**An Investigation of Stress and Resilience in Mothers  
 of Children with Autism Spectrum Disorder**

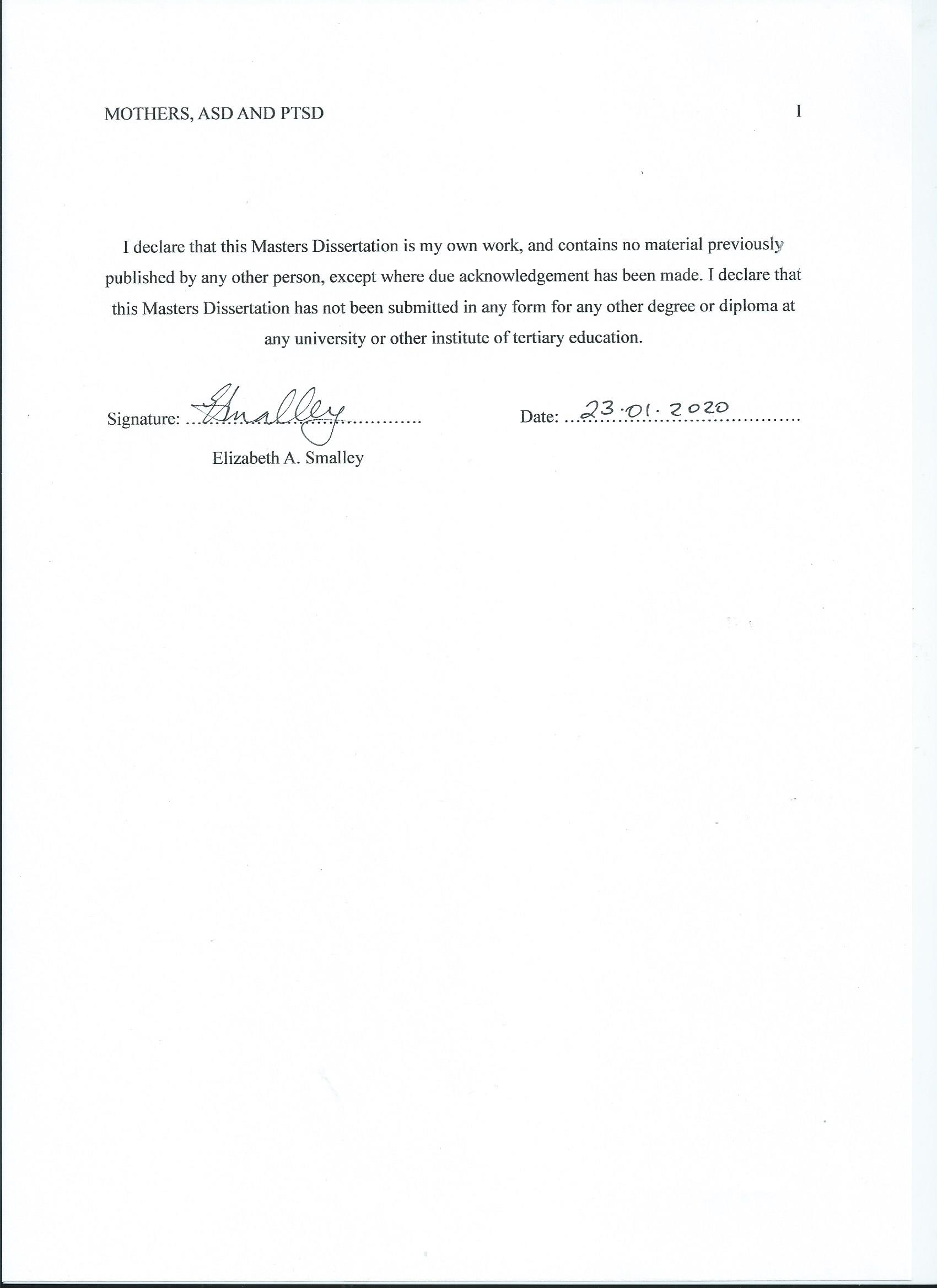
by

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Abstract

Children with autism spectrum disorder (ASD) present unique challenges for their caregivers, which often includes maladaptive behaviours that may range from annoying to deadly (Obeid & Daou, 2015). Recently, the nature of stress experienced by some mothers of children with ASD has been conceptualised using a trauma framework (Stewart, Knight, McGillivray, Forbes & Austin, 2017). Australian mothers (*n= 220)* of children with ASD aged between 4-16 years, completed an online survey inquiring into their experiences of trauma, the behaviours of their child, their level of aggravation in parenting, resilient coping and post-traumatic stress (PTSD) symptomology. A mediation moderation path model was used to determine whether the challenging behaviours of the child with ASD or previous traumatic experiences of the mother, influenced aggravation in parenting and PTSD symptomology in mothers and whether the outcome of PTSD may be moderated by the resilient coping of the mother. This study found that the challenging behaviours of the child with ASD were associated with increased aggravation in parenting and PTSD symptoms severe enough to warrant a provisional diagnosis of PTSD for almost a third of participants. Previous traumatic events did not influence the model. The relationship between aggravation in parenting and PTSD was not moderated by the resilient coping of mothers. Aggravation in parenting and PTSD are noted in the literature to have a negative effect on a mother’s capacity to parent, suggesting mothers of children with ASD should be screened for PTSD and offered supports addressing their level of trauma, in order to mitigate the potential impact of their child’s behaviour on their mental health.

***An Investigation of Stress and Resilience in Mothers  
 of Children with Autism Spectrum Disorder***

**Introduction**

Children with autism spectrum disorder (ASD; Appendix A) present unique challenges for their parents which often include unusual maladaptive behaviours that may range from simply annoying to deadly (Obeid & Daou, 2015). ASD is chronic in nature and characterized by (i) persistent deficits in social communication and interaction, (ii) repetitive, stereotyped behaviour and, (iii) limited interests (Conner & White, 2014). The prevalence of ASD has been estimated to be one child in 68 meeting the diagnostic criteria (Da Paz & Wallander, 2017) making it a significant global health issue (Bekhet, Johnson & Zauszniewski, 2012). Mothers are most often the primary carers of children with ASD, and hence have the greatest exposure to challenging behaviours. This increases the potential of developing a trauma response and associated negative outcomes (Fairthorne, Hammond, Fisher, Bourke & Leonard, 2014; Padden, James & Leader, 2015). Mothers of children with ASD experience more aggravation in parenting (Estes et al., 2013; Schieve et al., 2011), stress and negative mental and physical health outcomes (Fairthorne et al., 2014) than mothers of neurotypical children or children with other disabilities (Conner & White, 2014; Padden et al., 2015). Research has begun to explore the nature of the stress experienced by some mothers of children with ASD, to understand if a trauma framework may capture some of the symptomology experienced by a significant proportion of these mothers, associated with the challenging and often dangerous behaviours of their children (Roberts & Koenen, 2014; Stewart, Knight, McGillivray, Forbes, & Austin, 2016). Further defining the nature of the stress experienced by this group of mothers is crucial in the development of effective and efficient supports and interventions.

The current research proposes a path model whereby the intensity of the challenging behaviours of the child, increases aggravation in parenting and may predict the intensity of trauma symptomology experienced by some mothers. This model includes evaluating other traumatic life experiences of the mother, which have been shown to mediate trauma symptomology (Clancy et al., 2006; Gray, Litz, Hsu & Lombardo, 2004; Salcioglu, Urhan, Pirinccioglu & Aydin, 2017; Walker, McKune, Fergusson, Pyne & Rattray, 2016; Yehuda, Kahana, & Schmeidler, 1996). Not all mothers experience negative outcomes as a result of caring for a child with ASD, therefore resilient coping was included in the model to determine if it may be a moderating and protective factor for mothers (Almedom, 2005; Lawrence & Fauerbach, 2003; Tsai, Harpaz-Rotem, Pietrzak & Southwick, 2012).

**Challenging Behaviours**

Up to 94% of children living with ASD exhibit a range of challenging behaviours (Jang, Dixon, Tarbox & Granpeesheh, 2011). Repetition of these behaviours are more common and extreme with a comorbid intellectual disability (Matson & Nebel-Schwalm, 2007). The severity of challenging behaviours has been shown to be positively related to the severity of ASD (Jang et al., 2011). An intellectual disability, which may be present in up to 70% of children with ASD, has been shown to increase challenging behaviours (Hannon & Taylor, 2013; La Malfa, Lassi, Bertelli, Salvini & Placidi, 2004). Challenging behaviours may include destruction of property, faecal smearing, verbal and physical aggression (Lecavalier, Leone, & Wiltz, 2006) and absconding or elopement with the risk of drowning or other serious accidents (Jang et al., 2011; Matson, Mahan, Hess, Fodstat & Neal, 2010; Matson & Nebel-Schwalm, 2007; Rojahn et al., 2011).

Elopement is a serious risk factor for 50% of children and adolescents with ASD (Gorlin, McAlpine, Garwick & Wieling, 2016), usually commencing by age 4 and peaking at 5.5 years, with the risk increasing with the severity of ASD (Anderson et al., 2012). Anderson and colleagues (2012) reported that 24% of elopers were at risk of drowning and 65% were at risk of a traffic accident. Elopement is the highest cause of mortality for children with ASD aged between 5 and 10 years (Stewart, Knight, McGillivray, Forbes & Austin, 2017). Anderson and colleagues (2012) reported that 29% of children with ASD eloped several times a day, 35% at least once a week, and 43% of parents could not get a good night sleep due to remaining vigilant in keeping their child safe.

Self-injurious behaviours occur in approximately half of the children with ASD and include hitting themselves in the head, biting themselves on the arms or fingers, throwing themselves on the furniture, eye-poking and picking their skin creating lesions (Gorlin et al., 2016; Rojahn et al., 2011). Head-banging is common and one of the main causes of hospitalisation and mortality for children with ASD (Duerden et al., 2012). The typical age for self-harm is 11 – 25 years with an average age of onset of 12 years (Hannon & Taylor, 2013).

Suicidal ideation, suicide attempts and completions are more common in older adolescents with ASD than neurotypical adolescents (Hannon & Taylor, 2013). Higher functioning individuals have been shown to be more at risk of suicide because they have more cognitive capacity to plan and complete suicide, than those with diminished cognitive capacity (Culpin et al., 2018). Depression is common for adolescents with ASD. Risk factors include social isolation, abuse, being bullied and being male (Dickerson Mayes, Gorman, Hillwig-Garcia & Syed, 2013; Mandell, Walrath, Manteuffel, Sgro & Pinto-Martin, 2005). Children with ASD experience bullying at higher rates than neurotypical children or children with other disabilities, with some reports suggesting the rate to be as high as 94%, which may increase externalising behaviours and vicarious trauma for mothers (Mandell et al., 2005; Sreckovic, Brunsting & Abel, 2014).

Children with ASD are twice as likely to experience physical and sexual abuse than neurotypical children, leading to suicide attempts and running away (Mandell et al., 2005). Children with ASD are at the greatest risk of filicide-suicide, where 55% of children with disabilities murdered by their parents had ASD with an average age of 10.5 years (Coorg & Tournay, 2012). The tragic implication being that life with ASD is not worth living for the child or the parent and death is the only reprieve. Some behaviours may be experienced by mothers as trauma, where there is a danger to self or others or learning of traumas their child has experienced through bullying or abuse (Matson et al., 2010; Matson & Nebel-Schwalm, 2007; Rojahn et al., 2011).

The challenging behaviours of children with ASD often pose a threat to themselves, their carers and others (Padden et al., 2015), particularly mothers, who have the greatest exposure to these types of repetitive traumatic events (Conner & White, 2014; Totsika et al., 2011). Parent mental health outcomes have been shown to be similar for those with and without a child with ASD when challenging behaviour has been controlled for, suggesting that it may be the challenging behaviours that adversely affect the poorer mental health outcomes of mothers (Totsika et al., 2011).

**Trauma**

Trauma relates to events that pose a significant or perceived threat to the safety of the individual or their loved ones, and are shocking and overwhelming (American Psychiatric Association, 2013). Chronic stress due to trauma has been associated with lower cortisol levels and blunted cortisol responses which have been shown in veteran populations (Clancy et al., 2006), Holocaust survivors (Yehuda et al., 1995), first responders (Boyd et al., 2018; Walker et al., 2016) and individuals with posttraumatic stress disorder (PTSD; Appendix B). Similar patterns of blunted cortisol responses in mothers of adolescents and adults with ASD and challenging behaviours (Seltzer et al., 2010; Yehuda, Boisoneau, et al., 1995; Yehuda, Kahana, et al., 1995) indicates that a physiological trauma response may be occurring. This suggests that there may be a link between the challenging behaviours, which mothers may experience as trauma, and some associated symptoms similar to PTSD. In turn, these may contribute to the poorer physical and mental health outcomes experienced by mothers of children with ASD and challenging behaviours (Barker, Mailick, & Smith, 2014; Fairthorne et al., 2014; Johnson, Frenn, Feetham, & Simpson, 2011).

People who have experienced multiple traumas have shown greater vulnerability to developing PTSD (Bomyea, Risbrough & Lang, 2012; Parslow et al., 2006). The diathesis-stress model takes into account residual or situational, ecological and biological risk factors (Bomyea et al., 2012; McKeever & Huff, 2003) which has shown that the greater the intensity of these variables, the greater the risk to the individual of developing PTSD. The residual or situational variable refers to the severity of the trauma, which has been shown to be a primary risk indicator for PTSD (Bomyea et al., 2012; Fontana & Rosenheck, 1994; McKeever & Huff, 2003). Mothers of children with ASD may experience severe trauma, such as the elopement or injury of their child. The repetition of trauma (Lecavalier, Leone, & Wiltz, 2006; Schieve, Blumberg, Rice, Visser, & Boyle, 2007), which creates a higher dosing effect (Yehuda et al., 2008; Yehuda, Kahana, Schmeidler, et al., 1995), increases the risk of developing PTSD symptomology. The ecological pathway refers to the support systems and environment of the individual. It has been found that chronic or prolonged exposure to stress increases the risk of developing PTSD (Bomyea et al., 2012; Parslow et al., 2006; Shepherd & Wild, 2014). It has been shown that mothers of children with ASD experience prolonged and intense levels of stress (Johnson et al., 2011; Keen et al., 2010; Lecavalier et al., 2006; Schieve et al., 2007). In addition, social support systems have been shown to diminish due to the behavioural challenges of the child (Bromley et al., 2004; Kuhn & Carter, 2006), whereby isolation and stress are increased, adding risk factors for the development of PTSD symptomology. Completing the diathesis-stress model, biology may contribute predisposing risk factors to the development of PTSD such as hereditary neurobiological vulnerabilities resulting from changes which may have occurred due to parental exposure to trauma (McKeever & Huff, 2003).

The DSM-5 definition of PTSD (APA, 2013) recognises witnessing or hearing about the traumatic event of a loved one and includes repeated traumas or dosing, as risk factors for the development of PTSD (Yehuda, Boisoneau, et al., 1995). The repeated and dangerous behaviours of a child with ASD fit the trauma criteria, placing mothers of children with ASD and behavioural challenges, at an increased risk of developing PTSD. Previous studies have shown the rate of PTSD among mothers of children with ASD to be 20%. One study where participants were predominantly mothers, found that receiving the diagnosis of ASD for their child was itself a traumatic event, where mothers subsequently experienced flashbacks and avoided triggering memories of the diagnosis being given (Casey et al., 2012). A qualitative study found mothers of children with ASD reported PTSD symptoms related to the challenging behaviours of their child, where there was a severe threat of injury or death to the child, the parent or others due to the behaviour of the child with ASD (Stewart et al., 2017).

**Risks to Mothers of Children with ASD**

ASD and associated hyperactivity, behavioural and emotional problems of the child, has been shown to put the mental health of the mother at greater risk than mothers of neurotypical children (Totsika et al., 2011). The constant and repeated first hand and vicarious trauma resulting from repetitive and sterotypied self-harm, suicidal ideation, elopement and hearing of abuse to their child, have been shown to have negative outcomes for mothers already at risk of poorer physical and mental health, and premature death, compared to the general population (Fairthorne et al., 2014). Mothers of children with ASD are 40% more likely to die of cancer, 150% more likely to die of cardiovascular disease and 200% more likely to die from misadventure (Fairthorne et al., 2014). They experience increased depression and reduced quality of life (Zablotsky, Anderson, & Law, 2013). There is often a significant impact on the mother’s ability to socialise (McStay, Trembath & Dissanayake, 2014; Vasilopoulou & Nisbet, 2016) and work (Meirsschaut, Roeyers & Warreyn, 2009; Vasilopoulou & Nisbet, 2016), which in turn, can increase isolation and mental health risk factors.

The externalising behaviours of children with ASD have been strongly associated with high levels of stress for mothers (Lecavalier et al., 2006). Up to 79% of parents report high levels of stress and 88% report behavioural management problems (Dickerson Mayes et al., 2011). The Aggravation in Parenting Scale was developed to measure the levels of frustration and stress parents experience related to caring for their children (Schieve et al., 2011). Mothers have shown higher levels of aggravation in parenting, reporting their child was harder to care for and did things that bothered them a lot. They felt angry and that they had given up more of their life to meet the needs of their child than expected (Estes et al., 2013). Often children with ASD have persistent patterns of crying, not sleeping, agitation and tantrums, where the parent spends considerable time dealing with ‘meltdowns’ (Gorlin et al., 2016). Approximately half of the children with ASD experience high anxiety, depression and irritability (Hannon & Taylor, 2013). The greater the symptomology of ASD, and the greater the number of comorbid psychiatric disorders occurring for the child, the greater the risk to the mother of developing depression and having a lower quality of life (Zablotsky et al., 2013). Challenging behaviours may contribute to diminished feelings of parenting self-efficacy for mothers who experience persistent failure in managing the behaviours of their child, which then impacts negatively on their resilience and coping capacity (Keen et al., 2010; Limonero et al., 2014; Meirsschaut et al., 2009).

