



AutismCRC

Investigating autistic burnout (#AutBurnout)

FINAL REPORT

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February 2022



MACQUARIE
University
SYDNEY · AUSTRALIA



Australian Government
Department of Industry, Science,
Energy and Resources

AusIndustry
Cooperative Research
Centres Program

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ISBN: 978-1-922365-28-6

Citation: Arnold, S, Higgins, J., Weise, J., Desai, A., Pellicano, E. & Trollor, J. (2021). Investigating autistic burnout #AutBurnout: Final Report. Brisbane: Autism CRC.

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Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants.

The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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1. Executive summary

Although reported on social media by autistic people for some time, there has been little recognition of autistic burnout in the academic literature. Autistic burnout has been described as a debilitating condition negatively impacting functioning, even leading to suicidal ideation. Autistic adults have linked autistic burnout to the stress of masking or camouflaging, and living in an unaccommodating neurotypical world. This project sought to define autistic burnout, deepen understanding and create awareness of this syndrome within the research and autism communities. No scientific literature on autistic burnout existed at the time the project commenced.

In Phase 1, we defined autistic burnout using Grounded Delphi Method. Autistic adults were positioned as experts by lived experience of autistic burnout ($n=23$). They co-produced a definition of autistic burnout intended for clinicians and the autistic and autism communities. Qualitative data gave a thick description (Geertz, 2017) of the autistic burnout experience, that is, a description accessible to those outside of the autistic community. A conceptual framework was developed from the open-ended round 1 survey. By the round 3 survey there was a high level of agreement with the draft definition. Autistic burnout was defined as a highly debilitating condition characterised by exhaustion, withdrawal, executive function problems and generally reduced functioning, with increased manifestation of autistic traits – and distinct from depression and non-autistic burnout (Higgins et al., 2021).

In Phase 2, we sought to validate emerging definitions of autistic burnout, with definitions recently published by Raymaker et al. (2020) in addition to our published definition arising from Phase 1. We aimed to explore the validity of these definitions and determine factors associated with more severe autistic burnout. Using a co-produced mixed-methods online survey, 141 autistic adults with self-identified experience of autistic burnout endorsed characteristics described by Higgins et al. (2021). No consensus could be reached on criteria regarding the duration of autistic burnout. We also trialled the pre-publication burnout measure developed by Raymaker et al. (2020), which appeared to have poor specificity. We found that autistic burnout appears to be associated with camouflaging and depression. Perspectival incognizance, that is, an inability to be aware of and understand another's personal existential experience of life akin to Milton's (2012) double empathy problem, was associated with onset, recovery and ineffectiveness of non-autistic clinicians.

Further work is needed to differentiate autistic burnout from other conditions, with complex relationships to depression and numerous reports of misdiagnosis. Clinicians need better understanding of the accompanying complexity to be considered in treatment planning. Research is also needed to develop and validate measures and screening tools to assist clinicians and researchers to understand this syndrome.

2. Introduction

Autistic burnout has been described in online accounts by autistic adults for some time, see for example #AutBurnout and #AutisticBurnout. Particularly at the commencement of this project, there was little to no mention of autistic burnout in the academic literature. Anecdotal accounts described a debilitating condition that severely impacts all areas of functioning. There were suggestions of a link between autistic burnout and suicidal ideation – and that autistic burnout was caused by the stress of living in an unaccommodating neurotypical world and masking or camouflaging autistic traits. That is, the exhaustion of “putting on my best normal” (Hull et al., 2017, p. 2519). One autistic self-advocate noted, “burnout is an integral part of the life of an Autistic person... yet nobody, apart from Autistic people, seems to know about it” (Rose, 2018).

In contrast, occupational burnout has been the subject of academic research and debate for some time. Freudenberger was the first to describe occupational burnout as “becoming exhausted by making excessive demands on energy, strength, or resources in the workplace” (1974, p. 159). Occupational burnout is not classified in the DSM-5 and though does have an entry in the ICD-10 and ICD-11 as an occupational phenomenon though not classified as a specific medical condition (World Health Organization, 2019). Based on the seminal work of Maslach (Maslach & Leiter, 2016), the ICD-11 describes burnout relating to unmanaged work-related stress, resulting in the three components of perceived exhaustion, mental distance or cynicism from one’s employment, and perceived reduced professional efficacy. However, the definition of occupational burnout, and its intersection with depression remain contested (Heinemann & Heinemann, 2017; Korczak et al., 2010).

