

Compensation for Everyday Challenges Experienced by Autistic People

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Outline

1. What we already know about compensatory approaches used by autistic people
2. Our quantitative and qualitative study examining autistic adults' compensation for differences in sensory processing, executive function, and daily living skills

Background

A Definition of Compensation

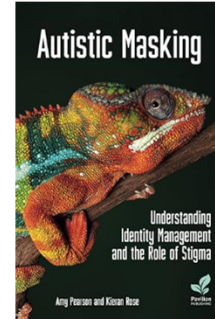
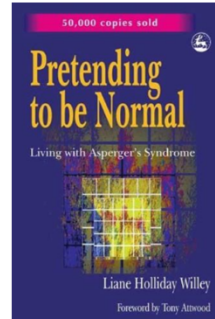
- General conceptualization:
 - People achieving “typical” or better than expected performance on a task through the recruitment of additional cognitive, psychological, neurobiological, or other resources



Livingston & Happe (2017). *Neuroscience & Biobehavioral Reviews*.

Compensation in Autism

- Often thought of in terms of social differences
- Many terms used in the literature
 - **Masking** (Pearson & Rose, 2021; Cook et al., 2018; Wiley, 1999)
 - **Adaptive morphing** (Lawson, 2020)
 - **Passing as non-autistic** (Lisback et al., 2021)
 - **Social camouflaging** (Hull et al., 2017; English et al., 2021)
 - **Social compensation** (Livingston, Shah & Happe, 2019; Livingston, Shah, Milner & Happe, 2020)



Compensation for Social Differences

- Autobiographical accounts describing lived experiences of “pretending” to be non-autistic or masking (Wiley, 1999)
- Spurred qualitative research on social compensation (Hull et al., 2017)
- Quantitative research (Lai et al., 2017), including the development of self-report measures (Hull et al., 2019)

Compensation for Social Differences: Across Development

- **Children** (Dean et al., 2017; Parrish-Morris et al., 2017; Rynkiewicz et al., 2016)
- **Adolescents** (Bernadin et al., 2017; Hull et al., 2021; Jorgenson et al., 2020)
- **Adults** (Cage & Troxell-Whitman, 2019; Hull et al., 2020; Schuck et al., 2019)

Compensation for Social Differences: Autistic > Neurotypical

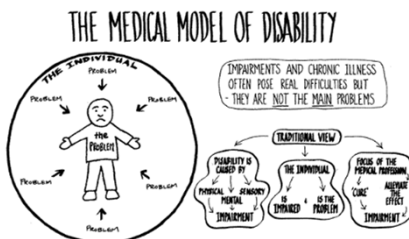
- Autistic people self-report more social compensation or masking relative to neurotypical people
 - Autistic adolescents > Neurotypical adolescents (Jedrzejewska & Dewey, 2021)
 - Autistic adults > Neurotypical adults (Dean et al., 2017; Hull et al., 2019; Hull, Lai, et al., 2020; Livingston et al., 2020; Robinson et al., 2020)

Compensation for Social Differences: Associations

- **Diagnostic timing** (Bargiela et al., 2016; McQuaid, Lee & Wallace, 2022; Milner et al., 2023)
- **Mental health** (Cage & Troxell-Whitman, 2019; Cassidy et al., 2018; Hull et al., 2019; McQuaid, Sadowski, Lee & Wallace, 2023)
- **Executive functioning** (Hull, Petrides, & Mandy, 2021)
- **Sex assigned at birth** (Lai et al., 2017; McQuaid, Lee & Wallace, 2022; Milner et al., 2023)
- **Gender identity** (Hull et al., 2020; McQuaid, Lee & Wallace, 2022)

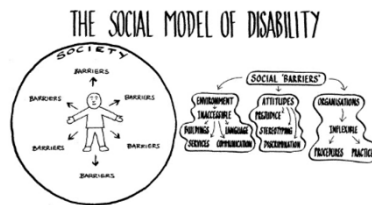
Compensation in Autism

- Current conceptualizations of compensation in autism focus person-level changes in behavior
- Accordingly, most measures focus on how autistic people change their own behavior to “compensate” for everyday (e.g., social) challenges they face
- This is akin to the medical model of disability



Compensation in Autism

- However, context is incredibly important, so that person-environment fit is critical
- Harkens to neurodiversity perspective wherein disability is dependent on how your brain fits in your context (culture, time, specific environment/space, etc.)
- This is more akin to the social model of disability
- Thus, we wanted to create and utilize measures that assay how people change not only their behavior but also their environment to compensate for daily challenges



Compensation in Autism

- Most conceptualizations of compensation in autism also focus narrowly on social differences rather than other difficulties
- Autistic people frequently cite other areas as representing barriers to optimal outcomes, including:
 - Executive Function challenges
 - Sensory processing differences
 - Daily Living Skills difficulties



Compensation in Autism

Therefore, we sought to investigate possible compensatory strategies and approaches that autistic people harness to combat challenges experienced in the areas of sensory differences, executive functioning, and daily living skills.