**Resilience**

Resilience is the ability to face stress in an adaptive manner, where risk factors and protective factors such as social and personal supports (Tsai et al., 2012), are brought into a positive balance (Bekhet et al., 2012). Lower self-efficacy in mothers of children with ASD has been shown to increase depression over time and has been associated with the mother’s feelings of guilt and parental stress (Bayat, 2007). Coping skills relate to the ability of an individual to use behavioural and cognitive strategies which may be active or avoidant (Tsai et al., 2012). Many mothers have developed positive adaptive coping skills that may moderate negative outcomes for mothers of a child with ASD and challenging behaviours (Bekhet et al., 2012). Active coping strategies include cognitive restructuring to change the perception of the stressor or problem solving. Avoidant coping is the use of thoughts and actions to avoid the stressor such as avoidance of social situations or wishful thinking (Tsai et al., 2012). Avoidant coping styles and lower resilience have been shown to be predictive for the development of PTSD (Daniels et al., 2012; Hooberman, Rosenfeld, Rasmussen & Keller, 2010). All mothers will not respond to the challenges they face in the same way (Schieve et al., 2011). Resilience and coping skills may be protective factors for mothers, enabling them to grow through experience and thrive through positive adaption to the circumstances (Bayat, 2007; Gerstein, Crnic, Blacher & Baker, 2009).

**Aims and Significance of the Present Study**

With increasing numbers of families living with a child with ASD (Da Paz & Wallander, 2017), it is important to understand the psychological impact of the associated challenging behaviours. Mothers often provide the majority of unpaid primary support for their child, which may come at the expense to their own wellbeing and mental health (Fairthorne et al., 2014; Padden et al., 2015). The aim of this study was to test a conceptual model of the precursors to PTSD symptomology in mothers of children with ASD and challenging behaviours. This research will explore the relationship between the challenging behaviours of a child with ASD and the resulting state of the mother, measured using a PTSD framework. Other traumatic experiences not related to their child, and aggravation in parenting will be measured. In addition, the potential role of resilience and coping skills, as moderators of the relationship between aggravation in parenting and PTSD symptoms, will be tested. It has been shown that mothers of children with ASD experience high levels of depression, anxiety and stress (Da Paz & Wallander, 2017; Estes et al., 2013; Johnson et al., 2011), which have been controlled for in this model. This model (see Figure 1) proposes the following hypotheses:

**Hypotheses**

1. There will be a relationship between the challenging behaviours of the child with ASD and PTSD symptoms experienced by the mother, which will be mediated by maternal aggravation in parenting.
2. There will be a relationship between previous traumatic events experienced by the mother, and PTSD symptoms experienced by the mother, which will be mediated by maternal aggravation in parenting.
3. The relationship between aggravation in parenting and PTSD will be moderated by resilient coping.

**Method**

**Ethics Statement**

Approval to conduct this study was granted by the Curtin University Human Research Ethics Committee (Appendix C).

**Participants**

Participants were 220 mothers of a child or children with ASD, living in Australia, recruited from ASD support groups using snowball sampling on the Facebook social media platform (Appendix D, E). Demographic information is included in Table 1. It was found that 79% of respondents were born in Australia, 73% had one child with ASD, while 27% had more than one child with ASD, 78% were partnered, and 55% had a bachelor’s degree or higher, 15% worked full-time and 44% reported being unable to work due to caring for their child with ASD.

Table 1

*Demographic Characteristics of Mothers of Children With ASD*

|  |  |
| --- | --- |
|  | Number of participants (%) |
| Age of mothers |  |
| 18-25  26-35  36-45  46-55  56-65  65+  Relationship status  Single  Partnered  Separated divorced  Education completed  Less than Year 10  Year 10  Year 12  Bachelor  Master  Doctorate  Other  Working  35> hours a week  35< hours a week  Unemployed  Student  Unable due to the caring role  Place of birth  Australia  Elsewhere  State of residence  Queensland  New South Wales  Tasmania  South Australia  Northern Territory  Western Australia  Age of children  1-5  6-10  11-16  Children with ASD  1  2  3  4  Child lives with mother  Full time  50> | 2 (0.91)  38 (17.27)  118 (53.63)  59 (26.82)  3 (1.36)  0  24 (10.91)  172 (78.18)  24 (10.91)  4 (1.82)  26 (11.82)  37 (16.82)  87 (39.55)  30 (13.64)  5 (2.72)  31 (14.10)  34 (15.45)  77 (35)  5 (2.27)  8 (3.64)  96 (43.64)  174 (79.10)  46 (20.91)  11 (5)  27 (12.27)  0  3 (1.36)  1 (0.45)  106 (48.18)  30 (13.64)  98 (44.55)  92 (41.82)  160 (72.73)  47 (21.36)  9 (4.10)  4 (1.82)  196 (89.10)  24 (10.91) |

**Procedure**

Participants were invited to click on a link to the online survey using the Qualtrics platform where 155 questions were answered, taking approximately 20 minutes.

**Measures**

**The Nisonger Child Behaviour Rating Form.** The Nisonger Child Behaviour Rating Form – Parent Version Part III (NCBRF-P; Aman, Tassé, Rojahn, & Hammer, 1996) is a 66 item scale (Appendix F) used to rate problem behaviour using a four point Likert scale ranging from 0 (the behaviour did not occur or was not a problem) to 3 (the behaviour occurred a lot and was a severe problem). Problem behaviour items have six subscales: Conduct Problems, Insecure/Anxious, Hyperactive, Self-Injury/Stereotypic, Self-Isolated/Ritualistic and Overly Sensitive. Mothers rated those behaviours over the last month (Aman et al., 1996; Norris & Lecavalier, 2011). The mean internal consistency value (Cronbach’s α) was 0.85 (Rojahn et al., 2010). The sub-scales were summed to give an overall behaviour score.

**The Life Events Checklist**. The Life Events Checklist (LEC-5; Appendix G; Weathers et al., 2013) is a 17 item self-report questionnaire designed to screen for potentially traumatic events in a respondent’s lifetime. Mothers rated their experiences over a lifetime using six response options (happened to me, witnessed it, learned about it, part of my job, not sure, doesn’t apply). The LEC-5 has adequate psychometric properties as a stand- alone measure of lifetime trauma with good interrater reliability across all items (kappa=.61) and retest reliability (*r* = .82, *p* < .001 Gray et al., 2004). The LEC-5 was not designed to be scored with clinical cut off points but used more as an indicator of Criterion A in the diagnosis of PTSD. In this study, the summed scores were used as a comparison measure as part of the proposed model.

**The Aggravation in Parenting Scale**. The Aggravation in Parenting Scale (Appendix H; Yu & Singh, 2012) is a four item self-report questionnaire and consists of four questions rated over the past month using a four point Likert scale ranging from 1 (none of the time) to 4 (all of the time). The instructions included, ‘Keeping in mind the experience of parenting your ASD child’ (Stewart, et al., 2017). Scores range from 0-16. Scores above 6 indicate high aggravation in parenting, where a normative population would score 2.1 (Yu & Singh, 2012). Good internal consistency has been reported for this scale (Cronbach’s α = 0.63, Yu & Singh, 2012).

**The Brief Resilient Coping Scale.** The Brief Resilient Coping Scale (BRCS; Sinclair & Wallston, 2004) is a four item self-report questionnaire with a five point Likert scale ranging from 1 (does not describe me at all) to 5 (describes me very well, Appendix I). The BRCS measures the tendency to cope with stress in an adaptive manner (Sinclair & Wallston, 2004). Scores range from 4-20 with low resilient copers having scores of 4-13, medium resilient copers 14-16 and high resilient copers 17-20. Psychometric properties reported for this scale are test-retest reliability of .71 and internal consistency of α = .69 (Sinclair & Wallston, 2004).

**The PTSD Checklist for DSM-5**. The PTSD Checklist for DSM-5 (PCL-5; Blevins, Weathers, Davis, Witte & Domino, 2015) is a 20 item self-report questionnaire that measures the presence and severity of PTSD symptoms (Appendix J). Items on the PCL-5 correspond to the DSM-5 criteria for PTSD and may be used as a screening tool for making a provisional diagnosis of PTSD. Mothers will rate their symptoms over the last month on a five point Likert scale ranging from 0 (not at all) to four (extremely). The question was adapted to include, ‘Keeping in mind the experience of parenting your ASD child’ (Stewart et al., 2017). The PCL-5 provides a total symptom distress score ranging from 0-80, and symptom clusters align with the DSM-5 PTSD criteria. A provisional diagnosis of PTSD may be made when the total score exceeds 33. The PCL-5 has good internal consistency (Cronbach’s alpha = .94) and test-retest reliability (r = .82, Blevins et al., 2015).

**The Depression, Anxiety, Stress Scale.** The Depression, Anxiety, Stress Scale (DASS-21; Lovibond & Lovibond, 1995) is a 21 item self-report questionnaire with a four point Likert scale with responses ranging 0 (not me at all) to 3 (most of the time) related to the previous seven days (Appendix K). Cronbach’s α for the DASS-21 subscales are .94 for depression, .87 for anxiety and .91 for stress (Antony, Bieling, Cox, Enns & Swinson, 1998).

**Data Analysis**

**Statistical procedure*.*** MPlus (Version 5.2; Muthén & Muthén, 2008) was used to test the overall fit of the model (Figure 1) and the significance of each of its direct and indirect effects. Standard errors for each effect was estimated with a bootstrapping procedure based on 1000 draws from the data. In addition, the reliability of each of the psychometric scales was input to the MPlus analysis in order to accommodate the measurement error inherent in such scales.

**Sample size*.*** In order to reliably test the structural equation model (SEM), it was recommended to include at leastfive participants for each free parameter in the model, although 20 participants per free parameter are the ideal (Kline, 2005). A free parameter is a parameter that must be estimated from the sample data. The free parameters in the structural equation SEM include the path coefficients (5 parameters), the disturbances of the endogenous variable (2 parameters), and the variances of the exogenous variables (4 parameters). The minimum sample size for testing this SEM would, therefore, be 5[5 + 2 +4] =55. Approximately 110 participants would represent an adequate sample size.

**Results**

**Descriptive Statistics**

The total score for behavioural challenges measured using NCBRF-P (*M =* 135.08, *SD =* 27. See Table 2 for subcategories and comparisons to norms).

Table 2

*Assessment Results for the Nisonger Child Behaviour Rating Form – Parent Report (NCBRF)*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Assessment | Means | Standard Deviations | Averaged norms for children aged 4-16 years | Standard Deviations |
| Total Score (NCBRF) | 135.08 | 27 | 63.41 | 4.77 |
| Sub-scales of NCBRF |  |  |  |  |
| Self-injurious/stereotypic | 14.26 | 3.67 | 2.89 | 4.15 |
| Self-isolated/ritualistic | 12.71 | 2.98 | 5.29 | 4.74 |
| Hyperactive | 23.12 | 5.09 | 13.05 | 7.53 |
| Conduct Problem  Insecure/Anxious | 31.98  27.70 | 9.07  7.27 | 17.65  7.12 | 12.83  7.31 |

Note: Norms for children aged between 4-16 years were averaged for comparison to the present data. This table shows that mothers of children with ASD reported higher scores for behavioural challenges for each sub-test and the overall total (Matson & Nebel-Schwalm, 2007).

Aggravation in Parenting scores (Table 3) were found to be high for 91.82% of mothers, (*M =* 9.10, *SD =* 2.53).

Resilient coping, measured using the BRCS (Table 3), found 68.64% of mothers of children with ASD reported low levels (*M =* 12.06, *SD =* 3.38).

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Table 3

*Assessment Results for Mothers of Children with ASD and Normative Data for Aggravation in Parenting, Resilient Coping and PTSD Symptomology*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Assessment | Mean | Standard Deviation | Clinically Significant Levels % | Norms % Clinically Significant |
| Aggravation in Parenting Clinically Significant High > 6 | 9.10 | 2.53 | 91.82 | 5.1 |
| Resilience (BRCS) Clinically Significant Low < 13 | 12.06 | 3.38 | 68.64 | 24.6 |
| Trauma (PCL-5) Provisional Diagnosis of PTSD > 33 | 23.67 | 15.04 | 31.36 | 4.4 |

*Note:* Norms for: Aggravation in Parenting from Yu and Singh (2012), BRCS from Kocalevent et al. (2017), PTSD from Cooper, Metcalf & Phelps (2014).

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Table 4

*Mothers of Children with ASD DASS-21 Scores in the Moderate to Extremely Severe Range*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Means | Standard Deviations | Extremely Severe *n* (%) | Severe *n* (%) | Moderate *n* (%) | Totals *n* (%) |
| Depression | 13.97 | 5.62 | 25 (11.36) | 16 (7.27) | 12 (5.45) | 53 (24.09) |
| Anxiety | 11.01 | 4.21 | 26 (11.82) | 10 (4.55) | 19 (8.64) | 55 (25) |
| Stress | 13.34 | 4.06 | 15 (6.82) | 22 (10) | 38 (17.27) | 75 (34.09) |

*Note:* The mean scores for depression fall into the severe range (11-13), anxiety the extremely severe range (10+) and stress the severe range (13-16).

**Testing the Mediation Moderation Model**

Data were visually inspected and incomplete data sets were removed from the sample leaving 220 complete data sets. MPlus (Version 5.2; Muthén & Muthén, 2008) was used to test the significance of each pathway in the model. Standard errors for each path coefficient were estimated with a bootstrapping procedure based on 1000 draws from the data. In addition, the reliability of each of the psychometric scales was input to the MPlus analysis in order to control for the measurement error inherent in such scales. The model, with its path parameters, is presented in Figure 1. Associations between demographic and end endogenous variables are presented in Table 5.

*β* = .719, *p* < .001

*β* = .741, *p* < .001

*β* = .111, *p* = .122*β* = - .041, *p* = .591

*Figure 1.* The mediation moderation model with path parameters. Significant pathways are highlighted with dashed lines. The full mediation moderation model is shown in Figure 1.

**Test of the Model.** The results indicate that the pathway from challenging behaviours to aggravation in parenting to PTSD was significant, supporting the first hypothesis. The first hypothesis was supported. The behaviour of the child did significantly affect levels of PTSD in the mother and was mediated by aggravation in parenting. The second hypothesis was not supported. Trauma unrelated to the behaviour of the child with ASD, experienced by the mother, did not significantly contribute to levels of PTSD in the mother. The third hypothesis was not supported. The pathway between aggravation in parenting and PTSD was not moderated by the resilient coping of the mother.

Table 5

*Associations Between Demographic Variables and Endogenous Variables (N = 220)*

|  |  |  |  |
| --- | --- | --- | --- |
|  | PTSD | Aggravation in Parenting | Resilience |
| State | 0.029 | 0.025 | 0.017 |
| Marital Status | 0.021 | 0.010 | 0.022 |
| Working Status  Education  Work  Full/Part-time  Country Born  Mother’s Age  Child’s Age  Number of Children with ASD | 0.022  -0.027  -0.012  -0.033  -0.164\*  -0.145\*  0.083 | 0.017  0.068  -0.040  -0.012  -0.072  -0.100  0.099 | 0.026  0.113  0.050  -0.003  0.099  0.082  0.041 |

*Notes: \* p* < .05, \*\* *p* < .01

The associations in Rows 1 – 3 are estimated by eta-squared; associations in Rows 4 – 9 are estimated by the Pearson correlation. On the basis of the significant associations reported in Table 1, mother’s age and child’s age were controlled when analysing the relationships between ‘aggravation’ and ‘PTSD’, and between ‘resilience’ and ‘PTSD’.

**Discussion**

This aim of this study was to further define the relationship between the challenging behaviours of a child with ASD and the stress response of mothers. It was found that 31.36% met the criteria for a provisional diagnosis of PTSD. Mothers surveyed were predominantly aged between 36-45 years, partnered and the children lived with them full-time. Slightly more than half of the participants reported being educated to the level of bachelor or above, higher than the Australian average of 24% (ABS, 2016). Few mothers reported working full-time, while almost half reported being unable to work due to the responsibilities of caring for their child. Typically up to 75% of mothers of children aged 6-14 years of age work full-time (ABS, 2016). Although the mothers surveyed were more highly educated than mothers in the general population, they were five times less likely to be employed full-time. The majority of mothers had one child with ASD, although four mothers reporting having four or more children with ASD.

**Comparing the Results with the General Population**

The NCBRF-P scores indicated that the overall behaviour score for the children with ASD was double the norms reported for neurotypical children (Matson & Nebel-Schwalm, 2007). Self-injurious and stereotypic behaviours were almost five times, insecure and anxious behaviours were almost four times, self-isolated and ritualistic behaviours were almost two and a half times, hyperactivity and conduct problems were almost double the norms for neurotypical children. The scores confirm that mothers of children with ASD experience a higher frequency and intensity of challenging behaviours than mothers of neurotypical children.

The LEC-5 indicated that many mothers had experienced various other traumatic events such as having witnessed a murder, having been raped or held in captivity, as well as having experienced disasters. Previous trauma did not contribute significantly to the model, as hypothesised, which was unexpected, as the cumulative effect of trauma has been documented (Yehuda, et al., 1995). The results of the LEC-5 indicate that the lack of significance was not due to participants not having experienced other trauma, but that previous trauma did not influence the levels of PTSD symptomology in this sample.

Aggravation in Parenting scores were found to be high for 91.82% of mothers, which was higher than previously reported for parents of children with ASD (36.6%) and 18 times higher than for parents of neurotypical children (5.1%, Schieve et al., 2011). The difference in this study could be due to the severity of ASD in this population, where a greater severity of behavioural, emotional and health challenges with the child with ASD has been associated with greater ‘Aggravation in Parenting’ scores. The type of medical care and insurance was referred to by Schieve et al. (2011) where some children were being cared for out of home, which may have produced a lower rate of aggravation for parents. Although data is not available, it could be hypothesised that Australian parents may experience higher ‘Aggravation in Parenting’ scores due to increased appointments for assessments in order to access the National Disability Insurance Scheme. An increase in appointments for assessments or interventions has been shown to increase the level of aggravation a parent may experience (Schieve et al., 2011). This study indicates that this sample of mothers were well educated, but almost half (44%) reported being unable to work due to caring responsibilities, which may have led to an increase in aggravation, where mothers are unable to follow their chosen path.