Where occupational burnout is linked directly to the workplace, autistic burnout is described anecdotally as pervasive and is as a response to autistic adults coping with daily living in a primarily neurotypical world. The only other study published at the time of our Phase 1 write-up was the work of Raymaker et al. (2020) who used interview and social media data to arrive at the following definition of autistic burnout:

... a syndrome conceptualised as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterised by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus.

3.Phase 1

In Phase 1, we used Grounded Delphi Method (GDM) (Howard, 2018) to co-produce a definition of autistic burnout. GDM combines grounded theory, which is useful for theory building, with the Delphi method, which is useful in areas with little established research. We recruited 23 autistic adults who had lived experience of autistic burnout. They acted as experts by experience, as the Delphi method aims to draw consensus on a topic area using expert opinion. This work has been published, and we refer the reader to this manuscript for a more thorough description of processes and findings (Higgins et al., 2021).

Over three rounds of primarily online survey, consensus was reached, with 90% of experts by lived experience agreeing the definition of autistic burnout developed described their experiences. In the first round, grounded theory was applied to analysis of open-ended questions probing experts experience of autistic burnout. A thick description (Geertz, 2017) of autistic burnout was generated, that is, a rich description that is accessible to those outside of the autistic community. Participants described a debilitating condition, with a core category of energy that was linked to major categories of onset, impact and recovery (strategies), with ancillary categories of temporal qualities and differentiating from depression (see Figure 1, Table 1).

