The Association of Adverse Life Events and Parental Mental Health on Emotional and Behavioural Outcomes in Young Adults with Autism Spectrum Disorder

Running Head: Life Events and Mental Health in Adults with ASD

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Lay Abstract

People with autism experience high rates of mental health difficulties throughout childhood and into adult life. Adverse life events and parental stress and mental health may contribute to poor mental health in adulthood. We used data at three time points (12, 16, and 23-years) to understand how these factors relate to symptoms at 23-years. We found that emotional and behavioural problems in childhood, adverse life events and parent mental health were all associated with increased emotional and behavioural problems in adulthood.
Abstract

People with autism spectrum disorder (ASD) are at increased risk of developing co-occurring mental health difficulties across the lifespan. Exposure to adverse life events and parental mental health difficulties are known risk factors for developing a range of mental health difficulties. This study investigates the association of adverse life events, parental stress and mental health with emotional and behavioural problems in young adults with ASD. 115 young adults with ASD derived from a population-based longitudinal study were assessed at three time-points (12, 16, and 23-years) on questionnaire measures of emotional and behavioural problems. Parent-reported exposure to adverse life events and parental stress/mental health were measured at age 23. We used structural equation modelling to investigate the stability of emotional and behavioural problems over time, and the association between adverse life events and parental stress and mental health and emotional and behavioural outcomes at 23-years. Our results indicate that exposure to adverse life events was significantly associated with increased emotional and behavioural problems in young adults with ASD, while controlling for symptoms in childhood and adolescence. Higher reported parental stress and mental health difficulties were associated with a higher frequency of behavioural, but not emotional problems, and did not mediate the impact of adverse life events. These results suggest that child and adolescent emotional and behavioural problems, exposure to life events and parent stress and mental health are independently associated, to differing degrees, with emotional or behavioural outcomes in early adulthood.

Key Words: Anxiety, Co-morbid conditions, Depression, Environmental risk factors, Stress.
Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition with lifelong implications for mental health and quality of life. With much of the research to date being focused on childhood, a greater understanding of the factors that influence the experiences and outcomes of adults with ASD is needed. Adults with ASD are at disproportionate risk of having co-occurring mental health difficulties, including a greater frequency of emotional and behavioural difficulties, when compared to those without ASD (Lai et al. 2019). Prominent amongst these are significant emotional difficulties, with a higher than expected prevalence rate of anxiety and depression compared with the general population (Hollocks et al. 2019). Young people with ASD have significant levels of behavioural problems; with prevalence rates of oppositional defiant disorder (ODD) and conduct disorder in children with ASD being estimated to be around 30% (Simonoff et al. 2008), and around 12% for disruptive and conduct disorders more broadly across the lifespan (Lai et al. 2019). While less is known about the prevalence of behaviour problems in adults with ASD (e.g., aggression, non-compliance, irritability etc.), evidence suggests that both emotional and behavioural symptoms remain relatively stable into adolescence (Simonoff et al., 2013) and early adulthood (Woodman et al., 2016), and predict rates of employment, social engagement and the continuation of emotional and behavioural symptoms into adulthood (McCauley et al., 2020).

Current understanding of the impact of adverse life events on people with ASD

In young people without ASD, exposure to adverse life events is associated with higher rates of both emotional and behaviour problems and a
number of different mental health difficulties (Tiet et al. 2001), particularly depression and anxiety (Lewis et al. 2019). There are several possible theoretical explanations for the association between adverse life events and emotional and behaviour problems. This includes mediation through poor emotion regulation skills (McLaughlin & Hatzenbuehler 2009), which are known to be a particular difficulty for those with ASD (Mazefsky & White 2014). There is evidence to suggest that adults with ASD both experience more adverse life events (Berg et al., 2016; Haruvi-Lamdan et al. 2020), and perceive those events as more stressful, than those without ASD (Bishop-Fitzpatrick et al. 2017; Taylor & Gotham 2016). Relatively few studies have investigated the impact of adverse life events on emotional and behavioural outcomes in those with ASD. Taylor and Gotham (2016) found that of a relatively small sample of young adults recruited during their last year of high school nearly half had experienced an adverse life event which was rated by parents as being traumatic for their child, and that this experience was associated with increased symptoms of low mood. This is supported by research in children with ASD showing that those who have experienced adverse life events are more likely to have anxiety, depression and behavioural problems (Kerns et al. 2017). Overall, the limited literature suggests that those with ASD are both at an increased risk of experiencing adverse life events and more likely to experience detrimental effects as a result (Kerns et al 2015).