The majority of mothers (68.64%) were found to have low levels of resilient coping, at three times the normed rate for females in the same age group (Kocalevent et al., 2017).

The prevalence of PTSD in an Australian civilian population in a 12 month period has been reported to be 4.4% (Cooper et al., 2014). The PCL-5 indicated that almost a third (31.36%) of mothers met the criteria for a provisional diagnosis of PTSD, which is seven times the rate of the Australian population. The present study was 11% higher than previously reported rates of PTSD symptomology among mothers of children with ASD (Casey et al., 2012; Stewart et al., 2017). The present study used a score of 33 as the clinical cut off, recommended by the authors of the PCL-5, to determine a provisional diagnosis of PTSD (Blevins et al., 2015). Another study (Stewart, 2017) elected to use a higher clinical cut off score of 38 to determine a provisional diagnosis of PTSD, which returned a lower rate of 18.6% of parents, predominantly mothers, experiencing PTSD symptomology. The difference to the present study may be accounted for due to having seven fathers, rather than all mothers, in the participant group, as men report lower rates of PTSD than women (Peirce, Burke, Stoller, Neufield & Brooner, 2009; Yehuda et al., 2008), and the selection of a more stringent cut point, five points higher than the present study.

Scores reported using the DASS-21 indicate that mothers of children with ASD experience symptoms related to depression at six times the rate, anxiety at seven times the rate and stress at three times the rate, of a typical population aged between 25 – 90 years (Crawford, Cayley, Lovibond, Wilson & Hatley, 2011). This result supports previous research findings that mothers of children with ASD experience high levels of depression, anxiety and stress reported by Lai et al. (2015), where the means for each subcategory were lower, but remained higher than the norms for this measure. The sample in Lai et al. (2015) was Singaporean Chinese which may account for some of the differences in mean scores, where it has been found that the DASS-21 may not translate reliably due to the collectivist culture in Asia where an 18 item DASS measure was found to more closely represent Asian culture (Oei, Sawang, Goh & Mukhtar, 2013)

**Interpreting the Findings of this Model**

This study found that the relationship between the challenging behaviours of children with ASD and PTSD in mothers was significant, mediated by ‘Aggravation in Parenting’ scores. For almost one-third of mothers, the challenging behaviours of the child were being experienced as severe enough to have met the diagnostic criteria for a provisional diagnosis of PTSD. This study further documents the link between the challenging behaviours of the child with ASD and a trauma response, with the associated symptomology for a subgroup of mothers (Schnabel et al., 2019; Stewart, et al., 2017; Totsika et al., 2011).

The challenging behaviours of children with ASD have been shown to increase stress and social isolation and decrease the quality of life and health (Fairthorne et al., 2014) of mothers. This study confirms that mothers of children with ASD experience a greater frequency, intensity and variety of challenging behaviours than mothers of neurotypical children (Aman et al., 1996). It is, therefore, unsurprising that mothers of children with ASD experience high levels of ‘Aggravation in Parenting’.

‘Aggravation in Parenting’ measures the level of stress and frustration parents experience in raising their children and is negatively associated with parental well-being and internal locus of control and positively associated with depression (Schieve et al., 2011). Children of parents with high aggravation have been found to be less mature socially and emotionally, and have lower levels of cognitive school readiness than their peers (Schieve et al., 2011). High scores in ‘Aggravation in Parenting’ have been linked to poor executive functioning in children who may have a reduced capacity to pay attention and self-regulate (Gee & Asim, 2018). The current study shows that mothers of children with ASD experience parenting aggravation at 18 times the rate of parents with neurotypical children. Previous research found 55% of parents of children with ASD experienced high levels of ‘Aggravation in Parenting’ compared to 11% for parents of typical children (Schieve et al., 2007). The rate of ‘Aggravation in Parenting’ increased to 66% for parents whose child with ASD had recently required additional special health care services (Schieve et al., 2007). ‘Aggravation in Parenting’ of a child with ASD was higher than parents of children with other disabilities, with child behaviour being one of the primary mediating factors. It was noted that other sociodemographic factors resulted in little variation in the level of parenting aggravation (Schieve et al., 2011). In this study, mothers reported that they found their child much harder to care for than most, their child did things that really bothered them a lot, they were giving up more of their life to meet the needs of their child than expected, and they felt angry with their child (Yu & Singh, 2012). A majority of mothers in this study reported high levels of ‘Aggravation in Parenting’, indicating decreased satisfaction and enjoyment of parenting. This research finds that the behaviours of the child with ASD significantly increased ‘Aggravation in Parenting scores. Due to diminished coping capacity, parents have reported greater parental stresses, lower satisfaction with the parent-child bond, more depression and anxiety, and greater use of avoidant coping strategies, than parents of neurotypical children (Lai et al., 2015).

These findings suggest that PTSD symptomology experienced by mothers, does not appear to be precipitated by other traumatic life events, unrelated to their child with ASD, such as child sexual abuse, physical violence or natural disasters for example. This result was unexpected as it has been shown that previous exposures to trauma may predispose individuals to developing PTSD (Briere et al., 2016; Suliman et al., 2009; Yehuda et al., 1995). Research has indicated that the PTSD dose-response curve, measured as the number of direct and indirect combat events, tended to reach a plateau at 25-30% (Yehuda et al., 2015). Those results are similar to this study, which may indicate the level of dosing and the severity of trauma that mothers experience through the repetitive behaviours of their child, may be a factor in explaining why this population of mothers have a higher rate of PTSD than infantry in combat or Vietnam veterans. Up to 89% of adults experience a traumatic event at least once in their lifetime (Breslau et al., 1998), but only 4.4% of the general population go on to develop PTSD (Creamer, Burgess & McFarlane, 2001). Mothers, therefore, may have recovered from previous trauma and not developed PTSD as a result of a specific traumatic event. This study indicates that previous trauma did not significantly influence PTSD symptomology in mothers of children with ASD, and the high rate of PTSD among mothers of children with ASD may be related to the behaviours of the child.

Resilient coping was expected to be a protective, moderating factor of PTSD in the model as it measures the tendency for an individual to cope with stress in an adaptive manner, experiencing lower levels of stress (Kocalevent et al., 2017). Greater resilience and coping have been found to moderate PTSD symptomology (Bensimon, 2012; Tsai et al., 2012) and provide a buffer against depression, anxiety and stress in mothers of children with ASD (Bitsika & Sharpley, 2013). However, in this research, the level of coping resilience did not moderate the risk of developing PTSD symptomology and was therefore not a protective factor for mothers of children with ASD as hypothesised in this model. This study found that almost 68.64% of mothers scored in the extremely low range for resilient coping which may have made detecting a significant beneficial relationship with high resilient coping difficult.

Depression, stress and anxiety are reported to be higher in mothers of children with ASD than the general population and has been shown to be related to the challenging behaviours of the child with ASD (Bitsika & Sharpley, 2013; Conner & White, 2014; Lai et al., 2015). This research confirms again that mothers of children with ASD experience elevated symptoms of depression, anxiety and stress at many times the rate of the general population. Individuals experiencing PTSD also report elevated levels of depression, anxiety and stress (Creamer et al., 2001). The relationship between these psychological markers, challenging behaviours and PTSD symptomology in mothers did not form part of this model but may benefit from further investigation.

This study suggests that a relationship exists between the challenging behaviours of a child with ASD and PTSD symptoms reported by mothers, which was mediated by ‘Aggravation in Parenting’. Almost a third of mothers reported symptoms severe enough to meet the criteria for a provisional diagnosis of PTSD. The severity of the trauma and the number of exposures have been shown to increase the risk of PTSD (Bomyea et al., 2012; Fontana & Rosenheck, 1994; Parslow et al., 2006; Sayed et al., 2015). Mothers of children with ASD experience both severity and repeated exposure to trauma through the behaviours of their child, potentially increasing their risk of developing PTSD.

Previous studies have shown that when parents, predominantly mothers, receive the diagnosis of ASD for their child, 20% experienced PTSD symptomology (Casey et al., 2012), a similar rate to an Australia qualitative study of mothers of children with ASD (Stewart, et al., 2017). In this study, linking the challenging behaviours of children with ASD, to PTSD symptomology in mothers, indicated a higher rate of PTSD symptomology than previously reported.

Lack of post-trauma support has been found to be the most predictive factor for PTSD in female Vietnam veterans, which was not the case for male veterans (Bomyea et al., 2012). Lack of social and family support, social rejection and the severity of the trauma were the most predictive causal factors for PTSD for veterans (Fontana & Rosenheck, 1994; Iversen et al., 2008; Resick et al., 2012). Sayed and Charney (2015) found that post-trauma access to resources such as social support was necessary for better outcomes and recovery (Bomyea et al., 20,12). Mothers of children with ASD may find themselves in the position of needing and wanting support following a traumatic behavioural event by their child, but feeling unable to reach out due to social rejection, the behaviour of the child (Papageorgiou & Kalyva, 2010), being socially isolated (Lecavalier et al., 2006; Roberts & Koenen, 2014), feeling ashamed they were unable to prevent the behaviour, fearful of being reported as a negligent mother, and fear of being judged and misunderstood (Sousa, 2011).

The loss of resources is a crucial factor in predicting vulnerability and the development of PTSD (Bomyea et al., 2012; Fontana & Rosenheck, 1994). Mothers of children with ASD have reported the loss of social resources (Zaidman-Zait et al., 2017) and support through isolation due to the behaviour of their child (Anderson et al., 2012; Kuhn & Carter, 2006; Zablotsky et al., 2013). The loss of financial resources and being unable to work due to their caring role has been highlighted in this study where only 15% of mothers reported working full-time and almost 44% reported an inability to work due to their caring role. Furthermore financial strain in families with a child with ASD has been found to be associated with lower engagement with community-based support services (Papageorgiou & Kalyva, 2010).

**Implications**

PTSD has been shown to decrease parenting satisfaction and the quality of the relationship between children and parents (Casey et al., 2012; Leen-Feldner et al., 2013). PTSD in mothers not only poses a risk to themselves and the child with ASD but also to other children in the family (Creamer et al., 2001). Research related to parents with PTSD indicates that the children, as well as parents, experience negative biopsychosocial effects, showing a strong intergenerational transmission of stress (Leen-Feldner et al., 2013). It has been observed that when PTSD was present in mothers there was a four times increase in the likelihood of the children developing PTSD (Leen-Feldner et al., 2013; Schmid et al., 2013). The children may be more at risk of developing internalising disorders, behavioural problems, changes in their HPA-axis functioning and poorer mental health outcomes (Leen-Feldner, Feldner, Bunaciu, & Blumenthal, 2010; Leen-Feldner et al., 2013). There is a stronger association between mothers with PTSD and children developing PTSD than fathers with PTSD (Yehuda, Boisoneau, et al., 1995). The risk factors for children developing PTSD increases when both parents have PTSD (Yehuda et al., 2015). At this time it is unknown whether fathers may also develop PTSD symptoms as a result of the challenging behaviours of their child with ASD.

Parents with PTSD experience functional impairment and may expose their children to some adverse symptoms of the disorder such as dysregulated mood, behaviours and cognitions which may create vulnerability for the child to PTSD and other mental health conditions (Danielson, Hankin, & Badanes, 2015; Leen-Feldner et al., 2013; Padden et al., 2015; Roberts & Koenen, 2014; Schechter et al., 2005). Levels of conflict within families are often elevated and parents may be likely to over-react when disciplining, using anger, hostility and violence and an increased risk of child abuse (Coorg & Tournay, 2012). Mothers with PTSD have been shown to have lower engagement with their children and difficulty with attachment (Schechter et al., 2005). Studies have shown PTSD is often comorbid with depression, anxiety, and substance use which adds a further potential risk for mothers and their families (Creamer et al., 2001; Walker et al., 2016; Yehuda et al., 2015). These potentially negative outcomes have been reinforced, with this study confirming that mothers experience high levels of parenting aggravation.

These findings have important implications for mothers of children with ASD and the people and agencies supporting them and their children. The results add to the growing body of evidence that mothers of children with ASD not only experience stress but some, more specifically, trauma. This research indicates that it could be important to screen mothers of children with ASD for PTSD, and offer supports and interventions. Intervention points could include the behaviour of the child, reducing the level of aggravation in parenting that mothers experience to minimise the negative impact on mothers, their children and their families.

**Limitations**

This study offers a number of valuable insights into the nature of stress experienced by mothers of children with ASD in relation to the behaviour of their child, however, there are a number of limitations. This data was collected using snowball sampling which has the potential for bias and may not be representative of the population being researched. In this sample, the majority of mothers were partnered, born in Australia with high levels of education. The results may differ if the sample was reflective of the general population with more single participants, those with less education and more ethnic diversity. Lower education and less social support resources have been found to increase the risk for elevated scores in ‘Aggravation in Parenting’ and PTSD and lower resilience, in which case the rate of PTSD may be higher in a more representative sample. The data were collected using anonymous self-reports and symptom checklists rather than gold-standard diagnostic assessments administered by a trained clinician, however the time that would take was prohibitive for this research nationwide, using a large sample size. The rate of PTSD is double for females compared to males (Cooper et al., 2014), therefore this research may not generalise to fathers. The experience of fathers parenting a child with ASD has been shown to be different than mothers (Kuhn & Carter, 2006; Leen-Feldner et al., 2010; Papageorgiou & Kalyva, 2010; Wolf et al., 1989). It could be useful to find a way to reach this population to further enhance the understanding of both parent’s experiences.

**Future Research**

This research has shown that 31.36% of mothers of children aged 4-16 years with ASD met the criteria for a provisional diagnosis of PTSD. As such, investigating interventions to help minimise the impact of trauma on them and those they care for would be vitally important. Including other variables in the model could be illuminating, such as the gender of the child, the number of children with ASD and other co-morbidities of mother and child, as a potential risk factors. Further research may explore how mothers with children over 16 years of age compare in relation to trauma. It is unknown if mothers adapt and develop coping strategies with years of practice, or become worn down by the repeated ‘dosing’ of trauma. Future research may investigate posttraumatic growth scenarios, to discover if common themes for thriving in the situation may exist and if they could be replicated as protective factors for mothers. A model for assessing PTSD for mothers of children with ASD may be investigated in the future, to determine if using the PCL-5 is the best measure to capture the experience of this group of mothers. Comparisons to veterans have been made, where this group of mothers experience a higher rate of PTSD symptoms than Vietnam veterans, but it may not be the most appropriate comparison, and does such a sensational comparison help or hinder developing the most appropriate or useful interventions to support this group? Although a third of mothers in the current study reported PTSD symptoms, the other two thirds did not meet the diagnostic criteria so a further investigation of other protective factors may be enlightening, such as incorporating a measure for social and professional supports accessed by mothers. Further investigation into why some mothers reported low resilience, but did not report PTSD symptoms could include looking more in depth to specific behaviours of the child with ASD for example, to determine if some behaviours create greater vulnerability to PTSD symptoms than others. Additional questions may be asked about the mental state of the mother and whether medication has been used effectively to moderate some symptoms such as depression or anxiety, influencing outcomes. Future research may investigate the experiences of fathers of children with ASD and the relationship between the behavioural challenges of the child and the potential for the development of PTSD. Previous research has been limited by the small numbers of fathers who participate in research related to ASD. It could be useful to investigate the experiences of siblings to understand their level of trauma resulting from PTSD in their mother and the first-hand exposure to the dangerous and challenging behaviours of their sibling with ASD, with the hope of offering effective interventions and supports to reduce the negative impact on them. As ASD is a lifetime disability, and mothers will continue to be exposed to the behaviours of their child, exploring interventions that can support this group of mothers in the ongoing situation would be challenging, but much needed.

**Conclusion**

These findings have important implications for mothers of children with ASD and the people and agencies supporting them and their children. This study shows that a large subgroup of mothers of children with ASD meet the criteria for a provisional diagnosis of PTSD. Secondly, this study shows a strong relationship between the challenging behaviours of the child and PTSD symptomology in mothers, mediated by aggravation in parenting. The model indicates that previous traumatic life events and resilient coping did not contribute significantly to PTSD symptomology. The model may be simplified such that the challenging behaviours of a child with ASD, led to an increase in parental aggravation resulting in PTSD for almost a third of mothers in this study. Thirdly, this study confirms previous findings that children with ASD experience greater challenging behaviours than neurotypical children (Aman et al., 1996), with self-injurious behaviours and anxiety being four times that of neurotypical children. Fourthly this study confirms previous findings that mothers of children with ASD experience high levels of depression, anxiety, stress and aggravation in parenting. Finally, this study found 68.64% of mothers self-reported extremely low levels of resilient coping. Although resilient coping did not moderate PTSD in the proposed model, it highlights a cause for concern for the wellbeing of this group of mothers, the majority of whom feel their circumstances are beyond their capacity to cope.

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Appendix A

DSM-5™ Diagnostic Criteria Autism Spectrum Disorder 299.00 (F84.0)

A. Persistent deficits in social communication and social interaction across multiple contexts, as

manifested by the following, currently or by history

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of

behaviour.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of

behaviour.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

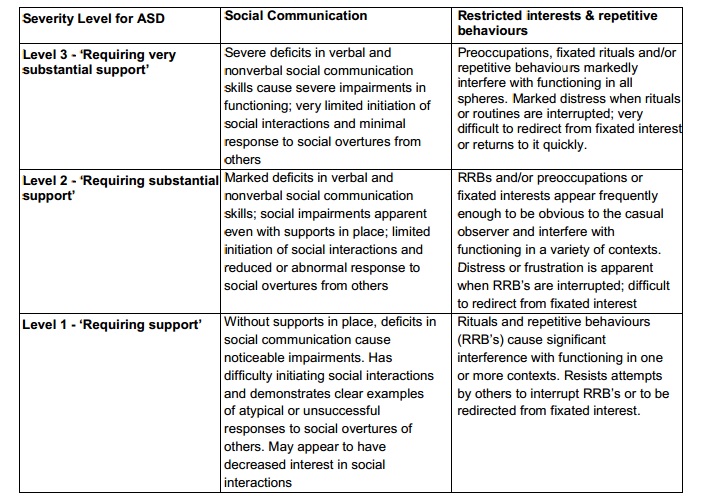
(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or

behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder

for definition)

(Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)



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Appendix B

DSM-5 Criteria for Posttraumatic Stress Disorder (PTSD)

In 2013, the American Psychiatric Association revised the PTSD diagnostic criteria in the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5)1. PTSD is included in a new category in DSM-5, Trauma- and Stressor-Related Disorders. All of the conditions included in this classification require exposure to a traumatic or stressful event as a diagnostic criterion.

