



Autistic Minds are Magical!

For a Deeper Understanding of and
Better World for Autistic People

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"It is our choices Harry that show what we truly are, far more than our abilities."



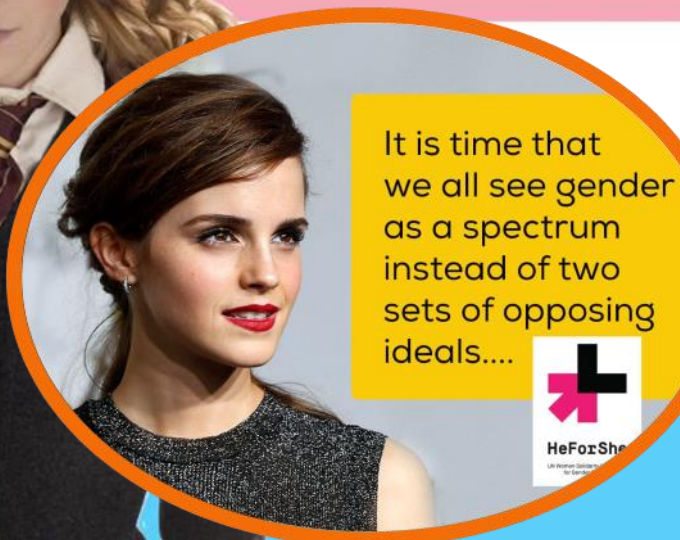
Albus Dumbledore

Harry Potter and The Chamber of Secrets

Sadly, JK Rowling has made anti-trans comments that have hurt and alienated many of us. A Powerpoint slide can't explain how painful this is to so many people. Because of this, I almost didn't create the following presentation. Emma Watson, Daniel Radcliffe, and many others have been vocal in their advocacy for the trans community. Hermione certainly believes in social justice for all and I feel like her character embodies the value of neurodiversity..... So, I'm not letting either JK Rowling or the Florida Department of Health stop me.....

Transgender women are women. Any statement to the contrary erases the identity and dignity of transgender people and goes against all advice given by professional health care associations who have far more expertise on this subject matter than either Jo or I.

Daniel Radcliffe
British Actor
On J.K. Rowling's 'transphobic' tweets
June 8, 2020



It is time that we all see gender as a spectrum instead of two sets of opposing ideals....



HeForShe

Don't care
about other
people.

Don't feel
emotions

Caused by
"Refrigerator
Moms"

Lack Theory
of Mind

No Humanity

"Hopefully
they'll grow
out of it."

"Everyone is a
little on the
spectrum."

Vaccines
Cause Autism

Autism is an epidemic.

May **curiosity** be
your patronus
charm!

Openness to new
information



"My daughter Rose was just diagnosed and now I'm wondering if I could be autistic as well."

Hermione Granger
Minister of Magic



"Goodness no, Hermione, you're so clever. Sure, you're a bit socially odd, but you care so much about other magical creatures. You certainly don't lack theory of mind or empathy for others...."

Madame Pomphrey



Is that really what the most updated research shows about autistic people?
Hermione



Autism Spectrum Disorder DSM-5 Diagnostic Criteria



- **Persistent Deficits in Social Interaction** (deficits in all 3 below)
 - social-emotional reciprocity “struggle with back and forth”
 - nonverbal communication – “difficulty reading cues”
 - developing and maintaining relationships – “difficulty making friends”
- **Restricted, Repetitive Patterns of Behavior, Interests, and Activities** (need at least two below)
 - Stereotyped and repetitive speech, movement, and use of objects
 - Excessive adherence to routines and rituals, or resistance to change
 - Difficulty shifting from one activity to another
 - Highly restricted interests that are abnormal in intensity
 - Hyper/hypo reactivity to sensory stimuli



"You're doing it wrong, basing your diagnostic criteria on obvious behavioral presentations and missing higher masking autistics, especially adult women."
Hermione

Hermione has done her own research and is here to update the muggle healthcare system!





Common Muggle Myth:

“Autistic People Lack Empathy. They have no Theory of Mind.”

“Honestly... Don't you read?”



[Brain](#). 2010 May; 133(5): 1515–1525.

Published online 2010 Apr 5. doi: [10.1093/brain/awq060](https://doi.org/10.1093/brain/awq060)

PMCID: PMC2859151

PMID: [20371509](https://pubmed.ncbi.nlm.nih.gov/20371509/)

Empathic brain responses in insula are modulated by levels of alexithymia but not autism

[Geoffrey Bird](#),^{1,2,*} [Giorgia Silani](#),^{✉3,*} [Rachel Brindley](#),² [Sarah White](#),² [Uta Frith](#),² and [Tania Singer](#)³

Alexithymia : Decreased Perception of Emotional Detail

“color blindness for one’s inner emotional experiences”

Detailed Emotional Perception
of One’s Feelings

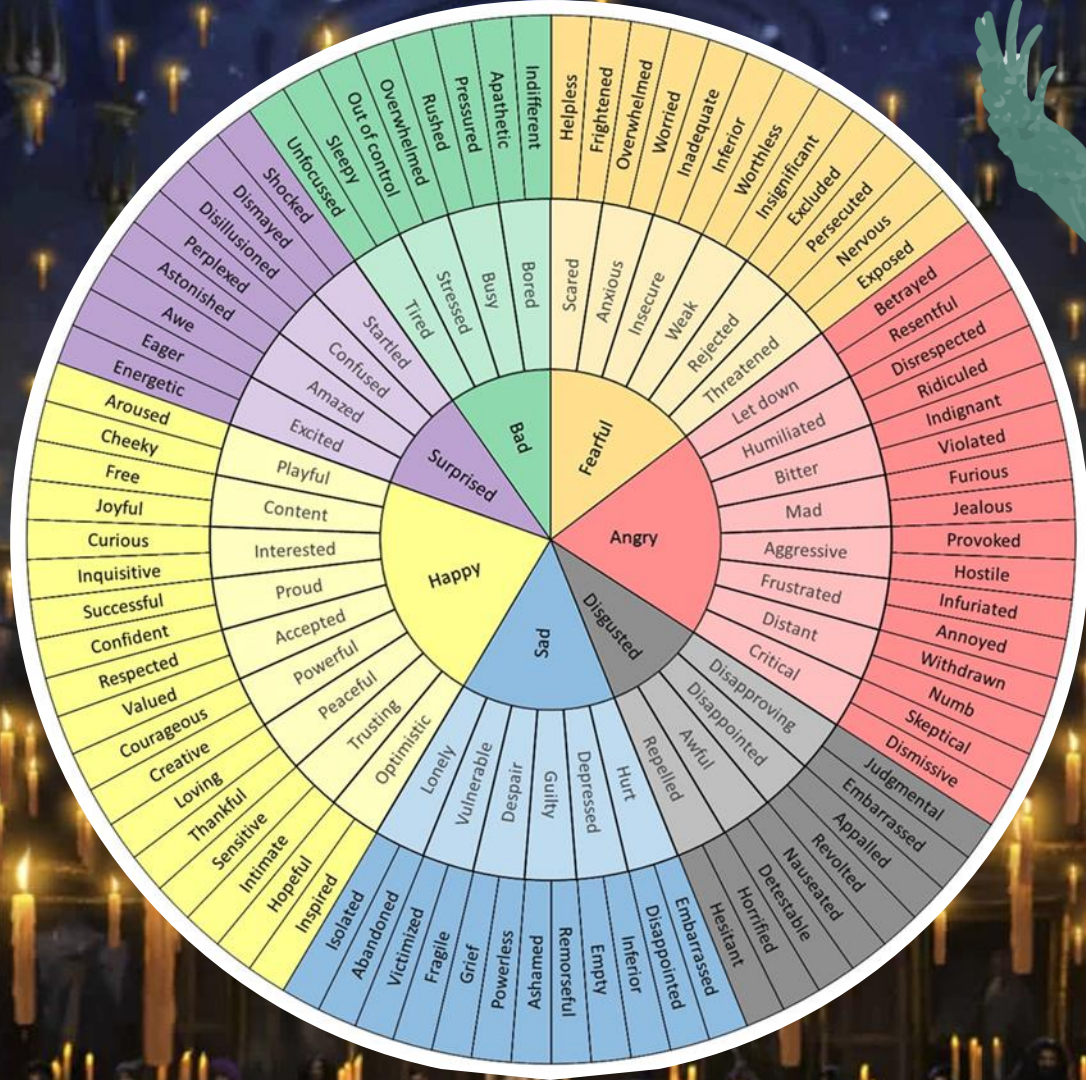


Bertie Bott's **EVERY** Flavor Beans

Alexithymia

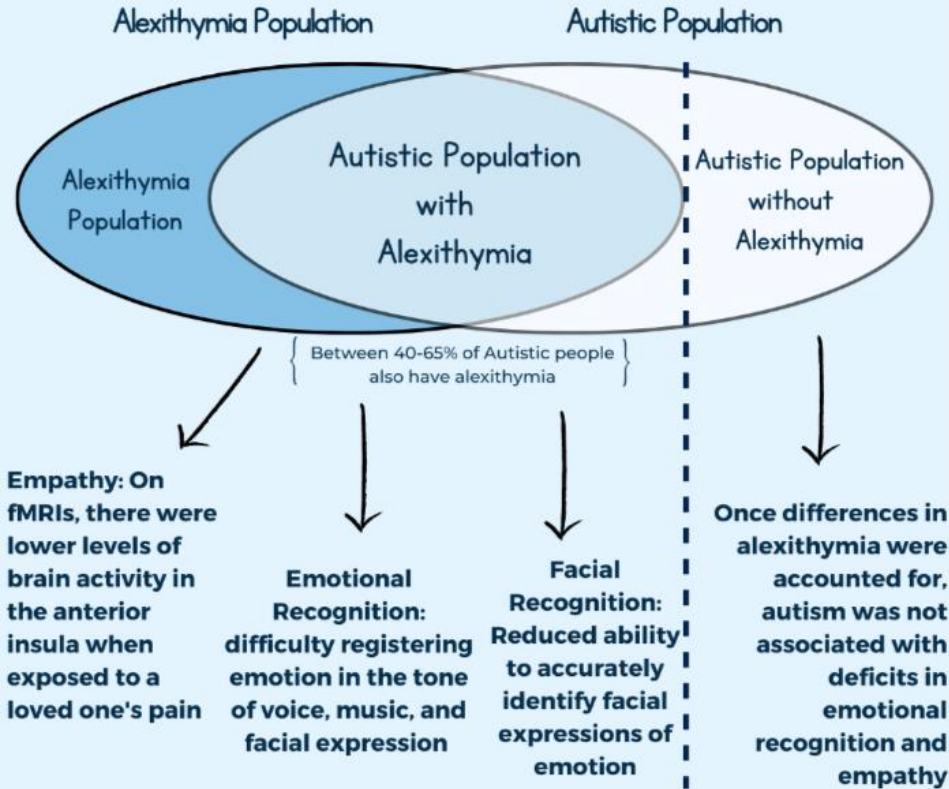
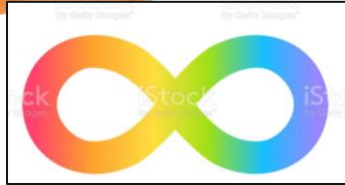


Jelly Beans Melted Together



<https://neurodivergentinsights.com>

Dr. Neff

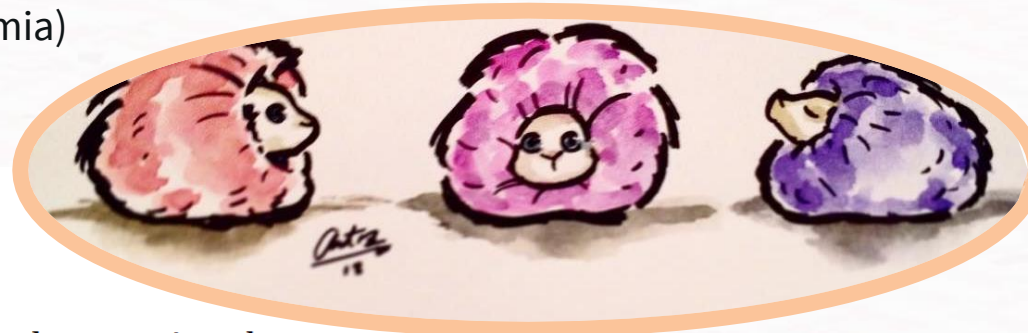


Neurodivergence and Alexithymia

Neurodivergent
Pygmy Puff



- Alexithymia can occur in neurotypical people, but rates are much higher in neurodivergent populations.
- About 40-65% of autistic people are estimated to have alexithymia.
 - Many of our traditional perceptions of autism are based on autistic people with **severe** alexithymia, a subset of the autistic population at large.
- Studies also suggest that alexithymia is more common in ADHD (gross estimates 20-40% of ADHDers also have alexithymia)



[Transl Psychiatry](#). 2013 Jul; 3(7): e285.

Published online 2013 Jul 23. doi: [10.1038/tp.2013.61](https://doi.org/10.1038/tp.2013.61)

Mixed emotions: the contribution of alexithymia to the emotional symptoms of autism

[G Bird](#)^{1,2,*} and [R Cook](#)³

> [Psychol Med.](#) 2012 Nov;42(11):2453-9. doi: 10.1017/S0033291712000621. Epub 2012 Apr 4.

Measuring the effects of alexithymia on perception of emotional vocalizations in autistic spectrum disorder and typical development

P Heaton ¹, L Reichenbacher ¹, D Sauter ¹, R Allen ¹, S Scott ¹, E Hill ¹



> [Turk Psikiyatri Derg.](#) 2021 Summer;32(2):109-117. doi: 10.5080/u23775.

The Relationship Between Alexithymia and Impulsiveness in Adult Attention Deficit and Hyperactivity Disorder

[Article in English, Turkish]

Seda Kiraz, Sencan Sertçelik, Serap Erdoğan Taycan





A Primer on Types of Empathy

Affective Empathy – “feeling with someone”

Shared emotional experience.

Activates **mirror neurons**.

I feel joy in my heart as I look into Dobby's eyes and know that he is free!



Autistic people **with alexithymia** struggle to understand and perceive both their own emotions and those of other people.

• **The ability to perceived detailed emotions occurs on a spectrum and is a skill that can be cultivated.**

- Some people can pick out 100s of different flavors of jelly beans, while others only recognize 5 different flavors.
- People can practice tuning in and cultivating a finer granularity/detail of emotional perception
- This improves a person's ability to both respond to others' emotional needs and understand and communicate their own emotional needs

Dr. Neff's Alexithymia Workbook:

<https://neurodivergentinsights.com/neurodivergentstore/p/alexithymia-workbook>

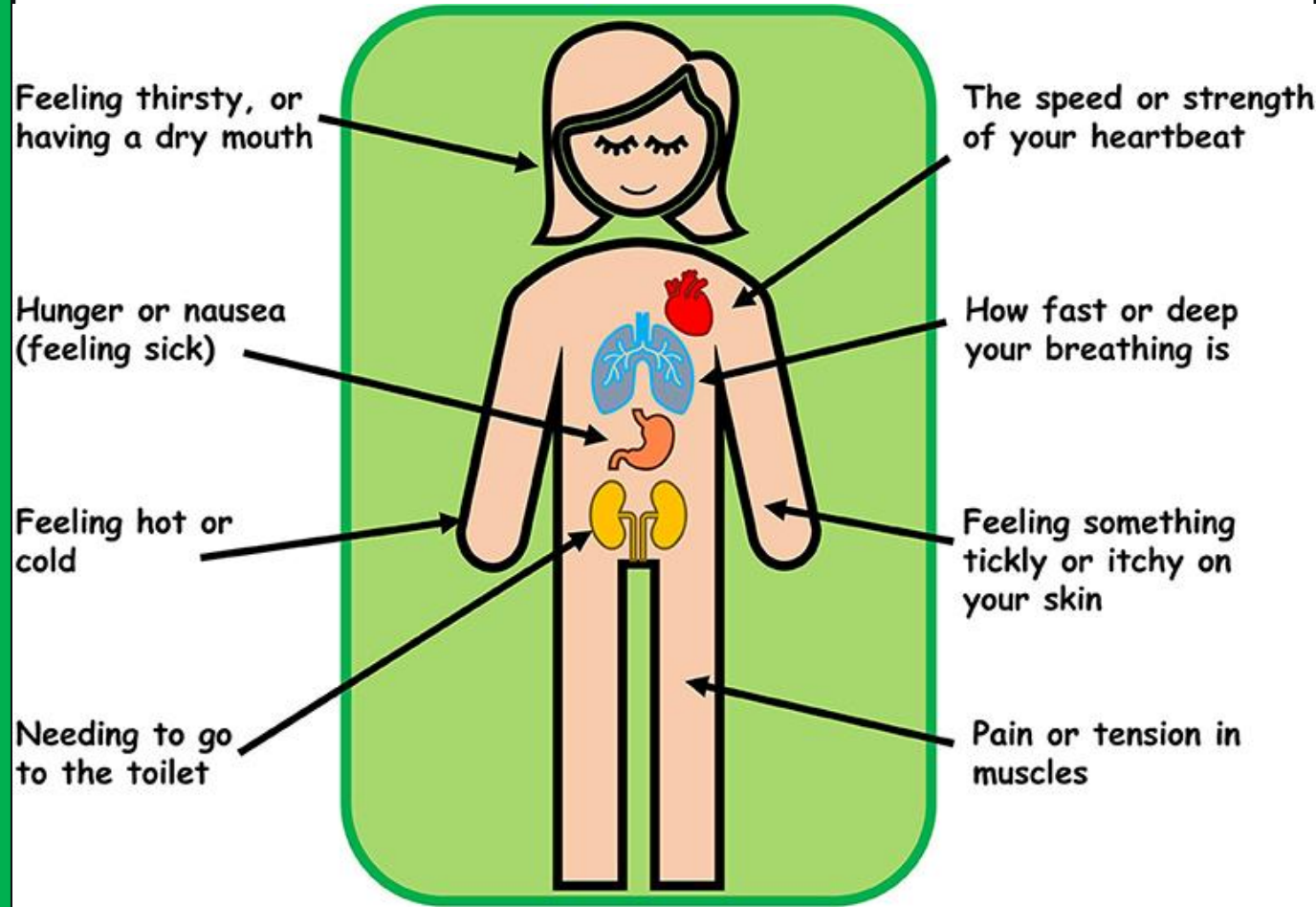
Strategies for Cultivating Emotional Perception

