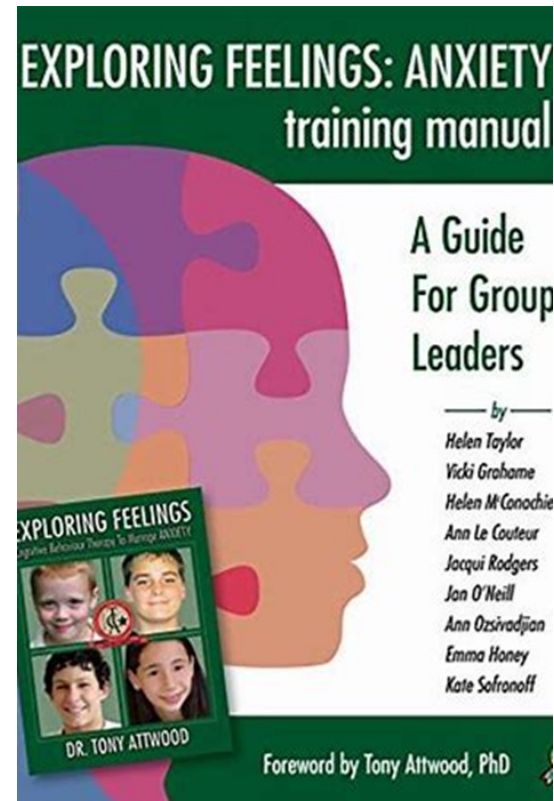
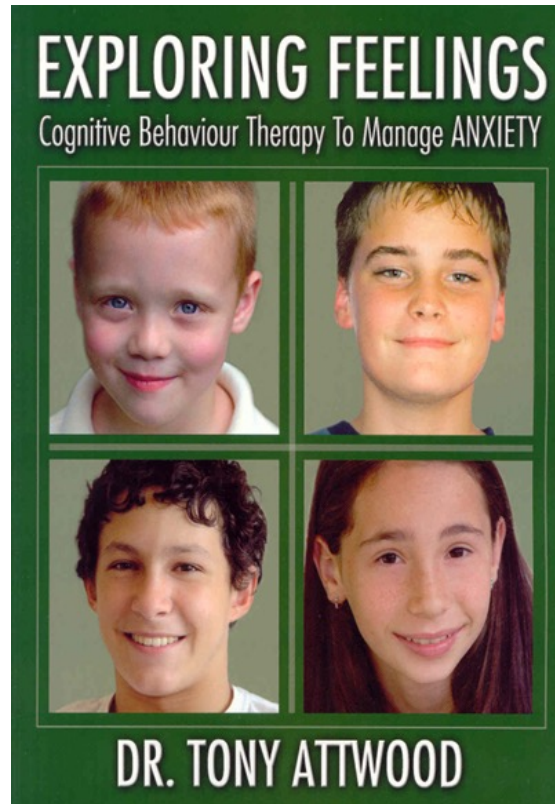
[www.jkp.com](http://www.jkp.com)



# Exploring Feelings

[www.FutureHorizons-autism.com](http://www.FutureHorizons-autism.com)

4 RCT Evaluations of Exploring Feelings for Anxiety and ASD



# CBT Programs for Anxiety in Autistic Children

- ***Exploring Feelings*** (Attwood 2004)
- ***Cool Kids*** (Chalfant et al 2007)
- ***Facing Your Fears*** (Reaven et al 2011)
- ***Building Confidence*** (Fujii et al 2013)
- ***Coping Cat*** (Keehn et al 2013)

# Adaptations to CBT: Emotional Toolbox

- **Physical Tools:** For well-being and energy release
- **Sensory Tools:** For feeling comfortable and reducing stress
- **Relaxation Tools:** For feeling calm and confident
- **Pleasure Tools:** For feeling good
- **Self-awareness Tools:** meditation, Yoga, Mindfulness for interoception and self-regulation