Note that DSM-5 introduced a preschool subtype of PTSD for children ages six years and younger. The criteria below are specific to adults, adolescents, and children older than six years.

All of the criteria are required for the diagnosis of PTSD.

*Criterion A: stressor (one required)*

The person was exposed to: death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence, in the following way(s):

Direct exposure

Witnessing the trauma

Learning that a relative or close friend was exposed to a trauma

Indirect exposure to aversive details of the trauma, usually in the course of professional duties (e.g. first responders, medics).

*Criterion B: intrusion symptoms (one required)*

The traumatic event is persistently re-experienced in the following way(s):

Unwanted upsetting memories

Nightmares

Flashbacks

Emotional distress after exposure to traumatic reminders

Physical reactivity after exposure to traumatic reminders

*Criterion C: avoidance (one required)*

Avoidance of trauma-related stimuli after the trauma, in the following way(s):

Trauma-related thoughts or feelings

Trauma-related external reminders

*Criterion D: negative alterations in cognitions and mood (two required)*

Negative thoughts or feelings that began or worsened after the trauma, in the following way(s):

Inability to recall key features of the trauma

Overly negative thoughts and assumptions about oneself or the world

Exaggerated blame of self or others for causing the trauma

Negative affect

Decreased interest in activities

Feeling isolated

Difficulty experiencing positive affect

Criterion E: alterations in arousal and reactivity

Trauma-related arousal and reactivity that began or worsened after the trauma, in the following way(s):

Irritability or aggression

Risky or destructive behavior

Hypervigilance

Heightened startle reaction

Difficulty concentrating

Difficulty sleeping

Criterion F: duration (required)

Symptoms last for more than 1 month.

*Criterion G: functional significance (required)*

Symptoms create distress or functional impairment (e.g., social, occupational).

*Criterion H: exclusion (required)*

Symptoms are not due to medication, substance use, or other illness.

Two specifications: Dissociative Specification In addition to meeting criteria for diagnosis, an individual experiences high levels of either of the following in reaction to trauma-related stimuli:

Depersonalization. Experience of being an outside observer of or detached from oneself (e.g., feeling as if "this is not happening to me" or one were in a dream).

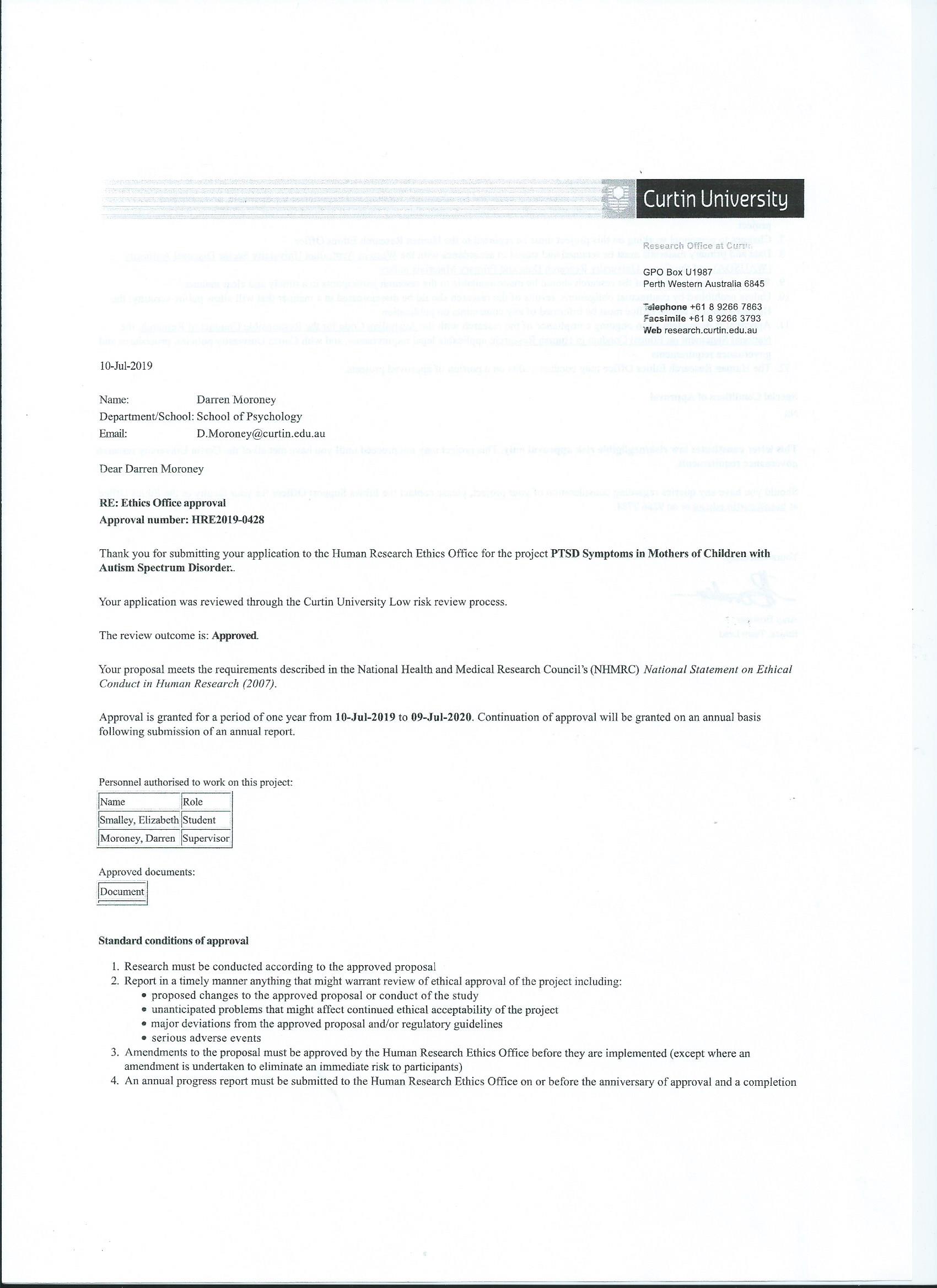
Derealization. Experience of unreality, distance, or distortion (e.g., "things are not real").

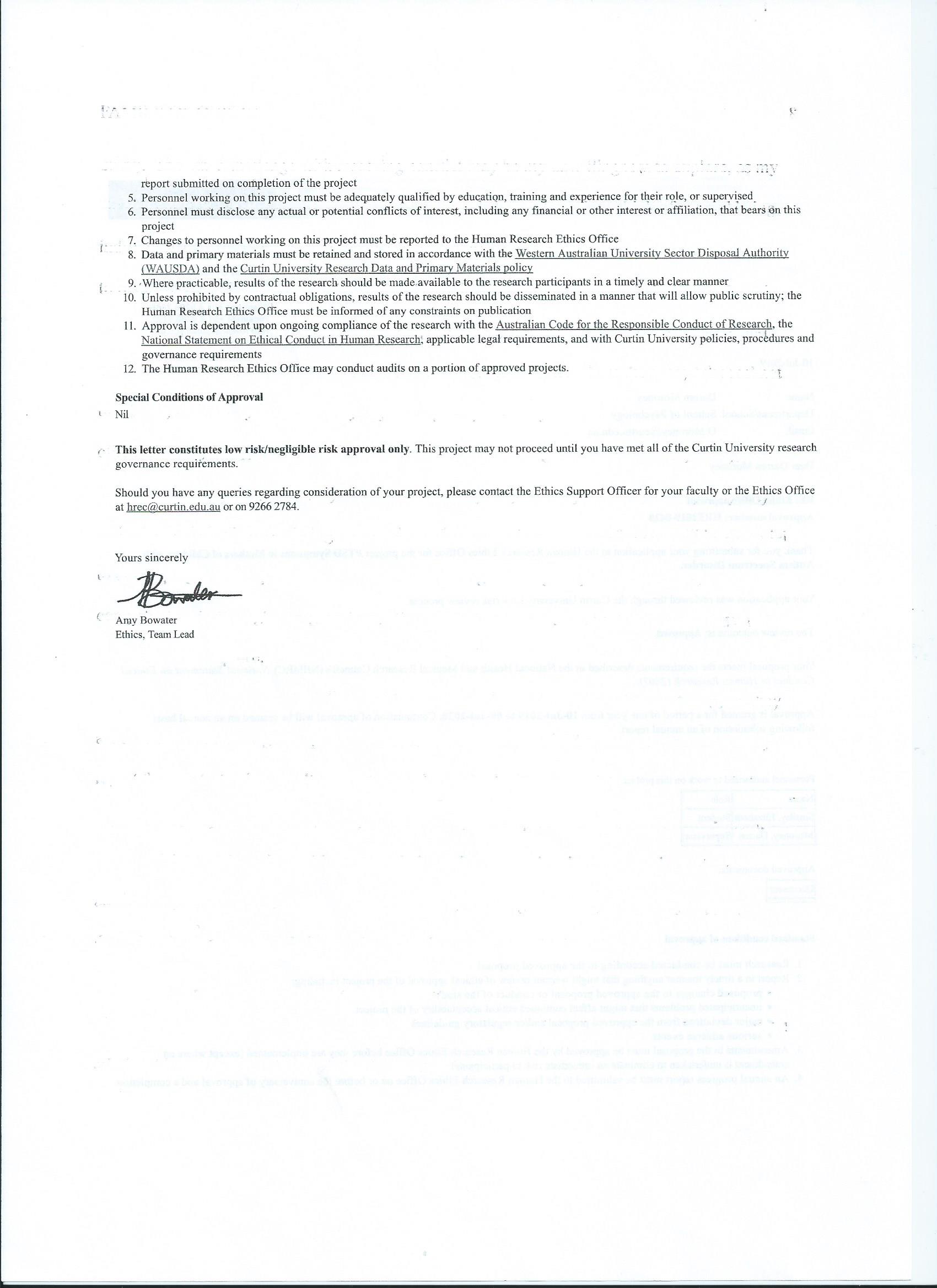
Delayed Specification. Full diagnostic criteria are not met until at least six months after the trauma(s), although onset of symptoms may occur immediately.

1 American Psychiatric Association. (2013) Diagnostic and statistical manual of mental disorders, (5th ed.). Washington, DC: Author.

Appendix C

Curtin University Human Research Ethics Approval





Appendix D

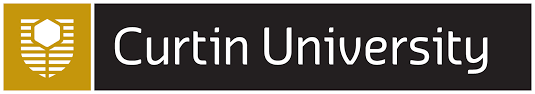


**Research participants wanted.**

If you are the mother of a child aged between 3 and 16 years old, who has been diagnosed with autism spectrum disorder, living in Australia, who lives with you more than half time, we would love to hear about your experiences. We hope that by hearing about your experiences we can help improve the lives of families living with autism. If you would like share your experiences with us anonymously, we have a short 15 – 25 minute multiple choice online survey. If you would like to know more please click on this link: <https://curtin.au1.qualtrics.com/jfe/form/SV_9uGmlxGRP69A67b>

Curtin University Human Research Ethics Committee (HREC) has approved this study (HRE2019-0428).

Appendix E

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*Mothers of Children With ASD*

**PARTICIPANT INFORMATION STATEMENT**

|  |  |
| --- | --- |
| **HREC Project Number:** | HRE2019-0428 |
| **Project Title:** | An Investigation of Stress and Resilience in Mothers of Children who have Autism Spectrum Disorder. |
| **Principal Investigator:** | Dr Darren Moroney, Academic, Curtin School of Psychology |
| **Student researcher:** | Elizabeth Smalley |
| **Version Number:** | 2 |
| **Version Date:** | 6/6/19 |

**What is the Project About?**

* Mothers of children living with autism spectrum disorder (ASD) often take the role of primary caregiver. This role can be challenging at times, and has been associated with elevated levels of stress. An emerging area of research is to explore the experiences of mothers, particularly in relation to their child’s challenging and/or dangerous behaviours.
* This project seeks to develop a better understanding of the nature and impact of the stresses experienced by mothers caring for a child with ASD, with the aim of informing improved interventions, supports, and mental health outcomes for caregivers and their families.
* We are seeking approximately 110 mothers to take part in this survey.

**Who is doing the Research**?

* This project is being conducted by Elizabeth Smalley, under the supervision of Darren Moroney, as part of the Master of Psychology (Counselling) program at Curtin University.
* There will be no costs to you and you will not be paid for participating in this project.

**Why am I being asked to take part and what will I have to do?**

* We are looking for mothers of children aged between 3 and 16 years with ASD.
* You will be asked to complete an online survey containing questions about your experiences as a parent, previous exposure to stressors, and your child’s behaviour.
* The questionnaire will take approximately 15-25 minutes to complete.

**Are there any benefits’ to being in the research project?**

* There may be no direct benefits to you for participating in this research, however, you may appreciate an opportunity to share your experiences and add to the growing body of research in this area.

**Are there any risks, discomforts, or inconveniences from being in the research project?**

* Other than giving up some of your time to complete the questionnaire, we do not expect that there will be any risks or inconveniences associated with taking part in this study. Some questions about past and present stresses may cause some discomfort. You may wish to stop answering questions and leave the survey, or you may reach out to the support services listed below.
* We have been careful to make sure that the questions in the survey do not cause you any distress.
  + If you do feel anxious about any of the questions, you do not need to answer them.
  + If any of the questions cause some concern or upset you, please contact the following services for support:
    - Your GP for a referral to a psychologist
    - Relationships Australia 1300 364 277
    - Centrecare 9325 6644
    - Lifeline (crisis support) 13 11 14

**Who will have access to my information?**

* + The information collected in this research will be non-identifiable (anonymous). This means that information is anonymous and will not include a code number or name. No one, not even the research team will be able to identify your information.
  + Any information we collect and use during this research will be treated as confidential.
  + Only the following people will have access to the information we collect: The researchers and the Curtin University Ethics Committee.
  + Electronic data will be stored on a password-protected computer.
  + The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended, and then it will be destroyed.
  + All data will be non-identifiable, so we will not be able to locate your set of responses, should you wish to access or remove them.
  + A summary of the results of this research may be presented at conferences or published in professional journals.

**Will you tell me the results of the research?**

* Once the project has been completed (2020), a summary of the overall results can be sent to you upon request. Please see contact details below.

**Do I have to take part in the research project?**

* Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to.
* If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just exit the survey. If you choose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues. We will be unable to destroy your information because it has been collected in an anonymous way.

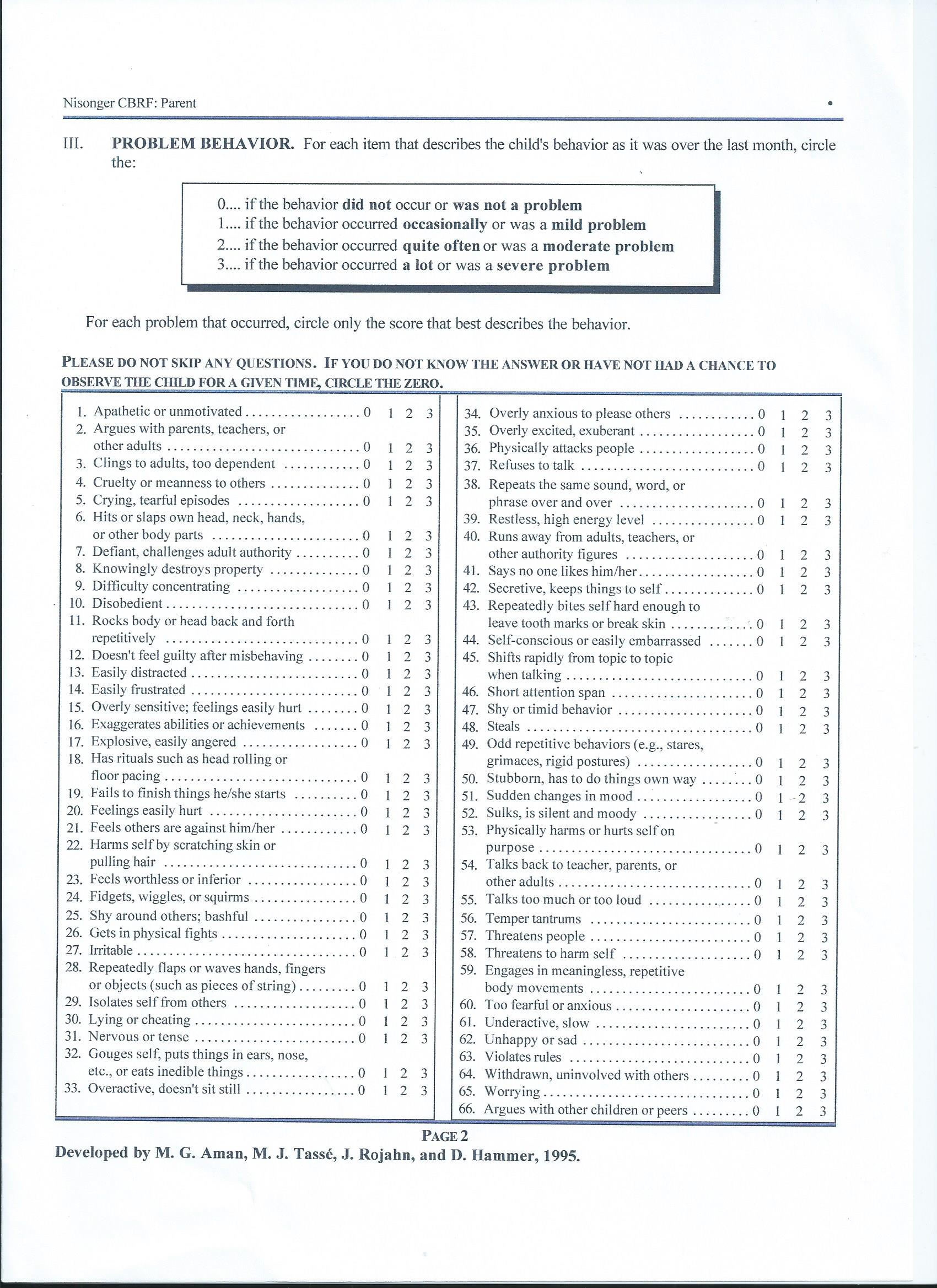
**What happens next, and who can I contact about the research?**