Whilst the focus of this paper is not on trauma, or post-traumatic stress disorder (PTSD), as typically defined, evidence suggests that exposure to a range of adverse life events can lead to a later PTSD diagnosis in those with ASD (Hoch & Youssef, 2020). There is an emerging literature which aims to better
understand the impact of adverse event and trauma in ASD, how these events may be perceived differently, and possible differences in clinical presentation (see Rumball, 2019 for a review). For example, a recent study with a group of autistic adults found that participants frequently experienced both events which would be considered in the current diagnostic nomenclature (e.g., DSM-5 criteria) around PTSD as “traumatic”, but also other “non-DSM-5” traumas, such as being bullied, a breakdown in relationships with a significant other, or social difficulties. These experiences were nevertheless perceived by participants as traumatic and associated with symptoms of PTSD (Rumball et al., 2020). This suggests that in those with ASD, exposure to a range of situations that may not be perceived as traumatic by those without autism, may nevertheless result in significant emotional symptoms. There is also evidence to suggest that exposure to trauma in ASD may lead to both the “more typical” emotional response but also increased behavioural problems (Brenner et al., 2018; Rittmannsberger et al., 2020). Together this highlights the need to understand the role of adverse life events in the development and maintenance of emotional and behavioural difficulties in ASD and what factors may exacerbate or be protective against these effects.

The influence of parental stress and mental health on the frequency of emotional and behavioural problems of people with ASD

Research in the general population has identified well established connections between high parental stress and mental health difficulties and the mental health of their children, with evidence suggesting this is primarily driven by environmental, rather than genetic factors (D’Onofrio et al., 2007; Eley et al., 2015). This pattern of association has also been identified for both emotional and behaviour problems in young people with ASD (see Yorke et al 2018 for a review).
For example, higher levels of negative expressed emotion by parents of both children and adults with ASD are related to a greater frequency of behavioural problems (Romero-Gonzalez et al. 2018). Furthermore, levels of parental stress have been suggested to moderate the relationship between exposure to adverse events and the severity of emotional problems (Weiss et al., 2015). This suggests that parental stress and mental health may be an important factor associated with emotional and behavioural problems in young adults with ASD.

The relationship between parental stress and emotional and behavioural problems in their children is particularly relevant for this population, as there is evidence to suggest that parents of those with ASD experience more stress than parents of typically developing children or even parents of those with other developmental difficulties (Hayes & Watson, 2013), and that the stress resulting from caring for an adult with ASD and no intellectual difficulties is comparable to that experienced by caregivers of an individual with schizophrenia or major depression (Grootscholten et al., 2018).

The aim of this current study is to investigate the impact of adverse life events experienced in early adulthood on emotional and behavioural problems in young adults with ASD. Given that these symptom domains are reported to be stable from adolescence into adulthood, the effect of life events on adult symptoms will be considered while controlling for the effect of symptoms across childhood and adolescence. Using structural equation modelling (SEM) we will also investigate the relative independent contributions of parental stress and mental health and adolescent emotional/behavioural symptoms on outcomes in adulthood.
Methods

Participants

This study included 115 participants recruited as a part of the larger Special Needs and Autism Project (SNAP). SNAP includes data from 158 young people with ASD and their parents, who have been followed up from childhood and into early adulthood. The study consisted of three waves of data collection at the average age of 12, 16, and 23 years of age. This analysis included only participants who had a completed parent-reported life events scale at 23 years and therefore only 115 of the 126 participants assessed were included in this analysis (See Supplementary Materials for more detail on study participation, and Simonoff et al., 2019 for full participant characteristics at 23 years). The original SNAP population cohort study was derived from 56,946 children born between July 1, 1990 and December 31, 1991, in 12 districts of the South Thames region of London, United Kingdom. The sample was obtained by screening with the Social Communication Questionnaire (Rutter et al., 2003) all children on the special needs register of child health services as well as those with a clinical ASD diagnoses (see Baird et al. 2006 for full details). ASD diagnoses were confirmed according to the ICD-10 criteria based on a full assessment, including the Autism Diagnostic Interview-Revised (Lord et al., 1994), the Autism Diagnostic Observation Schedule-Generic (Lord et al., 2000), and detailed cognitive assessment including measures of intellectual and adaptive functioning.