# Emotional Toolbox

- **Social Tools:** To feel connected, gain help and combat loneliness
- **Thinking Tools:** Adaptive thinking
- **Medication Tools:** To reduce the depth and duration of feeling anxious
- **Inappropriate Tools:** Avoidance, self-harm, illegal drugs, and misuse of legal drugs



# Depression

**One in three** autistic adolescents have signs of a clinical depression

Those signs may have been apparent as young as 7 years old

Treatment needs to address many aspects of autism



# Reasons an Autistic Person Can Sometimes feel Sad

## Depression Questionnaire

- Loneliness
- Being rejected or humiliated by people at school/work
- Being bullied and teased by people at school/work
- Feeling exhausted from trying to be accepted and liked
- Believing the criticisms of students at school or of work colleagues
- Being sensitive to the suffering of others

# Depression Questionnaire

- Exhaustion from always feeling anxious
- Being aware of your faults and being a perfectionist
- Taking corrections in school/work as personal criticism
- Being bored at school/work
- Not feeling understood by teachers/line manager/  
colleagues/friends
- Not getting the school grades or work performance to match your  
intelligence or qualifications
- Worry about whether you will ever have a relationship

# Depression Questionnaire

- Worry about whether you will have a successful career or career change
- Believing that past bad experiences will continue forever
- feeling constant pressure to fit in and be like everyone else
- Experiencing the loss of a friendship, pet, or family member
- Not being able to cope with intense sensory sensitivity
- Experiencing too many changes in your life
- Being diagnosed as autistic

# Depression Questionnaire

- Getting into trouble because of your anger
- Not having enough strategies to feel happy again
- Not being understood by your parents/partner or other close family members
- Feeling invisible at school/work
- Over-analysing your performance in social situations
- Being aware of and troubled by social injustice
- Being unemployed or under-employed
- Experiencing or having experienced abuse
- Distress regarding gender identity

# The Discovery of Autism



## Moving from **Diagnosis to Discovery**

- Autism defined by strengths

## **Advantages in social interaction**

- Loyal and dependable, speaking one's mind, avoiding ritualistic small talk, seeking sincere, genuine friendships, exchange of valuable information and advice

# Characteristics of Depression Associated with Autism

- A change in the special interest to a **morbid or macabre topic**
- Watching movies with a **theme of death and despair**
- An attempt to understand morbid thoughts and deep negative inner emotions



# Unhelpful Tools

## Alcohol or drugs

- To temporarily gain relief from anxiety, depression and low self-esteem
- Create a sense of **emotional detachment and emotional control**
- Around 25% of those in alcohol and drug dependency services have signs of Autism
- Initially alcohol removes the barriers of social inhibition and facilitates social inclusion. Reduces anxiety and acceptance in a marginalised peer group of fellow alcohol and drug users

# Unhelpful Tools

## Self-harm

- Self-hatred
- To feel something because of a pervasive numbness
- To feel physical pain to block emotional pain
- To create a sense of relaxation



# 'Depression Attack'

- Arrive unexpectedly and are extremely intense
- An emotional 'implosion'
- A desperate need to end the despair
- Can be intense but fortunately brief



# Managing a Meltdown/Depression Attack

- **Do**



- Stay calm – **GPS**
- **Affirm and validate** the child's emotion
- **One person** dealing with the situation
- Confirm **the feeling will go**
- Keep **other people away**
- **Minimal speech**
- **Special interest** as an 'off switch'
- Seek a **safe place for solitude**

- **Not Do**

- **Interrogation**
- Focus on **disapproval and consequences**
- *When I'm upset, the last thing I want to do is talk to someone*
- *I can hear but my brain can't process what people say*
- Try not to **jolly up** or use **comfort and affection**
- *Human comfort has always been a mystery*