↓

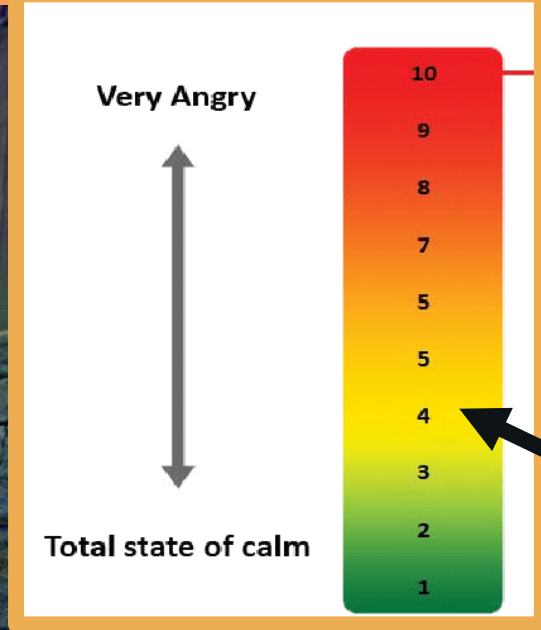
	Unpleasant	Pleasant	
High Arousal	<div>Infuriated</div> <div>Angry</div> <div>Panic</div> <div>Frustrated</div> <div>Annoyed</div> <div>Unpleasant</div> <div>Alarmed</div> <div>Rage</div> <div>Terror</div> <div>Fear</div>	<div>Excited</div> <div>Pride</div> <div>Determination</div> <div>Amused</div> <div>Anticipation</div> <div>Curious</div> <div>Happy</div> <div>Glad</div> <div>Delighted</div> <div>Pleasant</div>	High Arousal
Low Arousal	<div>Melancholy</div> <div>Apathy</div> <div>Depressed</div> <div>Sad</div> <div>Grief</div> <div>Disinterest</div> <div>Despair</div> <div>Bored</div> <div>Gloomy</div> <div>Tired</div>	<div>Gratitude</div> <div>Serenity</div> <div>Relaxed</div> <div>Calm</div> <div>Content</div> <div>Satisfied</div> <div>Coziness</div>	Low Arousal
	Unpleasant	Pleasant	

- **Somatic check-ins**
 - mindfulness, body scan
- **Emotional check-ins**
- **Practice labeling emotions**
 - May help to start with behavioral description and progress to emotion words ie “breaking dishes feeling state,” “stuck-in-bed feeling state”
- **Practice gauging emotional intensity**

Impaired Interoception in Autism

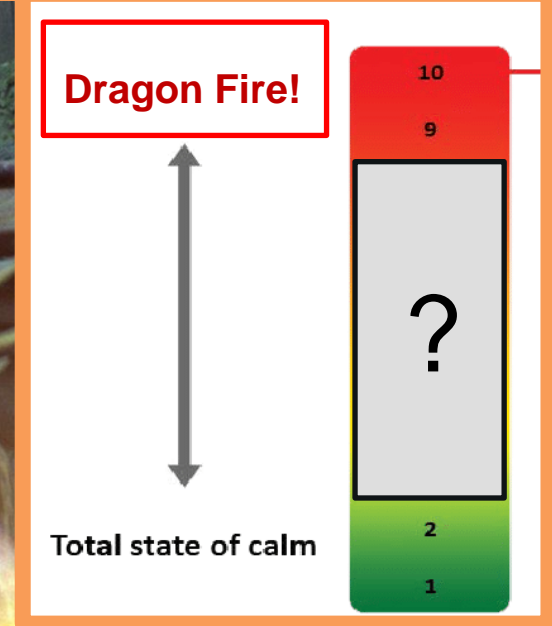


Both Alexithymia and Impaired Interoception Contribute to Autistic Meltdown



Getting hungry, I better get a snack!

Neurotypical Thermometer



Alexithymia and Impaired Interoception Thermometer




Original Article

Alexithymia according to Bucci's multiple code theory: A preliminary investigation with healthy and hypertensive individuals

Michela Di Trani  ▾, Rachele Mariani ▾, Alessia Renzi ▾, Paul Samuel Greenman ▾, Luigi Solano ▾

First published: 03 October 2017 | <https://doi.org/10.1111/papt.12158> | Citations: 19



**Alexithymia is associated
with hypertension!**

[J Clin Med.](#) 2018 May; 7(5): 112.

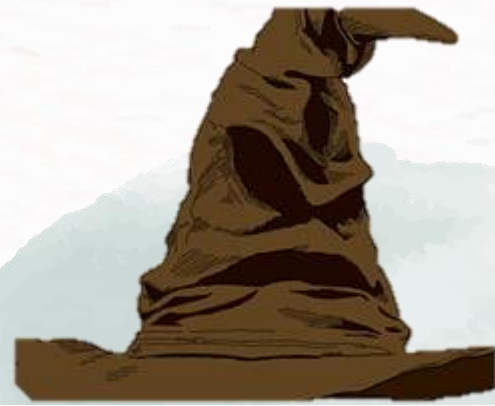
Published online 2018 May 10. doi: [10.3390/jcm7050112](https://doi.org/10.3390/jcm7050112)

PMCID: PMC5977151

PMID: [29748483](https://pubmed.ncbi.nlm.nih.gov/29748483/)

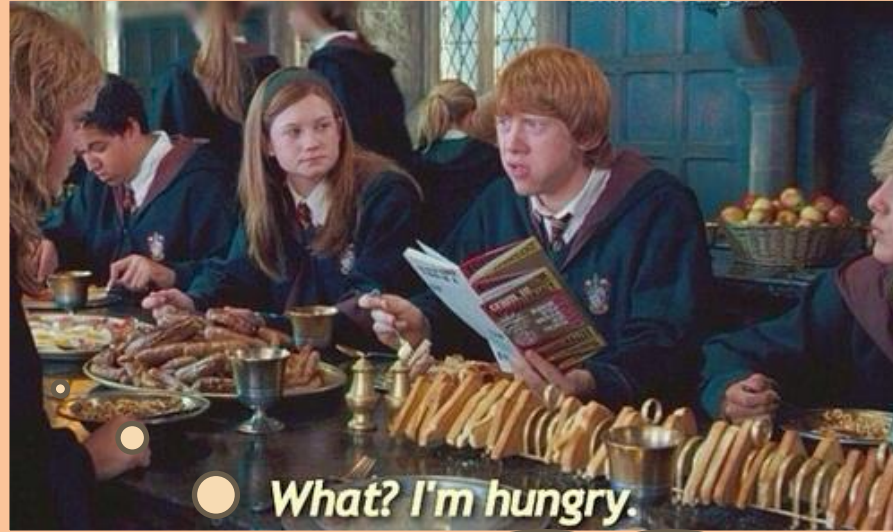
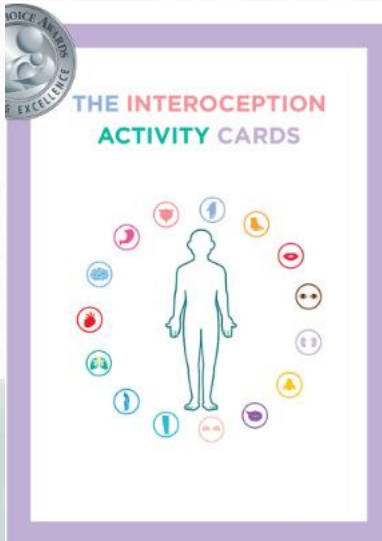
Alexithymia and Somatosensory Amplification Link Perceived Psychosocial Stress and Somatic Symptoms in Outpatients with Psychosomatic Illness

[Mutsuhiro Nakao](#)^{1,2,*} and [Takeaki Takeuchi](#)^{2,3}

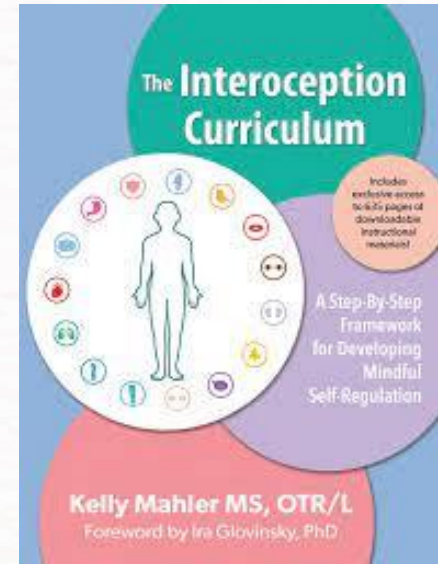


Kelly Mahler's Resources for Cultivating Interoception

<https://www.kelly-mahler.com/>



Are you hungry Ron? Or is your interoceptive perception of fullness just impaired?



Three Types of Empathy.....

Affective
Empathy

Cognitive
Empathy

Compassionate
Empathy



Compassionate Empathy

“feeling for someone”

Concern, sympathy, desire to help

I care about Dobby and I want to help. I am inspired to advocate for equal rights for house elves everywhere!



Autistic individuals often experience an intense sense of social justice and equal concern for both non-human and human life.



Spare Socks for
Liberating House Elves



They tend to greatly value fairness and equality, treating others the same irrespective of social hierarchy.

May have an unusually strong moral compass.



Impaired Cognitive Empathy or A Cultural Misunderstanding....

Cognitive Empathy –

Understanding another's perspective.

I'm thinking about how helpless Dobby felt enslaved to Lucius Malfoy and how important his freedom is to him and can understand what he wants to do next.

Also referred to as “theory of mind” or “perspective taking.”

“House Elves is not Paid Sir!”



-Winky



Perspective taking between neurotypes.... Tricky business

Milton, D. E. M. (2012). "On the ontological status of autism: The 'double empathy problem.'" *Disability and Society*. 27(6). 883-887.



DOUBLE EMPATHY PROBLEM

Different neurotype

From neurotypical to autistic
From autistic to neurotypical



Not efficient



@dat_autistic_advocate

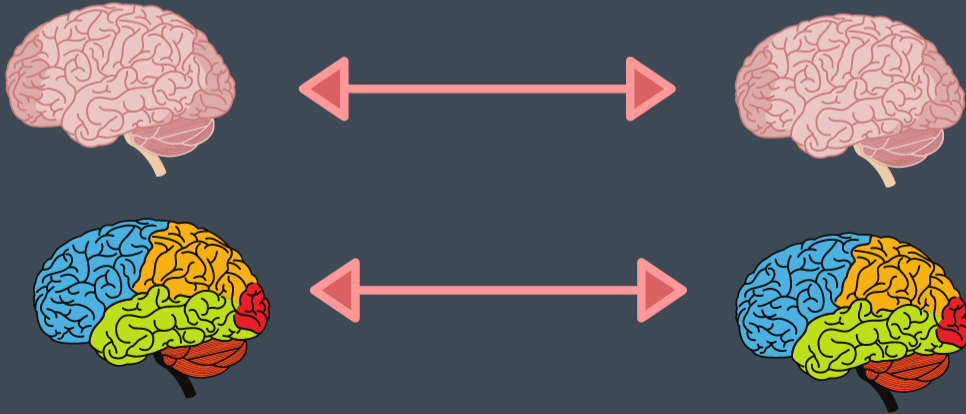
DOUBLE EMPATHY PROBLEM

Communication between same neurotype

From neurotypical to neurotypical
From autistic to autistic



Efficient



@dat_autistic_advocate



Autistic individuals tend to have more accurate cognitive empathy for other autistic individuals than neurotypical people have for autistic people.

Those who share a similar neurotype are likely to understand each other better.



Autistic Culture

Neurotypical Culture

- Communication is direct and clear.

- Communication includes subtext, is context dependent, and implied.

- Communicating accurate information is priority.

- Solidifying a relationship within a social hierarchy is important.

- Detailed understanding is important.

- Big picture is important.

- What is logical/most expedient?

- What is socially acceptable?

Three Types of Empathy.....

Affective
Empathy

Cognitive
Empathy

Compassionate
Empathy



Autistic People and ADHDers May **Express** Empathy Differently

– through sharing a personal story where they experienced a similar feeling

Harry Potter doesn't even seem to know I exist! *sob*

I can't believe I saw Ron kissing Lavender Brown! I'm so hurt.

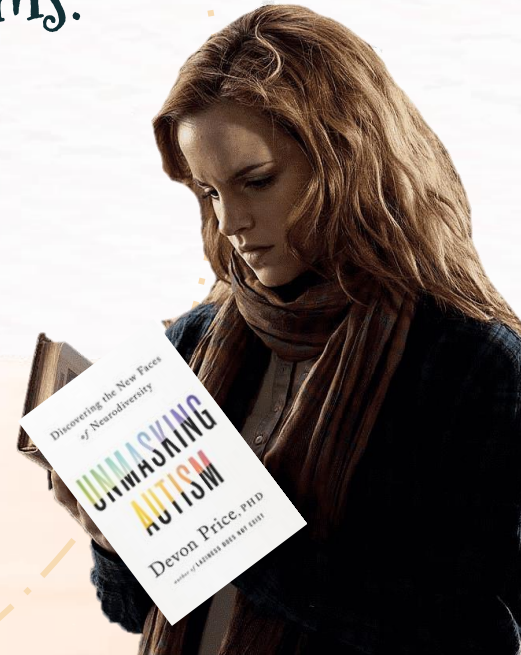
I'm looking for some empathy here Hermione and you're just talking about yourself!



"After I share this vulnerable personal story of romantic rejection, Ginny will know that I understand her!"

-Hermione thinks to herself

Many autistic people are actually hyper-aware of the emotions of others, experiencing them more intensely and often have a strong sense of social justice and care for all life forms.





Social deficits? Or social differences....



Hypothesized Autistic vs Neurotypical Language Processing

Neurotypical Language Processing

- **Top down (big picture first)** processing that includes context and social relationship
- Interprets context at sentence level, understands gestalt and pragmatics
- More easily perceives sarcasm, figures of speech, and non-literal meanings

Autistic Language Processing

- **Bottom up (details first)** processing that emphasizes accuracy of information exchange
- Interprets context at specific word level, precise
- Difficulty “reading between the lines,” literal interpretations

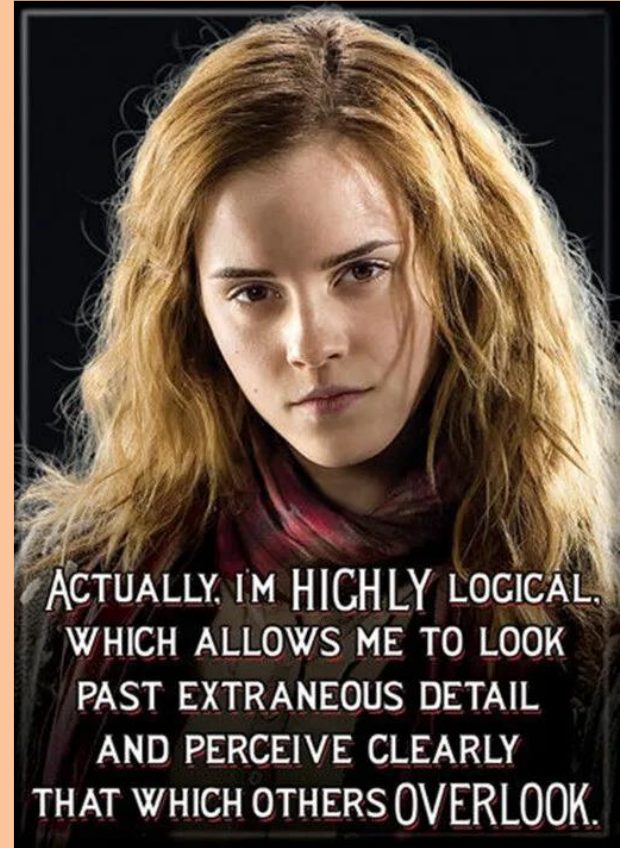
Different Communication Priorities

Neurotypical Priorities During Communication

- Establish a relationship that fits within the social hierarchy
- Put people at ease with superficial small talk
- Make a good impression in order to connect
- What is socially acceptable?

Autistic Priorities During Communication

- Exchange accurate and precise information
- Share a specific interest in order to connect
- What is reasonable/logical and most expedient?



Different Communication Styles

Neurotypical Communication Style

- Use subtle/implicit communication and non-verbal cues to soften feedback.
- Readily adjust tone and cadence depending on audience to solidify relationship (talking to boss vs talking to romantic partner)
- Easily intuit turn-taking and how to initiate/end a conversation
- Context is implied

✦ Autistic Communication Style

- Use direct and to the point communication to make feedback clear and precise.
- May speak more formally with same tone irrespective of audience (may talk to teacher same way as their friend)
- May need let everything out and tell the truth or say nothing at all
- Difficulty feigning interest or knowing that they are expected to feign interest
- Difficulty intuiting turn taking and initiating/ending conversation
- May give an unexpected level of context for clarity.
- May overshare “TMI” or under-share
- Often do much better in one-on-one interactions than when engaging with a group





Hermione info dumping upon first contact....