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved in the
original study by the South East London Research Ethics Committee (05/MRE01/67), with the most recent wave of data collection having been reviewed by the Camberwell and St. Giles NRES Committee number 12/LO/1770, IRAS project number 112286.

**Measure of life events**

*Adverse Life Events Questionnaire.* Adverse life events were measured by a questionnaire adapted specifically for SNAP, completed by parents, about the experiences of their child. The 27 questions included in this measure were combined from several different sources (13 were taken an adapted from the E-Risk study life events questionnaire) and were designed to cover a wide range of possible life events, including: 1) illness or death of a close relative or significant other; 2) witnessing or experiencing the injury and death of another or interpersonal trauma (e.g., being deliberately harmed by another); 3) being arrested or convicted of a crime 4) employment or financial difficulties; and 5) problems with relationships. Except for category one (illness or death of a close relative), which records events that have occurred “ever”, the time frame for the questions was the previous five years (See Supplementary Materials for full details). Each question can be answered “yes” or “no” indicating the events occurrence or absence in the respective time frame. For the current analysis a total adverse life events score was created to represent the events occurring in the last five years (not including items coded as occurring “ever” as they may have occurred prior to waves 1 and 2 and so their specific effects on mental health at 23 years only could not be ensured). We also excluded those related to being arrested or convicted of a crime, which were removed as these are particularly
likely to be related to questions regarding behaviour problems in this population (see statistical analysis section).

**Mental health measures**

**Young adult measures**

*Strengths and Difficulties Questionnaire (SDQ)*. The SDQ (Goodman, 1997) is an emotional and behavioral screening questionnaire consisting of 25 questions, measuring five domains: 1) emotional symptoms; 2) conduct problems; 3) hyperactivity/inattention; 4) peer relationship problems; and 5) prosocial behavior. The current analysis focused on parent-report, which was collected at 12, 16 and 23 years and includes only the emotional and conduct problems (as a measure of behavior problems) subscales. In addition to being a screening instrument (i.e., not designed to be diagnostic), normative data is not available for the parent-report adult version of the measure and the proportion of individuals reported to be above clinical cut-off should be interpreted with caution.

**Measures about parents**

The *Family Stress and Coping Interview (FSCI)* is a parent-reported measure of stress and coping in families of people with developmental disabilities (Nachshen et al., 2003). The FSCI consists of 23 life-span issues that are rated on a five-point Likert scale between “0” (not stressful) and “4” (extremely stressful), which can be summed to create a total score. The FSCI has strong psychometric properties, including high internal consistency ($\alpha = 0.89$) and good stability and discriminant validity across those with different degrees of maladaptive coping styles (Nachshen et al., 2003).
The Beck Anxiety Inventory (BAI) is a validated questionnaire used to measure parent reported symptoms of anxiety (Beck, Epstein, et al., 1988). Estimated rates of clinical levels of anxiety were calculated using the published cut-off scores for moderate or severe symptoms of anxiety.

The Beck Depression Inventory (BDI), is a validated questionnaire used to measure parent reported symptoms of depression (Beck, Steer, et al., 1988). Estimated rates of clinical levels of depression were calculated using the published cut-off scores for moderate or severe symptoms of depression.

The General Health Questionnaire-12 (GHQ-12) is a 12-item questionnaire developed to screen for psychiatric difficulties (Goldberg & Blackwell, 1970) and is particularly sensitive to symptoms of depression (Romppel et al., 2013). The GHQ-12 has adequate psychometric properties and good internal consistency (α = 0.92) for use in the general adult population (Elovanio et al., 2020).

All measures of parent stress and mental health were collected at 23 years. To incorporate the variance from each of these inter-related measures for the purpose of this analysis they were aggregated into a single latent variable.

**Statistical analysis**

Analysis consisted of a series of nested cross-lagged regression analyses in the form of structural equation models (SEM). An SEM is an extension of the standard general linear model which allows the simultaneous estimation of multiple associations between independent, dependent and latent variables. This allows the estimation of the relationship between independent and dependent variables while accounting for the relative contingencies between them. These
individual relationships can be constrained to establish the best fit of the data to the model.