# Autism, Gender and Identity



# Lived Experience of Gender Dysphoria in Autistic Young People and Their Parents

- Cooper et al (2022) *European Child and Adolescent Psychiatry*
- 15 young autistic adolescents aged 13-17 years who identified as transgender and their parents
- In-depth interviews to generate differences in parent-child perspectives
- **Coping with distress**
- Once distress was identified as being due to gender incongruence, many autistic young people understood gender-affirming treatments to be **the solution to their distress** and this became their focus

# Lived Experience of Gender Dysphoria in Autistic Young People and their Parents

- **Puberty** was frequently cited as being very difficult, with an increase in gender distress
- The **body changing** in unwanted ways
- Feeling trapped in one's body
- *It's looking in the mirror and wanting to die,... because you hate yourself that much*

# Lived Experience of Gender Dysphoria in Autistic Young People and their Parents

- Some participants described **specific dysphoria**, e.g. just about genitals
- Most autistic young people were **highly motivated to access physical interventions** with puberty blockers, hormonal interventions and surgery (interest and expertise)
- While most young people wished to make a physical transition, parents and young people **did not always align** in their viewpoints
- Parents **wanted to reduce the distress** while also emphasising their desire to **slow down the process**

# Lived Experience of Gender Dysphoria in Autistic Young People and their Parents

- Participants described **difficulties communicating and connecting with gender clinicians**
- *I'm not very good at the airy-fairy sort of emotional talk they want me to do (alexithymia)*
- **Working out who I am**
- Young autistic people **prioritising gender identities** and related needs, and parents more focussed on **autism identities** and needs
- **Autism was often unimportant to their sense of self**

# Lived Experience of Gender Dysphoria in Autistic Young People and their Parents

- Some parents described how they felt their children were making sense of themselves and social differences through **the lens of gender diversity**
- *Is she trying out different identities when she feels more insecure about how she's coming across socially? Does she try out different identities, and is gender identity just part of that*
- Parents were more likely to describe how autism influenced their child's thoughts about gender, often citing **black-and-white thinking**
- Their child's high expectations of other's abilities to adjust and use **correct pronouns** immediately after coming out

# Healthcare Clinician Perspectives on Gender Dysphoria and Autism

- Cooper et al. (2022) *Autism*
- Interviews with **16 healthcare clinicians** who worked with autistic people who experienced distress about gender incongruence
- Most framed autism and gender dysphoria as interrelated rather than one causing the other
- Young people were often focused on **gender dysphoria as the main cause of distress**, but other causes of distress often existed

# Healthcare Clinician Perspectives on Gender Dysphoria and Autism

- *If you've got a more black-and-white concrete way of thinking about this stuff, then it may be easier to reach a conclusion about being transgender whereas someone who's neurotypical might be able to consider things in a more complex way or a more nuanced way*
- Concern that a specific, rigid and detailed vision of what should happen during a gender transition could **reduce satisfaction with the outcomes**
- Undertaking a gender transition **led to more complex social situations** to navigate, increasing social challenges

# Healthcare Clinician Perspectives on Gender Dysphoria and Autism

- *They get to puberty and they start questioning gender and wondering if some of the differences that they've noticed between them and their peers might be about gender*
- Clinicians wanted to understand whether gender needs were **'secondary' to autism needs or at the 'forefront'** when meeting patients
- Autism could contribute to a feeling of **freedom from gender norms**
- Sensory differences and other changes during **puberty, as a 'tipping point'**

# Healthcare Clinician Perspectives on Gender Dysphoria and Autism

- *Puberty can be really problematic for autistic young people, for all sorts of reasons to do with change, body, smell, periods, all sorts of stuff to do with **sexual feelings that feel unmanageable***
- Tension between clinician and patient thinking styles and aims, between their aim of exploring gender identity and their **patient's aims of accessing physical interventions to change their bodies**

# Gender Dysphoria: Conflict Versus Congruence

- Coleman-Smith et al (2020) *Journal of Autism and Developmental Disorders* 50 2643-2657
- Ten autistic adults with gender dysphoria
- Qualitative study using Grounded Theory using semi-structured interviews