-Quantitative findings

We also asked autistic people to provide information on their lived experiences of other forms of compensation that we did not capture in our questionnaires.

-Qualitative findings



Our Study Part 1: Quantitative

Compensation Study

- ***We hypothesized that:***
 - autistic adults employ a wide variety of techniques and strategies to compensate for their differences in sensory, executive, and daily living skills domains.
 - autistic people assigned female sex at birth engage in more of these compensatory techniques/strategies than those assigned male sex at birth.

Compensation Study: Quantitative

- Online study
 - Autistic adults aged 18 years and older
 - Community-based diagnosis or self-diagnosis
 - Currently living in United States

Participant Characteristics I

	N=216
Age: <i>M</i> (<i>SD</i>)	33.24 (14.31)
Range	18-81 years
Sex assigned at birth (Frequency)	157 Female : 59 Male
Gender identity (Frequency)	Gender Diverse 56 : Cisgender 160
Race (Frequency)	African American or Black 7 (3.24%) Asian 12 (5.56%) More than one race 16 (7.41%) Native American 3 (1.39%) White 177 (81.94%) Unknown 1 (0.46%)
Ethnicity (Frequency)	Latina/o/e 15 (6.94%)

Participant Characteristics II

	N=216
Bachelor's degree or higher (Frequency)	Yes 130
Enrolled education program (Frequency)	Yes 55
Currently employed (Frequency)	Yes 122
Ever employed (Frequency)	Yes 185

Participant Characteristics III

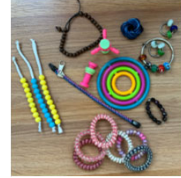
Diagnosis age: <i>M</i> (<i>SD</i>)	25.14 years (16.08)
Range	2-79 years
Diagnosis source (Frequency)	Prof diagnosis 185 (85.65%) Self-diagnosed 31 (14.35%)

Compensation for EF Challenges

- New measure developed
- Co-produced with autistic researchers
- Informed by autistic narratives/lived experiences
- 17 items that capture two EF components:
 - Flexibility
 - Emotion regulation

Compensation for EF Challenges

Example Items:



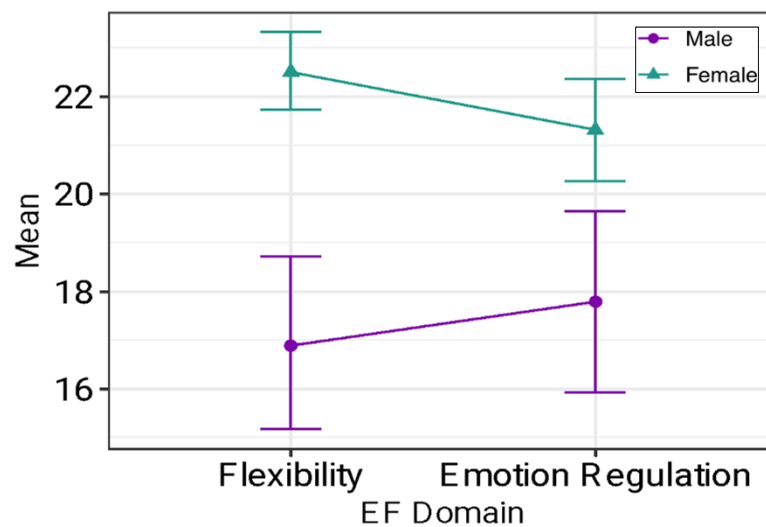
Flexibility

- "I avoid new situations or environments because I do not like unpredictability."

Emotion Regulation

- "I use a fidget (or some object) in order to calm or soothe myself in new situations."

Findings: Compensation for EF Challenges



Compensation for Sensory Differences

- Co-produced with autistic researchers
- Informed by qualitative literature and autistic narratives/lived experiences
- 16 questions, organized by 8 sensory domains:
 - *Auditory*
 - *Gustatory*
 - *Tactile*
 - *Visual*
 - *Oral Texture*
 - *Olfactory*
 - *Proprioception*
 - *Vestibular*

Compensation for Sensory Differences

Example Items:



Auditory

- "I ask people to speak more softly because sometimes their voice seems too loud to me."

