



Executive Summary: Stress, Coping and Resilience: An Investigation into the Well-Being of Partners of Individuals with Asperger's Syndrome

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In 2010 – 2011 we (Dr Lisa Abel and Dr Vicki Bitsika) undertook research to investigate the mental health outcomes of individuals in AS-NT relationships. We specifically focused on the influence of fatigue, resilience and stress (coping) on depression and anxiety in NT partners. Taking a functional analytic approach, we also assessed the extent to which NT partners had experienced reinforcer losses (social, emotional and cognitive) since the onset of their NT-AS relationship. One hundred and twenty-two partners (113 females) completed the questionnaire component of the research program, and 17 participants completed the interview; 16 of these came from the original sample of 122. The average age of NT partner was 48.6 years, and the average age of their AS partner was 50 years. The average age of the AS partner at diagnosis was 46.5 years. Eighty-one percent of the NT partners taking part in the study were married, and from the interview data the average number of years partners had spent in their NT-AS relationship was 20.5 years (range: 2 years to 46 years). Partners' scores indicated that they were experiencing mild-moderate levels of anxiety and depression, and it was found that fatigue, resilience and (non-productive) coping were all significant predictors of partners' anxiety and depression. The interview data revealed many of the partners had experienced a decrease in, and in many cases a cessation of recreational &/or social activity since the onset of their AS-NT relationship. Many partners also reported experiencing increases in anxiety and depression symptoms since the onset of their relationship with their AS partner. In relation to planning and decision making for their families and/or partnerships, many partners reported having the sole responsibility for this. Partners also reported an absence of free-flowing exchange and emotional content in their communication with the AS partner. Additionally, due to a lack of understanding and support from others, partners reported having difficulty with communicating their relationship experiences and challenges. Overall, there appears to be a pattern of restriction and control in relation to partners' social, emotional, cognitive and communication behaviours, however, given the nature of AS partners feel as though they need to maintain these behaviours in order to avoid crises. While these compensatory behaviours are designed to manage the day-to-day challenges of their relationships, the long-term outcome is that these behaviours impact upon partners' health & well-being, as evidenced by partners' reports of increased anxiety, depression and isolation. Recommendations for NT partners is to re-introduce previous reinforcers - physical activity, social interaction, emotional engagement with others - as a way of helping to facilitate positive coping and increase physical and mental well-being.

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