* If you would like to participate, please agree to the statement below by checking the box, and you will be directed to the online survey.
* If you have any further questions, you can contact:
  + Elizabeth Smalley e: elizabeth.smalley@postgrad.curtin.edu.au
  + Darren Moroney e: d.moroney@curtin.edu.au p: 9266 7279

The Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE 2019-0428). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

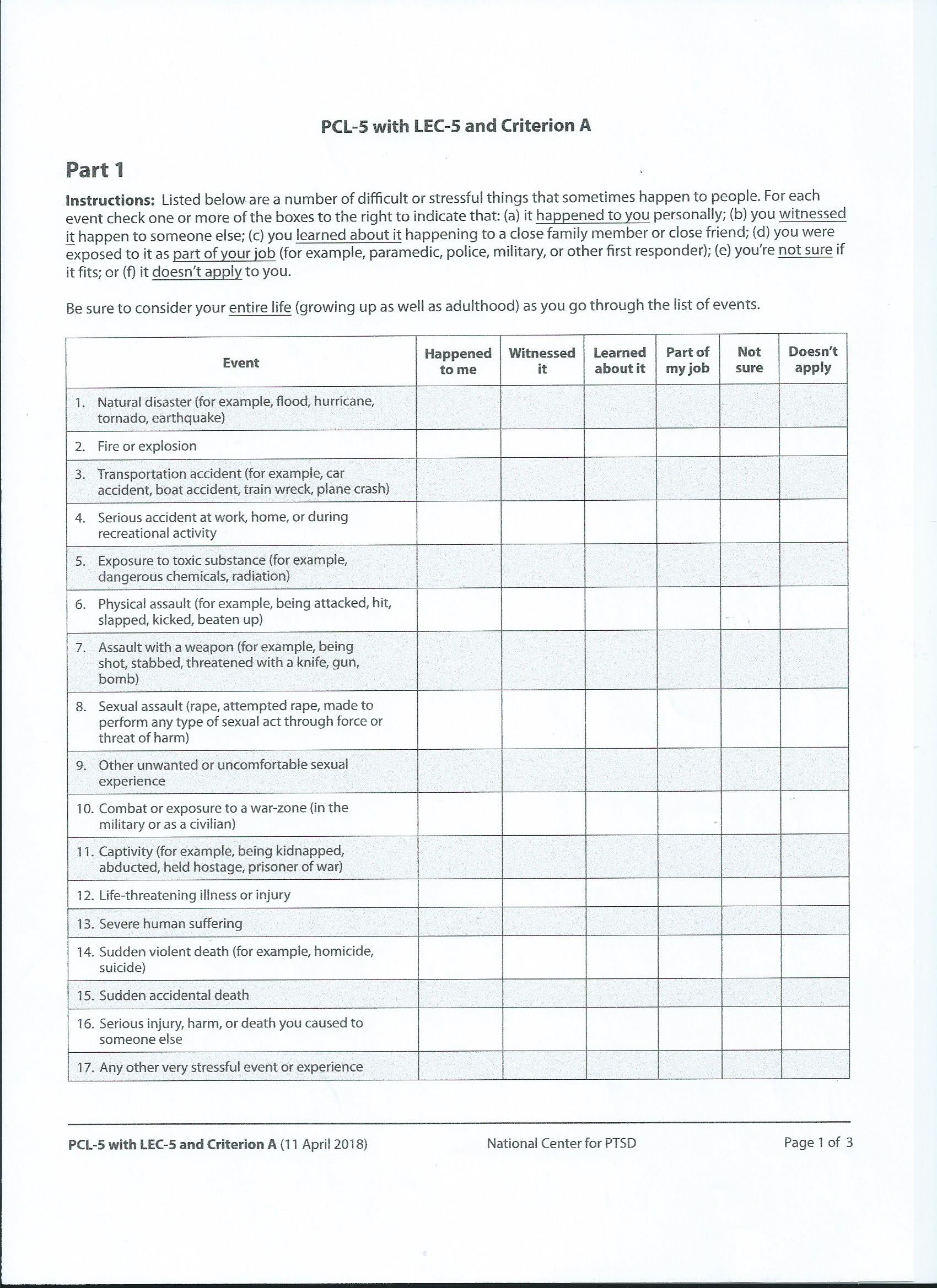
Appendix F

Nisonger Child Behaviour Rating Scale – Parent Report Part III (NCBRS)



Appendix G

Life Events Checklist – 5 (LEC-5)



Appendix H

Aggravation in Parenting Questionnaire

1. Over the last month have you felt you child with autism was much harder to care for than most children?

• None of the time

• Some of the time

• Most of the time

• All of the time

1. Over the last month have you felt your child with autism did things that really bothered you a lot?

• None of the time

• Some of the time

• Most of the time

• All of the time

1. Over the last month have you felt you were giving up more of your life to meet the needs of your child with autism?

• None of the time

• Some of the time

• Most of the time

• All of the time

1. Over the last month have you felt angry with your child with autism?

• None of the time

• Some of the time

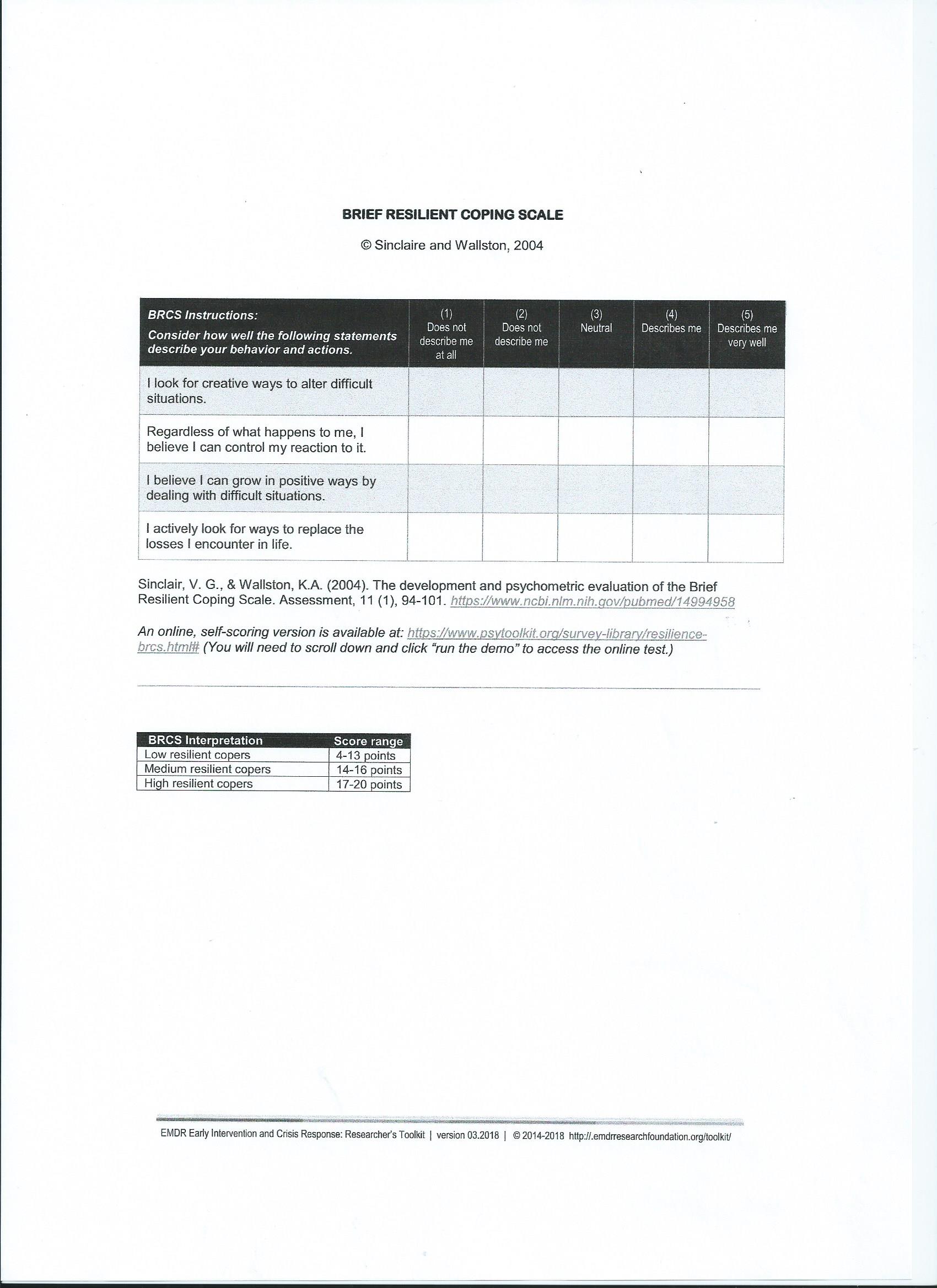
• Most of the time

• All of the time

Adapted from Yu & Singh (2012)

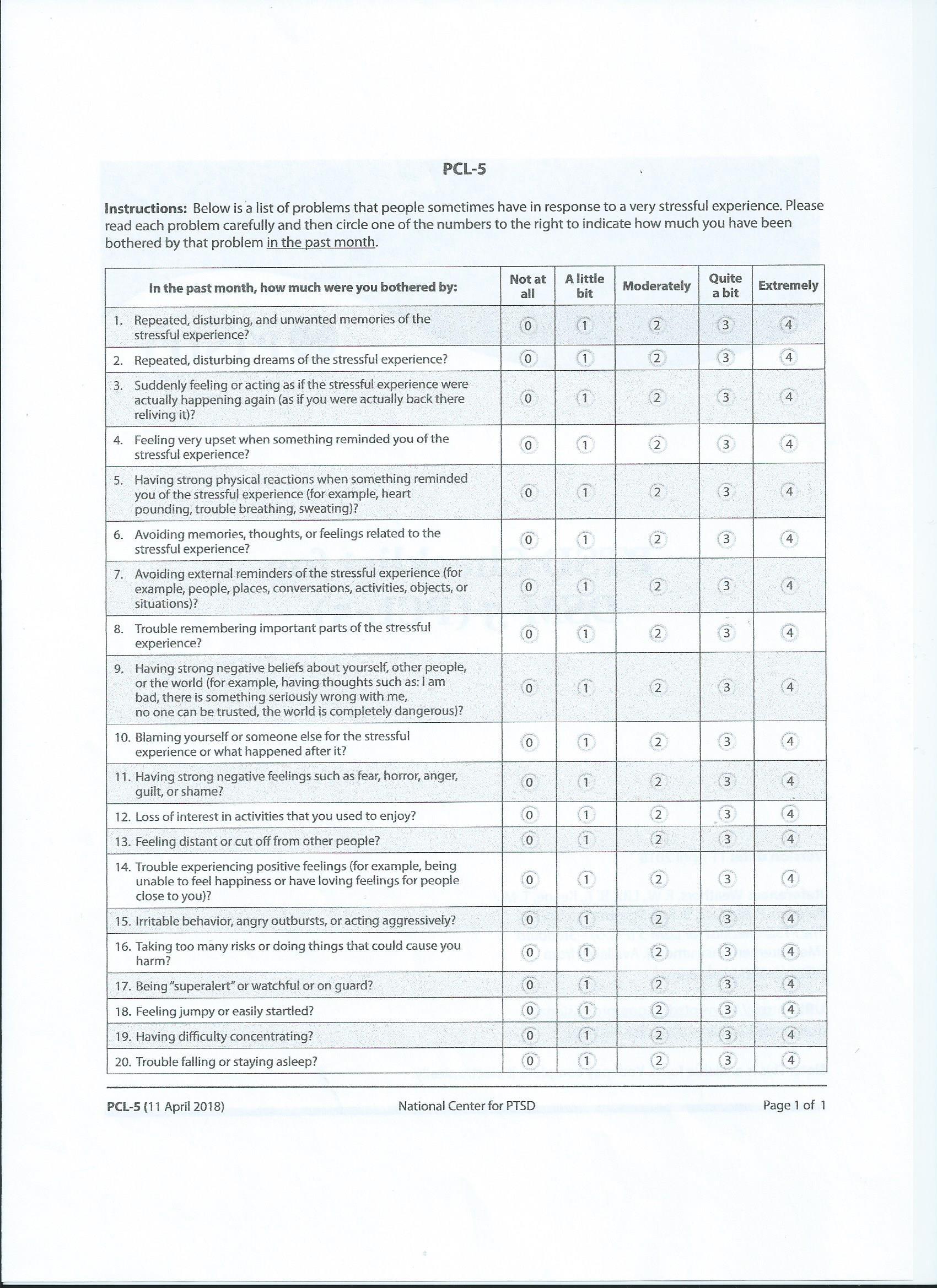
Appendix I

The Brief Resilience Coping Scale (BRCS)



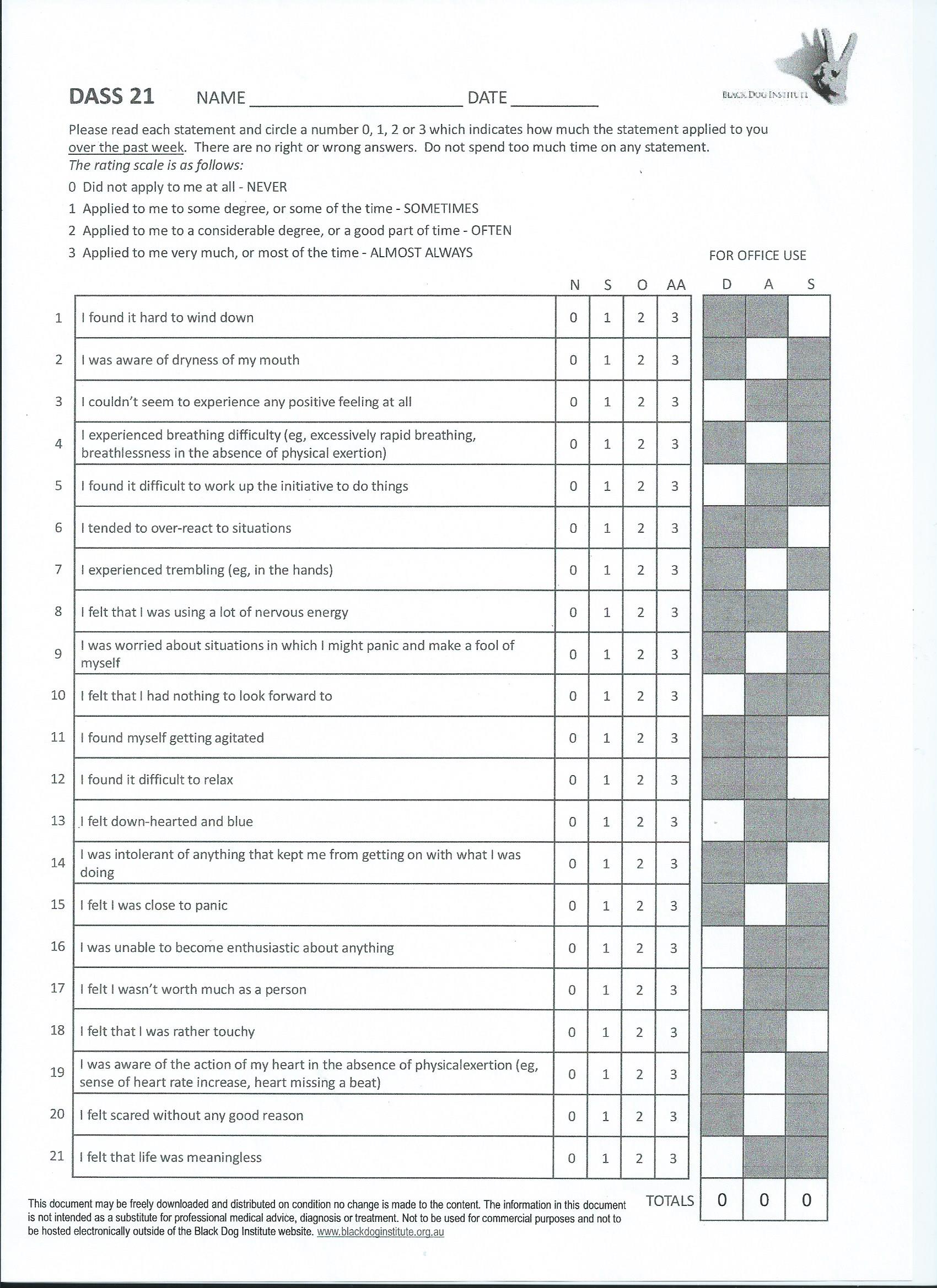
Appendix J

Posttraumatic Stress Checklist – 5 (PCL-5)