**Are you sure
that's a real spell?**

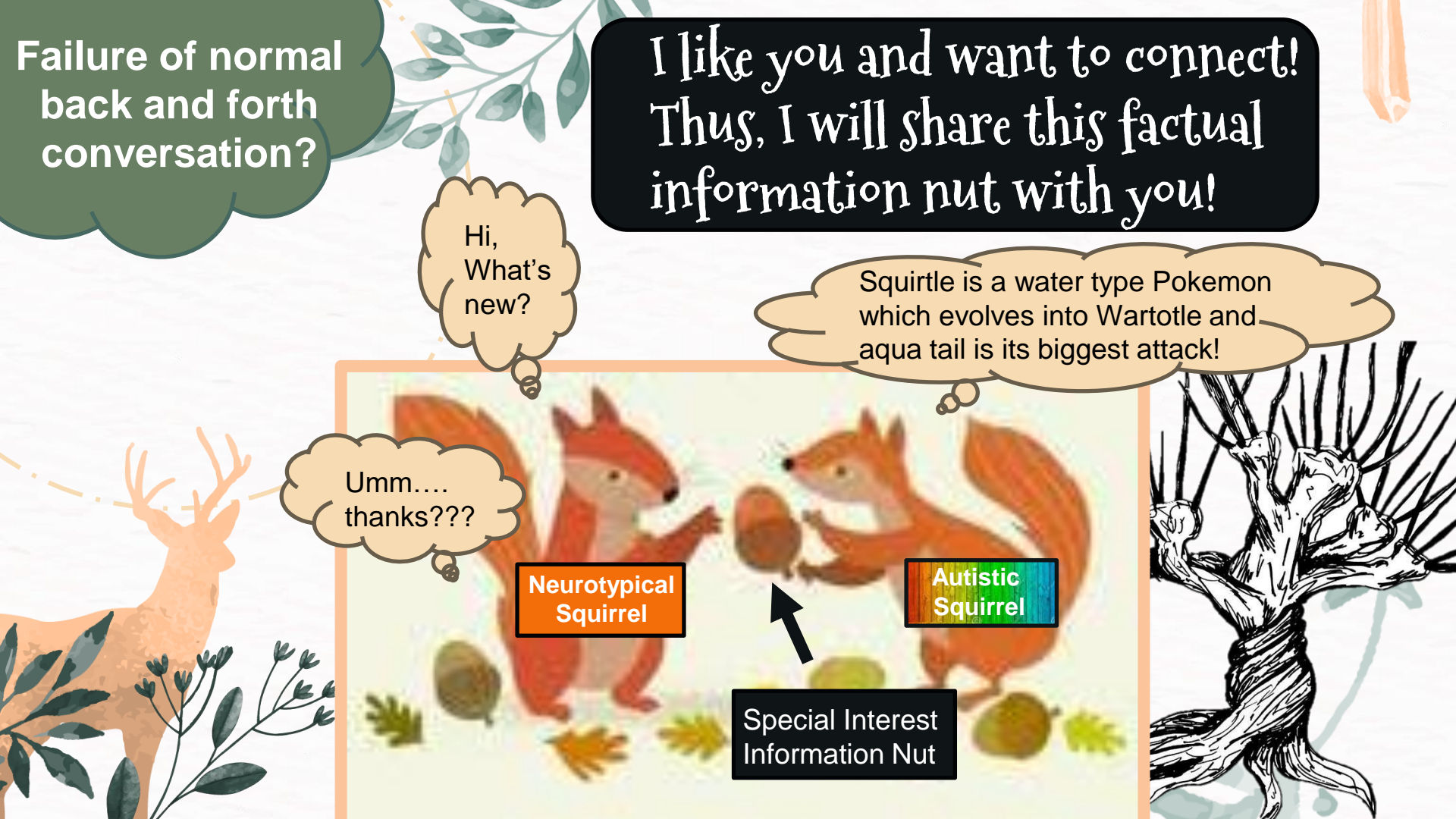
**Well, it's
not very good, is it?
I've tried a few
simple spells just
for practice and it's
all worked for me.
Nobody in my family's
magic at all, it
was ever such a surprise
when I got my letter...**

**...but I was ever
so pleased, of course,
I mean, it's the very
best school of witchcraft
there is, I've heard...**

**...I've learned
all our course books by
heart, of course, I just
hope it will be enough...**

**...I'm Hermione
Granger, by the way...**

...WHO ARE YOU?



Failure of normal
back and forth
conversation?

Hi,
What's
new?

I like you and want to connect!
Thus, I will share this factual
information nut with you!

Squirtle is a water type Pokemon
which evolves into Wartotle and
aqua tail is its biggest attack!

Umm....
thanks???

Neurotypical
Squirrel

Autistic
Squirrel

Special Interest
Information Nut

Ankylosaurus could not move any faster than a human could walk with a layer of outer armor of thick plates of bone fused to a layer of keratin, even on its eyelids!

I like you and want to connect!
Thus, I will share these knowledge flowers with you!

Kevlar, steel, polyethylene, and ceramic are some of the best materials for body armor manufacturing.

Special Interest
Flowers

Two Autistic Bees!

What a great back and forth conversation!
What social reciprocity!





A Diverse Knowledge Garden is Growing!

Different Thinking Styles in Autism



Bottom-Up

- Neurotypicals tend to start with top-down gestalt assumptions.
 - Faster processing and response time, efficient.
- Autistics tend to process all details first to compose a whole picture.
 - Slower processing, but make less assumptions, leading to greater accuracy
 - Less susceptible to optical illusions
 - Less susceptible to preconceived notions

Associative

- Make unusual connections
- Creative problem-solvers

Analytical

- Tend to reason in a more logically consistent manner

Good at Pattern Recognition

Monotropic Attention

Autistic Mind Inside Special
Interest Vortex of Attention



Neurotypical Feeling Ignored

<https://stimpunks.org/glossary/monotropism/>



The **Pain** of Suddenly Transitioning Out of a Special Interest Flow State



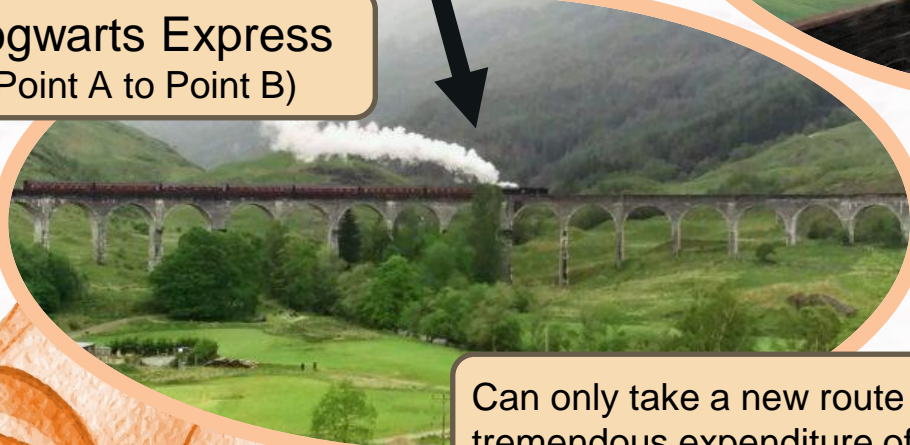
Mandrake In State of Flow, Roots
Burrowing Deep Into Their Special Interest



Mandrake Uprooted!!!

Monotropic Attention

Hogwarts Express
(Point A to Point B)



Can only take a new route with
tremendous expenditure of energy.

Flying Car!



No Telling Where it Will End up!





Supporting Transitions

- Plan ahead as much as possible to reduce anxiety.
- Consider a visual schedule.
- Allow extra time for an autistic individual to adjust.
- Organize tasks in larger chunks.
- Sandwich less demanding events/tasks between more demanding ones.
- Spice up transitions with stimulation – ie preferred podcast while in car

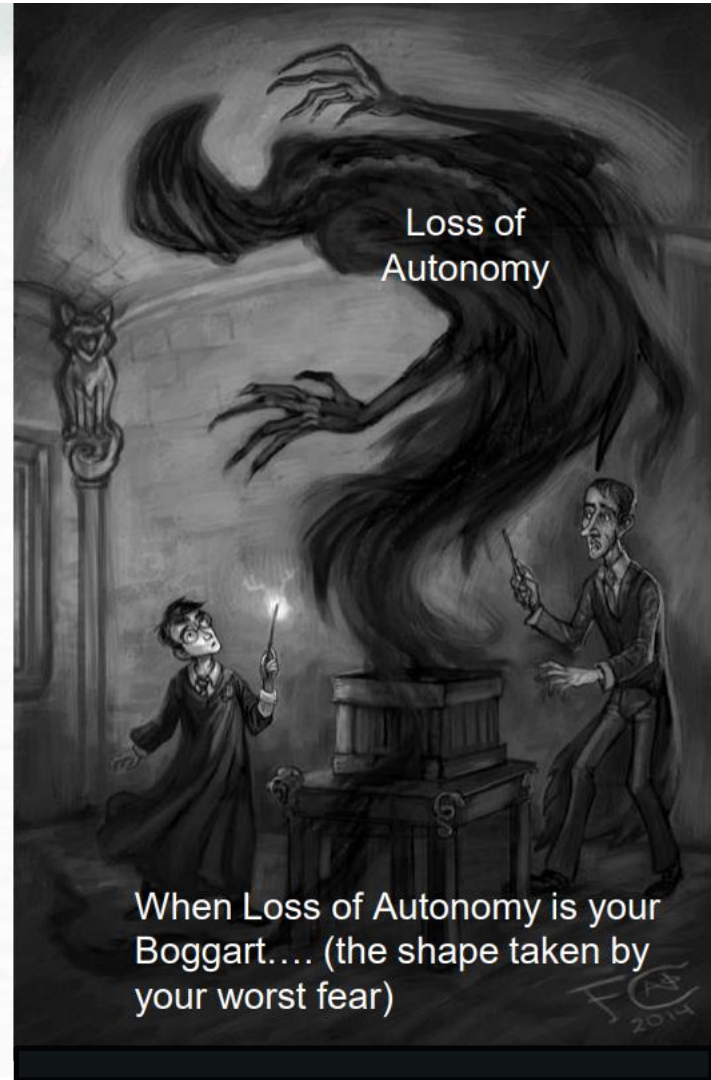


*"You just
stroke the spine
of course!"*
-Hagrid

PDA: Pathological Demand Avoidance

“Pervasive Drive for Autonomy”

- Is more complex than “I don’t want to do that.”
- A trauma response to perceived threats to autonomy triggered by a demand.
- Give choices and provide invitations instead of instructions.
- Can be very debilitating.
- More pervasive and intense than ODD (Oppositional Defiant Disorder).

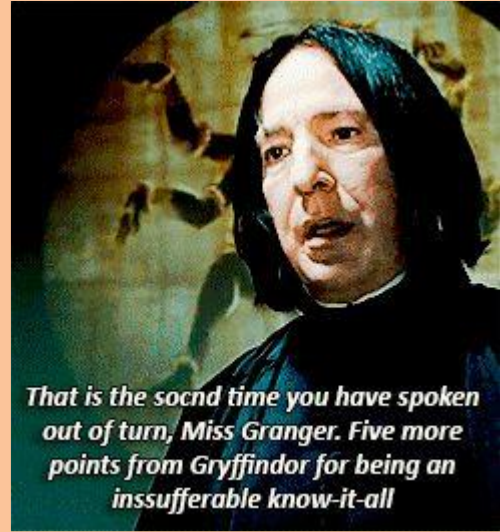


“It makes so much sense now why I was so misunderstood for so many years....” -Hermione Granger



Autistic Intention

Everyone is going to appreciate so much that I have this interesting and factual piece of information to share!



Neurotypical Assumption

You are trying to show off to advance your standing in the social hierarchy!

“People seemed to get the wrong first impression of me a lot.”
-Hermione Granger



Autistic Intention

Ron is going to appreciate so much that I am helping him to improve his hygiene!



Neurotypical Interpretation

Who does she think she is; My mom?
Is she making fun of me?

“I notice that people keep getting mad at me but I don’t know why and nobody will explain!” -Hermione



Granger



Autistic Intention

Hermione: “Years of speech therapy have finally paid off! This cute boy will notice me when I help him out with his pronunciation!”



Neurotypical Interpretation

Ron: “Thanks for showing me up and making me look like an idiot!”

“People accuse me of not caring what other people think. I actually care quite a lot. Other people are just confusing. Its safer to stick with what I know how to do really well..... Reading.

-Hermione Granger



Currently reading:

Camouflage: The Hidden Lives of Autistic Women. (A Graphic Novel by Dr. Sarah Bargiela.



Miscommunication is Risky



Vulnerable to Being
Manipulated

Sharing too little
(distant)

Difficulty Feigning Interest
in nonpreferred topics

Sharing too
much (TMI)

Not Knowing that
Something a Friend
Shared is Confidential

Sharing too little
(distant)

Difficulty
Initiating
Conversations

“Too Direct”

Not Recognizing When
Conversations are Ending

Missing what is
Implied

“Missing Cues”

Misunderstanding Other
People's Intentions

Autonomic Ladder

Ventral Vagal
Safe and Connected



Sympathetic
Fight or Flight



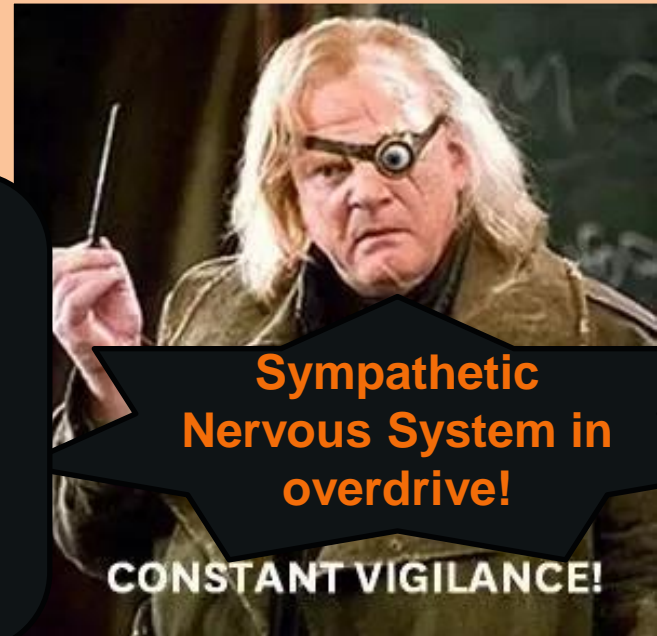
Dorsal Vagal
Immobilized, Collapsed



In a state of constant hypervigilance anticipating rejection/miscommunication, it is both draining and difficult to truly connect.



"Am I talking too much? Am I interrupting? Am I building on what the other person says? It's exhausting. Other people seem to manage all this unconsciously."
-Hermione



**Sympathetic
Nervous System in
overdrive!**

CONSTANT VIGILANCE!



I'M GOING TO BED...
BEFORE EITHER OF YOU
COME UP WITH
ANOTHER CLEVER IDEA
TO GET US KILLED.

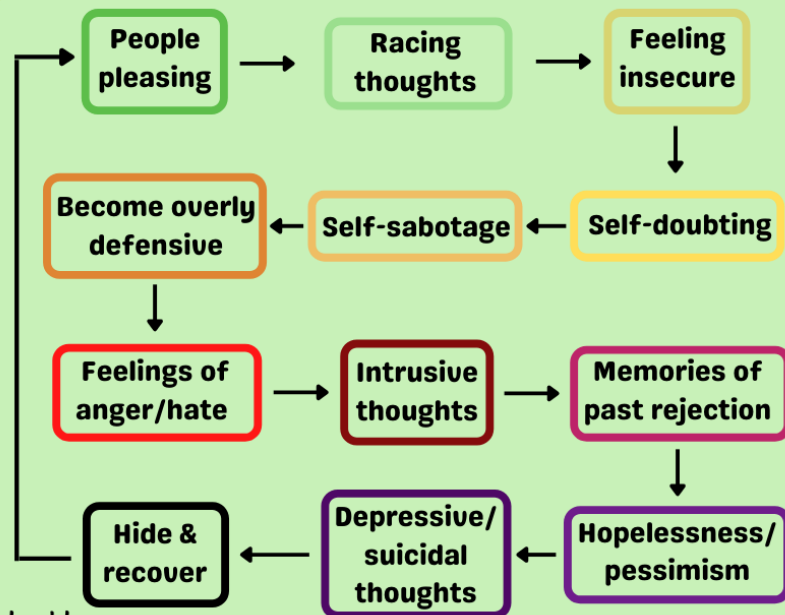
OR WORSE,
EXPELLED.
Unwanted
Rejected

"I don't think we
should invite her next
time."

SHE NEEDS TO SORT OUT
HER **Rejection Sensitivity Dysphoria**

Rejection Sensitivity Dysphoria Can **FEEL** Worse Than Death!

Experiencing Rejection Sensitivity



@Autisticallity

What helps?

There is not one universal way to magically stop this feeling of Rejection Sensitivity...

However, if you are experiencing it then try to distance yourself from the situation and distract yourself in a way comfortable to you. The feeling passes eventually and cutting yourself off from the situation can help stop yourself from feeling worse and becoming hateful or thinking dark thoughts.