The models were designed to investigate the impact of adverse life events and parental stress and mental health as independent predictors of emotional and conduct symptoms at age 23, while accounting for emotional and conduct symptoms at ages 12 and 16. The final models were constructed in three parts with the aim to address the above questions. Firstly, an initial model was constructed to test the structural invariance (or stability) of the two symptom domains over time. Secondly, a model was constructed examining the impact of adverse life events on emotional and conduct problems at 23 years. Finally, a latent variable representing parental stress and mental health was added as a covariate to investigate whether this acts as an additional predictor of emotional or behavioural problem at 23 years. The parental stress and mental health latent variable consisted of four observed variables: i) parental depression (BDI), ii) parental anxiety (BAI), iii) the Family Stress and Coping Interview and iv) the GHQ-12. For a figure showing all paths included in the hypothesised model see Supplementary Materials 3.

Models were evaluated for goodness-of-fit to the data and compared using chi-square likelihood ratio test of comparative model fit, comparative fit index (CFI), and root mean square error of approximation (RMSEA). An adequate model fit is indicated by a chi-square likelihood ratio test p-value ≥ 0.05, CFI ≥ 0.95 and a RMSEA ≤ 0.08 (Hu & Bentler, 1999). SEM was performed in the statistical modelling software Mplus version 5 (Muthén & Muthén, 2012). The strength of the individual associations between variables in the SEM models are presented using standardised beta-coefficients (β). There were data missing from
several variables (see Table 1 for details), and these were treated as missing at random and dealt with using full information maximum-likelihood estimation. It is generally recommended that SEM analyses include approximately ten participants for each observed variable included in the model (Bentler & Chou, 1987), but that other factors such as including latent variables may reduce sample size requirements (Wolf et al., 2013). Therefore, the current sample size is considered adequate for the analyses undertaken.

As this sample consisted of a sub-set of the wider SNAP study sample, rates of life events are weighted using sampling weights based on the study design calculated as described previously (Baird et al; 2006). Weights were not applied to SEM analyses to allow for comparison of model-fit statistics.

**Results**

**Descriptive statistics**

The final sample had a mean age of 23.1 years (range 21.3 – 25.1) and was predominantly male (104 males:11 females) with a mean full-scale IQ of 84.5 (range 40 -124) at wave 3 of data collection. Twenty-eight of the 115 participants (approximately 24%) could be considered to have an intellectual disability (defined as FSIQ<70). Mean SDQ scores, and the proportion of the sample scoring in the clinical (“abnormal range”) range based on published norms for the SDQ at each time point are shown in Table 1. Seventeen percent of parents scored in the moderate or severe range on the BDI and 13% in the moderate or severe range on the BAI. The scores on parental measures of mental health are displayed in Table 2. For descriptive purposes we also visualised the relationships between change in SDQ scores (from 16 to 23 years) as a function of exposure to low, medium and high exposure to life events calculated based on
interquartile range, with low being those scoring in the lower quartile, high in the upper quartile, and medium between the upper and lower quartile (see Figure 1).

The occurrence and nature of adverse life events experienced by young adults with ASD

The most frequent life events reported by parents were: having moved residence \((n=52); \text{weighted prevalence 43\%}\), witnessing someone being injured or someone dying \((n=19; 35\%)\) or been in contact with a government agency regarding welfare \((n=38; 35\%)\) in the last 5 years. Reports of problems with being bullied \((n=38; 18\%)\), being unemployed or seeking work for longer than a month \((n=47; 24\%)\), relationship problems with a close friend, neighbour or relative \((n=24; 13\%)\) were also common. Potentially traumatic events, like being involved in a serious accident, being deliberately harmed by another adult, or being hospitalised, each occurred in around 6-10\% of the sample (see Table 3 for full results). In order to test whether intellectual ability influenced the number of adverse life events we compared the total number of life events reported by parents of children with an FSIQ of $\geq 70$ to those with a FSIQ $< 70$ and found no significant difference \((\text{high IQ group } (n = 69) \text{ mean } = 5.0; \text{ low IQ group } (n = 28) \text{ mean } = 5.04; t= 0.03; p = .48; \text{ see Supplementary Material 4})\).

Structural invariance and stability of symptoms over time
To investigate the relative contributions of factor loadings over time for the SDQ emotional symptoms and conduct problems scales, basic models were compared both with and without equality constraints between timepoints. There were no notable differences in model fit-parameters between the unconstrained (CFI = 0.85, RMSEA 0.086) and the model with equality constraints (CFI = 0.85, RMSEA 0.083) for the emotional symptoms scale, indicating invariance in factor loadings across the three timepoints. Similarly, for the conduct problems scale there was no difference in model-fit parameters between the unconstrained (CFI = 0.80, RMSEA 0.079) and constrained models (CFI = 0.80, RMSEA 0.074), indicating invariance in factor loading across timepoints. As longitudinal invariance in factor loading has been demonstrated, both scales were included as observed variables in the main analysis.