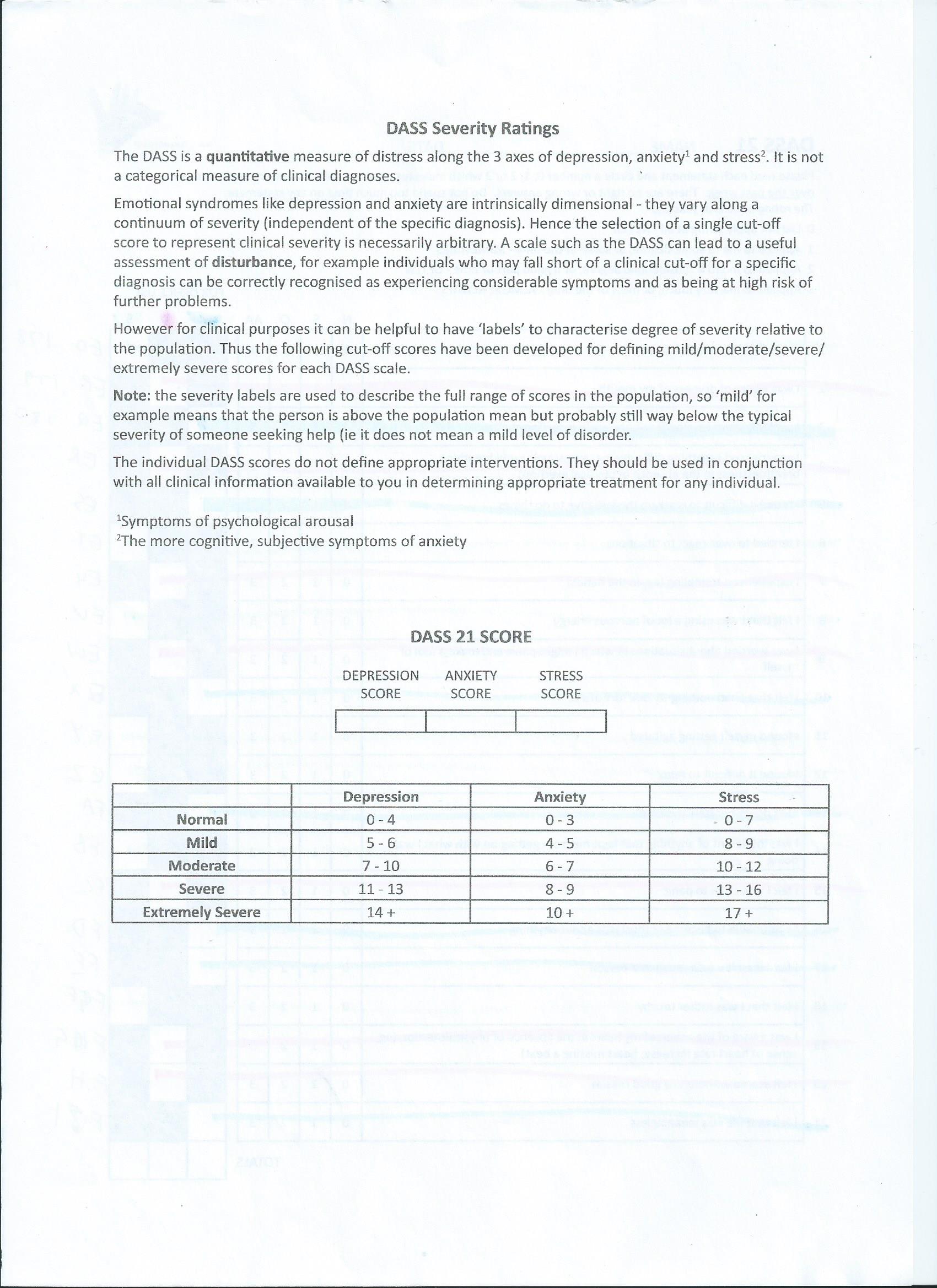
Appendix K

The Depression, Anxiety, Stress Scale (DASS 21)



Appendix K

Depression, Anxiety, Stress Scale Score Sheet



(Lovibond & Lovibond, 1995)

Appendix L

Extended Literature Review

An Investigation of Stress and Resilience in Mothers

of Children with Autism Spectrum Disorder

Elizabeth Smalley

Student Number:19396387

Curtin University

Abstract

Parenting a child with Autism Spectrum Disorder (ASD) presents unique challenges which can be made more complex by some of the high risk behaviours these children exhibit (Obeid & Daou, 2015). Children with ASD are more at risk of drowning and accidents due to absconding, self-harm, aggression, depression, anxiety and suicidal ideation. Mothers of children with ASD often experience higher levels of depression, anxiety and stress than parents of neuro-typical children and children with other developmental delays (Conner & White, 2014; Padden, James, & Leader, 2015). Recent research has begun to explore whether a trauma framework may fit some of the symptomology experienced by a significant proportion of these mothers (Roberts, Koenen, & Lyall, 2014; Stewart, Knight, McGillivray, Forbes, & Austin, 2016). Within a trauma framework, the concept of resilience plays an important role. Maternal resilience is explored in this parenting context.

An Investigation of Stress and Resilience in Mothers  
 of Children with Autism Spectrum Disorder

Children with Autism Spectrum Disorder (ASD) present unique challenges for their mothers which often include unusual maladaptive behaviours that may range from simply annoying to fatal (Obeid & Daou, 2015). Mothers of children with ASD experience more stress and negative mental and physical health outcomes (Fairthorne, Hammond, Bourke, Jacoby, & Leonard, 2014) than mothers of neurotypical children or children with other disabilities (Conner & White, 2014; Padden et al., 2015). Research has begun to explore the nature of stress experienced by some mothers of children with ASD, to understand if a trauma response model may be able to capture some of the symptomology experienced by a significant proportion of these mothers, associated with the challenging and often dangerous behaviours of their child (Roberts, Koenen, Lyall, 2014; Stewart, Knight, Mcgillivray, Forbes, & Austin, 2016). Some mothers of children with ASD may not experience such negative outcomes, which may be moderated by variations in the resilience and coping skills used by individuals (Bekhet, Johnson, & Zauszniewski, 2012). Developing a better understanding of the relationships between the experiences and outcomes for mothers of children with ASD could be useful in the creation of targeted and effective interventions and supports for mothers who are most often the primary carers (Padden et al., 2015).

ASD is chronic in nature and characterized by persistent deficits in social communication and interaction, repetitive, stereotyped behavior and limited interests (Conner & White, 2014). Estimates of the prevalence of ASD have been increasing to one child in 68 meeting the diagnostic criteria (Da Paz & Wallander, 2017) making it a significant global health issue (Bekhet et al., 2012). Various hypotheses for the increase have been suggested which include broader diagnostic criteria, greater awareness, earlier diagnosis and the realisation that ASD is a lifelong condition (Matson & Kozlowski, 2011). Up to 94% of children living with ASD experience a range of challenging behaviors (Jang, Dixon, Tarbox, & Granpeesheh, 2011).

The challenging behaviours of children with ASD often pose a threat to themselves, their carers and others (Padden et al., 2015), particularly mothers, who have the greatest exposure to these types of repetitive traumatic events (Conner & White, 2014; Costa, Steffgen, & Ferring, 2017; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). Parent mental health outcomes have been shown to be are similar for those with and without a child with ASD, when challenging behaviour has been controlled for, suggesting that it may be the associated challenging behaviours that negatively affects outcomes for parents (Totsika et al., 2011).

Trauma relates to events that pose a significant or perceived threat to the safety of the individual or their loved ones, and are shocking and overwhelming (American Psychiatric Association, 2013). Chronic stress due to trauma has been associated with lower cortisol levels and blunted cortisol responses which have been shown in veteran populations (Dennis, Calhoun, & Erkanli, 2006), Holocaust survivors (Yehuda, Kahana, & Schmeidler, 1996), first responders (Boyd et al., 2018; Walker, Mckune, Ferguson, Pyne, & Rattray, 2016) and individuals with post-traumatic stress disorder (PTSD) (Oquendo et al., 2003). A similar pattern of blunted cortisol responses has been found in mothers of adolescents and adults with ASD and challenging behaviours (Lovell, Moss, & Wetherell, 2012; Padden et al., 2015; Seltzer et al., 2010). This suggests that there may be a link between the challenging behaviours, which mothers may experience as trauma, and some associated symptoms similar to PTSD. It may be that experiencing the challenging behaviours as trauma may contribute to the poorer outcomes experienced by mothers of children with ASD and challenging behaviours.

Resilience is the ability to face stress in an adaptive manner, where risks and protective factors such as social and personal supports (Tsai, Harpaz-Rotem, Pietrzak, & Southwick, 2012), are brought into a positive balance (Bekhet et al., 2012). Many mothers have developed positive adaptive coping skills that may mediate negative outcomes for mothers of a child with ASD and challenging behaviours (Bekhet et al., 2012). Coping skills relate to the ability of an individual to use behavioural and cognitive strategies which may be active or avoidant (Tsai et al., 2012). Active coping strategies include cognitive restructuring to change the perception of the stressor or problem solving. Avoidant coping is using thoughts and actions to escape direct confrontation with the stressor such as avoidance of social situations or wishful thinking (Tsai et al., 2012). Avoidant coping styles and lower resilience have been shown to be predictive for the development of PTSD (Daniels et al., 2012; Hooberman, Rosenfeld, Rasmussen, & Keller, 2010).

Understanding the nature and impact of the stress experienced by this group of mothers caring for a child with ASD and challenging behaviours, and mediating factors related to resilience and coping, may contribute to improving interventions, supports and outcomes for them and their families.

**Autism**

The etiology of ASD is still largely unknown (Bourgeron, 2016). It was first described by Leo Kanner in 1943 as extreme autistic aloneness where the child’s behaviour was believed to be the result of an anxiously obsessive desire for the maintenance of sameness, and characterized as an extreme emotional disturbance without cognitive impairment that was regarded as a type of schizophrenia (Verhoeff, 2013). This relates to present day criteria in the DSM-5 (APA, 2013) of social deficits but does not describe sterotypied behaviours, communication deficits or cognitive impairments which may occur in up to 70% of individuals with ASD (Hannon & Taylor, 2013).

More recently biological and genetic etiologies are considered more likely contributing factors to ASD (Sousa, 2011; Verhoeff, 2013). Familial and twin studies indicate that the heritability of ASD may be close to 50% (Bourgeron, 2016) although some studies suggest heritability is as high as 86% (Tick, Bolton, Happ, Rutter, & Uhling Rijsdijk, 2015). Particular genes and highly penetrant mutations and genomic imbalances (Betancur, 2011) have been identified that are relevant to individuals with ASD and an intellectual disability, where the possibility of abnormal synaptic plasticity and neuronal/synaptic homeostasis may increase the risk of ASD (Bourgeron, 2016; Packer, 2016). Up to 103 disease genes and 44 genomic loci have been attributed as contributing to ASD behaviour and intellectual disability, which suggests that perhaps both may share common genetic bases (Betancur, 2011; Bourgeron, 2016). Betancur (2011) proposes that ASD may be a behavioural manifestation of many different genetic and genomic disorders. Environmental exposure to toxins, maternal diabetes, the maternal immune system, the age of both parents and various medications have been explored with no definitive conclusions due to the numerous confounds (Bölte, Girdler, Peter, & Marschik, 2019; Nardone & Elliott, 2016).

The diagnostic criteria have evolved to reflect the changes in understanding ASD. The first time ASD was entered in the DSM (1980) it was described as a pervasive developmental disorder, separate from schizophrenia. The main features for diagnosis of ASD outlined in Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013) include persistent deficits in social communication and interaction across a range of contexts, restricted, repetitive patterns of behaviour, interests or activities, symptoms having been present from early childhood and cause significant impairment, not better explained by another disorder (APA, 2013). (See Appendix A for full criteria). ASD now has one category with three levels of severity ranging from level 1: requiring support, to level 3: requiring very substantial support (APA, 2013). Diagnosis of children with ASD in Australia is often provided by a multidisciplinary team which may include pediatricians, speech pathologists, occupational therapists and psychologists, however, unlike the United Kingdom (Rogers, Goddard, Hill, Henry, & Crane, 2016) there is no standardized procedure at this time (Bent, Barbaro, & Dissanayake, 2017). It is therefore appropriate to ask mothers to confirm that their child has been diagnosed by a qualified professional which may be any of those listed above.

**Challenging Behaviours**

Children with ASD often exhibit challenging and dangerous behaviours, which are more common and extreme with a comorbid intellectual disability (Matson & Nebel-Schwalm, 2007). Some behaviours may be experienced by mothers as trauma, where there is a danger to self or others or learning of traumas their child has experienced through bullying or abuse (Matson, Mahan, Hess, Fodstad, & Neal, 2010; Matson & Nebel-Schwalm, 2007; J Rojahn et al., 2011). The severity of challenging behaviours has been shown to be positively related to the severity of ASD (Jang et al., 2011). An intellectual disability which may be present in up to 70 % of children with ASD has been shown to increase challenging behaviours (Hannon & Taylor, 2013; La Malfa, Lassi, Bertelli, Salvini, & Placidi, 2004). Challenging behaviours may include destruction of property, fecal smearing, verbal and physical aggression (Lecavalier, Leone, & Wiltz, 2006) and absconding or elopement with the risk of drowning or other serious accidents (Jang et al., 2011; Matson et al., 2010; Matson & Nebel-Schwalm, 2007; J Rojahn et al., 2011).

Elopement is a serious risk factor for 50% of children and adolescents with ASD, usually commencing around age 4 and peaking around 5.5 years, with the risk increasing with the severity of ASD (Anderson et al., 2012). Anderson and colleagues (2012) reported that 24% of elopers were at risk of drowning and 65% at risk of a traffic accident. Elopement is the highest cause of mortality for children with ASD aged between 5 and 10 years (Stewart et al., 2016). Anderson and colleagues (2012) reported that 29% of children with ASD eloped several times a day, 35% at least once a week, and 43% of parents could not get a good night sleep due to remaining vigilant in keeping their child safe.

Self-injurious behaviours occur in approximately half of children with ASD and includes hitting themselves in the head, biting themselves on the arms or fingers, throwing themselves on the furniture, eye poking and picking their skin creating lesions (Gorlin, Mcalpine, Garwick, & Wieling, 2016; J Rojahn et al., 2011). Head-banging is common and one of the main causes of hospitalization and mortality for children with ASD (Duerden, Taylor, & Roberts, 2012). The usual age for self-harm is 11 – 25 years with an average age of onset of 12 years (Hannon & Taylor, 2013).

Suicidal ideation, suicide attempts and completions are more common in older adolescents with ASD than neurotypical adolescents (Hannon & Taylor, 2013). Higher functioning individuals are more at risk of suicide because they have more cognitive capacity to plan and complete a suicide, than those with diminished cognitive capacity (Culpin et al., 2018). Depression is common for adolescents with ASD. Risk factors include social isolation, abuse, being bullied and being male (Dickerson Mayes, Gorman, Hillwig-Garcia, & Syed, 2013; Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005). Reports as high as 94% of children with ASD experience bullying, higher than any other disability, possibly leading to vicarious trauma for mothers (Mandell et al., 2005; Sreckovic, Brunsting, & Able, 2014).

Children with ASD are twice as likely to experience physical and sexual abuse than typical children, leading to suicide attempts and running away (Mandell et al., 2005). Children with ASD are at the greatest risk of filicide-suicide, where 55% of children with disabilities murdered by their parents, had ASD with an average age of 10.5 years, with some reporting altruistic motives, with one third of parents having a mental illness (Coorg & Tournay, 2012). The tragic implication being that life with ASD is not worth living for the child or the parent and death is the only reprieve.

Despite research that confirms children with ASD often have comorbid challenging behaviours, there are few measures that quantify and describe the behaviours (Norris & Lecavalier, 2011). Often multiple behaviours are grouped together, reducing the reliability of the measure (Norris & Lecavalier, 2011). A possible reason for this is that although up to 70% of children with ASD present with challenging behaviours (La Malfa et al., 2004), it is not considered a core feature of ASD (Matson & Nebel-Schwalm, 2007). Possible measures include the Aberrant Behaviour Checklist (Aman, Singh, & Field, 1985; Johannes Rojahn, Helsel, & Rojalm, 1991) developed for adults, the Behaviour Problem Inventory (Rojahn et al., 2011) for individuals aged 14 – 91 years, PDD Behavioural Inventory for children aged 2-12 years, and the Nisonger Child Behaviour Rating Form (NCBRF) (Aman, Tassé, Rojahn, & Hammer, 1996) developed for children aged 3 – 16 years, but validated for use with children with ASD for 3 -18 years (Matson & Nebel-Schwalm, 2007; Norris & Lecavalier, 2011), and the Developmental Behavioural Checklist (Einfeld et al., 1995) for children aged 4- 18 years. The NCBRF is validated for use by parents for children with ASD and has been validated for use with children with a comorbid intellectual disability (Aman et al., 1996; Rojahn et al., 2011). (See Appendix B). It is comprised of 66 questions focusing on behaviours with subscales for conduct problems, insecure/anxious, hyperactive, self-injury/stereotypic, self-isolated/ritualistic and overly sensitive behaviours and the scores can be totaled for an overall score for problem behaviours. (Norris & Lecavalier, 2011) It has been validated in large clinical trials and in several languages, has the age range appropriate for a measure for children, and is freely available (Aman et al., 1985; Norris & Lecavalier, 2011), making it an appropriate measure for use with mothers of children with ASD, with or without an intellectual disability, to capture the severity of behaviours they are being exposed to.

**Risks to Mothers of Children with ASD**

The constant and repeated first hand and vicarious trauma resulting from repetitive and sterotypied self-harm, suicidal ideation, elopement and hearing of abuse to their child, can have negative outcomes for mothers who become at risk of poor physical and mental health and premature death compared to the general population (Fairthorne et al., 2014). Research has shown that externalising behaviours of children with ASD has been strongly associated with high levels of stress for mothers (Lecavalier et al., 2006). Up to 79% of parents report high levels of stress and 88% report behavioural management problems of their child with ASD (Dickerson Mayes, Calhoun, Murray, Ahuja, & Smith, 2011). Often children with ASD have persistent patterns of crying, not sleeping, agitation and tantrums, where the parent spends considerable time dealing with ‘meltdowns’ (Gorlin et al., 2016). Approximately half of children with ASD experience high anxiety, depression and irritability. The greater the symptomology of ASD and the greater the number of comorbid psychiatric disorders occurring the child, the greater the risk to the mother of depression and lower quality of life (Zablotsky, Anderson, & Law, 2013). Challenging behaviours may contribute to diminished feelings of parenting self-efficacy for mothers who experience persistent failure in managing their child’s behaviours, which impacts negatively on their resilience and coping capacity (Keen, Couzens, Muspratt, & Rodger, 2010; Limonero et al., 2014; Meirsschaut, Roeyers, & Warreyn, 2009).