If you feel someone is experiencing it give them space if that is what they want and once the feelings have calmed then try to reassure them and give clarity on things if they want/need it.

@Autisticallity



Autisticallity

To find more
infographics....
autisticallity.co.uk

My autistic ass when i open up
the slightest to someone



Sensory Challenges



Podcast Episode

220. Why So Many Women Don't Know They are Autistic with Katherine May

We Can Do Hard Things with Glennon Doyle



- Autistics do not habituate to intrusive sensory stimuli over time the same as NTs.

- exposure therapy is not effective
 - can't just "tune it out"

- Sensory overwhelm impairs both processing of information and communication.

- You can't hear a bell ringing when a bomb is going off.

- Causes emotional dysregulation

The
Electricity
of
Every
thing

A Woman's Walk in the
Wild to Find Her Way Home
Katherine May



“Why are you Overwhelmed so Easily?”
Slow processing or **much more information to process?**

Neurotypical Cauldron



Just a gestalt
sense of what's
going on

“One person couldn't feel that much at one time! They'd explode!”

-Ronald Weasley

Autistic Cauldron



Sensory
Details

Analyzing other
people's behavior to
figure out what is
socially expected of you

Language
Details

“Just because you have the emotional range of a teaspoon Ron, doesn't mean we all have!”

-Hermione Granger

**Some types of sensory sensitivity include,
but are not limited to, the following:**

STIMULI	HYPER-SENSITIVE REACTION	HYPO-SENSITIVE REACTION
SIGHT	May exhibit discomfort with sun or glare	May like bright colors
TOUCH	May be bothered by tags on the inside of clothing	May seek textures or rub arms and legs
TASTE	May only eat certain textured foods	Might like intensely flavored foods
SMELL	May be oversensitive to scents of any kind (deodorant, perfumes)	May want to smell everything
SOUND	May cringe or cover ears at loud noises	May speak loudly or want music loud
TEMPERATURE	May not sense the cold and prefer cool clothes in the winter	May prefer warmer clothes in the summer
PAIN	May overreact to minor injuries or scrapes	May have a delayed response to injury or pain

<https://www.autisticrealms.com/resources>

Hermione describes her sensory diet for us....

THE NEURODIVERGENT FRIENDLY WORKBOOK OF DBT SKILLS

A workbook of Dialectical Behavior Therapy (DBT) skills reframed to be neurodivergent friendly. Includes an added bonus of accessible sensory strategies.

Written & designed by Sophie
@livedexperienceeducation

Building a Family Sensory Toolkit



Building a Sensory Tool Kit

Sense

Difficulty

What helps

Sight		
Hearing		
Taste / food		
Smell		
Touch		
Proprioception (body awareness)		
Vestibular (movement and balance)		
Interoception (internal sense eg hot / cold / hungry / pain)		

Why not try this for everyone in your family, it may help to open up conversations!

AUTISTIC REALMS



Neurodiversity
Affirming

Hermione's Sensory Diet

I'm hypersensitive to vestibular input so I can't ride in the flying car with Ron for long trips.

I'm hyposensitive to smells so I eat extra spicy foods and use calming scents.

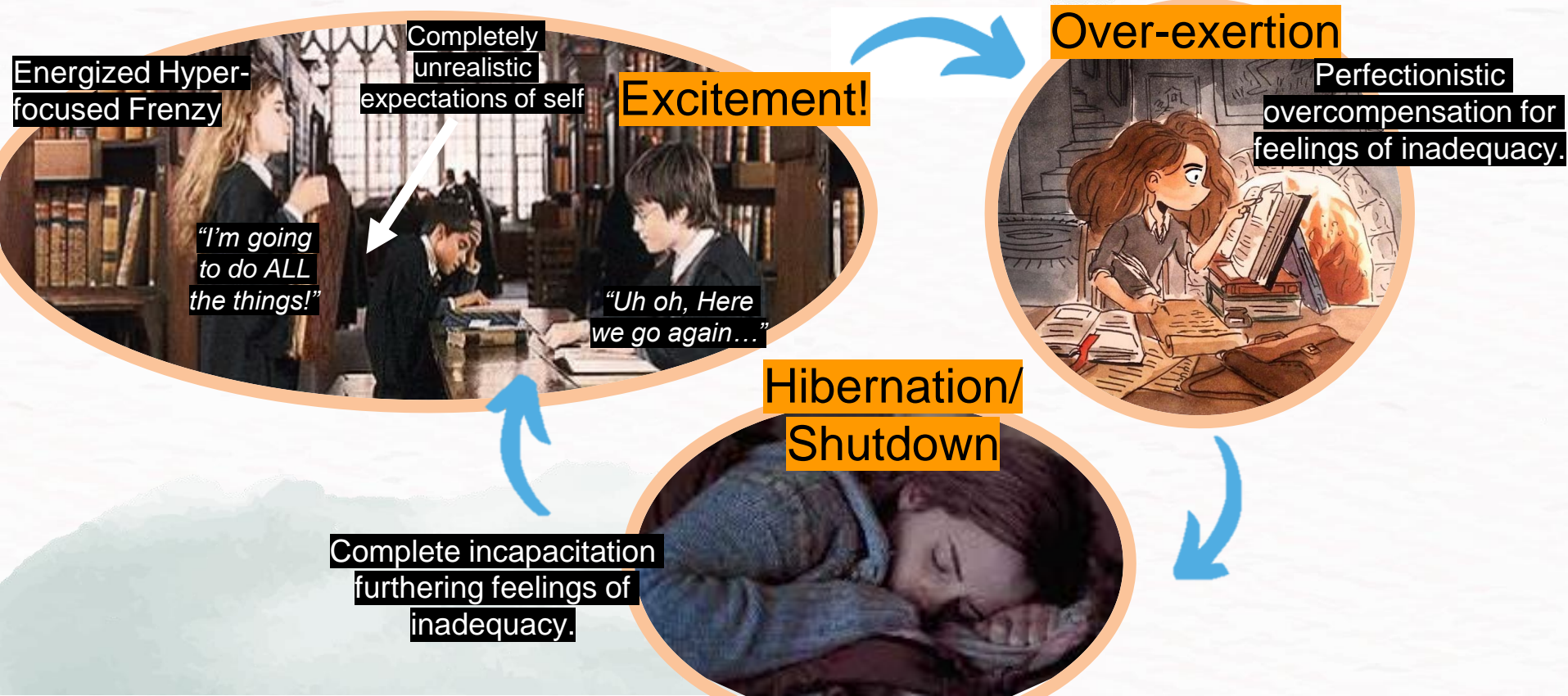


*Hmm, I love
the smell of
books!*

I'm both hypo and hypersensitive to touch so I use seamless socks and roll myself up into a weighted blanket when I'm stressed.

I'm hypersensitive to loud sound and bright lights, so if we're going to Hogsmeade for some shopping, I bring ear plugs and sunglasses.

Boom and Bust Cycle” of ADHD and Autism



Autistic Shutdown



- Temporary fatigue, irritability, and emotional overwhelm
- Typical onset after high stimulation or high socialization demands
- Benefit from rest, time unmasking, sensory detox, and engagement in special interests.

Autistic burnout....

- When an autistic person keeps pushing themselves beyond their body's signals to stop through the demands of socialization, masking, etc
- Prolonged intense fatigue, loss of skills, and reduced sensory tolerance
- Can look like depression, but unlike depression, patients are generally psychologically quite motivated but physically incapable of activity
- Unlike depression, behavioral activation can exacerbate this condition

Autistic Burnout:
A Brief Guide to Recovery
and Prevention

e-Book by
Jennifer Kemp
MPsych(Clinical)

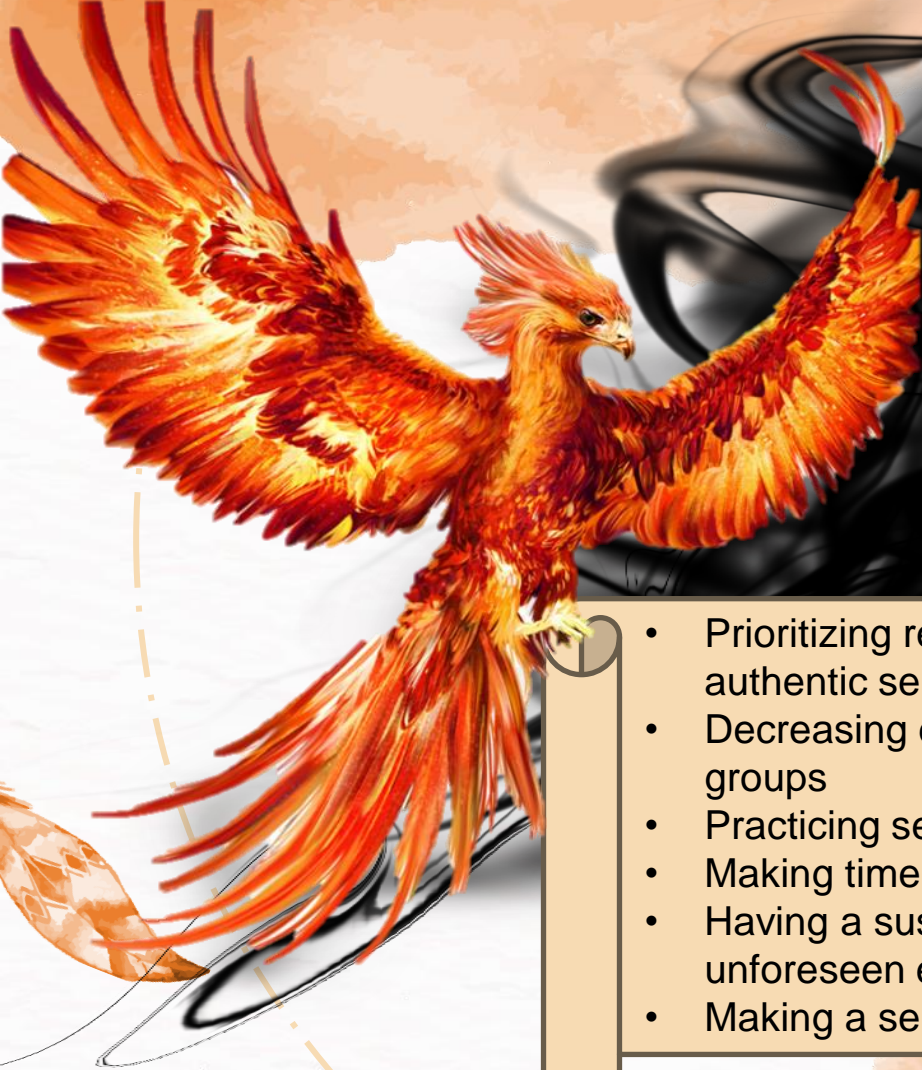
Free online at:
<https://Jenniferkemp.com>

AUTISM IN ADULTHOOD
Volume 2, Number 2, 2020
Mary Ann Liebert, Inc.
DOI: 10.1089/aut.2019.0079

Original Research

**"Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew":
Defining Autistic Burnout**

Dora M. Raymaker, PhD^{1,2} Alan R. Teo, MD, MS³⁻⁶ Nicole A. Steckler, PhD⁶ Brandy Lentz,¹
Mirah Scharer, BS,¹ Austin Delos Santos,¹ Steven K. Kapp, PhD^{2,7} Morrigan Hunter, MA,²
Andee Joyce, BA,² and Christina Nicolaidis, MD, MPH^{1,2,5,8}



Preventing Autistic Burnout

- Prioritizing relationships where you feel safe being your authentic self and unmasking
- Decreasing demands of masking, small talk, and socializing in groups
- Practicing self-check ins to monitor stress, hunger, fatigue, etc
- Making time for restorative solitude and special interests
- Having a sustainable daily routine that allows space for unforeseen events
- Making a sensory diet part of your routine.



“We have to keep other people at arm's length, because letting them see our hyperfixations, meltdowns, obsessions, and outbursts could mean losing their respect. But locking ourselves away means we can't ever be fully loved.”

— Devon Price, Unmasking Autism: Discovering the New Faces of Neurodiversity

“To Mask or Not To Mask...
That is the Question”

-Hermione



What is Masking?

Masking for Neurotypicals

- To mask or camouflage parts of ourselves in order to fit in with those around us.
- This is a strategy employed often subconsciously by all humans.

Masking for Autistics-

- Suppressing behaviors like stimming that autistic people find soothing but others find weird
- Avoiding discussing special interests
- Developing complex social scripts to get by in social situations
- Closely watching and analyzing neurotypicals to mimic their facial expressions, body language, and behavior
- Exhibiting excessive accommodation and helpfulness towards others to avoid rejection



*“My Mask is My Shield, but
Sometimes Shields can be
Suffocating....” -Hermione*

Stimming (repetitive self-regulatory behaviors)



Benefits of Stimming:

- Provides controlled predictable sensory feedback
 - Since autistic people don't habituate to sensory stimuli and notice/process more details, they are bombarded with more "sensory surprises" than neurotypicals.
- Emotionally regulating
- Common Examples:
 - arm or hand-flapping, finger-flicking, rocking, jumping, spinning, twirling, head-banging, repetitive activities involving the senses (such as repeatedly feeling a particular texture)
- Distinguish from OCD compulsions which are unpleasant and cause distress.

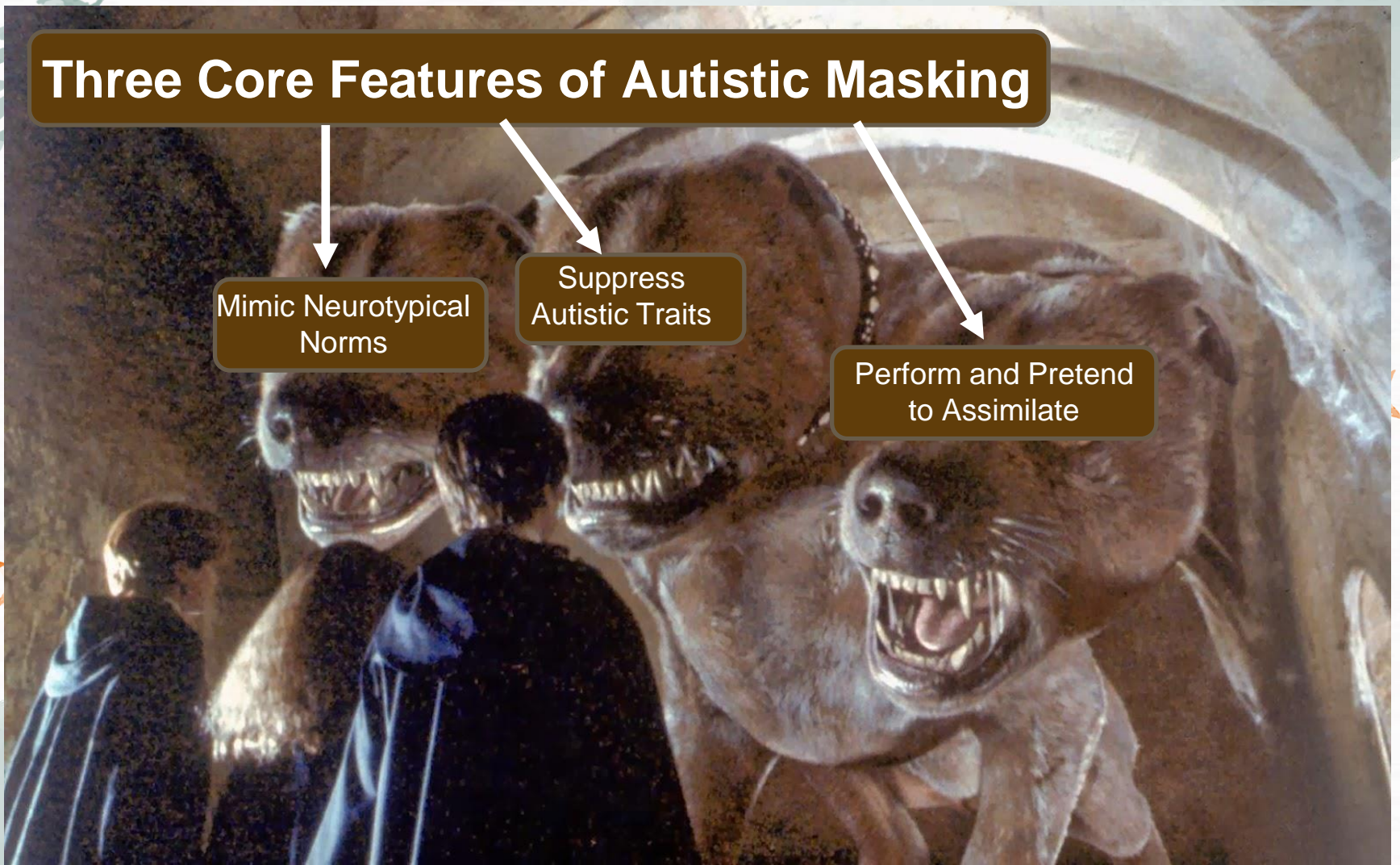


Three Core Features of Autistic Masking

Mimic Neurotypical
Norms

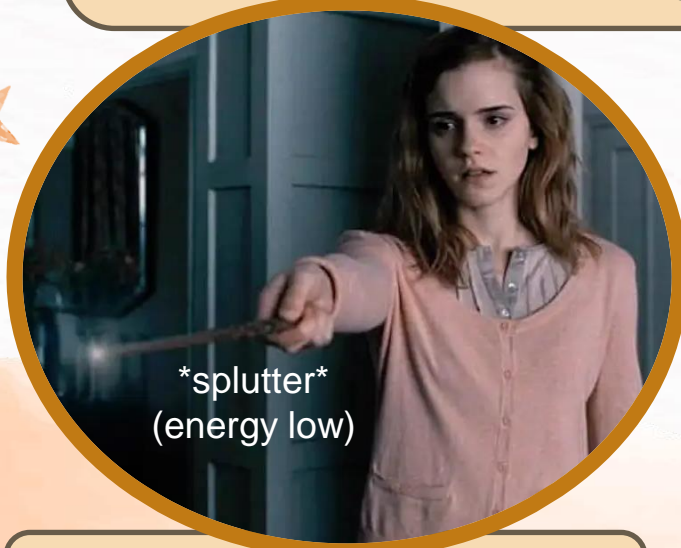
Suppress
Autistic Traits

Perform and Pretend
to Assimilate



The Cost of Masking

A masking autistic individual is simultaneously expending massive amounts of cognitive and emotional energy (mimicking, accommodating, performing) while suppressing their primary sources of energy renewal (stimming, special interests).



splutter
(energy low)

Spell Casting While Masking



Spell Casting While
Authentically Autistic

Masking for the movies.....