The relationship between adverse life events and emotional symptoms and behaviour problems at 23 years when accounting for childhood symptoms.

Our initial model with adverse life events (measured at 23 years) and emotional and conduct problems at 16 years predicting symptom severity at 23 years, with additional pathways between emotional and conduct problems at 16 years and frequency of adverse life events, had good fit to the data ($\chi^2 (11) = 15.1, p = .18$; CFI = 0.97, RMSEA 0.057; see Figure 2a). The model indicated that adverse life events were significantly associated with both emotional ($\beta = 0.20, SE = 0.08; p = .012$) and conduct problems at 23 years ($\beta = 0.24, SE = 0.08; p < .01$). There was no significant association between either emotional problems ($\beta = -0.12, SE = 0.10; p = .24$) or conduct problems ($\beta = 0.17, SE = 0.10; p = .10$) at 16 years and number of life events. This model also indicated direct associations between emotional problems at 16 years and conduct
problems at 23 years (β = 0.23, SE = 0.09; p < .01); and conduct problems at 16 years and emotional problems at 23 years (β = 0.17, SE = 0.09; p = .046). Full-scale IQ was included as a covariate in the model and was significantly negatively associated with conduct problems at 23 years (β = -0.25, SE = 0.08; p < .01), but not emotional problems.

[INSERT FIGURE2 ABOUT HERE]

The impact of parental stress and mental health on emotional symptoms and conduct problems and relationships with adverse life events.

First, we confirmed that the proposed parental stress and mental health latent variable was valid by conducting a confirmatory factor analysis (CFA). CFA showed adequate model fit ($\chi^2$ (2) = 6.6, p = .04; CFI = 0.98, RMSEA 0.07), with each of the four variables loading significantly onto the latent construct.

Building on the model described above, the parental stress and mental health latent variable was regressed onto both emotional and conduct problems at 23 years, while life events were regressed onto the latent variable (see Methods section). This analysis indicated good model fit ($\chi^2$ (42) = 52.1, p = .13; CFI = 0.97, RMSEA 0.046; see Figure 2b) and revealed that a greater frequency of adverse life events was significantly associated with greater parental mental health difficulties (β = 0.22, SE = 0.09; p = .02), while at the same time parental stress and mental health was significantly associated with increased conduct (β = 0.18, SE = 0.08; p = .03), but not emotional problems at 23 years (β = 0.10, SE = 0.08; p = .25). The direct associations between life events and both conduct (β = 0.20, SE = 0.08; p = .02) and emotional problems remained significant (β = 0.17, SE = 0.08; p = .03). To test whether adverse life events may impact on
conduct problems and 23, via reduced parental mental health and coping, a test of indirect versus direct effects was conducted. There was no significant indirect effect of this path (indirect path: $\beta = 0.03$, SE = 0.02; $p = .11$), suggesting that adverse life events and parental mental health can be considered independently associated with conduct problems at 23 years.

A sensitivity analysis was conducted removing unemployment from the total life events score. This is because this was one of the most endorsed life events and one which may differ most from the general population and within the ASD sample (i.e., reflecting both never having had paid employment and those who have lost employment) (Shattuck et al., 2012). This had no influence on the results presented above and all significant associations remained so.
Discussion

This study showed the moderate to strong stability of emotional and behavioural problems in young people with ASD and a significant association between exposure to adverse life events on the rates of emotional and behaviour symptoms in adulthood, while controlling for the effect of symptoms in adolescence. We also showed that parental stress and mental health is significantly and negatively associated with their child’s exposure to adverse life events. In turn, poorer parental stress and mental health was related to more behavioural, but not emotional, problems.

The finding that both high rates of emotional and behavioural problems in people with ASD remain high across childhood and into early adulthood is consistent with the previous literature from this sample (Simonoff et al. 2013; Stringer et al. 2020), and others (McCauley et al., 2020; Woodman et al., 2016). Despite the overall stability of the constructs over time, there is an apparent decrease in the proportion of those meeting the clinical cut-off for both emotional and behavioural problems in adulthood. This finding is consistent with evidence to suggest that the prevalence of some mental health difficulties experienced in childhood and adolescence may reduce overtime, while others may increase (Costello & Maughan 2015). This may also relate to the use of the SDQ which is primarily designed to detect symptoms present in childhood and adolescence and therefore may not be sensitive to the differences seen in adult presentations.