# Gender Dysphoria: Conflict Versus Congruence

- **Trans male** participants' families permitted some flexibility in childhood to behave more congruently with their sense of masculinity – tomboy
- **Trans females** were **denied flexibility** in experimenting with or expressing femininity
- As puberty dawned, **pressure from others to conform** to typical gender presentations intensified
- Puberty also intensified GD feelings, challenging attempts at ignoring and suppressing them

# Gender Dysphoria: Conflict Versus Congruence

- Most participants described **hating their body and not recognising it as their own**
- Despite attempted suppression, participants' sense of an alternatively-gendered self **strengthened over time**
- Some explored their mandated gender status to better understand it and find a comfortable way of expressing it
- *I did go through a stage of exploring my femininity... and choosing to go out in the evenings in a skirt and seeing how it felt... and it felt a bit like doing drag*

# Gender Dysphoria: Conflict Versus Congruence

- Learning about transgenderism was a **key moment in their lives**
- Relief in having a **term to conceptualise their experiences** and not being **alone** in feeling as they do
- Hope that their distress could be addressed through transition and medical interventions
- As knowledge of GD and treatment options grew, so did the sense of **conflict with others who restricted their gender expression**
- Frustration at themselves for continuing to **'live a lie'**

# Gender Dysphoria: Conflict Versus Congruence

- Most participants spoke of relief having socially transitioned, describing it as when their **'life properly began'**
- Those transitioning to male reported rapid improvements in dysphoria as taking hormones and growing facial hair made them feel **instantly recognisable as masculine**
- The trans women felt **physical changes were slower**, and some facial masculinisation continued to be a source of discomfort with their appearance
- Conflicts remained as they navigated the social world with a continuing fear of hostility and a sense of difference due to having **two stigmatised identities**

# Clinical Guidelines for ASD and Gender Dysphoria

Strang et al. (2018) *Jr. Clinical Child and Adolescent Psychology* 47, 105-115.

## Assessment

- Gender referrals should be **screened for ASD**. The patient should be referred to an ASD specialist for ASD diagnostics.
- Clinicians and parents sometimes **dismiss GD as a trait of ASD**, e.g., as an over-focused or unusual interest.
- Autistic adolescents may have **limited self-awareness** and may struggle to recognise or understand their gender concerns until later in development.

# Clinical Guidelines for ASD and Gender Dysphoria

- These young people may struggle to see or consider an “in-between” solution, such as being a **feminine male**
- Gay or bisexual adolescents with ASD may concretely assume that their sexual **attraction to the same gender means that they must be a different gender.**

## Treatment

- Some adolescents with co-occurrence struggle with **treatment compliance.** They may not see the purpose or may not have sufficient organisational skills to attend regular appointments

# Clinical Guidelines for ASD and Gender Dysphoria

- An autistic adolescent may not know how to present as a different gender, such as choosing/obtaining appropriate clothing. **Parent/caregiver involvement** may be necessary to guide the gender exploration process.
- Adolescents who are clearly in an exploratory phase of gender, e.g., with unclear or inconsistent signs of GD, should be encouraged to **explore their gender identity over time** before being considered for any potentially irreversible gender-related medical treatments

# Clinical Guidelines for ASD and Gender Dysphoria

## Social

- The co-occurrence can often lead to **increased social isolation**, as both ASD and GD can in themselves be isolating, and together the impact is exacerbated (NT peer encouragement)
- Sometimes, the primary social contact that these adolescents have is through **Internet-based transgender-related blogs/groups**, and this may be where they are first introduced to the concept of GD/transgenderism.

