



SESSION II

Burnouts, Meltdowns, and Shutdowns

Presenters: Jane Mantzalas (La Trobe University) and Julianne Higgins* (University of New South Wales)

Discussants: Cheryl Dissayanake (La Trobe University) and Amanda Richdale (La Trobe University)

Thursday, July 7 at 7:00pm ET

Course Materials

The purpose of these materials is to help provide an introduction to the INSAR Institute session on understanding autistic people's research priorities. The materials were designed to prepare students and trainees who are unfamiliar with this research with the general background to receive the most educational benefit from the session. Toward this objective, we have prepared the following: (1) learning objectives for this session, (2) key terms and concepts, (3) a selection of recommended resources. These materials are considered supplemental to the presentation.

In collaboration with Jane Mantzalas and Julianne Higgins, these materials were developed by Sowmyashree Mayur Kaku (Post Doctoral Research Associate at St. John's Medical College Hospital, India; sowmeey@gmail.com), Ellie Taylor (Doctoral Candidate in Occupational Science program at University of Southern California, USA; taylor.elinor9@gmail.com), Dr. Nick

Fears (Postdoctoral Research Fellow at University of Michigan and incoming Assistant Professor at Louisiana State University, USA; nfears@lsu.edu), Elizabeth Perkovich (Doctoral Student in developmental, cognitive, and behavioral neuroscience at the University of Houston, USA; esperkovich@uh.edu) and Fathima Muhsina Kodakkadan (Doctoral Candidate at Anglia Ruskin University in Cambridge, UK; muhsinak19@gmail.com). Feel free to contact us with questions/comments. Register for this webinar and other sessions in this series at: <https://www.autism-insar.org/page/Institute2022>.

Learning Objectives

The INSAR Institute for Autism Research was established in direct response to requests from students and trainees for multidisciplinary training opportunities. The INSAR Institute team is also working to engage stakeholders. The INSAR Institute priorities are to provide a (1) freely available, (2) multidisciplinary training platform for young scientists and others from various backgrounds that (3) allows for international participation. The overarching goal of the INSAR Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists may learn from each other to ultimately advance the understanding of autism.

The current session, Burnouts, Meltdowns, and Shutdowns is presented by Jane Mantzalas (PhD candidate) and Julianne Higgins (autistic adult and researcher). A team of trainees worked in tandem to prepare this handout and the web presentation. At the conclusion of this session, participants will:

1. **Understand** the concepts of autistic burnout, meltdowns, and shutdowns and their impact on autistic people through references to current research and lived experience.
2. **Identify** prevention and recovery strategies for burnouts, meltdowns, and shutdowns, and discuss a conceptual model of risk and protective factors for autistic burnout.
3. **Learn** how family, social, and environmental factors can influence autistic burnout, meltdowns, and shutdowns.

Key Terms with references:

Autistic burnout: A state of extreme cognitive, physical, and emotional exhaustion from stress and demands associated with being an autistic person in a predominantly non-autistic world.

Meltdown: An externalising response to overwhelming emotional, sensory, or physical stressors that may manifest as screaming, crying, hitting, and distress.

Shutdown: An internalising response/withdrawal from interpersonal interactions due to emotional, cognitive and/or sensory overwhelm that may manifest as dissociation, mutism, or appearing 'frozen'.

(1. [Meltdowns - a guide for all audiences \(autism.org.uk\)](https://www.autism.org.uk) 2. [Meltdowns and shutdowns | Ambitious about Autism](#))

Masking: Conscious or unconscious cognitive or behavioural strategies used to suppress or alter natural autistic responses during social interactions or sensory experiences.

(Pearson, A., & Rose, K. (2021). *A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice*. *Autism in Adulthood*, (3)1, 52-60. doi:10.1089/aut.2020.0043)

Stimming: (Abbreviation for 'self-stimulatory behaviours') Behaviours that facilitate sensory and emotional self-regulation during overwhelming and stressful situations.

(Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*. doi:10.1177/1362361319829628)

Alexithymia: Difficulty identifying and describing one's emotions or feelings.