"I had to wear less comfortable clothing and all these extra hair products that exacerbated my sensory issues. I made sure to keep smile and look pleasant and never talk about my special interest in SPEW. The muggle world isn't ready for an autistic female lead so I played my part but it really took a toll on me."

-Hermione



Autism in Adulthood > Vol. 3, No. 4 > Original Research

Open Access



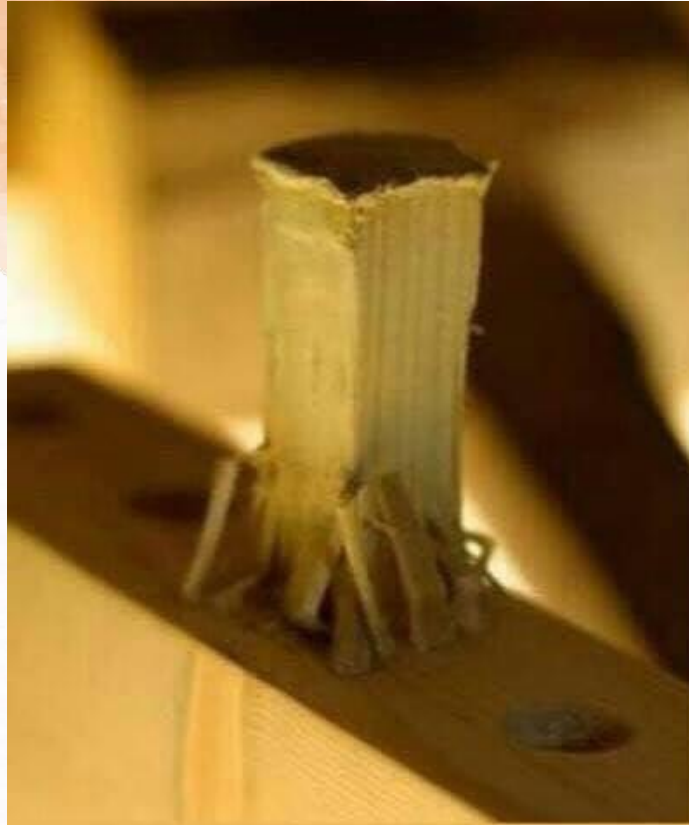
Autistic Adults' Experiences of Camouflaging and Its Perceived Impact on Mental Health

Louise Bradley , Rebecca Shaw, Simon Baron-Cohen, and Sarah Cassidy

Published Online: 7 Dec 2021 | <https://doi.org/10.1089/aut.2020.0071>

“Most of us are haunted by the sense there’s something “wrong” or “missing” in our lives—that we’re sacrificing far more of ourselves than other people in order to get by and receiving far less in return.”

— Devon Price, Unmasking Autism: Discovering the New Faces of Neurodiversity



"Autistics are the ultimate square pegs, and the problem with pounding a square peg into a round hole is not the hammering is hard work.

It's that you're

destroying the peg."

~Paul Collins

Âû

A cost benefit analysis



To Mask

- Safety
- Job Security
- Less risk of rejection
- Society is more receptive/willing to listen to them

Not To Mask

- Freedom
- Lower risk of suicide, anxiety, and depression
- More energy and creativity
- Authentic self-understanding
- Authentic relationships



"As an adult and minister of magic, I am in a place of privilege. I have more autonomy and can choose when to mask and when not to mask."

"Now I only mask when giving speeches or attending large diplomatic gatherings. I make sure to manage my energy reserves by planning time during the day to recover from periods of masking and putting less demands on myself on those days."

Not all autistics have this privilege."

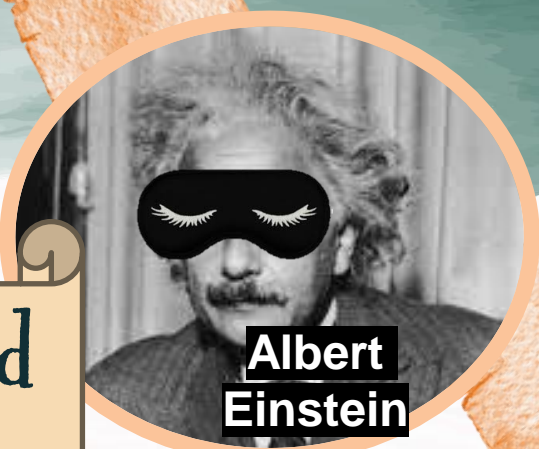
-Hermione

- [Bradley, L., Shaw, R., Baron-Cohen, S., Cassidy, S. \(2021\). Autistic Adults' Experiences of Camouflaging and Its Perceived Impact on Mental Health. Autism in Adulthood, 3\(4\), 320-329](#)
- [Cassidy, S., Bradley, L., Shaw, R., Baron-Cohen, S. \(2018\). Risk markers for suicidality in autistic adults. Molecular Autism 9, 42.](#)



**Isaac
Newton**

**Charles
Darwin**



**Albert
Einstein**

What does our world
lose when autistics are
fully masked?



**Emily
Dickinson**



Charles Schulz



**Jim
Henson**



What are the costs/benefits to our Society?



When Autistics Mask

- Society feels comfortable and secure in the status quo
 - Social systems are stable
- Social systems don't need to face their inherent flaws, inequalities, and inconsistencies

When Autistics Don't Mask

- Society gains novel insights from autistic individuals
 - Social systems change/grow/improve
 - Different perspectives are valued
 - Social systems are able to grapple with inequalities and change



Pretending to be someone else all the time doesn't allow an individual to figure out who they really are or what they really want. When their attention is constantly focused on other people's needs and expectations, they can lose the ability to advocate for themselves.



Autistic women and gender non-conforming autistics are especially vulnerable to becoming victims of sexual assault.

- Years of masking with focus on what others want from them may render them less able to figure out what they truly want sexually/romantically and more likely to cede to the wants of others.
 - They learn to not trust themselves.
- Having been rejected and isolated so much that they are more likely to believe that abuse they are suffering from their partner is deserved or that it is worth it since they have few relationships.
- Less able to read the sexual/romantic intentions in others, more likely to interpret sexual innuendo literally, not figuratively, and so less able to identify unwanted advances.
- Autistics are more likely to be enticed by the sense of belonging and simple rules/structure offered by religious cults.



[Front Behav Neurosci.](#) 2022; 16: 852203.

PMCID: PMC9087551

Published online 2022 Apr 26. doi: [10.3389/fnbeh.2022.852203](https://doi.org/10.3389/fnbeh.2022.852203)

PMID: [35558435](https://pubmed.ncbi.nlm.nih.gov/35558435/)

Evidence That Nine Autistic Women Out of Ten Have Been Victims of Sexual Violence

[Fabienne Cazalis](#),^{✉1,*},[†] [Elisabeth Reyes](#),²,[†] [Séverine Leduc](#),³ and [David Gourion](#)⁴

“Women are not less impacted by their autism. They are just less seen.”

Devon Price in Unmasking Autism: Discovering the New Faces of Neurodiversity

Doyle and Wilson 2020 sampled 486 autistic adults and found higher levels of additional psychiatric diagnoses in autistic women and non-binary autistic people. (31% of autistic women compared to 18% of men had 2 or more psychiatric disorders.)



What about the girls.....



- Research indicates that autistic females mask more often and more effectively than autistic males.
 - Masking is an independent risk factor for suicide
- Often present as less autistic on the surface, but experience more internal turmoil.
 - Women tend to be internalize stress instead of externalizing it (men)
 - Being able to compensate for / hide a challenge is NOT the same as not having that challenge
- Girls are more likely to make eye contact and have social reciprocity so tend to fly under the radar until their teens.
- Girls tend to have less atypical interests (people and animals) than boys (data), but the intensity of their interest is clearly autistic
- Women are diagnosed later in life and are more likely to be misdiagnosed.
 - Commonly misdiagnosed borderline personality disorder or “behavioral problems.”

“You’re so high functioning!
You don’t look autistic.”

-well meaning doctor/therapist

“Meanwhile,
beneath the
surface.....”

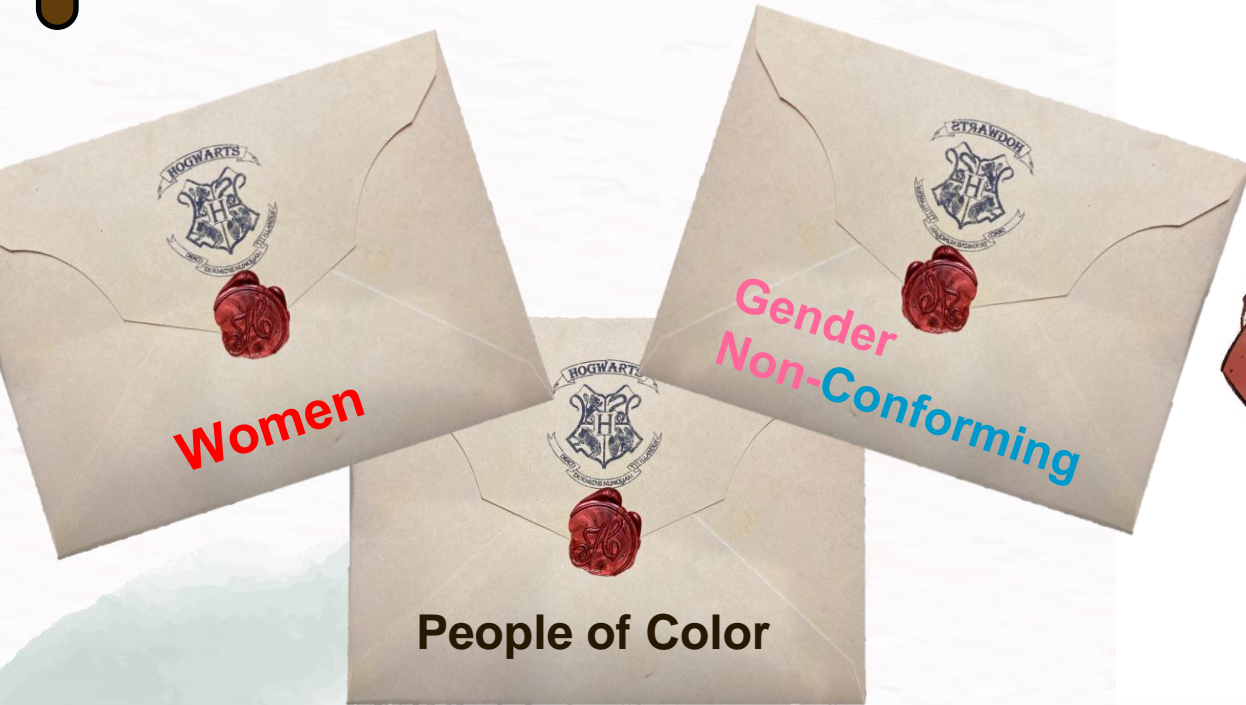


What about the girls.....



- Have higher social motivation than boys and are more likely to have friendships, but they follow atypical patterns
 - Series of intense singular friendships instead of a circle of friends
 - Better able to initiate relationships, but more difficulty sustaining them
 - May gravitate towards friendships with disabled peers to be in a helping role
- Girls are more likely to experience relational conflict and believe that the conflict was all their fault.
- Autistic women tend to connect less with stereotypical female roles.
 - -more likely to be reprimanded in the workplace
 - -an autistic style of communication/behavior is more socially acceptable for men than for women

Unseen Autistics!



Autism Comes in All Colors



Black autistic children are 2.6 times more likely to be misdiagnosed than white autistic children, most commonly with a diagnosis of adjustment disorder or conduct disorder (Mandell et al, 2007, Straiton and Sridhar 2021).

Black autistic children are diagnosed later and typically experience poor quality of care with less access to services.



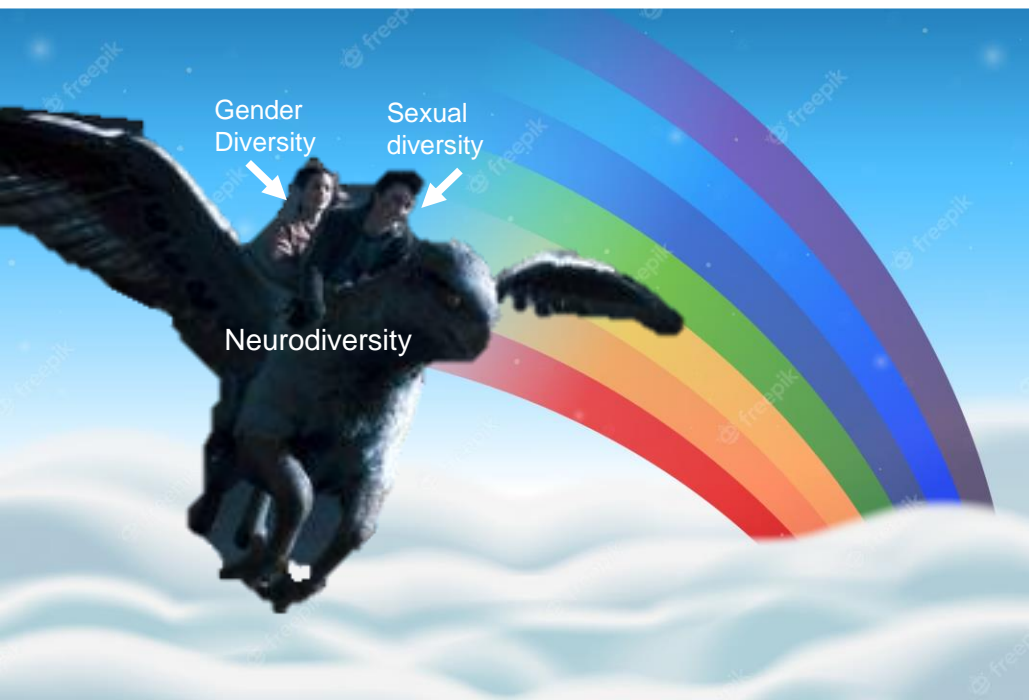
Intersectional Marginalization – nowhere to safely belong

“I’m the only person of color in my online autistic adult support group and sometimes they don’t even realize when they are making racist comments. But I don’t belong with black people either. They call me “an Oreo” and accuse me of “being too white.” Thank goodness I have you Crookshanks!”

Hermione



With Neurodiversity Comes Gender and Sexual Diversity Too!



- Autistic children are 7.59 times more likely to be gender non-conforming.
- ADHD children are 6.64 times more likely to be gender non-conforming

Comparative Study > Arch Sex Behav. 2014 Nov;43(8):1525-33. doi: 10.1007/s10508-014-0285-3. Epub 2014 Mar 12.

Increased gender variance in autism spectrum disorders and attention deficit hyperactivity disorder

John F Strang¹, Lauren Kenworthy, Aleksandra Dominska, Jennifer Sokoloff, Laura E Kenealy, Madison Berl, Karin Walsh, Edgardo Menvielle, Graciela Slesaransky-Poe, Kyung-Eun Kim, Caroline Luong-Tran, Haley Meagher, Gregory L Wallace

Affiliations + expand

PMID: 24619651 DOI: 10.1007/s10508-014-0285-3

- 69.7% of autistic people reported being non-heterosexual vs 30% of neurotypicals.

> Autism Res. 2018 Jan;11(1):133-141. doi: 10.1002/aur.1892. Epub 2017 Nov 21.

Sexual Orientation in Autism Spectrum Disorder

R George¹, M A Stokes¹

Affiliations + expand

PMID: 29159906 DOI: 10.1002/aur.1892



Autism and Sex

augasm

noun [aw-gaz-uhm] ∞

1. the intense experience of joy and excitement over someone being unapologetically and authentically Autistic

see also:
Autistic joy; neuroqueer

@Autisticality

- Autistic people are less likely to engage in traditional relationship structures.
 - They are more likely to be polyamorous and practice kink.
- Autistic women are much more likely to be non-heterosexual than autistic men.
- Autistic people are more likely than neurotypical people to be asexual or aromantic, but most autistic people are sexual.

A Different Autistic Experience of Gender

For autistics, “Possibilities of gender expression are dictated not by what has been learnt to be possible but by what is experienced as real.”

• Is This Autism? A Guide for Clinicians and Everyone Else.

• Autistic people are more likely to be genderqueer (not identify with a particular gender).

• Transgender autistics are more likely to have their gender identity invalidated because of their autism.

• People may assume that an autistic person is less capable of accurately defining their own gender.