Gustatory

- "I avoid certain foods because the flavor is too strong (e.g., too salty or sweet)."

Tactile

- "I cut the labels out of my clothes because I do not like how they feel against my skin/body."

Visual

- "I use softer lighting (e.g., natural or incandescent lights) because certain artificial lighting (e.g., fluorescent light) bothers me."

Compensation for Sensory Differences

Example Items:



Oral Texture

- "I avoid certain foods because of their consistency or the way they feel in my mouth."

Olfactory

- "I carry something with a smell I like in case I am bothered by someone's perfume or another smell."

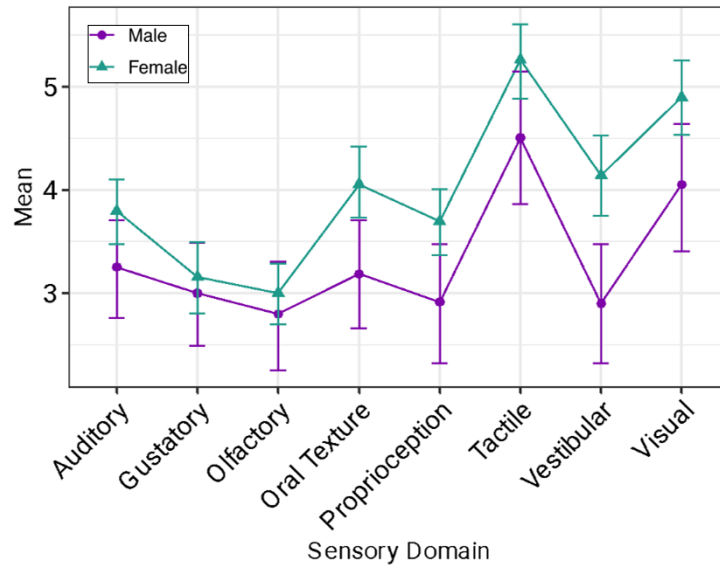
Proprioception

- "When walking down a hallway, I run a hand along the wall to "guide" me so that I avoid bumping into the wall or other people."

Vestibular

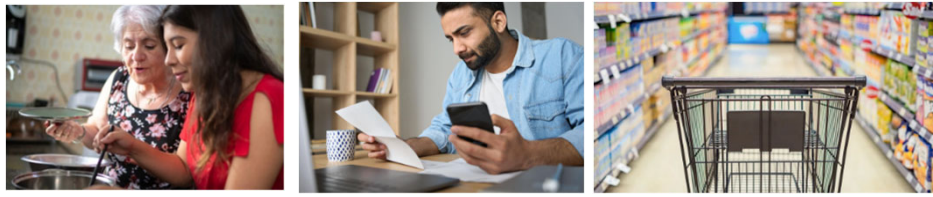
- "When I ride an escalator, I take my time getting on and off so as not to feel off balance."

Findings: Compensation for Sensory Differences



Compensation for Daily Living Skills Challenges

- Everyday Compensation (EComp) Questionnaire (Farias et al., 2020 *J Int Neuropsychol Soc*)
- Measure developed for use in older adults
- Queries cognitive compensatory strategies within the context of daily living skills
- Organized by functional domain: Appointments, Cooking, Finances, Shopping



Compensation for Daily Living Skills Challenges

Example Items:

Appointments

- "Prepare ahead by gathering items that need to be brought to appointment"

Cooking

- "Make only simple, familiar meals"

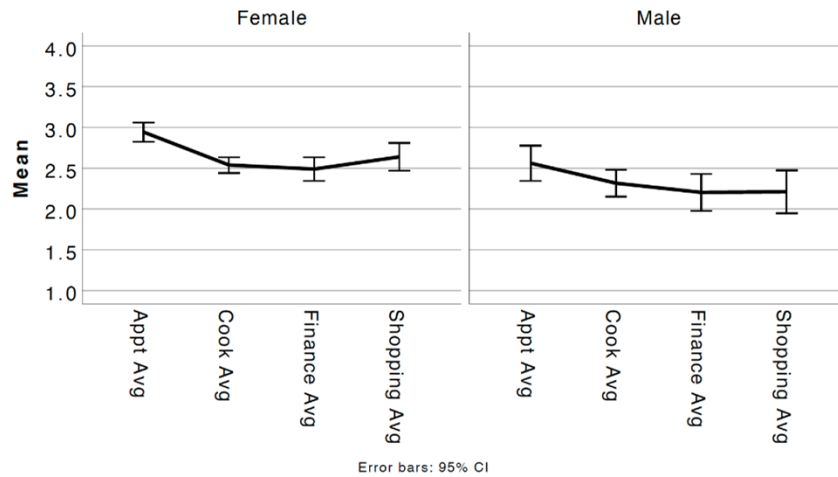
Finances

- "Pay bills immediately when they arrive so bills are not forgotten"