(Kinnaid, E., Stewart, C., & Tchanturia, K. (2019). *Investigating alexithymia in autism: A systematic review and meta-analysis*. *European Psychiatry*, 55, 80-89. doi:10.1016/j.eurpsy.2018.09.004)

Interoception: The ability to perceive bodily states (e.g.,) hunger, pain, tiredness, thirst, fatigue.

(Shah, P., Hall, R., Catmur, C., & Bird, G. (2016). *Alexithymia, not autism, is associated with impaired interoception*. *Cortex*, 81, 215-220. doi:10.1016/j.cortex.2016.03.021)

Job Demands-Resources Model of Burnout: A theory of workplace stress that proposes burnout occurs when job demands consistently exceed job resources.

(Bakker, A. B., Demerouti, E., & Verbeke, W. (2004). *Using the job demands-resources model to predict burnout and performance*. *Human Resource Management*, 43(1), 83-104. doi:10.1002/hrm)

Conservation of Resources Theory: A motivation model that suggests individuals strive to acquire, protect, and replenish resources, and that burnout can occur if their efforts do not produce expected returns.

(Hobfoll, S.E., & Freedy, J. (2017). *Conservation of resources: A general stress theory applied to burnout*. In W. B. Schaufeli, C. Maslach, & T. Marek (Eds.), *Professional burnout: Recent developments in theory and research* (pp. 115-129). New York: Routledge)

Recommended Readings & Resources

- Halim, A. T., Richdale, A. L., & Uljarević, M. (2018). Exploring the nature of anxiety in young adults on the autism spectrum: A qualitative study. *Research in Autism Spectrum Disorders*, 55, 25-37. doi:10.1016/j.rasd.2018.07.006
- Higgins, J. M., Arnold, S. R. C., Weise, J., Smith, P., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism*, 1-14. doi:10.1177/13623613211019858
- Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*. doi:10.1177/1362361319829628
- Keville, S., Meek, C., & Ludlow, A. K. (2021). Mother's perspectives of co-occurring fatigue in children with autism spectrum disorders. *Fatigue: Biomedicine, Health & Behavior*, 9(4), 209-226. doi:10.1080/21641846.2021.2008169
- Mantzas, J., Richdale, A. L., Adikari, A., Lowe, J., & Dissanayake, C. (2021). What is autistic burnout? A thematic analysis of posts on two online platforms. *Autism in Adulthood*, 4(1), 52-65. doi:10.1089/aut.2021.0021
- Mantzas, J., Richdale, A. L., & Dissanayake, C. (2022). A conceptual model of risk and protective factors for autistic burnout. *Autism Research*, 15, 976-987. doi:10.1002/aur.2722
- Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2020). 'When my autism broke': A qualitative study spotlighting autistic voices on menopause. *Autism*, 24(6), 1423-1437. doi:10.1177/1362361319901184
- Pearson, A., & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood*, (3)1, 52-60. doi:10.1089/aut.2020.0043
- Phung, J., Penner, M., Pirlot, C., & Welch, C. (2021). What I wish you knew: Insights on burnout, inertia, meltdown, and shutdown from autistic youth. *Frontiers in Psychology*, 12, 1-14. doi:10.3389/fpsyg.2021.741421
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaides, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in Adulthood*, 2(2), 1-12. doi:10.1089/aut.2019.0079

- Samuel, P., Yew, R. Y., Hooley, M., Hickey, M., & Stokes, M. A. (2022). Sensory challenges experienced by autistic women during pregnancy and childbirth: A systematic review. *Archives of Gynecology and Obstetrics*, 305(2), 299-311. doi:10.1007/s00404-021-06109-4
- Steward, R., Crane, L., Roy, E. M., Remington, A., & Pellicano, P. (2018). "Life is much more difficult to manage during periods": Autistic experiences of menstruation. *Journal of Autism and Developmental Disorders*, 48, 4287-4292. doi:10.1007/s1083-018-3664-0
- Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding stigma in autism: A narrative review and theoretical model. *Autism in Adulthood*, 4(1), 1-16. doi:10.1089/aut.2021.0005