The cost of raising a child with ASD has been estimated to be 8.5 times more than raising a neurotypical child (Fairthorne et al., 2014). Careers may be interrupted and marriages may experience strain and fail, adding to parental stress (Fairthorne et al., 2014). Mothers often report a deep sense of grief and loss having a child with ASD, as well as worrying about their child’s future and what will happen to their child when they are no longer able to care for them (Ferná Ndez-Alcántara et al., 2016). Mothers of children with ASD are 40% more likely to die of cancer, 150% more likely to die of cardiovascular disease and 200% more likely to die from misadventure than other mothers due to the stress of parenting a child with ASD (Fairthorne et al., 2014) and experience increased depression and reduced quality of life (Zablotsky, Anderson, & Law, 2013). ASD and associated hyperactivity, behavioural and emotional problems in the child, has been shown to put the mental health of the mother at greater risk (Totsika et al., 2011). There is often a significant impact on the mother’s ability to socialize (Mcstay, Trembath, & Dissanayake, 2014; Vasilopoulou & Nisbet, 2016) and work (Meirsschaut et al., 2009; Vasilopoulou & Nisbet, 2016) which increases her isolation and mental health risk factors.

**Experiences of Trauma for Mothers of Children With ASD**

Parents of children who have been in serious accidents, have asthma or childhood cancer have been shown to experience trauma reactions (Casey et al., 2012; Phipps, Larson, Long, & Rai, 2006). There are two main aspects of trauma for mothers of children with ASD. One is when the diagnosis is received (Casey et al., 2012) and the other is ongoing daily parenting, trying to manage and cope with behavioural difficulties (Lecavalier et al., 2006). Research has shown that 20% of parents experience post-traumatic stress symptoms following the diagnosis of their child with ASD (Casey et al., 2012). Symptoms include re-experiencing, intrusive thoughts, avoidance of reminders, constant feelings of uneasiness and being easily startled (Casey et al., 2012). Klauber (1998) reports diagnosis is a personal and private disaster of similar magnitude and as traumatizing as a major public disaster for parents. It is an experience outside of typical human experience which could be traumatic for anyone.

An association between ASD and PTSD in mothers was reported for the first time in 2014 (Roberts, Koenen, Lyall, Ascherio, & Weisskopf, 2014), due to the exposure to multiple chronic stressors involved with mothering a child with ASD. It was found that a lack of support, due to the isolation many mothers experience as a result of the behaviours of their child, increased the risk of PTSD (Roberts et al., 2014). Isolation may be intensified as mothers report experiencing negative attitudes towards disability and criticism of their parenting when in public, causing them to withdraw socially (Stewart et al., 2016) as an avoidant coping strategy which has been linked to an increased risk of PTSD (Tsai et al., 2012). Due to the high risk to the child, families have reported not going out and enjoying activities away from the home environment where the child was secure, further contributing to social isolation for the family (Anderson et al., 2012). The hypervigilance required by parents is further intensified with children with ASD having twice the death rate of the general population, where causes of death include suffocation and epilepsy (Mouridsen, Bronnum-Hansen, Rick, & Isager, 2008). However Roberts and associates (2014) recommend caution with this interpretation as it unknown if there may be a common cause of PTSD and ASD, rather than one being the cause of the other.

Changes in the DSM-5 (APA, 2013) Criterion A for PTSD includes exposure to a traumatic or stressful event where actual or threatened death or serious injury through direct experience, witnessing the event in person, learning that it occurred to a close family member or friend, or through repeated or extreme exposure to aversive details of the event. The majority of children with ASD have comorbid challenging behaviours which would meet the criteria for trauma outlined in Criterion A for PTSD (APA, 2013) e.g. head banging, which is a leading cause of death for children with ASD, absconding, often multiple times a day, with associated risks of traffic accidents or drowning, aggression towards siblings or parents, including repetitive biting, kicking and punching. As a result mothers have repeated exposure to stressful or traumatic events, so it is interesting that there is presently no known data regarding rates of PTSD among mothers of these children (Stewart et al., 2016).

What is known is that repeated exposure to trauma or dosing, increases the risk of PTSD. Research into the hypothalamic-pituitary-adrenal-axis hyperactivity of mothers of children with ASD found the profiles of these mothers (Seltzer et al., 2010) to be similar to the profiles of first responders , combat soldiers (Yehuda, Boisoneau, Lowy, & Giller, 1995), Holocaust survivors and individuals diagnosed with PTSD (Yehuda et al., 1996). While it has been reported that mothers of children with ASD experience chronic and extreme stress, it may be that the stress may be characteristic of a trauma response in some cases (Stewart et al., 2016). More recently PTSD has been explored as a way of understanding the experiences of mothers with children with ASD and comorbid challenging behaviours, which places themselves or others in danger (Stewart et al., 2016; Stewart, McGillivray, Forbes, & Austin, 2017). PTSD Criterion B which refers to intrusive symptoms and Criterion C which refers to avoidance (APA, 2013), have been reported in qualitative studies (Stewart et al., 2016) and quantitative studies (Padden et al., 2015; Seltzer et al., 2010). Criterion D, and negative alterations in cognitions and mood have been well documented (Anderson et al., 2012; Bekhet et al., 2012; Schieve et al., 2011).

**Post-traumatic Stress Disorder**

Post-traumatic stress disorder (PTSD) has been acknowledged from ancient times and previously reported as shell shock, soldier’s heart and war neurosis. Originally PTSD was used to describe symptoms related to trauma from exposure to war and combat. Recently the definition has expanded to include a variety of traumas, either experienced, witnessed or relating to a close family member or friend, including natural disasters, violence and sexual abuse (Salcioglu, Urhan, Pirinccioglu, & Aydin, 2017). Since the Vietnam War it has been referred to as PTSD (Crocq & Crocq, 2000), entering the DSM for the first time in 1980 (APA, 1980). Prior to 1980 the DSM I (APA, 1952) included Gross Stress Reaction, while DSM II (APA, 1968) referred to Transient Situational Disturbance. Symptoms of PTSD include intrusive and recurrent memories of trauma, avoidance of trauma stimuli, numbing and or negative changes in mood or cognitions related to trauma, and changes in reactivity and arousal (APA, 2013). (See Appendix C for full criteria). Usually recovery occurs within one month following a trauma (Shore, 2002) and the psychophysiological reactions diminish. However, a small percentage of individuals experience continuing biopsychosocial symptoms in the four clusters for PTSD set out in the DSM-5 (APA, 2013).

Measures for PTSD may take the form an interview such as the gold standard Clinician Administered PTSD Scale (CAPS) (Gray, Litz, Hsu, & Lombardo, 2004), developed by the National Centre for Post-traumatic Stress Disorder (NCPTSD) in the United States of America. The interview must be administered by specifically trained clinicians, and takes approximately one hour, making it unsuitable for an online assessment. The PTSD Checklist for DSM-5 (PCL-5) (Attachment D) (Wortmann et al., 2016) is a 20 item self-report questionnaire that measures the presence and severity of PTSD symptoms using a five point Likert scale. Items on the PCL-5 correspond to the DSM-5 criteria for PTSD and may be used as a screening tool to make a provisional diagnosis of PTSD. The Life Events Checklist (LEC-5) (Attachment E) (Gray et al., 2004) is a 17 item self-report questionnaire designed to screen for potentially traumatic events in a respondents lifetime and is often administered at the same time as the PCL-5. The LEC-5 has shown temporal stability and good convergence with a previously established trauma measure, the Traumatic Life Events Questionnaire (TLEQ), with variables between the two showing strong correlation (Gray et al., 2004). One valuable aspect of the LEC-5 is that it includes questions about multiple types of exposure to the same event, and differentiates between direct or witnessed exposure (Gray et al., 2004), which is now part of the DSM-5 criteria for PTSD. This aspect of the measure would be useful in assessing experiences of mothers of children with ASD and comorbid challenging behaviours as they are likely to have witnessed repeated dangerous behaviours of their child.

**Resilience**

Resilience is the capacity of an individual to prevail in the face of adversity, stressful situations and trauma with the capacity to adapt positively (Bekhet et al., 2012) and bounce back (Windle, Bennett, & Noyes, 2011; Windle et al., 2011). Resilience theory is the balancing of risk and protective factors. Risk factors predispose an individual to physical and mental health challenges by affecting how they adapt to stress (Bekhet et al., 2012). Risk factors for families with a child with ASD include the severity of the ASD, the quality of the marriage, parental anger regarding the diagnosis, resulting stressors imposed upon the parent (Benson & Karlof, 2009) and the number of children with ASD in the family (Ekas, Lickenbrock, & Whitman, 2010). Protective factors promote resilience by reducing the negative reaction to stress to achieve a more positive outcome (Bekhet et al., 2012). For families with a child with ASD this would include social, family and school support, the age of the child, time since diagnosis (the longer since diagnosis the less stress), locus of control, cognitive appraisal and religious and spiritual beliefs (Ekas, Whitman, & Shivers, 2009). The degree of difficulty parenting a child with ASD may become easier in late adolescence, but other studies have found the degree of difficulty remains unchanged with the age of the child (Mcstay et al., 2014; Meirsschaut et al., 2009)).

Indicators of resilience include self-efficacy, acceptance, sense of coherence, optimism, positive family functioning and enrichment (Bekhet et al., 2012). Self-efficacy describes how much confidence a person may have in their ability to succeed. For mothers with a child with ASD, the greater her confidence, the less stress is experienced, promoting greater resilience and mental health (Bayat, 2007). Lower self-efficacy in mothers of children with ASD has been shown to increase depression over time and has been associated with the mother’s feelings of guilt and parental stress (Bayat, 2007). Bayat (2007) reported that accepting the chronic and unchanging nature of ASD, and appreciating what they have rather than lamenting what they have not, increased coping for mothers. Coping describes using cognitive and behavioural strategies to manage internal or external situations where demands on an individual’s resources are beyond their capacity (Sinclair & Wallston, 2004). A sense of coherence may be described as cognitive, behavioural and motivational skills that indicate that life is manageable, meaningful and comprehensible (Antonovsky, 1993). Optimism, joy and spirituality have been found to increase resilience (Ekas et al., 2010, 2009). While individuals may not have control over the risk factors they face, strengthening resilience and coping by increasing positive cognitions, improving cognitive reappraisals and having support has been shown to increase resilience (Bekhet et al., 2012).

There is no gold standard measure for resilience among the many measures of resilience available (Windle et al., 2011). Based on resilience theory the Connor-Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003; Windle et al., 2011) was tested with individuals with PTSD to determine if an increase in resilience using pharmacotherapy reduced the symptoms of PTSD, and the results were positive. This indicates an inverse relationship between resilience and PTSD symptoms, so that increasing resilience may be a useful intervention. It has been argued that the CD-RISC may not effectively measure resilience, but rather characteristics such as sense of humour, faith, optimism, patience and self-efficacy, which is more an assessment of protective factors rather than resilience (Smith et al., 2008). Another measure is The Resilience Scale (Wagnild, 2009;Wagnild & Young, 1993) which has also been criticized for measuring protective factors based on personal characteristics and coping styles such as perseverance, meaningfulness and existential aloneness (Smith et al., 2008). These measures have been described as characteristics that may increase resilience (Smith et al., 2008). Endeavouring to capture resilience in the briefest most reliable questionnaire containing only six items, Smith and colleagues developed the Brief Resilience Scale (BRS), with a five point Likert scale, testing it against the previously mentioned scales (Smith et al., 2008). The BRS was found to be reliable measure for resilience, in particular, the ability to bounce to back, which is the most reductionist definition (Smith et al., 2008).

The Brief Resilience Coping Scale (BRCS) consists of four questions with responses on a five point Likert Scale.(Attachment F). This measure has the additional construct of coping which has been defined as managing stress in an adaptive manner (Sinclair & Wallston, 2004). Resilient coping refers to the positive adaption when a significant threat is present (Sinclair & Wallston, 2004), distinguishing it from coping or resilience because it refers to the ability to adapt positively despite high stress (Sinclair & Wallston, 2004). Resilience coping includes using cognitive appraisal skills flexibly to actively solve a problem, which has been positively associated with higher education (Sinclair & Wallston, 2004). Four themes emerge through the questions which include tenacity, optimism, creativity, and an aggressive approach to problem solving (Sinclair & Wallston, 2004), which would make the BRCS an appropriate measure for mothers of children with ASD, who may actively seek out solutions.

A weakness of resilience measures is the lack of sensitivity to detect change (Windle et al., 2011), but the BRCS has been shown to be sensitive enough to detect change in populations of older adults (Tomás, Sancho, Melendez, & Mayordomo, 2012), adults with rheumatoid arthritis (Sinclair & Wallston, 2004) and adolescents in a Spanish population (Limonero et al., 2014; Tomás et al., 2012). These studies were validated on predominantly female participants, making it an appropriate measure for mothers. Confirmatory factor analysis confirmed the unidimensionality of the scale, internal reliability, consistency, temporal stability (Limonero et al., 2014; Sinclair & Wallston, 2004) and test retest reliability and validity (Sinclair & Wallston, 2004). The advantage of the BCRS is that it measures resilient coping, is brief, simple, reliable and understandable, making it a useful measure for carers (Limonero et al., 2014).

The Aggravation in Parenting (AiP) scale contains four questions with a four point Likert scale response. (Appendix G). It was developed from the Parenting Stress Index and the Child Rearing Scale, to measure frustration and stress parents experience specifically related to caring for their children (Schieve, Blumberg, Rice, Visser, & Boyle, 2007; Yu & Singh, 2012). It has been shown to be reliable (Schieve et al., 2007), having been used with a large sample (73030) of children aged 4 – 17 years. The AiP has shown significantly higher levels of aggravation among mothers of children with ASD, associated with higher levels of depression and a lower internal locus of control. The study did not include any specific information about the behaviour of the child with ASD, which the researchers reported would have been useful (Schieve et al., 2011). High levels of aggravation were not shown to be inevitable for parents of a child with ASD however, and some protective factors were noted such as community and health support and insurance to cover the supports required (Schieve et al., 2011).

**Conclusions**

Despite abundant evidence confirming many children with ASD have associated behavioural challenges (Matson & Rivet, 2008; Obeid & Daou, 2015), little research has been conducted to understand the specific behaviours that mothers find most stressful and which impact most negatively on their mental health (Norris & Lecavalier, 2011). Often various behaviours are grouped together, or form part of an adaptive assessment with few questions about behaviour (Norris & Lecavalier, 2011) making it difficult to determine specifically which behaviours are most distressing to mothers and need addressing to alleviate distress and improve outcomes for children and mothers. Not only are the children at risk of harm to themselves and others, but mothers in particular are at higher risk of developing depressive symptoms, anxiety and stress (Padden et al., 2015), as well as increased health risks with a higher likelihood of premature death than the general population due to cancer, cardiovascular disease and misadventure (Fairthorne et al., 2014), reduced quality of life (Hsiao, 2016), and a high risk of parenting aggravation (Schieve et al., 2011).

An area of emerging research is the inquiry into the type of stress experienced by mothers of children with ASD (Roberts et al., 2014). A trauma frame work may be appropriate to understand the clusters of symptoms some mothers of children with ASD experience (Stewart et al., 2016). Research has shown that mothers of children with ASD have a similar HPA axis and cortisol response as first responders, war veterans, active military personnel and Holocaust survivors, indicating that a physiological trauma response may be occurring (Seltzer et al., 2010; Yehuda, Boisoneau, et al., 1995; Yehuda, Kahana, et al., 1995). Some mothers receiving the diagnosis of ASD for their child, have experienced some PTSD symptoms, where they experience flashbacks and avoid triggering memories of incident (Casey et al., 2012). Changes in the DSM-5 definition of PTSD (APA, 2013) now includes witnessing or hearing about an event of a loved one, and includes repeated traumas or dosing (Yehuda, Boisoneau, et al., 1995), where more trauma may lead to a greater likelihood of developing PTSD. The repeated and dangerous behaviours of a child with ASD, such as absconding multiple times a day, at risk of death or serious injury (Anderson et al., 2012), could fit the trauma criteria (APA, 2013). In a small sample of mothers, it has been found that 20% do experience PTSD symptoms (Stewart et al., 2016).

While the negative aspects of mothering a child with ASD have been established, it cannot be assumed that every mother will respond to the challenges they face in the same way (Schieve et al., 2011). Resilience and coping skills may be mediating factors for mothers, enabling them to grow through the experience and thrive through positive adaptions to the circumstances (Bayat, 2007; Gerstein, Crnic, Blacher, & Baker, 2009).

This research will explore, possibly for the first time, the impact of a child with ASD and challenging behaviours, on the mother, using a trauma framework to capture the resulting state of the mother, which may be mediated by resilience and coping skills. Due to the increasing numbers of families living with a child with ASD, it is important to use community resources in the most efficient and effective manner. This research is important because knowing more specifically how to target interventions will improve outcomes for the mother, the child with ASD and their family, enabling them to continue the often arduous care and support of their child, usually for the rest of their life.

**Hypotheses**

1. There will be a relationship between challenging behaviours of the child with ASD and PTSD symptoms experienced by the mother which will be moderated by other trauma experienced by the mother. It is expected that PTSD symptoms will increase where the mother has been exposed to other traumatic events.
2. There will be a relationship between the challenging behaviours of the child with ASD and PTSD symptoms experienced by the mother which will be moderated by the resilience of the mother. It is expected that PTSD symptoms will have an inverse relationship with resilience such that high resilience is a protective factor against PTSD symptoms.
3. Aggravation in parenting will mediate the relationship between the challenging behavior of the child and the resilience of the mother such that higher aggravation in parenting would have an inverse relationship to resilience and PTSD symptoms of the mother.

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Appendix A

DSM-5 Criteria for Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1.       Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2.       Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3.       Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in  sharing imaginative play or in making friends; to absence of interest in peers.

*Specify*current severity: Severity is based on social communication impairments and restricted repetitive patterns of behaviour. (See table below.)

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1.       Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2.       Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3.       Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4.       Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify* current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour. (See table below.)