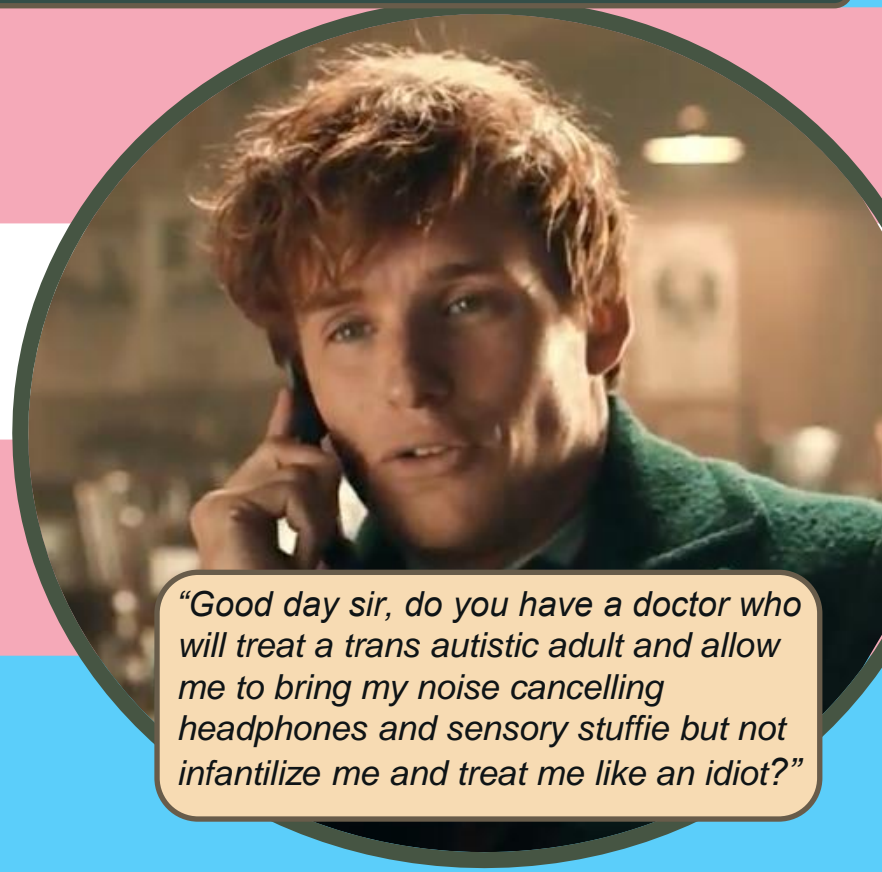
Thus, they are at higher risk of depression, anxiety, and suicide.



Intersectional Marginalization – No One with the Expertise to Treat Me

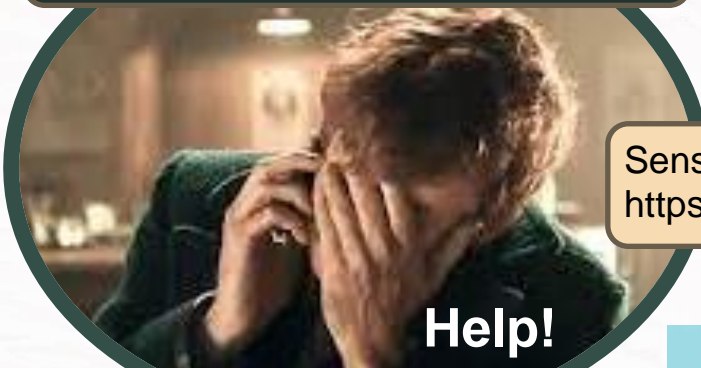
“I’m trying to find a new therapist and I have to choose between someone who will understand trans people or someone who understands autism. I can’t have both. Finding a knowledgeable primary care doc is even harder!”

–Newt Scamander



“Good day sir, do you have a doctor who will treat a trans autistic adult and allow me to bring my noise cancelling headphones and sensory stuffie but not infantilize me and treat me like an idiot?”

Some more resources:



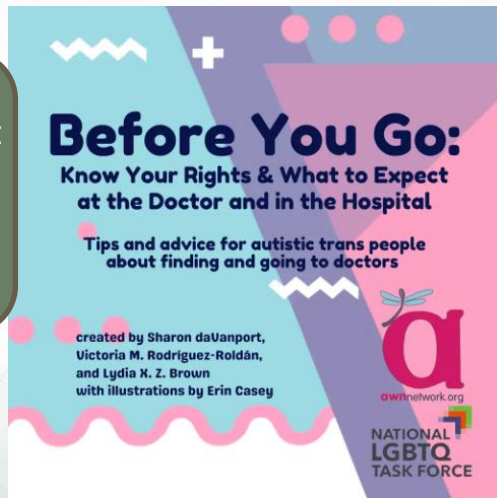
Help!

“Wearing a chest binder really contributes to my sensory overload, but if I don’t, people will misgender me. I just have to live life uncomfortably and choose between being sensory friendly or gender friendly.” -Newt



<https://awnnetwork.org/resource-library/>

Sensory-friendly chest binders:
<https://amorsensory.com/>



Trans Autistic Healthcare
Guide

EXPLORING NEUROQUEER IDENTITIES:

Exploring the Intersectionality of ADHD, Autism, and Genderqueerness



REBECCA MINOR
Clinician, Consultant,
Parent Coach,
Gender Specialist, LLC



DR. NEFF
Clinical Psychologist,
Author, Consultant
Neurodiv

<https://neurodivergentinsights.com/>



<https://autisticltd.co.uk/research/>
“Stories from Across
the Double Rainbow.”

*"Thank you for these excellent books
Hermione!"*

-Madam Pomphrey

A COMPREHENSIVE RESOURCE FOR MENTAL HEALTH PROFESSIONALS, EDUCATORS & STUDENTS



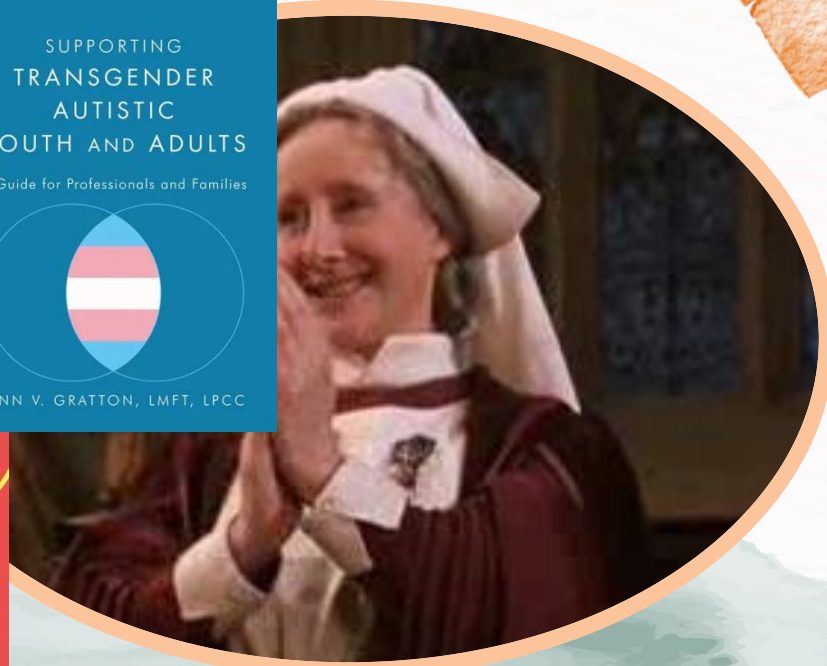
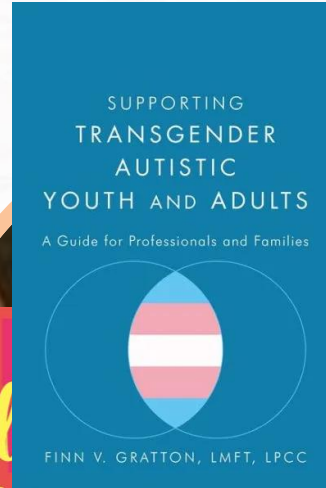
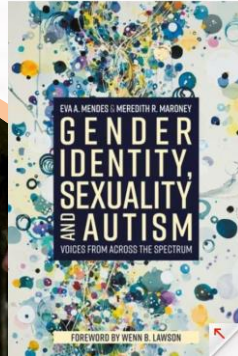
A CLINICIAN'S GUIDE to GENDER AFFIRMING CARE

WORKING with TRANSGENDER & GENDER NONCONFORMING CLIENTS

Includes information on:

- Gender identity, transition options & legal & ethical issues
- Trans clients' needs in the context of intersecting identities
- The clinician's role, implicit biases & ally development

Sand C. Chang, PhD
Anneliese A. Singh, PhD, LP
Lore M. Dickey, PhD
Foreword by Mira Krishnan, PhD



Chronic Health Issues And Autism



- Increased risk of chronic pain and unexplained somatic symptoms
-irritable bowel syndrome, fibromyalgia, chronic fatigue syndrome, and dysautonomia
- Increased risk of autoimmune conditions, hypermobility spectrum disorders (including Ehlers Danlos), Graves disease, PCOS.
- Autistic people's average **life expectancy is shorter by 16-30 years** compared to the general population, with cardiovascular disease as the number 1 cause of death.



- chronic stress and trauma**
- more difficulty accessing medical care**
- difficulty both recognizing and communicating symptoms to doctors**
- not taken seriously by or believed by their doctors**



Treatment of Catatonia in Autism

- IV lorazepam challenge is first-line treatment
 - Can reassess catatonic features after 5 minutes (following IV lorazepam), 15 minutes (following IM lorazepam), or 30 minutes (following oral lorazepam)
- ECT is second-line treatment
- Consider clozapine 3rd line (especially for less acute cases)

Avoid antipsychotics!
(Especially Typicals)

Busch-Francis Catatonia Rating Scale

<https://thompsoncenter.missouri.edu/wp-content/uploads/2019/04/Bush-Francis-Scale-with-a-few-references-4-18-19.pdf>



"You know Ron, they should have given her IM lorazepam instead of Haldol!"

Treatment of Catatonia in Autism

BAP Guidelines

https://www.bap.org.uk/pdfs/BAP_Guidelines-Catatonia.pdf

Evidence-based consensus guidelines for the management of catatonia: Recommendations from the British Association for Psychopharmacology



Journal of Psychopharmacology
2023, Vol. 37(4) 327–369
© The Author(s) 2023



Eur Psychiatry. 2022; 65(1): e4.

Published online 2022 Jan 25. doi: [10.1192/j.eurpsy.2021.2259](https://doi.org/10.1192/j.eurpsy.2021.2259)

PMCID: PMC8792870

PMID: [34906264](https://pubmed.ncbi.nlm.nih.gov/34906264/)


Catatonia in autism spectrum disorders: A systematic review and meta-analysis

[J. Vaquerizo-Serrano](#), ^{1, 2, 3, 4} [G. Salazar De Pablo](#), ^{1, 3, 4} [J. Singh](#), ^{1, 2} and [P. Santosh](#) ^{1, 2,*}

Catatonia in autism and other neurodevelopmental disabilities: a state-of-the-art review

[Shavon Moore](#), [Debha N. Amatyia](#), [Michael M. Chu](#) & [Aaron D. Besterman](#) 

npj Mental Health Research **1**, Article number: 12 (2022) | [Cite this article](#)



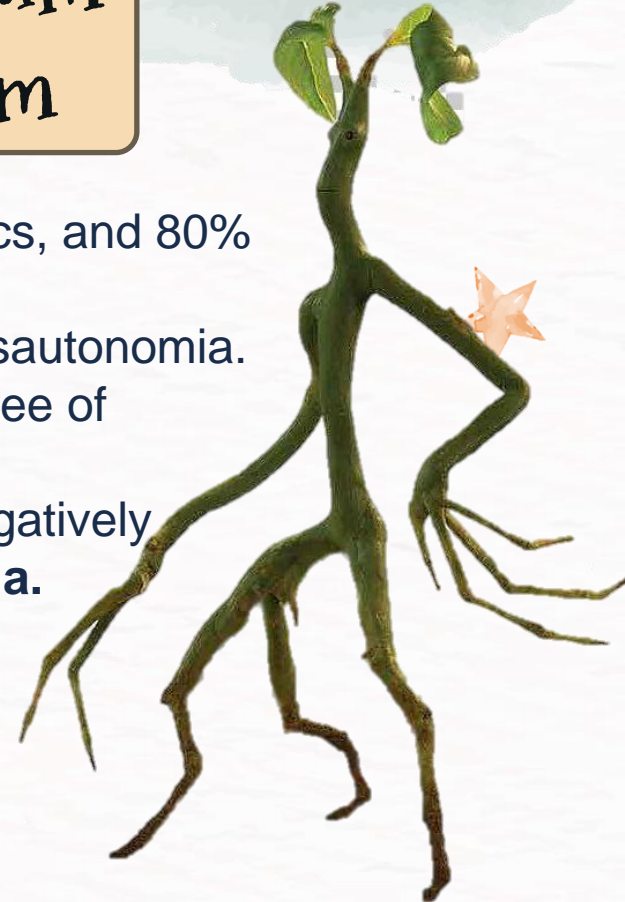
Hypermobility Spectrum Disorders in Autism

- Hypermobility is present in about 50% of all autistics, and 80% of autistic females.
- Commonly co-occurs with pain syndromes and dysautonomia.
- Degree orthostatic intolerance correlates with degree of hypermobility.
- Volume of parietal cortex has been found to be negatively correlated with degree of hypermobility – **dyspraxia**.

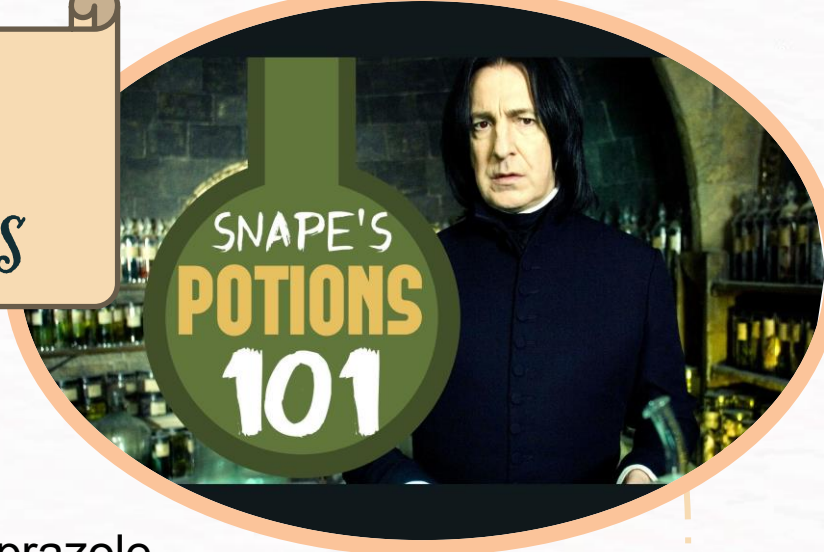
> Front Psychiatry. 2022 Feb 2;12:786916. doi: 10.3389/fpsy.2021.786916. eCollection 2021.

Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain

Jenny L L Csecs^{1 2}, Valeria Iodice^{3 4}, Charlotte L Rae⁵, Alice Brooke^{1 2}, Rebecca Simmons⁶,
Lisa Quadt^{1 2}, Georgia K Savage^{1 2}, Nicholas G Dowell^{1 7}, Fenella Prowse^{1 8},
Kristy Themelis^{1 9}, Christopher J Mathias^{3 4 10}, Hugo D Critchley^{1 2 6}, Jessica A Eccles^{1 2 6}



Special Notes on Psychiatric Medications in Autistic Patients



- Don't give everyone risperidone and aripiprazole
 - Have a low threshold for initiating metformin adjunctly to reduce metabolic side effects which can also decrease irritability
- Start at lower dosages and be ready to titrate more slowly
- Stimulants and SSRIs in particular have higher rates of side effects and lower effect sizes in autism
- Distinguish repetitive behaviors (self-regulating) from OCD (dysregulating and intrusive).

Psychiatric Medications Treat Common Co-morbidities

SSRIs and SNRIs

- Decrease anxiety, increase resilience and cognitive flexibility
- More prone to activation as a side effect

Buspirone

- Decrease anxiety and agitation

Stimulants

- Improve focus and impulse control
- Caution for possible worsening of social withdrawal

Atomoxetine

- Improve focus and impulse control

Psychiatric Medications Treat Common Co-morbidities

Guanfacine and Clonidine

- Decrease emotional reactivity, rejection sensitivity dysphoria, and improve impulse control and tics

Antipsychotics (lurasidone, aripiprazole, ziprasidone, risperidone)

- Decrease irritability and aggression

Amantadine

- Improve focus, decrease rigidity, improve OCD

Special Notes on Psychiatric Medications in Autistic Patients

“My wolfsbane potion did not have the intended effect last night...” —Remus Lupin

- Autistic patients are more likely than neurotypicals to experience unexpected side effects from medications and to have idiosyncratic responses to medications.
- If your patient has a side effect that doesn't make much sense, still try to give them the benefit of the doubt!
- Don't give up after one medication in a particular family doesn't work. Keep trying!