The finding of a significant association between exposure to adverse life events and emotional symptoms is consistent with the few studies that have looked specifically at the impact of adverse life events and trauma on mental health outcomes in youth with ASD (Taylor & Gotham 2016; Kerns et al. 2017).
However, this study builds upon the previous literature by using longitudinal data to demonstrate that this relationship remains, even when controlling for symptoms in childhood and adolescence. While taking this approach has demonstrated the important association between adverse life events on emotional symptoms it has also shown that, of those measured in the current analysis, the strongest predictor of mental health in early adulthood is symptom severity in adolescence. There is a lack of research looking at the association between adverse life events and behaviour problems in ASD; however, our current findings are consistent with the previously found associations between adverse life events and behaviour problems in both ASD (Brenner et al., 2018; Rittmannsberger et al., 2020) and non-ASD clinical populations (Tiet et al., 2001). This suggests that environmental factors, such as exposure to adverse life events, may interact with other vulnerability factors such as difficulties with emotional regulation (Mazefsky & White 2014) or cognitive factors such as cognitive inflexibility (Ozsivadjian et al., 2020), leading to increased emotional and behavioural difficulties in ASD.

We also found that parental mental health was significantly related to increased behavioural, but not emotional problems. While some previous research conducted with non-ASD participants has shown a relationship between parental measures and emotional symptoms (Yorke et al. 2018), it is the relationship with behavioural problems which is shown to be more consistent in the literature (Zaidman-Zait et al. 2014). It could be hypothesised that parent stress is more strongly linked to behavioural problems due to a reduction in parents’ ability to respond to their child’s emotional needs, leading to an escalation in behaviour problems (see Hastings 2002; Zaidman-Zait et al. 2014
for discussion). While we also found that a greater number of adverse life events was significantly related to greater parental stress and mental health difficulties, this was not found to be a mediating factor, but rather an independent predictor of behavioural problems in young adults. It is important to consider that whilst we measured the young adult exposure to life events, it may be expected that for some events there will be direct effects on parent stress, inflating this relationship.

**Study Strengths & Limitations**

This study has several strengths, including a relatively large sample of well-characterised participants with ASD, derived from a population sample, and who have been followed over a 11-year period. However, the current results should be interpreted in the context of several limitations. As this study included participants with a wide range of intellectual and verbal ability, we relied entirely on parental report. While this can be considered an advantage, as it enabled us to include those with lower levels of intellectual ability in the analysis, it may also have introduced some bias, particularly as some of the parents included are known to have clinical levels of depression and anxiety and so may have been more likely to endorse negative items on questionnaire measures (Angold et al. 1987). Whilst the sample is representative, it should be noted that we included a relatively small number of female participants and therefore it is unclear how generalisable the results are to females with ASD. Future population-based research should consider oversampling females to have adequate power to explore sex differences. In addition, reliance on parent report may mean that some life events (i.e. those not known to parents) may have gone undetected. Whilst good parent-child agreement has previously been reported for measures of emotional symptoms in youth ASD samples (Ozsivadjian et al. 2013), further
research investigating how specific life events are perceived by autistic people themselves and how this relates to their mental health is needed (Rumball et al., 2020). Finally, observational longitudinal designs such as SNAP do not identify causal factors when showing temporal prediction.

In a related point, the measure used to assess life events in this study has some limitations which need to be considered. Firstly, as the measure was a checklist of events rather than a measure of impact, it does not have known psychometric properties. This is not an issue in of itself, as the focus here was to capture the breadth of possible events know to be meaningful to individuals (Holmes & Rahe, 1967). This does mean however that an impact of these events should not be inferred beyond the associations shown in the current analysis. Future research is needed to understand the discriminant validity of the scale in relation to different outcomes, including symptoms of PTSD. Furthermore, due to limitations in sample size this study was only able to investigate the cumulative effect of all life events, rather than explore any differential impact of specific events. Future research should investigate the impact of event subtypes and how they may differentially relate to emotional and behavioural problems. Inclusion of a non-ASD comparison group would also be beneficial to explore whether these relationships are specific to ASD or are common across young adults but may differ in magnitude of effect.

