

## BRIEF REPORT: Prevalence and Impact of Significant Life Events for Adults with Asperger Syndrome

### Abstract

*Little is known about the significant life events experienced by adults with Asperger syndrome (AS), though these may result in psychiatric illness. This study looks at the prevalence and types of significant life experiences among 51 adults with AS, the largest-available-to-date sample of adults with AS in Ontario. The most frequently reported life events (in the last two months) included: unemployment; financial problems; mistreatment; disruptions in interpersonal relations; change in living arrangements; and disruptions of routine at work or school. The majority of respondents had at least one significant life event, 58.8% had experienced at least two, and 41.2% had at least three. A significant relationship was found between the number of life events and reported levels of distress. The results suggest that adults with AS may experience significant life events more frequently than adults with other types of developmental disabilities.*

Significant life events (such as changing residences, being harassed, or losing friends) have been linked to psychiatric disorders in the general population (e.g., Paykel, 2001) as well as in the individuals with developmental disabilities (DD) (Hastings, Hatton, Taylor & Maddison, 2004). Similar to the general population, stressful life events have been linked to the onset of mental illness in the individuals with DD (Esbensen & Benson, 2006; Hulbert-Williams et al., 2013; Monaghan & Soni, 1992). Adults with Asperger syndrome (AS), a pervasive developmental disorder without intellectual impairments, may be especially vulnerable to significant life events because of their already high levels of anxiety (Gillot & Standen, 2007) and their difficulty adjusting to changes (Barnhill, 2001). However, the occurrence of life events in those with AS have not been systematically studied.

Given their importance, it is surprising how little is known about the significant life events experienced by adults with AS. The current study uses self-report to look at the prevalence and the types of life experiences reported in a two-month period in an Ontario based sample of adults with AS. The relationship between life events and levels of distress is also examined.

### Methods

#### Participants

An online survey was completed by 66 adults with AS from across Ontario as part of a larger longitudinal study on the use of planned and emergency health services. The 51 participants that scored 26 or higher on the Autism Spectrum

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Quotient questionnaire (Baron-Cohen et al., 2001; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005) and had a formal diagnosis of autism spectrum disorder (ASD) or AS were included in the analysis ( $M$  Age = 34.9,  $SE$  = 1.62; 28 females, 23 males). Overall, participants were highly educated, with 62.7% of the sample having at least a college degree. Almost three quarters (74.5%) of the respondents reported being diagnosed with at least one mental health problem, and two thirds (66.7%) had at least one medical condition.

## Measures

The participants filled out a checklist of life events experienced over the previous two months derived from the Psychiatric Assessment for Adults with Developmental Disabilities Checklist (PAS-ADD checklist; Moss et al., 1998). Three additional items were added to the original PAS-ADD checklist, including: change in roommates, change in primary staff/worker, and recent trauma/abuse. Adults endorsed whether any of the events on the list had occurred in the past two months. They could also list additional significant experiences not captured within the list under "other." Life events were coded independently by two researchers: closely related items on the life events checklist were grouped into broader categories for the purpose of this analysis; "other" life events were placed either into the existing categories or into two additional categories (disruptions of routine related to school or work, and disruptions in or conflict with support).

Participants also completed the Brief Distress Scale (BDS) – a one-item measure on a 10-point scale that indicates how close the individual perceives their situation to be to crisis. The scale was slightly modified from its original "for families" form (Weiss & Lunsky, 2011).

## Analyses

Statistical analyses were conducted using chi-square (dichotomous variables) and t-tests (continuous variables) to examine the relations between predictor variables and number of life events as well as reported levels of distress. Additionally, Spearman's rank-order correlation was used to determine whether the total number of life events experienced correlated with distress

## Results

Individuals who indicated having at least one life event in the past two months did not differ in terms of age ( $M$  = 33.64,  $SD$  = 11.61) from individuals who did not ( $M$  = 39.08,  $SD$  = 10.93;  $t_{(49)} = 1.44$ ,  $p$  = .16). However, there was a marginally significant difference between the proportion of women (86.0%) and men (65.0%) reporting at least one life event,  $\chi^2_{(1, 49)} = 2.948$ ,  $p$  = .086. There was also a trend for those with two or more psychiatric diagnoses to report a higher number of life events than those experiencing one or no life events,  $t_{(49)} = 1.98$ ,  $p$  = .054.

The most common life events reported were: unemployed/seeking work for more than one month (25.5%), financial problems (25.5%), mistreatment (21.6%), and interpersonal disruptions (19.6%); however, no one life event occurred for more than a quarter of the sample. Table 1 lists the life events by category in order of the frequency with which they were reported. The majority of respondents (76.5%) had at least one significant life event in the last two months, with 58.8% having at least two and 41.2% having at least three. On average, each participant reported two life events ( $Mdn$  = 2,  $M$  = 2.39,  $SD$  = 2.29).