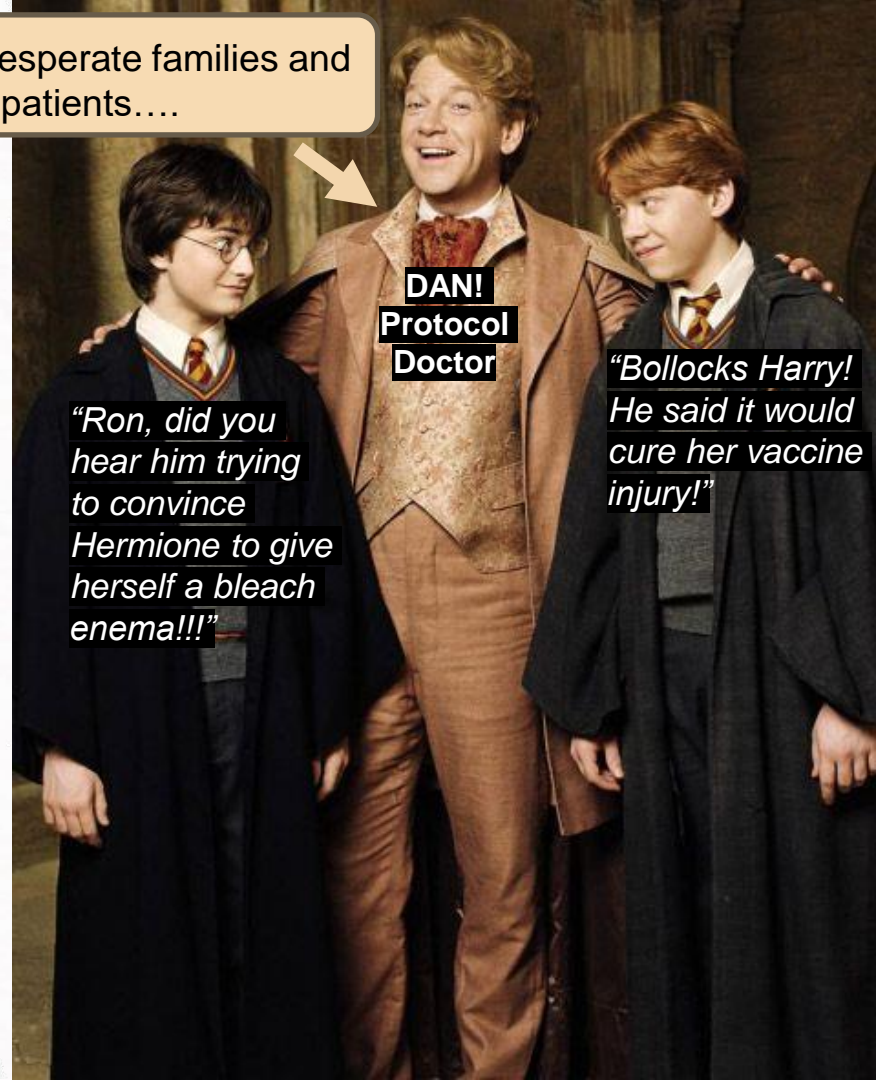


Protect Patients from Quackery!

Preys on desperate families and vulnerable patients....

- Quackwatch.org by Stephen Barrett, MD
 - <https://quackwatch.org/autism/>
- DAN (Defeat Autism Now) doctors
 - Believe autism is caused by vaccines and can be treated by detoxification and dietary supplements.
- Hyperbolic oxygen chambers
- Bleach Therapy
- Chelation

Just to name a few harmful and abusive “treatments”



DAN!
Protocol
Doctor

“Ron, did you hear him trying to convince Hermione to give herself a bleach enema!!!”

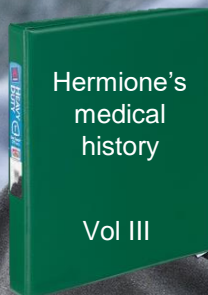
“Bollocks Harry! He said it would cure her vaccine injury!”



Chronic Invalidation and Dismissal

- **Don't comment; "You don't look autistic at all."**
 - High masking individuals may appear neurotypical and be quite affected.
 - Avoid implications that being "less autistic" is better.
- **Please do not dismiss their concerns.**
 - Many adults with autism may appear "normal" to the outside world due to advanced **masking** of symptoms.

"I have a binder of my medical hx for my appointments and made a spreadsheet of my symptoms to help my doctor. I offered just a few helpful NEJM metanalyses re my top three hypotheses."

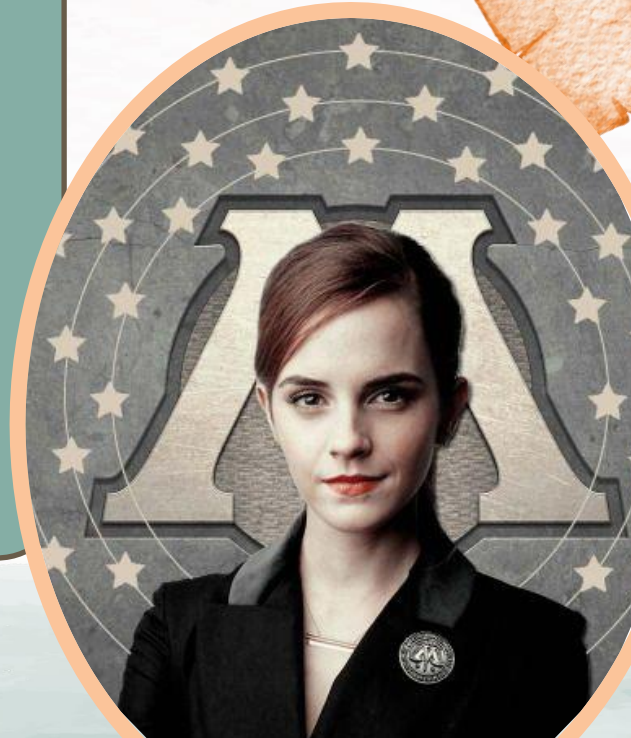


*"Ron told me I 'came on too strong.' Apparently presenting **too much** evidence makes the doctor not believe you! Rubbish!"*

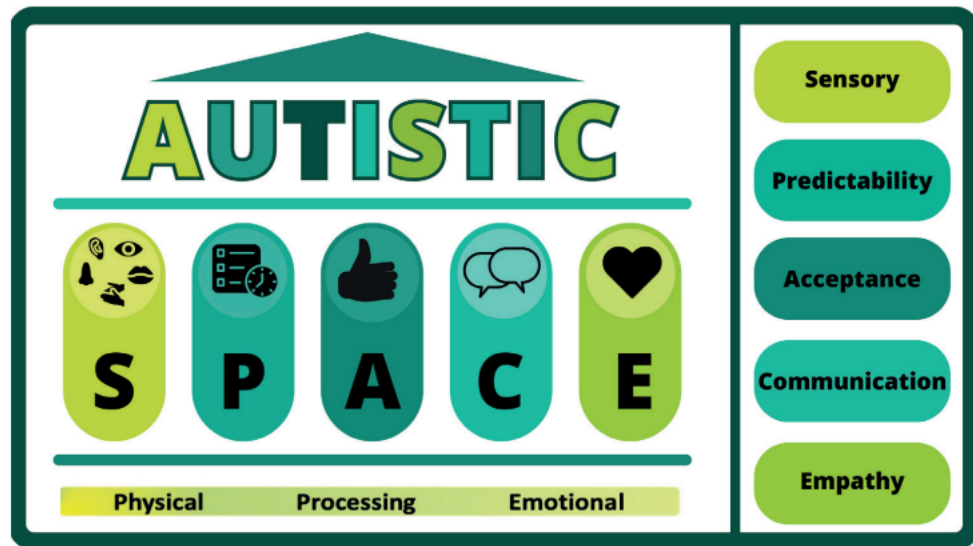
Increasing my awareness of the unique way house-elves perceive the world enabled me to be more helpful when advocating for them!

I learned from my experiences with SPEW “society for the promotion of elfish welfare” to create AuCK! “Autistic Cultural Knowledge” to improve healthcare for autistic people.

Hermione Granger
Minister of Magic



Muggle Doctor Mary Doherty uses the acronym SPACE.



Doherty, Mary, McCowan, Sue, Shaw, Sebastian CK. *“Autistic SPACE: A Novel Framework For Meeting the Needs of Autistic People in Healthcare Settings.”* British Journal of Hospital Medicine. Vol 54 No 4 Feb 2023.

A “triple empathy problem” leads to adverse healthcare outcomes for autistic adults: a qualitative analysis

Sebastian C. K. Shaw¹, Laura Carravallah², Mona Johnson³, Jane O’Sullivan⁴, Nick Chown⁵, Stuart Neilson⁶, Mary Doherty^{1,5}

¹Brighton and Sussex Medical School, Brighton, United Kingdom; ²Michigan State University, Michigan, United States; ³NHS Digital, United Kingdom; ⁴Cork University Hospital, Cork, Ireland; ⁵London South Bank University, London, United Kingdom ⁶Independent researcher, Cork, Ireland.



“The sensory overwhelm of the waiting room causes a complete meltdown so that I can barely talk once I get into the doctor’s office.”
-Newt Scamander

Ask autistic patients ways you can adjust the sensory environment of your office....

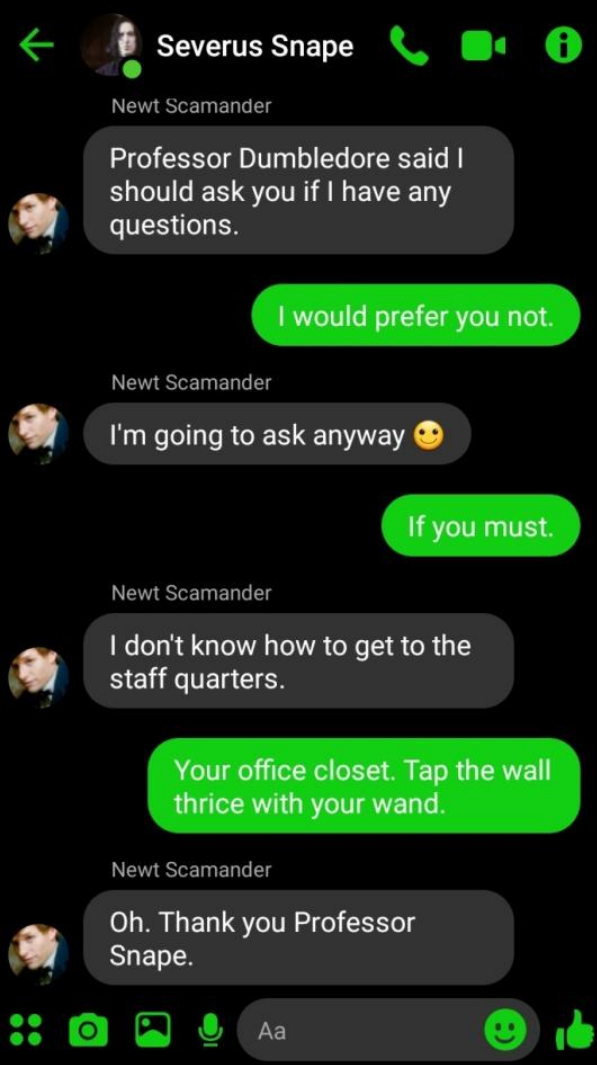
- Turn down lights, minimize noise, avoid scents, etc.
- Respect patients’ need to wear headphones, bring a comfort item, or stim during the appointment.
- Allow them to wait in the car instead of the waiting room.
- Sensory stimuli are more than a nuisance; they can completely derail an autistic individual’s ability to process information.
 - Like trying to hear a bell ringing when a bomb is going off in your head.



Sensory

Sunglasses to block out fluorescent lights





A Note on Situational Mutism

- Under stress, autistic people may lose the ability to speak.
- Offer alternative means of communication;
 - Text to speech app, picture boards, using the chat box during telehealth apt, etc

Just because someone is not speaking, does NOT mean that they cannot communicate



"Because my facial expressions are flat, doctors don't believe that I'm really in pain. I'm not good with words and just freeze during the appointment."

-Victor Krum

Victor Krum's Face While
in Severe Pain from
Ruptured Appendix

- Explaining the specifics of how the encounter will begin, proceed, and end and the expectations of their role as patient is very helpful.
- Warn patients before touching them.
- Give a head's up regarding transitions and allow time.
- Prepare a list of questions prior to the apt so they have time to contemplate their answers without being "put on the spot."
- Provide written instructions to take with them from the appointment.
 - Knowing explicitly what you want from them will offer security to an autistic patient.



"I just mean he's not particularly loquacious. Mostly, he watches me study."

-Hermione re Victor Krum



Predictability



Alexithymia and impaired interoception in autism can make answering open-ended questions about feelings or bodily sensations threatening and overwhelming for them.



Dr. Rancor

“How are you feeling?”

{{direct eye contact indicating interest}}

{{Shit, they're looking at me. What is the right answer? If I don't answer correctly, they will reject me like everyone else. I won't get treatment and I'll stay miserable. I'm sick and I really need this person to help me.}}

***“I DON'T KNOW HOW I
FEEL!!!”***

"I went to see a muggle therapist and they were offended when I asked for the evidence to support this particular treatment for me."

-Hermione Granger



- Facilitate an autistic patient's need for detailed factual information without taking offense.
- Neurotypical rituals of connection (ie intentional eye contact, small talk, and vague open-ended questions) may be aversive to autistics.
- Be as direct, concise, and specific as possible.
 - Instead of, "how's your sleep?"
 - Ask, "Do you have difficulty falling asleep, staying asleep, or sleeping too long?"
- Allow stimming, fidgeting, pacing around the room and other body movements used for emotional regulation.
 - Mirror what works for them.



Acceptance and Communication

Empathy plus Physical, Temporal, and Emotional Space

- Autistic people connect through their special interests.
 - If they are wearing a pikachu shirt, you have a good clue of how to open the conversation.
- Consider that autistic people may need more physical space.
- Allow additional time to process and respond to questions.
 - Rushing, repeating or restating the question when there is a delay in response may prolong processing time.
- Find creative ways to expand the appointment beyond the 15-30min time frame
 - Can take home list of questions to prepare for next apt.
 - Can review list of questions with therapist in therapy session.
 - Can read and process information outside of apt.
- Allow restorative solitude (without additional input) to recover if distressed.



Describing Your Symptoms

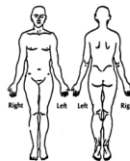
This worksheet covers the information healthcare providers (like physicians, physician assistants, and nurse practitioners) usually want to know about symptoms. Not all questions apply to all symptoms. **You do NOT have to answer every question.** But thinking through some of these questions may help you better describe your symptoms or answer your provider's questions.

Use this worksheet for your own reference. Healthcare providers may become overwhelmed if you ask them to read it. For more information and examples see [reference and link to toolkit]

What is the Symptom (or set of symptoms)? Describe them:

Location – What areas of your body are affected?

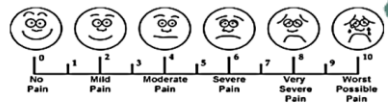
Optional: Put an X or shade in the areas of your body where the symptoms are.



Quality – If the symptom is pain, what is the pain like?

Severity – How bad is it? Does it bother you a little bit or a lot?

Optional: You may want to use a pain scale to describe how bad your pain is. Some people like these scales; others don't. If you are having pain, your provider may ask you to use a pain scale, so it may help you think about it in advance.



Duration – How long has it been going on? When did you first notice the symptom?

○ <https://autismandhealth.org/>

Sample Health Passport

<https://autismandhealth.org/inc/img/AHATsample2.pdf>

- What makes you the most frustrated/angry during appointments with Dr. Greeter?
- Any suggestions on what could make communication with Dr. Greeter easier?
- What has brought you joy or interested you lately?
- What are you proud of doing or grateful for lately? How have you pushed yourself outside your comfort zone lately?



**Jim Henson
died age 54 of a
very treatable
condition**



Neurodiversity-affirming
medical care is not just
about making autistic
people more comfortable; it
is about saving autistic
lives.....



The logo for 'The Autistic Culture Podcast' features the text 'THE Autistic Culture PODCAST' in a bold, sans-serif font. 'THE' is in a smaller, lighter blue font above 'Autistic'. 'Autistic' and 'Culture' are in a large, dark blue font, and 'PODCAST' is in a smaller, dark blue font below 'Culture'. The text is set against a background of concentric circles in orange, yellow, and light green, all within a dark blue square.

THE Autistic Culture PODCAST

Episode 14: Autistic Medical Needs

The Autistic Culture Podcast

Society & Culture

[Listen on Apple Podcasts ↗](#)



Those in Autistic culture are well aware of the unintentional discrimination and marginalization we face in our challenge to get good medical care. We have increased likelihood of dealing with sleep apnea, dysautonomia, fibromyalgia, allergies, asthma, eczema, psoriasis, PCOS, Hashimotos, Lupus, and headaches, but a much harder time getting the care we need. This shapes our culture in many ways. This episode is a special tribute to an autistic friend of the show who recently passed away, in part because of the difficulties Autistic people face in traditional medical institutions.

Visit us at AutisticCulturePodcast.com

Follow @LinguisticAutistic on TikTok



Rose's Diagnosis Brings Freedom, Hope, and Fear

"Discovering my daughter Rose's diagnosis has been both terrifying and liberating.

We rejoice at her gifts. I am grateful that she will start Hogwarts armed with this knowledge of herself; she will know that she is not a selfish know-it-all with poor social skills. She is exactly who she is meant to be.

But I grieve how much this world is not designed to understand her."


-Hermione Granger



A portrait of Ron Weasley from the Harry Potter series, looking slightly to the side with a concerned expression.

Ron was afraid....

“Ron and I had a major row over whether or not to have Rose diagnosed and when and how we should tell her...” -Hermione

A pair of large, vibrant blue wings with a key attached to the bottom, set against a light background.