**Clinical implications**

Given previous findings showing that people with ASD are at both an increased risk of experiencing traumatic or adverse life events (Kerns et al, 2015), and our present results that such events can continue to have a negative impact
on mental health in early adulthood, it is important to consider how the current
results may be able to guide clinical practice. The results described in this study
suggest three important and independent longitudinal relationships between
emotional and behavioural problems occurring in young adults with ASD. The first
of these is the strong predictive value of both the presence of emotional or
behavioural problems in childhood and adolescence. This emphasises the
importance of early intervention focused not only on what may be considered the
core characteristics of ASD (i.e., social communication difficulties), but also on
providing effective treatments for co-occurring mental health difficulties. The
second is related to the proposed vulnerability of this population to experiencing
adverse life events and the additional impact that this has on mental health. A
greater understanding of what experiences are most stressful for individuals with
ASD, and how this may differ from non-ASD populations, can enable the
development of autism specific psychoeducation and intervention strategies
(Rumball et al., 2020). Finally, evidence, which is consistent with our current
findings, that parent mental health may be associated with behaviour problems
throughout childhood and into adulthood (Zaidman-Zait et al. 2014), suggests
that increased support for parents may have a beneficial effect for both their own
and their children’s wellbeing across the lifespan.

In conclusion, this study showed that emotional symptoms at 23 years
were significantly associated with both adolescent emotional and behavioural
problems, and exposure to adverse life events, whilst more behavioural problems
at 23 years were additionally associated with higher parental stress and mental
health difficulties. These effects were found to be independently related to
emotional and behavioural outcomes at 23 years, suggesting they each
contribute to the mental health of young adults with ASD, and provide possible targets for intervention.
Author contributions:

Formulating the research question(s): MJH RMS ES; designing the study DS CL AP GB
TC ES; carrying out the study: RK SL JB, analysing the data: MJH RMS DS AP ES and
writing the article: all authors made contributions.

Declaration of conflicting interests:

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References


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173. https://doi.org/10.1002/aur.1433


https://doi.org/10.1007/s40489-018-0133-9

https://doi.org/10.1002/aur.2306


https://doi.org/10.1542/peds.2011-2864

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<th>% above clinical cut-off</th>
<th>SD</th>
<th>Range</th>
<th>Data available (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>23.1</td>
<td>0.80</td>
<td>21.3–25.1</td>
<td>115/115</td>
<td></td>
</tr>
<tr>
<td>Full-scale-IQ</td>
<td>84.5</td>
<td>24.2</td>
<td>40–124</td>
<td>99/115</td>
<td></td>
</tr>
<tr>
<td>Sex (Male:Female)</td>
<td>104:11</td>
<td>-</td>
<td>-</td>
<td>115/115</td>
<td></td>
</tr>
<tr>
<td>SDQ Emotional Problems 12 years</td>
<td>4.4</td>
<td>50%</td>
<td>2.6</td>
<td>0–10</td>
<td>105/115</td>
</tr>
<tr>
<td>SDQ Emotional Problems 16 years</td>
<td>3.4</td>
<td>53%</td>
<td>2.3</td>
<td>0–9</td>
<td>76/115</td>
</tr>
<tr>
<td>SDQ Emotional Problems 23 years</td>
<td>3.9</td>
<td>38%</td>
<td>2.4</td>
<td>0–9</td>
<td>115/115</td>
</tr>
<tr>
<td>SDQ Conduct Problems 12 year</td>
<td>3.2</td>
<td>47%</td>
<td>2.1</td>
<td>0–9</td>
<td>105/115</td>
</tr>
<tr>
<td>SDQ Conduct Problems 16 years</td>
<td>1.9</td>
<td>44%</td>
<td>1.7</td>
<td>0–8</td>
<td>76/115</td>
</tr>
<tr>
<td>SDQ Conduct Problems 23 years</td>
<td>2.2</td>
<td>17%</td>
<td>1.7</td>
<td>0–8</td>
<td>115/115</td>
</tr>
</tbody>
</table>

SDQ = Strengths and Difficulties Questionnaire
Table 2. Mean and Clinical Cut-off Scores on Measures of Parent Mental Health and Coping