Shopping

- "Check off items on a shopping list as they are found in the store"

Compensation for Daily Living Skills Challenges



Quantitative Study Summary and Conclusions

- Autistic adults endorse a wide variety and considerable usage of compensatory strategies and techniques to address differences in sensory processing, executive functioning, and daily living skills
- Autistic people assigned female sex at birth consistently report greater use of compensatory strategies and techniques for differences compared to those assigned male sex at birth

Our Study Part 2: Qualitative Data

Compensation Study: Qualitative

- Additional open-ended question to evaluate other compensation strategies not captured in previously described questionnaires
- “Please describe any additional strategies ...that you use to compensate for or cope with day-to-day challenges of any sort...”
- Of 216 participants, 126 provided responses

Executive Functioning	
Planning	Routines & Familiarity
<p>"I also use strategies to help myself manage known transitions between activities, and pre-plan events so I have less disruption and can more smoothly switch from one thing to the next."</p>	<p>"Using Google maps to map out the route there and then using the street view to see what the place looks like, what the parking situation is, etc so I know as much as possible what to expect once I get to a new place."</p>
<p>"I limit my time in stores. I plan and strategize everything to try to manage my limited energy."</p>	<p>"I have a VERY rigid eating schedule and rarely stray from my neighborhood or routine."</p>
<p>"doing copious research and planning before going somewhere new"</p>	<p>"The only time I leave the house is to shop twice a week, or walk the dogs."</p>
	<p>"planning ahead"</p>
	<p>"Go new places with a friend or acquaintance..."</p>
	<p>"Indulge my need to research and/or find out as much information as I need to feel more relaxed about an issue/situation"</p>
	<p>"keep my living environment pretty controlled"</p>
	<p>"I try to keep up with my routine as much as possible"</p>

EF - Emotion Regulation		
Self-soothing through Music or Other Media	Breaks, Alone Time	Stimming
<p>"Listening to music and/or watching one tv show repeatedly"</p>	<p>"Spending time alone, lots of down time."</p>	<p>"I use verbal stimming and not physical."</p>
<p>"...listen to the same music on repeat to wind down after social interactions..."</p>	<p>"taking more frequent breaks"</p>	<p>"allowing myself to stim"</p>
<p>"I listen to music to self regulate and influence my emotions."</p>	<p>"Set aside lots of time to decompress at the end of the day."</p>	<p>"I rub my fingers and mentally talk to myself to calm anxious thoughts"</p>
<p>"I listen to music I love to help me through stressful periods..."</p>	<p>"Taking time each day to do nothing or to do something monotonous"</p>	<p>"When overwhelmed I seek sensory input such as swinging on a swing set or spinning to help me regulate."</p>
<p>"...drawing on a regular basis every day, watching fictional tv on a daily basis"</p>	<p>"taking breaks to be alone"</p>	<p>"Use sensory strategies to calm down (weighted blanket, bath, balancing exercise)"</p>

Sensory Processing

<p>"I use all unscented hygiene products"</p>	<p>"I try to have my headphones and sunglasses on hand for times I may be in places with very bright lights or loud sounds."</p>	<p>"I just have to be aware of how I am feeling sensory wise and what I think I can handle for the day. For example some days I can go grocery shopping other days it's a sensory nightmare."</p>
<p>"I use a fan for white noise and temperature regulation."</p>	<p>"Getting a sensory diet and exercise to help with it."</p>	<p>"sunglasses, earplugs, headphones and fidgets to deal with sensory issues"</p>
<p>"The majority of my t shirts have the sleeves cut off because I don't like the way they feel on my armpits."</p>	<p>"headphones in public"</p>	
<p>"i also organized my closet to "categories" (depending on formality) and keep one thing in each category to ensure that i am wearing sensory friendly things and also each category has one color palette so i dont have to think about matching top/bottom or really think if an outfit is appropriate"</p>	<p>"I have the back of my head shaved (under cut) and my hair always in a bun to avoid the feeling of having hair on my neck"</p>	
	<p>"i use clear earplugs with my hair down in crowds or noisy environments"</p>	