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:  
- With or without accompanying intellectual impairment  
- With or without accompanying language impairment  
- Associated with a known medical or genetic condition or environmental factor  
(Coding note: Use additional code to identify the associated medical or genetic condition.)  
- Associated with another neurodevelopmental, mental, or behavioral disorder  
(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)  
- With catatonia

Table: Severity levels for autism spectrum disorder

|  |  |  |
| --- | --- | --- |
| Severity level | Social communication | Restricted, repetitive behaviours |
| Level 3 "Requiring very substantial support” | Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches | Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action. |
| Level 2 "Requiring substantial support” | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or  abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited  to narrow special interests, and how has markedly odd nonverbal communication. | Inflexibility of behaviour, difficulty coping with change, or other restricted/repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in  a variety of contexts. Distress and/or difficulty changing focus or action. |
| Level 1 "Requiring support” | Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful. | Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence. |

Social (Pragmatic) Communication Disorder

Diagnostic Criteria

A. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:

1.       Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.

2.       Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on the playground, talking differently to a child than to an adult, and avoiding use of overly formal language.

3.       Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.

4.       Difficulties understanding what is not explicitly stated (e.g., making inferences) and nonliteral or ambiguous meanings of language (e.g., idioms, humour, metaphors, multiple meanings that depend on the context for interpretation).

B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.

C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).

D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains or word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.

Appendix B

Nysonger Child Behaviour Rating Form Part III

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 1. | Apathetic or unmotivated . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 34. | Overly anxious to please others . . . . . | 0 | 1 | 2 | 3 |  |
|  | . . . . . |  | . . . . . . . |  |
|  | 2. | Argues with parents, teachers, or |  |  |  |  |  | 35. | Overly excited, exuberant . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  | other adults . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 36. | Physically attacks people . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 3. | Clings to adults, too dependent . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 37. | Refuses to talk . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 4. | Cruelty or meanness to others . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 38. | Repeats the same sound, word, or |  |  |  |  |  |
|  | 5. | Crying, tearful episodes . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |  | phrase over and over . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 6. | Hits or slaps own head, neck, hands, |  |  |  |  |  | 39. | Restless, high energy level . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  | or other body parts . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 40. | Runs away from adults, teachers, or |  |  |  |  |  |
|  | 7. | Defiant, challenges adult authority . . . . . . . . . . | 0 | 1 | 2 | 3 |  |  | other authority figures . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 8. | Knowingly destroys property . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 41. | Says no one likes him/her . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 9. | Difficulty concentrating . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 42. | Secretive, keeps things to self . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 10. | Disobedient . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 43. | Repeatedly bites self hard enough to |  |  |  |  |  |
|  | 11. | Rocks body or head back and forth |  |  |  |  |  |  | leave tooth marks or break skin . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  | repetitively . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 44. | Self-conscious or easily embarrassed . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 12. | Doesn't feel guilty after misbehaving . . . . . . . . | 0 | 1 | 2 | 3 |  | 45. | Shifts rapidly from topic to topic |  |  |  |  |  |
|  | 13. | Easily distracted . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |  | when talking . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 14. | Easily frustrated . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 46. | Short attention span . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 15. | Overly sensitive; feelings easily hurt . . . . . . . . | 0 | 1 | 2 | 3 |  | 47. | Shy or timid behavior . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 16. | Exaggerates abilities or achievements . . . . . . . | 0 | 1 | 2 | 3 |  | 48. | Steals . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 17. | Explosive, easily angered . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 49. | Odd repetitive behaviors (e.g., stares, |  |  |  |  |  |
|  | 18. | Has rituals such as head rolling or |  |  |  |  |  |  | grimaces, rigid postures) . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  | floor pacing . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 50. | Stubborn, has to do things own way . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 19. | Fails to finish things he/she starts . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 51. | Sudden changes in mood . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 20. | Feelings easily hurt . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 52. | Sulks, is silent and moody . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 21. | Feels others are against him/her . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 53. | Physically harms or hurts self on |  |  |  |  |  |
|  | 22. | Harms self by scratching skin or |  |  |  |  |  |  | purpose . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  | pulling hair . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 54. | Talks back to teacher, parents, or |  |  |  |  |  |
|  | 23. | Feels worthless or inferior . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |  | other adults . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 24. | Fidgets, wiggles, or squirms . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 55. | Talks too much or too loud . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 25. | Shy around others; bashful . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 56. | Temper tantrums . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 26. | Gets in physical fights . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 57. | Threatens people . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 27. | Irritable . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 58. | Threatens to harm self . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 28. | Repeatedly flaps or waves hands, fingers |  |  |  |  |  | 59. | Engages in meaningless, repetitive |  |  |  |  |  |
|  |  | or objects (such as pieces of string) . . . . . . . . . | 0 | 1 | 2 | 3 |  |  | body movements . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 29. | Isolates self from others . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 60. | Too fearful or anxious . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 30. | Lying or cheating . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 61. | Underactive, slow . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 31. | Nervous or tense . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 62. | Unhappy or sad . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 32. | Gouges self, puts things in ears, nose, |  |  |  |  |  | 63. | Violates rules . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  | etc., or eats inedible things . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 64. | Withdrawn, uninvolved with others . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  | 33. | Overactive, doesn't sit still . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  | 65. | Worrying . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  |  |  |  |  |  |  | 66. | Argues with other children or peers . . . . . . . . . | 0 | 1 | 2 | 3 |  |
|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

**Developed by M. G. Aman, M. J. Tassé, J. Rojahn, and D. Hammer, 1995.**

Appendix C

PTSD Criteria from DSM-5

Note: The following criteria apply to adults, adolescents, and children older than 6 years. For children 6 years and younger, see the DSM-5 section titled “Posttraumatic Stress Disorder for Children 6 Years and Younger” ([APA, 2013a](https://www.ncbi.nlm.nih.gov/books/NBK207191/box/part1_ch3.box16/)).

1. Exposure to actual or threatened death, serious injury, or sexual violence in one (or more) of the following ways:
   1. Directly experiencing the traumatic event(s).
   2. Witnessing, in person, the event(s) as it occurred to others.
   3. Learning that the traumatic event(s) occurred to a close family member or close friend. In cases of actual or threatened death of a family member or friend, the event(s) must have been violent or accidental.
   4. Experiencing repeated or extreme exposure to aversive details of the traumatic event(s) (e.g., first responders collecting human remains; police officers repeatedly exposed to details of child abuse). Note: Criterion A4 does not apply to exposure through electronic media, television, movies, or pictures, unless this exposure is work related.
2. Presence of one (or more) of the following intrusion symptoms associated with the traumatic event(s), beginning after the traumatic event(s) occurred:
   1. Recurrent, involuntary, and intrusive distressing memories of the traumatic event(s). Note: In children older than 6 years, repetitive play may occur in which themes or aspects of the traumatic event(s) are expressed.
   2. Recurrent distressing dreams in which the content and/or affect of the dream are related to the traumatic event(s). Note: In children, there may be frightening dreams without recognizable content.
   3. Dissociative reactions (e.g., flashbacks) in which the individual feels or acts as if the traumatic event(s) were recurring. (Such reactions may occur on a continuum, with the most extreme expression being a complete loss of awareness of present surroundings.) Note: In children, trauma-specific re-enactment may occur in play.
   4. Intense or prolonged psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event(s).
   5. Marked physiological reactions to internal or external cues that symbolize or resemble an aspect of the traumatic event(s).
3. Persistent avoidance of stimuli associated with the traumatic event(s), beginning after the traumatic event(s) occurred, as evidenced by one or both of the following:
   1. Avoidance of or efforts to avoid distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s).
   2. Avoidance of or efforts to avoid external reminders (people, places, conversations, activities, objects, situations) that arouse distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s).
4. Negative alterations in cognitions and mood associated with the traumatic event(s), beginning or worsening after the traumatic event(s) occurred, as evidenced by two (or more) of the following:
   1. Inability to remember an important aspect of the traumatic event(s) (typically due to dissociative amnesia, and not to other factors such as head injury, alcohol, or drugs).
   2. Persistent and exaggerated negative beliefs or expectations about oneself, others, or the world (e.g., “I am bad,” “No one can be trusted,” “The world is completely dangerous,” “My whole nervous system is permanently ruined”).
   3. Persistent, distorted cognitions about the cause or consequences of the traumatic event(s) that lead the individual to blame himself/herself or others.
   4. Persistent negative emotional state (e.g., fear, horror, anger, guilt, or shame).
   5. Markedly diminished interest or participation in significant activities.
   6. Feelings of detachment or estrangement from others.
   7. Persistent inability to experience positive emotions (e.g., inability to experience happiness, satisfaction, or loving feelings).
5. Marked alterations in arousal and reactivity associated with the traumatic event(s), beginning or worsening after the traumatic event(s) occurred, as evidenced by two (or more) of the following:
   1. Irritable behaviour and angry outbursts (with little or no provocation), typically expressed as verbal or physical aggression toward people or objects.
   2. Reckless or self-destructive behaviour.
   3. Hypervigilance.
   4. Exaggerated startle response.
   5. Problems with concentration.
   6. Sleep disturbance (e.g., difficulty falling or staying asleep or restless sleep).
6. Duration of the disturbance (Criteria B, C, D and E) is more than 1 month.
7. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
8. The disturbance is not attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition.

Specify whether:

With dissociative symptoms: The individual’s symptoms meet the criteria for posttraumatic stress disorder, and in addition, in response to the stressor, the individual experiences persistent or recurrent symptoms of either of the following:

1. Depersonalization: Persistent or recurrent experiences of feeling detached from, and as if one were an outside observer of, one’s mental processes or body (e.g., feeling as though one were in a dream; feeling a sense of unreality of self or body or of time moving slowly).
2. Derealization: Persistent or recurrent experiences of unreality of surroundings (e.g., the world around the individual is experienced as unreal, dreamlike, distant, or distorted). Note: To use this subtype, the dissociative symptoms must not be attributable to the physiological effects of a substance (e.g., blackouts, behaviour during alcohol intoxication) or another medical condition (e.g., complex partial seizures).

Specify whether:

With delayed expression: If the full diagnostic criteria are not met until at least 6 months after the event (although the onset and expression of some symptoms may be immediate).

Source: [APA, 2013](https://www.ncbi.nlm.nih.gov/books/NBK207191/box/part1_ch3.box16/), pp. 271–272.

Appendix D

PTSD Checklist for DSM-5

**PCL-5**

**Instructions:** Below is a list of problems that people sometimes have in response to a very stressful experience. Pleaseread each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **In the past month, how much were you bothered by:** | **Not at** | **A little** | **Moderately** | **Quite** | **Extremely** |
|  | **all** | **bit** | **a bit** |
|  |  |  |  |
|  |  |  |  |  |  |  |
| 1. | Repeated, disturbing, and unwanted memories of the | 0 | 1 | 2 | 3 | 4 |
|  | stressful experience? |
|  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 2. | Repeated, disturbing dreams of the stressful experience? | 0 | 1 | 2 | 3 | 4 |
|  |  |  |  |  |  |  |
| 3. | Suddenly feeling or acting as if the stressful experience were |  |  |  |  |  |
|  | actually happening again (as if you were actually back there | 0 | 1 | 2 | 3 | 4 |
|  | reliving it)? |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 4. | Feeling very upset when something reminded you of the | 0 | 1 | 2 | 3 | 4 |
|  | stressful experience? |
|  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 5. | Having strong physical reactions when something reminded |  |  |  |  |  |
|  | you of the stressful experience (for example, heart | 0 | 1 | 2 | 3 | 4 |
|  | pounding, trouble breathing, sweating)? |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 6. | Avoiding memories, thoughts, or feelings related to the | 0 | 1 | 2 | 3 | 4 |
|  | stressful experience? |
|  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 7. | Avoiding external reminders of the stressful experience (for |  |  |  |  |  |
|  | example, people, places, conversations, activities, objects, or | 0 | 1 | 2 | 3 | 4 |
|  | situations)? |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 8. | Trouble remembering important parts of the stressful | 0 | 1 | 2 | 3 | 4 |
|  | experience? |
|  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 9. | Having strong negative beliefs about yourself, other people, |  |  |  |  |  |
|  | or the world (for example, having thoughts such as: I am | 0 | 1 | 2 | 3 | 4 |
|  | bad, there is something seriously wrong with me, |
|  |  |  |  |  |  |
|  | no one can be trusted, the world is completely dangerous)? |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 10. | Blaming yourself or someone else for the stressful | 0 | 1 | 2 | 3 | 4 |
|  | experience or what happened after it? |
|  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 11. | Having strong negative feelings such as fear, horror, anger, | 0 | 1 | 2 | 3 | 4 |
|  | guilt, or shame? |
|  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 12. | Loss of interest in activities that you used to enjoy? | 0 | 1 | 2 | 3 | 4 |
|  |  |  |  |  |  |  |
| 13. | Feeling distant or cut off from other people? | 0 | 1 | 2 | 3 | 4 |
|  |  |  |  |  |  |  |
| 14. | Trouble experiencing positive feelings (for example, being |  |  |  |  |  |
|  | unable to feel happiness or have loving feelings for people | 0 | 1 | 2 | 3 | 4 |
|  | close to you)? |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 15. | Irritable behaviour, angry outbursts, or acting aggressively? | 0 | 1 | 2 | 3 | 4 |
|  |  |  |  |  |  |  |
| 16. | Taking too many risks or doing things that could cause you | 0 | 1 | 2 | 3 | 4 |
|  | harm? |
|  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| 17. | Being “super-alert” or watchful or on guard? | 0 | 1 | 2 | 3 | 4 |
|  |  |  |  |  |  |  |
| 18. | Feeling jumpy or easily startled? | 0 | 1 | 2 | 3 | 4 |
|  |  |  |  |  |  |  |

Appendix E

Life Events Checklist for DSM-5 Standard Version

**LEC-5**

**Instructions:** Listed below are a number of difficult or stressful things that sometimes happen to people. For eachevent check one or more of the boxes to the right to indicate that: (a) it happened to you personally; (b) you witnessed it happen to someone else; (c) you learned about it happening to a close family member or close friend; (d) you were exposed to it as part of your job (for example, paramedic, police, military, or other first responder); (e) you’re not sure if it fits; or (f) it doesn’t apply to you.

Be sure to consider your *entire life* (growing up as well as adulthood) as you go through the list of events.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Event** | **Happened** | **Witnessed** | **Learned** | **Part of** | **Not** | **Doesn’t** |
|  | **to me** | **it** | **about it** | **my job** | **sure** | **apply** |
|  |  |
|  |  |  |  |  |  |  |  |
| 1. | Natural disaster (for example, food, hurricane, |  |  |  |  |  |  |
|  | tornado, earthquake) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 2. | Fire or explosion |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 3. | Transportation accident (for example, car |  |  |  |  |  |  |
|  | accident, boat accident, train wreck, plane crash) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 4. | Serious accident at work, home, or during |  |  |  |  |  |  |
|  | recreational activity |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 5. | Exposure to toxic substance (for example, |  |  |  |  |  |  |
|  | dangerous chemicals, radiation) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 6. | Physical assault (for example, being attacked, hit, |  |  |  |  |  |  |
|  | slapped, kicked, beaten up) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 7. | Assault with a weapon (for example, being |  |  |  |  |  |  |
|  | shot, stabbed, threatened with a knife, gun, |  |  |  |  |  |  |
|  | bomb) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 8. | Sexual assault (rape, attempted rape, made to |  |  |  |  |  |  |
|  | perform any type of sexual act through force or |  |  |  |  |  |  |
|  | threat of harm) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 9. | Other unwanted or uncomfortable sexual |  |  |  |  |  |  |
|  | experience |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 10. | Combat or exposure to a war-zone (in the |  |  |  |  |  |  |
|  | military or as a civilian) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 11. | Captivity (for example, being kidnapped, |  |  |  |  |  |  |
|  | abducted, held hostage, prisoner of war) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 12. | Life-threatening illness or injury |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 13. | Severe human suffering |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 14. | Sudden violent death (for example, homicide, |  |  |  |  |  |  |
|  | suicide) |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 15. | Sudden accidental death |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 16. | Serious injury, harm, or death you caused to |  |  |  |  |  |  |
|  | someone else |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
| 17. | Any other very stressful event or experience |  |  |  |  |  |  |

Appendix F

Brief Resilience Coping Scale

Consider how well the following statements describe your behaviour and actions on a scale from 1 to 5. Please put an X through the number that best reflects your behaviour.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Does not | | |  |  |  |  |  | Describes | | |
| describe | | |  |  |  |  |  | me very | | |
| me at all | | |  |  |  |  |  |  | well | |
|  |  |  |  |  |  |  |  |  |  |  |
|  | 1 |  | 2 |  | 3 |  | 4 |  | 5 |  |
|  |  |  |  |  |  |  |  |  |  |  |
|  | |  |  |  | |  | |  | |  |
|  | 1 |  | 2 |  | 3 |  | 4 |  | 5 |  |
|  |  |  |  |  |  |  |  |  |  |  |
|  | |  |  |  | |  | |  | |  |
|  | 1 |  | 2 |  | 3 |  | 4 |  | 5 |  |
|  |  |  |  |  |  |  |  |  |  |  |
|  | |  |  |  | |  | |  | |  |
|  | 1 |  | 2 |  | 3 |  | 4 |  | 5 |  |
|  |  |  |  |  |  |  |  |  |  |  |

1. I look for creative ways to alter difficult situations.
2. Regardless of what happens to me, I believe I can control my reaction to it.
3. I believe I can grow in positive ways by dealing with difficult situations.
4. I actively look for ways to replace the losses I encounter in life.

Appendix G

Aggravation in Parenting

Over the last month have you felt:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | None of the time  0 | Some of the time  1 | Most of the time  2 | All of the time  3 |
| Your child is much harder to care for than most? |  |  |  |  |
| Your child did things that really bothered you a lot? |  |  |  |  |
| You are giving up more of your life to meet your  child’s needs than you ever expected? |  |  |  |  |
| You felt angry with your child? |  |  |  |  |
| Scores |  |  |  |  |

(Yu & Singh, 2012)