Figure 1: Integrative diagram from Phase 1 round 1 survey

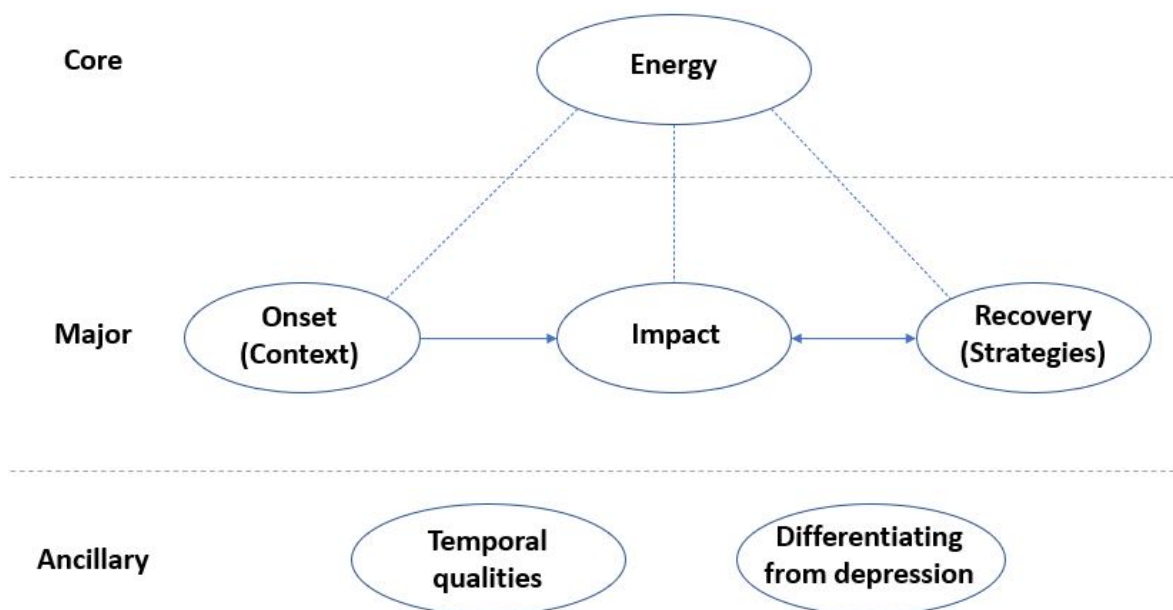


Table 1: Categories and subcategories from Phase 1 round 1 survey

Category	Subcategory
Energy (E)	(E1) Autism pre-diagnosis
	(E2) Supportive environments
	(E3) Disempowered
	(E4) Lack of control
	(E5) Camouflaging – masking*
Onset (O)	(O1) Social interaction
	(O2) Misunderstanding by and of others
	(O3) Unexpected change
	(O4) Cognitive overwhelm & overload* – demands exceeding capacity
	(O5) Sensory overwhelm & overload
	(O6) Work demands
Impact (I)	(I1) Increased manifestation of autistic traits
	(I2) Difficulty with emotion processing
	(I3) Decreased functional capacity
	(I4) Cognitive disruption*
	(I5) Confusion, dissociation
	(I6) Exhaustion
	(I7) Negative descriptions
	(I8) Self-image
	(I9) Trusting others (cynicism)
	(I10) Withdrawal – self isolation
	(I11) Suicide and Suicidal Ideation
Recovery Strategies (R)	(R1) Tenacity – persevering
	(R2) Space needed
	(R3) Self-knowledge
	(R4) Time needed
	(R5) Planning pacing
	(R6) Lack of appropriate support
	(R7) Incomplete recovery
	(R8) Unique recovery strategy
Temporal qualities (T)	(T1) One-off
	(T2) Intermittent
	(T3) Regular – ongoing
	(T4) Days – hours
	(T5) Weeks – months
Differentiating from depression (D)	(D1) Similarities
	(D2) Differences

* A glossary of the terms Camouflaging / Masking, Overload / Overwhelm, and Cognitive Disruption is provided in the Supplementary Materials of the published manuscript which may be helpful for some readers.

Autistic adults reported that “Autistic burnout is when I no longer have the energy reserves necessary to act Neurotypical”. The impact of autistic burnout cannot be understated, with some even describing suicidal ideation or suicide attempts. There was a complex relationship between autistic burnout and depression, though experts differentiated these conditions, describing that “depression is the side effect with burnout being the cause”.

Following round 1, the research team developed a draft definition of autistic burnout based on the findings. This definition was sent to the experts, who then completed a round 2 survey that questioned each element of the draft definition. A series of visual analogue scale items from strongly disagree to strongly agree were used, to be more accessible to our autistic experts, as well as open ended items to gather any additional commentary. The majority of 23 elements in the draft definition were endorsed in the round 2 survey, with 1 element needing revision because of low quantitative agreement, and 9 elements needing revision based on qualitative commentary.

The definition was revised and sent again to autistic experts, and a round 3 survey seeking agreement on the revisions and the overall definition was completed. All elements met the consensus endorsement criteria in round 3, and 19 of 21 experts in this round agreed or strongly agreed that the definition described their experiences. A fourth round of survey was not needed. The consensus definition is reproduced in Figure 2.

Phase 1 provided a definition and initial confirmation of the existence of an autistic burnout syndrome that is distinct from depression and driven by the stressors faced by autistic adults living in an unaccommodating neurotypical world. Several important differences were identified in the definition arising from Raymaker et al. (2020) and the definition arising from this phase of the research. Further research is needed to strengthen and validate our definition and understanding of autistic burnout – an issue that we addressed in Phase 2.

Figure 2: Consensus defined criteria for Autistic Burnout, reproduced from Higgins et al. (2021)

Preliminary defined criteria 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.

Differential diagnosis***

Depressive Episode. Autistic burnout has similarity to depression, though onset is primarily related to social interaction demands / masking fatigue, and overload. In autistic burnout, social withdrawal is a recovery strategy. Behavioural activation treatment approaches are not recommended.

Mainstream (non-autistic) burnout. Mainstream burnout onset and manifestation is typically related solely to employment. In autistic burnout, social interaction / camouflaging and / or unsupportive sensory environments are elements of onset. In contrast, cynicism, if evident, is related to non-autistic people rather than employment. The impact may extend to changes in autistic traits and, for some, regression.

Autistic 'meltdown'. Autistic burnout differs from meltdown experiences due to severity and duration of the exhaustion or fatigue. Whereas autistic meltdown can involve overpowering emotions, autistic burnout is more associated with perceived emotional numbness.

*Cognitive input, refers to thinking and mental processing

**Please note, executive function refers to "the mental capacity to focus attention, to process information while completing other tasks, and to plan and remember instructions"

***Differential diagnosis is the process of differentiating between two or more conditions which share similar signs or symptoms.