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (% above cut-off)</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAI - Mean</td>
<td>7.6</td>
<td>8.2</td>
<td>0-39</td>
</tr>
<tr>
<td>% minimal</td>
<td>57%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% mild</td>
<td>30%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% moderate</td>
<td>9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% severe</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI - Mean</td>
<td>9.4</td>
<td>10.6</td>
<td>0-46</td>
</tr>
<tr>
<td>% minimal</td>
<td>74%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% mild</td>
<td>9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% moderate</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% severe</td>
<td>7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GHQ-12</td>
<td>12.6</td>
<td>5.5</td>
<td>3-35</td>
</tr>
<tr>
<td>Family stress (FSCI)</td>
<td>27.9</td>
<td>16.6</td>
<td>0-67</td>
</tr>
</tbody>
</table>
Table 3. Frequency of Adverse Life Events as Reported by Parents of Young Adults with ASD

<table>
<thead>
<tr>
<th>Adverse life event</th>
<th>n</th>
<th>Weighted Prevalence (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Witnessed Injury or death</td>
<td>19</td>
<td>35% (9-62)</td>
</tr>
<tr>
<td>Been hospitalised for a physical condition</td>
<td>14</td>
<td>21% (0–46)</td>
</tr>
<tr>
<td>Diagnosed with a severe disease</td>
<td>6</td>
<td>6% (0–11)</td>
</tr>
<tr>
<td>Experienced a serious accident (e.g. house fire, car crash.)</td>
<td>11</td>
<td>9% (1-16)</td>
</tr>
<tr>
<td>Been seriously injured</td>
<td>3</td>
<td>4% (0-10)</td>
</tr>
<tr>
<td>Been bullied by someone</td>
<td>31</td>
<td>18% (5-32)</td>
</tr>
<tr>
<td>Deliberately harmed by another adult</td>
<td>12</td>
<td>6% (0-12)</td>
</tr>
<tr>
<td>Harmed in the course of being disciplined for bad behaviour</td>
<td>6</td>
<td>4% (0-10)</td>
</tr>
<tr>
<td>Contact with any agency about welfare (e.g., social services, police, health visitor)</td>
<td>38</td>
<td>35% (12-58)</td>
</tr>
<tr>
<td>Serious problems with a close friend, neighbour or relative</td>
<td>24</td>
<td>13% (4-22)</td>
</tr>
<tr>
<td>Moved away from parents or change of carer</td>
<td>9</td>
<td>31% (7-55)</td>
</tr>
<tr>
<td>Breakdown of relationships with partner</td>
<td>15</td>
<td>10% (2-17)</td>
</tr>
<tr>
<td>Breakdown of relationships with parent</td>
<td>11</td>
<td>9% (1-17)</td>
</tr>
<tr>
<td>Laid off/sacked from work</td>
<td>9</td>
<td>4% (0-8)</td>
</tr>
<tr>
<td>Moved to a new house or residence</td>
<td>52</td>
<td>43% (23–71)</td>
</tr>
<tr>
<td>Major financial crisis</td>
<td>7</td>
<td>8% (0-15)</td>
</tr>
<tr>
<td>Unemployed/seeking work for more than one month</td>
<td>47</td>
<td>24% (10-39)</td>
</tr>
<tr>
<td>Sexual problem(s)</td>
<td>7</td>
<td>7% (0-13)</td>
</tr>
</tbody>
</table>
Figure 1. Mean Change in SDQ Emotional and Conduct Problem Scales from 16 to 23 Year Associated with Low, Medium and High Exposure to Adverse Life
Figure 2. Relationship between Life Events and Childhood Mental Health Symptoms with Emotion and Conduct Problems at 23 years

Figure 2a. Model showing the relationship between adverse life events and emotion and conduct problem at 23 years

\[ \chi^2(11) = 15.1, \text{ CFI} = 0.97, \text{ RMSEA} = 0.06; \] ** significance at \( p \leq 0.01, \) * significance at \( p \leq 0.05; \) FSIQ regressed on Emotion & Conduct at 23 years. For clarity, non-significant associations not shown.

Figure 2b. Model showing the relationship between, parental mental health, adverse life events and emotion and conduct problem at 23 years

\[ \chi^2(DF) = 52.1(42), \text{ CFI} = 0.97, \text{ RMSEA} = 0.046; \] ** significance at \( p \leq 0.01, \) * significance at \( p \leq 0.05; \) FSIQ regressed on Emotion & Conduct at 23 years. For clarity, non-significant associations not shown.