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Raising a Child with an Autism Spectrum Disorder: The Experience of Stigma by Association, its Impact on Caregiver Wellbeing, the Influence of Signature Strengths, and the Experience of Growth

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Abstract

The life of a child with an Autism Spectrum Disorder (ASD) is known to include many difficulties, not only due to social, behavioural and communication difficulties, but also as the child does not fit society's specifications of 'normal.' Stressors encountered by caregivers raising a child with an ASD are well documented; however one often overlooked stressor for caregivers is *stigma by association*. Research to date has begun to explore the impact of stigma by association on the wellbeing of caregivers raising children with an ASD. However research is scarce, and has not yet addressed how some caregivers who experience stigma by association manage to resist this negative influence. Through two studies this thesis explored the experience of caregivers of children with ASDs New Zealand, looking in particular at stigma by association and whether personal signature strengths (particularly hope, gratitude and curiosity) may decrease its impact on caregiver wellbeing. It also examined whether, in spite of documented negative outcomes for caregivers, there is in fact room for a caregiver to experience growth as a byproduct of raising a child with an ASD.

Participants took part in interviews (Study One, six participants), or completed an online questionnaire (Study Two, 100 participants). All caregivers spoke of difficulties associated with raising their child which on the whole reflected previous research. Difficulties included practical restrictions, personal costs and social stigma. Every caregiver was found to have experienced stigma by association. Study Two participants had all encountered both enacted and internalised stigma by association in the previous six months, and stigma by association had a significant negative relationship with caregiver wellbeing. Positively, if a caregiver possessed higher levels of hope or gratitude, mediation analysis found the presence of these strengths decreased the influence of stigma by association on wellbeing. Promisingly, all caregivers were also able to identify many ways in which they had grown as a byproduct of the experience of raising their child, whether it was through increased positive emotions, experiences, or personal development. Findings suggest that in spite of caregiver's challenges they may not only survive, but thrive.

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