

# Defining Autistic Burnout using Grounded Delphi Method: Autistic Burnout through the Eyes of Experts by Lived Experience

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**Autistic burnout:**  
Not being able to function due to being overwhelmed by life (particularly being autistic but having to live life as a neurotypical)

## Project aim

Although commonly described by autistic people, there is a lack of research on autistic burnout. We sought to define autistic burnout using Grounded Delphi Method.

## Background

### #Autburnout

There is fervent discussion of #AutBurnout and #AutisticBurnout on social media, yet only recently has autistic burnout been mentioned in academic discourse by Raymaker et al. (2020).

## Method

### Grounded Delphi Method (GDM) (Howard, 2018)

GDM combines the Delphi method, useful in areas with little established literature, and grounded theory, useful for theory building (Päivärinta et al., 2011). Twenty-two autistic adults, as experts by lived experience, completed three rounds of surveys over a six-month period.

## Conclusions

Autistic burnout appears to be a debilitating condition with onset linked to everyday stressors faced by autistic people in an unaccommodating world. Therapeutic strategies such as behavioural activation would be contra-indicated. We are currently completing a follow-up study comparing this definition with the work by Raymaker et al. (2020) and an unpublished version of the AASPIRE Autistic Burnout Measure.

Round 1 open-ended items were jointly analysed by JH and SA. Peer researcher JH is a late-diagnosed autistic adult who has personally experienced autistic burnout. Visual Analogues Scales (VAS) in round 2 and 3 sought agreement with the draft definition.

Open-ended survey items were subjected to grounded theory analysis. A draft definition was developed and sent to experts	VAS items with further comments option aligned to each element of the definition. Definition was refined and returned to experts.	VAS items with further comment option aligned to each change to the definition. Consensus was reached and the definition finalised
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**Round 1**   **Round 2**   **Round 3**

## Results

Several themes were identified in Phase 1:

### Energy

"I have stopped wearing myself out by trying to operate in a neurotypical landscape", "Frequently have to postpone tasks or events due to loss of mental energy."

### Onset

"[Being] safety officer gained me enmity of... co-workers. I got confused, everything got too much. I walked away from my workplace..."

### Impact

"I spent 3 weeks in the psychiatric ward, was very tired... found it difficult to talk... just wanted to be far away from everyone... trust (others) less"

### Recovery

"When I have time on my own... I can recover", "I need time to find me and set myself to zero, recalibrating my brain", "I'm slowly coming out of burnout by understanding more about myself and autism."

### Temporal Qualities

"It depends on... the stressor... and how long I'm exposed to it... it can last all day, or only a few hours...", "Burnout has been 5 years so far", "this... burnout lasted... 2 years."

### Differentiating from Depression

"The sensory overstimulation is off the charts", "It's more intense...a complete mind, body, soul thing it's everything", "[Depression is] a side effect with burnout the larger cause."

**Consensus** was met in the round 3 survey and 90% of experts agreed or strongly agreed the following definition described their experiences:

### PRELIMINARY DEFINITION FOR AUTISTIC BURNOUT

Autistic Burnout is a severely debilitating condition with onset preceded by fatigue from camouflaging or masking autistic traits, interpersonal interactions, an overload of cognitive input\*, a sensory environment unaccommodating to autistic sensitivities and / or other additional stressors or changes. Onset and episodes of autistic burnout may interact with co-occurring physical and / or mental health conditions.

The following criteria must be met;

- 1 Significant mental and physical exhaustion
- 2 Interpersonal withdrawal.

With one or more of the following;

- 1 Significant reduction in social, occupational, educational, academic, behavioural, or other important areas of functioning.
- 2 Confusion, difficulties with executive function\*\*, and/or dissociative states.
- 3 Increased intensity of autistic traits and/or reduced capacity to camouflage/mask e.g. increased sensory sensitivity, repetitive or stimming behaviour, difficulty engaging or communication with others.

The condition is not better explained by a psychiatric illness such as depression, psychosis, personality disorder, trauma- and stressor-related disorders.

Extended or chronic episodes of autistic burnout may be preceded by brief or intermittent episodes.

### For more information

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