# Clinical Guidelines for ASD and Gender Dysphoria

## Medical treatments

- Because it is often harder for an autistic adolescent to comprehend the long-term risks and implications of gender-related medical interventions, **consenting to treatment may be more complex** in this population
- **Unrealistic thinking** about the transformational possibilities of medical interventions may be followed by disappointment/hopelessness when a young person's expectations for their body (or others' perceptions of them) fall short of reality

# Lived Experience of Gender Dysphoria in Autistic Adults

Cooper et al (2022) *Autism* 26, 963-974

- Interviews with 21 autistic adults, Interpretive Phenomenological Analysis
- A wide range of **negative emotional responses to their bodies**, including depression, anxiety, anger and disgust
- *I could never relax in my body and that in itself would bring its own discomfort*
- A sense of **distress and detachment from a body** which does not align with the individual's identity

# Lived Experience of Gender Dysphoria in Autistic Adults

- Sensory dysphoria, distress in their bodies linked to **sensory experiences** such as wearing uncomfortable clothing, the sensory challenges of puberty, including periods and the smell of blood
- Gender was one of many social expectations which **did not make sense to them**
- Challenges such as the tension between their need to undergo a physical gender transition **versus a need for sameness and routine**
- Barriers to accessing healthcare for their gender needs, such as being **believed and achieving support**

# Mental Health Correlates and Gender Dysphoria

Chang et al. (2021) *Autism*

- Taiwanese study
- 88 autistic and 42 control participants
- As an adult, the autistic participants endorsed the Adult Self-Report item **“I wish I was the opposite sex”** sometimes to very often

# Mental Health Correlates and Gender Dysphoria

Compared to autistic adults who did not endorse that statement

Greater levels of:

- **School and cyberbullying and victimisation**
- **Suicidal ideation**
- **Worse quality of life**
- **Depression and anxiety**

Lower levels of:

- **Parent reported family support**

# Clinical Experience

## **Sense of self**

- Knowing you are different
- Seeking an explanation
- A solitary and deeper self-analysis
- A natural philosopher – existentialism
- Seeking information on the Internet and Internet-based transgender-related blogs/groups

# Clinical Experience

## **Sense of self**

- A sense of connection, acceptance and encouragement – my tribe
- Value in the group for information (research)



# Clinical Experience

- **Depression**

- A tide of depression preceding and during puberty
- Suicidal ideation, **death of the previous self**
- **Resurrection**, a phoenix and a sense of re-birth

- **Education**

- Education on gender and sexual identity specifically **designed by and for autistic adolescents**
- The range of feminine and masculine characteristics
- Feminine male and masculine female
- *“Gender is not decided by your genitals...you don’t look between your legs to understand who you are”*

# Clinical Experience

- Careful evaluation of **motives behind sexual reassignment**
- Goal is for the person to realise their **authentic self**
- **Self-definition** includes gender AND values, interests, qualities, abilities, sexuality, spirituality, community roles
- Research confirms that parental **support and love** on the gender journey, whatever the final destination, is needed to maintain mental health



