



Dr Joanne Ltd.

22<sup>nd</sup> October 2024

Dear Wes Streeting, Secretary of State for Health and Social Care,

Thank you for taking the time to read our letter. We are writing to you about autistic burnout, and the lack of strategy around supporting autistic young people and adults, experiencing autistic burnout. To introduce ourselves, we are Viv Dawes and Dr Joanne Riordan, and both have professional expertise and lived experience in the area of autistic burnout.

Viv is a lived experience autism advocate, author and trainer. She is late diagnosed autistic and ADHD and the parent of an autistic teenager who is in recovery from burnout. Viv has worked extensively with vulnerable young people and adults for nearly 30 years, including as an NHS Senior Practitioner within the criminal justice system. She now provides support to autistic young people, adults and families of autistic children experiencing burnout. She has published several books on the subject (that have been endorsed by Dr Tony Atwood) and has a new book for autistic young people about burnout coming out with Jessica Kingsley Publishers next year.

Joanne is an Educational and Child Psychologist, with a specialism in creating neuro-affirming environments. Joanne has provided CPD on autistic burnout, to Local Authorities, schools, and fellow psychologists. Joanne also consults to families and schools, so that they can appropriately support young people in autistic burnout. Joanne is neurodivergent herself and has experienced neurodivergent burnout. Joanne has had family members who have experienced autistic burnout.

It is not just us who strongly feel that the Government need a robust strategy to support those in autistic burnout, and a vision for preventing autistic burnout. Viv emailed yourself and others (who were in the shadow cabinet at the time) earlier this year regarding the issue of autistic burnout. Viv included a link to the petition Viv started. The

petition received an astounding 40,000 signatures <https://www.change.org/p/make-schools-camhs-and-other-professionals-recognise-and-accept-autistic-burnout>

(The MPs mentioned were correct at the time)

Worryingly there is currently no data on the incidence of autistic burnout. However, anecdotally almost every autistic adult feels that on reflection they can identify times in their life they were in autistic burnout. Autistic burnout can be experienced at all ages.

Autistic burnout is recognised by the Royal College of Psychiatry, who describe it as:

*“a state of exhaustion, associated with functional and cognitive deterioration and an increase in autism symptomatology, as a consequence of coping with social interaction (including masking) and the sensory environment. It may be a short-lived state (as at the end of a working day), relieved by a relatively brief withdrawal from the stress. However, longer and more severe stress can produce a more sustained state (which entails some form of innate change) which has to wait on its natural remission. It overlaps symptomatically with anxiety and depression, and there may be a heightened risk of suicide.”*

In research by Samuel R. C. Arnold, Julianne M. Higgins et al, they describe autistic burnout as:

“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 change” ‘Confirming the nature of autistic burnout’ (2023)

Both our families have experienced the impact of autistic burnout, and here we write an extract each, outlining that lived experience:

- Viv: I know full well how hideous autistic burnout can be. I have experienced it throughout my life and this seriously affected jobs and many other aspects of my life. I had to watch a family member (who was only identified once in the grips of a crisis) deteriorate to such a degree that it seriously affected their education, health and mental wellbeing. I was also myself the child of an autistic mother, who was missed and misdiagnosed. She spent many years in and out of psychiatric units, due to what I now understand was extreme autistic burnout.
- Joanne: When autistic burnout has happened within my family, it has been me as a family member rather than professionals in the situation- who have been able to identify burnout and plan appropriate support. I worry so much about the families and autistic individuals, who do not have access to this knowledge.

It is important to note that autistic burnout is different to occupational burnout. Autistic burnout is mainly the result of existing in systems and environments that do not best cater to your needs or your neurotype. This leads to autistic individuals having to put in extra effort and experiencing more stress. Furthermore, another way of coping in these environments is masking. Masking means the autistic individual suppresses internal distress in social situations. This internalising of distress and anxiety is exhausting and increases our chances of regularly experiencing co-occurring mental health problems.

The current data is evidence enough that current support for the mental health of autistic individuals is not working. autistic children are 28 times more likely to experience suicidal thoughts and autistic adults are 9 times more likely to die by suicide. Targeting autistic burnout would help reduce pressure on mental health services, as well as improving support.

So, what do we want, in order to start the process of supporting autistic individuals in relation to autistic burnout?

- ⇒ A plan for raising awareness & understanding amongst professionals (across health, social care, education, and employment), through adequate CPD, informed by lived experience.
- ⇒ A clear strategy for supporting autistic individuals experiencing burnout. This must include how to provide rest and recovery time, for those in employment and of compulsory school age.
- ⇒ A strategy for providing safe and neuro-affirming environments, to reduce the incidence of autistic burnout.
- ⇒ A strategy for providing psychoeducation to autistic individuals, on how to prevent and understand what helps with recovery from autistic burnout.
- ⇒ Funding of research into incidence and prevalence rates of autistic burnout.
- ⇒ Clarification regarding the changes in The Mental Health Act announced in the King's Speech this year, regarding stopping autistic people being detained unnecessarily in psychiatric units (many of whom are likely to be experiencing autistic burnout).

We look forward to your reply.

Kind regards,

Viv Dawes and Dr Joanne Riordan