Data available suggest recovery, in particular from chronic burnout, may be assisted by:

1. withdrawal from social and / or interpersonal contact and externally-imposed demands, potentially requiring convalescence during an in-patient admission
2. time spent on personal interests
3. time spent re-regulating e.g. stimming
4. time spent reintegrating with Self and external world via gradual passive to active engagement in activities e.g. moving from listening to music to playing music; from watching video gaming to playing video games
5. a gradual return to daily routines, activities and responsibilities.

Recovery may be incomplete in comparison to previous functional capacity.

4.Phase 2

A manuscript “Confirming the nature of autistic burnout” describing Phase 2 in detail is currently under review. We encourage the reader to refer to this manuscript once it is available.

With the only literature on autistic burnout at the time of development of the Phase 2 study being Raymaker et al. (2020) and our under-review manuscript defining autistic burnout, Phase 2 involved an online survey that aimed to:

- (1) explore the content validity of emerging definitions;
- (2) quantify the duration, frequency and intensity of autistic burnout;
- (3) explore factors associated with more severe experiences of autistic burnout, and
- (4) examine the predictive validity of the measure developed by Raymaker et al. (2020) to determine current burnout.

We co-produced an online survey containing a variety of items based on the content of Raymaker et al. (2020) and Higgins et al. (2021) definitions. The survey also contained several standardized measures covering alexithymia, interoception, camouflaging, repetitive behaviors and sensory sensitivities, as our Phase 1 findings, and emerging conceptual papers (Pearson & Rose, 2021), suggested these attributes that are heightened in autism may be drivers of autistic burnout. We also included a measure of depression, given the complex relationship between depression and autistic burnout, akin to the relationship between depression and occupational burnout. Finally, we were fortunate to gain permission from Raymaker and colleagues to include a pre-publication version of the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Autistic Burnout Measure (AABM).

Regarding our first aim, quantitative and qualitative analysis of survey items that interrogated the content of emerging definitions suggest content validity of the definition developed in Phase 1. Exhaustion and social withdrawal were the most strongly endorsed characteristics regarding participants’ most recent autistic burnout experience. The Higgins et al. (2021) definition appears to more completely describe the autistic burnout experiences described by participants, though was not incompatible with the Raymaker et al. (2020) definition.

Regarding our second aim, no clear pattern emerged regards the duration or frequency of autistic burnout. Future research in this area is needed, and may be complicated by participants qualitative responses highlighting that both acute and chronic autistic burnout can be experienced.

Regarding our third aim, to determine factors associated with severity of autistic burnout, we first applied factor analysis to survey items that described the autistic burnout experience. Factor analysis determined four factors that we grouped into the *Autistic Burnout Severity Items (ABSI)*, we named the factors *Exhaustion*, *Cognitive Disruption*, *Heightened Autistic Awareness*, and *Overwhelm and Withdrawal*. Next, we conducted correlation and regression analysis predicting scores of the ABSI, as well as scores on the AABM. Although all measures (depression, camouflaging, repetitive behaviours, alexithymia, autism severity, sensory sensitivity and interoception) correlated with the ABSI, and all measures except camouflaging correlated with the AABM, in regression analysis, depression and camouflaging remained as predictors of the ABSI once all other measures were included in the analysis, and only depression predicted the AABM. Overall, this led to our hypothesis for future research, also informed by qualitative findings and our Phase 1 work, that autistic burnout is driven by daily stressors faced by autistic adults including the need to camouflage, and it can result in depression.

Regarding our fourth and final aim, the AABM questions participants on their experiences in the past three months. We compared the 103 participants who reported they were currently or had experienced autistic burnout in the last 3 months with the 33 participants who reported their most recent autistic burnout was more than 3 months ago. We conducted a receiver operative curve (ROC) analysis. The area under curve suggested poor specificity (AUC = .661; n = 136) of AABM tool, that is, it was not accurate in identifying who was and was not reporting on a current or recent experience of autistic burnout. This is visualised by the overlaid kernel density estimations presented in Figure 3.