# Clinical Experience

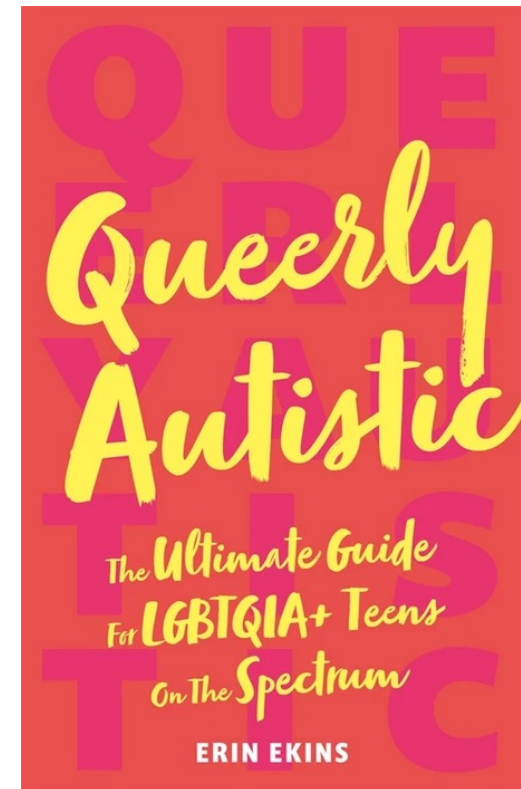
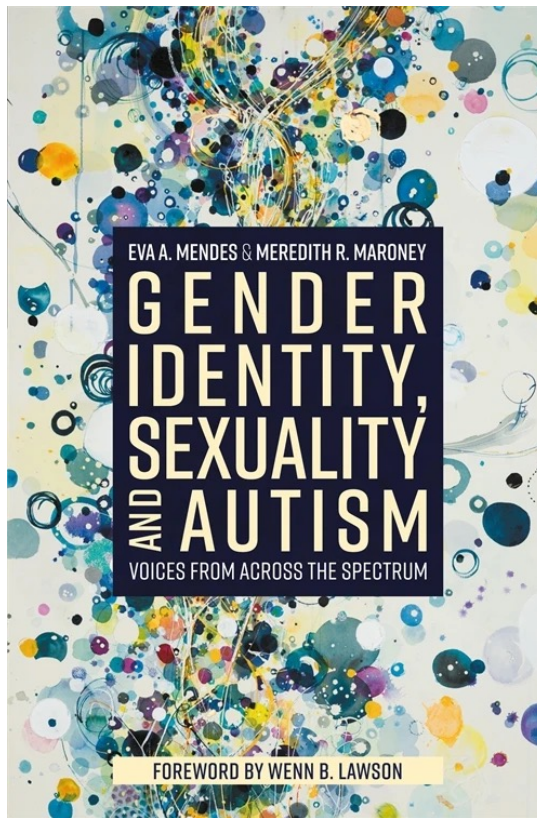
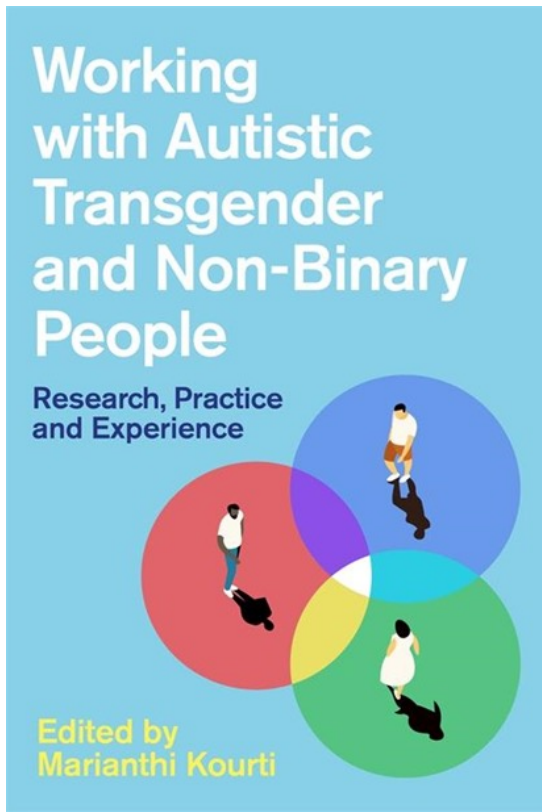


## Quality of life

- **Acceptance, inclusion and protection** by peers
  - To **solve a problem** (cure for autism, avoid being bullied, respect, social isolation)
  - Are there other solutions?
  - Development of a **positive sense of self**, irrespective of gender
- “My personality is more important than my gender”*
- A belief that changing gender is a pathway to a greater quality of life
  - Any challenges to that belief are perceived as heresy and automatically rejected

# Gender Dysphoria Literature

[www.jkp.com](http://www.jkp.com)



# Gender Dysphoria Literature