Overall, the average distress level reported on the BDS was 5.29 (out of ten;  $SD$  = 1.87), with more than a fifth (22.0%) of the participants indicating that they are currently in crisis or are on the verge of crisis. The types of life events experienced as well as the total number of life events were studied in relation to the participant's reported level of distress: participants that reported being unemployed/seeking work had higher levels of distress,  $t_{(49)} = 2.57$ ,  $p$  = .013, as did participants with financial problems,  $t_{(49)} = 3.22$ ,  $p$  = .002. Furthermore, a moderate relationship was found between the total number of life events and the reported levels of distress,  $r_{s(51)} = .50$ ,  $p$  < .001.

## Discussion

The findings suggest that significant life events occur with high frequency in adults with AS. Using the same measure with informants (rather than self-report) in a sample of 1155 adults with DD, Hastings et al. (2004) reported only

Table 1. Significant Life Events Listed in Order of Frequency for Adults with Asperger Syndrome (N = 51)

Type of Significant Life Event	n (%)
Unemployed/seeking work for more than one month	13 (25.5%)
Financial Problems (Major financial crisis, financial strain)	13 (25.5%)
Mistreatment (Harassment, teasing, discrimination, etc.)	11 (21.6%)
Interpersonal disruptions (Serious problems with close friends, break ups, divorce, etc.)	10 (19.6%)
Change in living arrangements (Change in residence, change in roommates)	8 (15.7%)
Disruptions of routine related to work or school (Finishing school, change of schedule at work, stress at work, etc.)	8 (15.7%)
Sexual Problem	8 (15.7%)
Serious illness or injury	7 (13.7%)
Serious illness of close relative, caregiver or friend	5 (9.8%)
Something valuable lost or stolen	5 (9.8%)
Alcohol Problem	4 (7.8%)
Death of a close person (Death of close relative, close family friend, caregiver or other relative)	3 (5.9%)
Disruptions in/conflict with support (Life-coach unavailable, difficulties with psychiatrist, loss of support)	3 (5.9%)
Problems with police or other authority	3 (5.9%)
Laid off or fired from work	2 (3.9%)
Recent trauma/abuse	2 (3.9%)
Other changes in routine	3 (5.9%)

Note: Frequency of life events are not mutually exclusive.

46.3% of the individuals experienced a life event in a 12-month period, compared to 76.5% reported here in two months in adults with AS. A similar study by Tsakanikos, Bouras, Costello and Holt (2007) indicated that 66.9% of their sample (adults with DD) experienced at least one life event in the past year. Although a direct comparison cannot be made due to the differences in how the data was collected (self-report versus informant report) and the time period (two months versus one year), the results of the current study nevertheless suggest that adults with AS may experience significant life events more frequently than adults with other types of developmental disabilities. This finding is troubling given the well-established

connection between mental illness and significant life events in the general population as well as individuals with DD (e.g., Hastings et al., 2004; Paykel, 2001).

The most commonly reported significant life events were unemployment and financial crises (or financial strain). This is surprising because of the high average level of education in the sample (almost two-thirds have a college degree or higher). However, this finding is consistent with the literature on outcomes of adults with AS which suggests that these adults have difficulty securing stable and skill-appropriate jobs despite their education (e.g., Howlin, 2000). The prevalence of unemployment and finan-

cial difficulties is especially problematic seeing as we found that these particular problems were associated with higher levels of distress. The other most commonly reported life events were interpersonal in nature (mistreatment and interpersonal disruptions): adults in our sample frequently perceived being harassed or teased, and often suffered from problems with partners and friends. These problems are consistent with the clinical profile of AS, and may also be related to the difficulties with employment and finances (Howlin, 2000).

As expected, we found that the total number of life events was positively correlated with distress levels. This suggests that the life events reported by the participants were perceived negatively and experienced as stressful. However, it may also indicate that individuals in distress may be better able to recall recent negative events.

In the current sample there was a trend for more women than men having at least one significant life event, which is in accordance with the study by Tsakanikos and colleagues (2007) related to adults with DD. No studies have compared the occurrence of life events in women to men with ASD specifically. There was also a trend for participants with two or more psychiatric diagnoses to report a higher number of significant life events. This finding is consistent with existing literature on life events and mental illness in adults with DD (e.g., Hastings et al., 2004; Hubbert-Williams & Hastings, 2008; Tsakanikos et al., 2007), but again has not been studied with those on the autism spectrum.

Individuals with AS reported a high frequency of life events on the significant life event checklist. Although valid, the measures we used are typically completed by caregivers and were developed for individuals with cognitive impairments that are not present in adults with AS. Further research needs to validate these measures in adults with AS. Furthermore, although we found that the distress levels were strongly correlated with the total number of life events, future research should directly assess whether the respondents consider the reported life events to be stressful.

## Key Messages From This Article

**People with disabilities:** Being stressed is hard and it happens often. When things happen in your life that upset you, it's important to get help to deal with it.

**Professionals:** Be mindful of the frequent stressful events in the lives of adults with AS, especially with regards to employment, finances and interpersonal problems; take care to mitigate their effects.

**Policymakers:** Support is needed to help adults with AS deal with stressful changes and to find stable and well-paid employment.

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