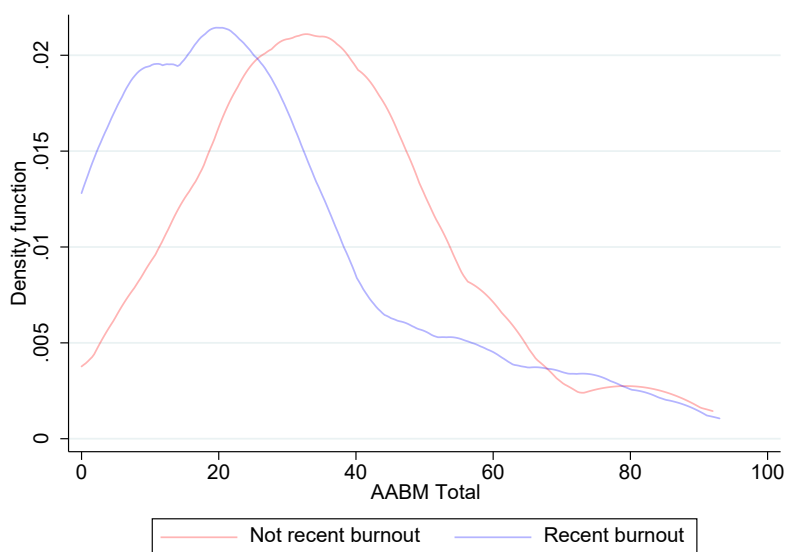


Figure 3: Kernel density scores on AABM vs. Have you been burnt out in the last 3 months?

5. Findings and implications

Across Phases 1 and 2, this project defined and established the validity of autistic burnout syndrome. This work has important implications for health providers supporting autistic adults, as well as future autism research. Of particular importance, qualitative data highlighted that some autistic adults did not benefit from standard psychological therapies, and as noted in our Phase 1 publication (see Higgins et al., 2021), treatments such as cognitive behaviour therapy (CBT) and behavioural activation may actually be contra-indicated. Whereas experts and participants noted withdrawal from social interaction is needed for recovery, behavioural activation in principle typically encourages people to increase their interaction. Also, experts and participants both noted cognitive overload as a stressor that can lead to onset of autistic burnout. CBT could further add to the cognitive load experienced by autistic adults.

This project also highlighted the need for the development of screening tools and measures that can be used in research and in clinical practice to identify autistic burnout. The pre-publication version of the AABM appears somewhat problematic. Our Phase 2 project in particular may offer a basis for future scale development research.

Perhaps most importantly, this project has highlighted the impact of unaccommodating neurotypical environments on autistic adults. Autistic people daily face adversity in social interaction, as described in Milton's (2012) double empathy problem, and underestimation of their self-awareness and ability to recognise the perspective of others as demonstrated by Heasman and Gillespie (2018). We identified a perspectival incognizance relating to this inability to be aware of and understand another's personal existential experience of life that was evident across onset and recovery from autistic burnout, as well as the ineffectiveness of some non-autistic clinicians. Overall, our results highlight the need to address social issues and sensory environments, to reduce stressors that can lead to autistic burnout or suicidal ideation for autistic adults.

6. Outputs

Including the development of an accessible project summary, we have presented on autistic burnout in several public forums including:

Higgins, J., Weise, J., Trollor, J., N., Pellicano, E., & Arnold, S. R. C. (May, 2021). *Defining Autistic Burnout using Grounded Delphi Method: Autistic Burnout through the eyes of experts by lived experience*. E-Poster presentation at the International Society for Autism Research 2021 Virtual Annual Meeting (online).

Higgins, J., Weise, J., Trollor, J., N., Pellicano, E., & Arnold, S. R. C. (2020, December). A *Consensus definition of autistic burnout*. Presentation at the Australian Society for Autism Research (ASfAR) Conference, Wellington, New Zealand (online).

Arnold, S. R. C., Lawson, L., Huang, Y. & Higgins, J. (2020). Autism in Adolescence and Adulthood: Findings from the Autism CRC's Longitudinal Studies Webinar. Presented to the APS PIDA IG 12-2-2020. https://www.youtube.com/watch?v=ow0FYij_HKI

Higgins, J. (2019, December 5th). Autistic voice in research: Thoughts and experiences from an autistic peer researcher. Presentation at the Aut2Connect meeting, Macquarie University, Sydney, Australia.

Arnold, S. R. C., Higgins, J. (2019). Autism CRC Program 3 Adulthood Webinar for Autism Month 2019 <https://www.autismcrc.com.au/news/webinars/adulthood-webinar-2019-26-april-2019>

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Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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