Maybe we shouldn't get her diagnosed....”

“Maybe we shouldn't tell her.

What if she uses it as an excuse?

I don't want her labeled like that.

An Accurate Diagnosis is the Key to Nonjudgmental Self-Understanding



"I explained to Ron how much I wish I knew that I was an autistic ADHDer sooner in life.

Now that I know, I am so much more forgiving of myself. The things I used to blame myself for and feel shame for, I know are just part of my neurodivergence. My autism diagnosis helped me to create a new operating manual for my brain. I'm more aware of my emotions, I'm better at taking care of myself, and I like myself much more."

-Hermione



Alohomora My Brain!



Diagnosis is Empowering!



*“Fear of a name only
increases fear of the
thing itself.”
-Albus Dumbledore*

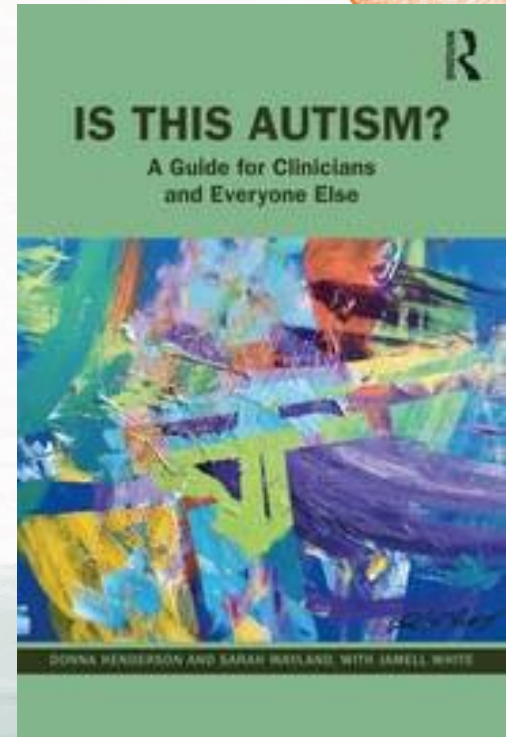
**Our attitudes as clinicians
matter. It is our job to
model for patients and their
families how to respond to
a new diagnosis.**

“Only accurate and neurodiversity-affirmative self-understanding can free an individual from a lifetime of self blame and shame.

Countless autistic individuals have beautifully expressed the freedom and validation they felt when they were finally recognized as autistic.

For many, understanding themselves through this lens has enabled them to experience less emotional distress, engage in better self-care, feel a sense of community, and advocate more effectively for their needs.”

Is This Autism? A Guide For Clinicians and Everyone Else by
Donna Henderson, Sarah Wayland, and Jamell White

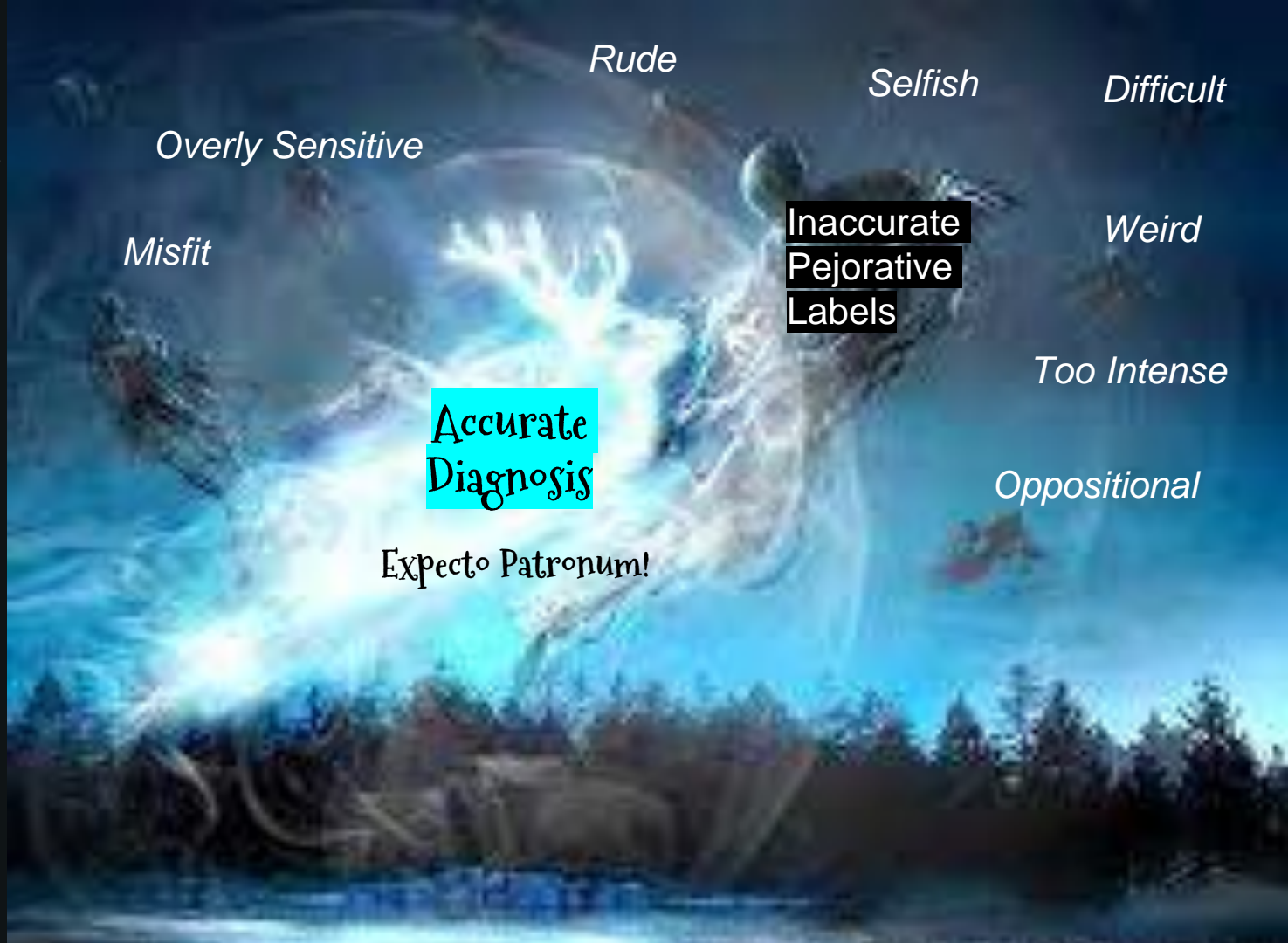


I did mourn the ways my life could have been different if I were diagnosed earlier. I want the years I spent so much energy trying to be “normal” back. I admit that a very young part of me will always feel ... less than I really am.



Helping my daughter has been very healing for both of us though.

“All the
horrible labels
I gave myself
before my
autism
diagnosis....”



Rude

Selfish

Difficult

Overly Sensitive

Misfit

**Inaccurate
Pejorative
Labels**

Weird

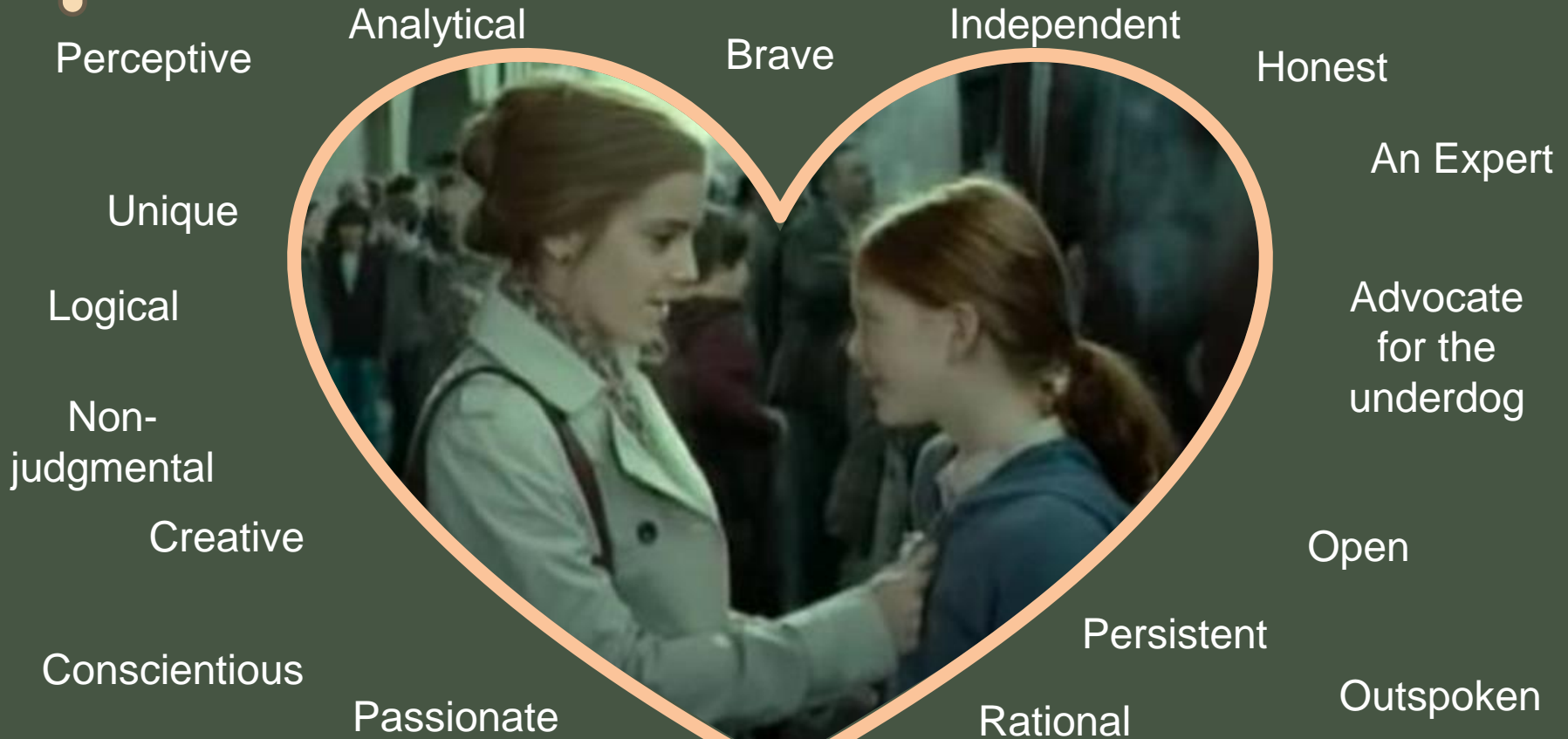
Too Intense

Oppositional

**Accurate
Diagnosis**

Expecto Patronum!

“This is What You Need to Understand About Yourself....”



“Thank God you
inherited your
mother’s brains!”

Ronald Weasley to Rose Weasley

Harry Potter and the Deathly Hallows





“Happiness can be found even in the darkest of times, if only one remembers to turn on the light...”

Of self-knowledge through accurate diagnosis.”

-Albus Dumbledore

Black autistic children are 2.6 times more likely to be misdiagnosed than white autistic children, most commonly with a diagnosis of adjustment disorder or conduct disorder (Mandell et al, 2007, Straiton and Sridhar 2021).



Never Underestimate the Power of an Accurate
Diagnosis!

Nor the harm of an inaccurate label.



"It was so healing to connect with other autistic witches and wizards and to know that I wasn't alone with my struggles and unique experience of the world!"



"I found videos and articles that helped Ron and Harry understand me and Rosie better too!"

Encourage patients to listen to thriving autistic people.....



“When most other brains around you can do things with ease that are a great struggle for you, the world can be quite painful my love.”



“Hogwarts Headmaster Neville Longbottom has dyslexia himself and has made sure that Rose has accommodations at school.

She has a designated sensory-friendly area she can escape to when overwhelmed.

He takes bullying very seriously and has worked to help the other students understand Rosie better.”



Trevor the Vth

Workplace Accommodations



"Being Minister of Magic comes with its challenges. My administrator gives me visual cues to keep on schedule since time is a tricky concept for me.

My staff minimize the number of group meetings I have to attend and facilitate written communication instead of auditory.

If I have to attend a large event with lots of stimulation, they plan time into my schedule for me to decompress.

Unfortunately, not all witches and wizards have the privilege of workplace accommodations. I'm working to change that."

Hermione

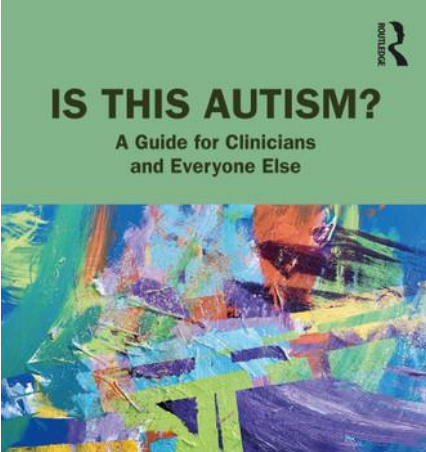


*"Now slip me snug around your ears,
I've never yet been wrong,
I'll have a look inside your mind
And tell where you belong!"*

Pretty sure the RAADS-R and
MIGDAS-2 have better
psychometric validity.

Diagnosis Resources

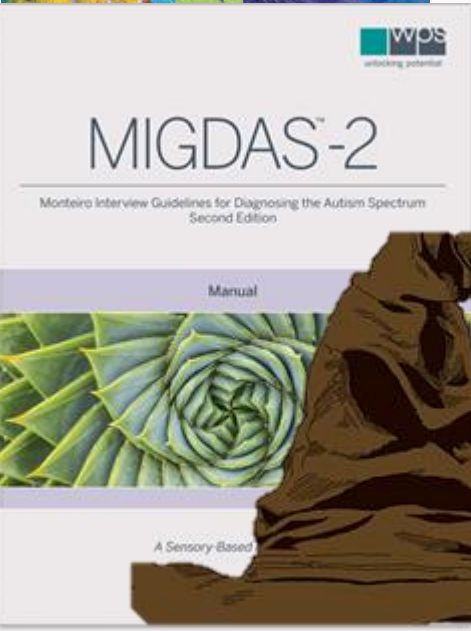





Diagnosis Resources



The
Adult Autism
Assessment
Handbook
A Neurodiversity Affirmative Approach



- ▶ Monteiro Interview Guidelines for Diagnosing the Autism Spectrum – Second Edition (MIGDAS-2)
 - ▶ <https://www.marilynmonteiro.com/>
- ▶ Autism Spectrum Quotient (AQ)
 - ▶ <https://embrace-autism.com/autism-spectrum-quotient/>
- ▶ Ritvo Autism Asperger Diagnostic Scale–Revised (RAADS–R)
 - ▶ <https://embrace-autism.com/raads-r/#test>
- ▶ Camouflaging Autistic Traits Questionnaire (CAT-Q)
 - ▶ <https://embrace-autism.com/cat-q/#test>



Traditional Medical Model

- There is a normal way of being, and anything significantly different from that needs to be fixed.
- The goal is to make the autistic person look less autistic or to find a cure.



Neurodiversity Model

- Diverse brain types are desirable and offer a benefit to society.
- The goal is to help the autistic person be their most authentic and functional self.

This Presentation Does Not Fit All Autistics.....

- The majority of autistic people are not intellectually disabled and the intention of this presentation was to highlight autistic people who may go undiagnosed and unrecognized into adulthood.
- This presentation did not cover autistics who are intellectually disabled or autistics with high support needs. I just want to acknowledge them and their families here.

Moving towards a more neuro-affirmative approach...

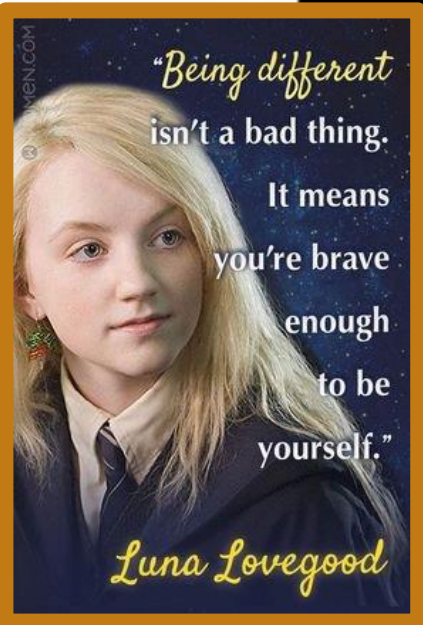
- Target autistic people's needs and challenges, NOT their autistic way of being.
 - ie enabling stimming with sensory items to self-regulate
- Support autistic patients connecting to other autistic patients and taking pride in their “autistic culture.”
- Highlight autistic strengths as well as challenges. And more...



Autistic Strengths!

- Strong sense of social justice
- Honesty
- Hyper-empathy
- Detailed perception and processing
- Outside the box logical thinking
- Expertise in area of special interest
- Less influenced by social norms/pre-conceived notions and thus more able to come up with novel ideas/observations.
- Just to name a few....





Neuro-affirmative Therapy

- Respects self-agency/autonomy as much as possible. No coercion.
- Celebrates neurological differences.
- Values lived experience of neuro-diverse individuals.
- Explores the functions of behaviors instead of focusing solely on their extinction.
- Free from guard-railing



For All The Unseen Autistics...

Thank you so much for listening!

Download slides from other presentations at our website:

Stacygreetermd.com

Email: stacygreetermd@gmail.com

To be added to the list to receive invites to future presentations and video recordings.

Special Thank You to:

Charnell Widnall at Autism Spectrum Counseling