Daily Living Skills

Planning & Organization	Visual Prompts	Technology
<p>"Always have my 'going out' items in the same pockets so I don't lose them"</p>	<p>"...have visuals all around the house..."</p>	<p>"I try and use technology as much as possible to compensate for my difficulties in day to day situations. I use Autopay whenever possible to reduce the chance of missing payments on things like Rent or Utilities"</p>
<p>"if something doesnt go in the dishwasher then i dont own it"</p>	<p>"i have a visual checklist on what chores i need to do EVERY NIGHT"</p>	<p>"I ... use an Alexa device, and a visual time management app..."</p>
<p>"Making lists of things to do and the order in which to do them"</p>	<p>"Post it notes everywhere to remind me of what I need to do/get done/buy/etc."</p>	<p>"I use my phone for alarms and calendar to keep track of my schedule and reminders"</p>
<p>"I buy the same days of the week"</p>	<p>"I put signs on walls to remind myself not to forget about some things"</p>	
<p>"I have multiple systems for appointment/event reminders."</p>		
<p>"I plan out my weekly activities and schedule days off after social time."</p>		

Broader Strategies

"I use an AAC device to communicate, have full time caregivers..."	"Choosing friends who share my identity."	"...I meditate when I feel overwhelmed, sometimes it's quiet meditation, and sometimes it's other forms of meditation like ritualistic dancing, singing, or drumming."
"I receive...community living support services to assist with shopping and hygiene reminders"	"I have few but close friends, individuals who do not expect me to behave or communicate like a neurotypical."	"Meditation and gym activities"
"creating things (art)"	"I attend psychotherapy with a psychologist who is an autism expert"	"spend time with cats"
"I ... find that my pets and hobbies are really important for coping."		"talking with my sister"
"Most of my issues are sensory or social, so I try to avoid objects or situations that trigger or increase my stress."		"allowing myself grace when executive dysfunction is high like if I can't shower that night or whatever it might be just giving myself more grace has helped me cope with my challenges"
"...avoid dining out or most other group social events."		
"Mostly, I use avoidance; however, this breeds loneliness."		

Ableism and Barriers

Ableism	Access
"Most of my difficulties ... are more due to ableism..."	"I have not yet had the opportunity to have quality therapy; I tried several therapists who had no specialty in autism and they were not helpful. It would be nice to be financially able to purchase therapy..."
"I don't socialize well because my sensory issues typically get ignored"	
"We have a lot to offer society and our friends. Maybe society should cope with us."	
Strategies Can Fall Short	"I...tried to seek help for my daily activities through daily activities through my insurance but they won't help me so my house doesn't get clean very well, etc."
"I don't have many great ways to deal with sensory environment, it's hard for me..."	
"I have emotional troubles stifling my anger because more often than not, when I am angry, I become angrier for having been angry."	"Without having consecutive days off, my energy is low and extra slow and my mental health takes a turn for the worse... Personally I do best with three days off in a row but I have bills to pay too."
"Nothing that has been largely beneficial."	

Qualitative Study Summary and Conclusions

- Autistic adults provided a wealth of additional information on strategies they use in compensating for challenges they experience on a daily basis
- Many of the reported strategies involved activities of enjoyment, repetition, or engagement that self-soothe and calm
- Many others involved adaptation of one's environment or the autistic person's "fit" with that environment

Overall Summary and Conclusions I

- Autistic people report a wide variety and rich array of compensatory strategies and techniques:
 - these approaches are increasingly well characterized for social differences experienced by autistic people
 - our own study begins to describe approaches utilized by autistic people to compensate for differences in executive function, sensory processing, and daily living skills

Overall Summary and Conclusions II

- As with compensation for social differences, autistic people assigned female sex at birth report greater use of compensatory techniques and approaches for sensory, executive function, and daily living skills differences than those assigned male sex at birth

Overall Summary and Conclusions III

- Many of these compensatory strategies are bespoke and self-generated
- Autistic people often have to adapt not only their own behavior and traits to fit into a predominantly neurotypical world but must also work against the grain to adapt their environment to optimize their success

Caveats and Future Directions

- Study limited to autistic adults without co-occurring intellectual disability
 - How might strategies and approaches differ for autistic people with co-occurring intellectual disability?
- Autistic adult participants were predominantly white, non-hispanic and well-educated
- Effectiveness of strategies still to be evaluated

- We are grateful to all of the autistic adults who volunteered their valuable time to help us with our research.
- We greatly appreciate the students in our lab who helped to check, score, and code these data so that we could share our findings with you.

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