

A preliminary study of perceived stress in adults with intellectual disabilities according to self-report and informant ratings¹

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Approximate word count: 4468 words

Keywords: Intellectual disability, stress

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¹ This is the authors' final corrected version of Lunsky, Yona and Bramston, Paul (2006) *A preliminary study of perceived stress in adults with intellectual disabilities according to self-report and informant ratings*. *Journal of Intellectual and Developmental Disability*, 31 (1). pp. 20-27. ISSN 1366-8250 DOI: 10.1080/13668250500488660

Abstract

Background. Stress is a major risk factor for mental health problems in individuals with intellectual disabilities, but few studies on stress have been conducted that take both the perspective of the person with the disability and the caregiver into account. The present study evaluated an informant version of the *Lifestress Inventory*, and compared it to the self-report version.. Method. Seventy pairs of individuals with intellectual disability and their caregivers completed the *Lifestress Inventory*, the *Inventory of Negative Social Interactions* and the *Birleson Depression Scale*. Results. Informant and self-report ratings on the *Lifestress Inventory* were internally reliable, showed modest agreement with each other and correlated with the negative Social Interactions and Depression measures. The most troublesome stressors reported by informants and self-reports differed, however, and families tended to agree more with self-reports than staff informants. Conclusions. The informant version of the *Lifestress Inventory* is a suitable parallel instrument but not a replacement for self reports.

Introduction

Research suggests people with intellectual disabilities (ID) experience at least as much or more stress than the general population (Hatton & Emerson, 2004), yet they have fewer resources (internal and external) to manage their stress (Lunsky & Neely, 2000). Potential stressors arise from the greater risk they face of being marginalised within our society (Annison, 2000), which manifests itself in prejudice and discrimination. So, not only are they faced with the personal challenges and demands of their disability, but also with the restricting environmental factors that others without a disability do not have to face

In order to conceptualise the impact of psychological and situational pressures on an individual with ID, it is helpful to briefly review the Lazarus model of stress (Lazarus & Folkman, 1984). This model holds that if the individual perceives an event as being overly challenging and beyond his/her ability to cope, then he or she is likely to experience stress. In cognitively appraising an event as manageable or unmanageable, the individual is thought to call upon: 1) previous experiences; 2) environmental supports; and 3) personal beliefs. The research on those with intellectual disabilities suggests that: 1) People with ID often have previous coping experiences that are less than positive (Hastings, Hatton, Taylor, & Maddison, 2004); 2) Those with ID have limited environmental supports (Lunsky & Benson, 2001; Reiss & Benson, 1984) and; 3) Those with ID have low beliefs in their own abilities (Jahoda, Cattermole, & Markova, 1988). The combination of these three factors when appraising a situation would greatly increase the likelihood of stress occurring.

Stress has long been recognised as a major risk factor for mental and physical health problems, thus it is surprising that so little research on stress has been carried out with people with ID, who often have multiple medical and psychiatric issues. One of the reasons so little research has been published is the absence of reliable and valid measures. Few existing measures of stress for the ID population consider both major life stressors as well as minor events or daily hassles (Bramston et al., 1999). In addition, existing measures of stress employ either exclusively informant views or exclusively self-reports. Below we review the limited research on stress according to informant and self report perspectives.

Only one measure of stress faced by individuals with ID has been developed specifically for caregivers/informants: Groden and colleagues (2001) developed an informant measure of stress for individuals with autism, the *Stress Survey Schedule*. The scale is completed by the caregiver and considers anticipation/uncertainty, changes & threats, unpleasant events, pleasant events, sensory/personal contact, food related activity, social/environmental activities and ritual related stress -- all factors particularly relevant to individuals with autistic spectrum disorders. Autism has significant overlap with intellectual disability, with 75% of individuals with autism having ID and up to 30% of people with ID having autism (see Bradley & Lofchy for review, 2005). As a result, some of the items on the Groden et al. scale might have relevance to the broader population with ID, but the measure has yet to be researched amongst this group.

The impact of significant life events (major stressors) and their relationship to mental health crises in those with ID has been well-documented (e.g., Stack et al., 1987; Ghazziudin, 1988; Hatton & Emerson, 2004; Nadarajah, Roy, Harris, & Corbett, 1995). One recent study (Hastings, Hatton, Taylor, & Maddison, 2004) summarized information on 17 major life events for 1155 individuals with ID according to informants, using the *PAS-ADD checklist* (Moss et al., 1998) and reported a relationship between significant life events and psychopathology, particularly in the affective domain. Another recent study (Owen et al., 2004) on 93 individuals with ID in an institutional setting used the *Life Events List* (LEL), a 20-item informant completed list of negative life events thought to be particularly relevant to individuals with ID in a long term residential setting. This study reported that the most common stressful life events experienced were staffing and residence changes, conflict, family bereavements and relationships and illness or injury, and individuals exposed to such life events were rated as displaying more aggression and at higher risk for affective disorders. Although both of the scales (*PAS-ADD checklist* and *LEL*) employed in these two studies provide information on overall frequency of stressful life events, they do not assess the impact of such events and also do not address forms of stress other than major life events (e.g., daily hassles).

Only two measures relating to stress faced by individuals with ID have been developed specifically as a self-report. A self-report measure of anxiety, the *Glasgow Anxiety Scale* (Mindham & Espie, 2003), was recently published. It appears to successfully tap self-reported anxiety in people with an intellectual disability using a 35-item inventory with a 3-point Likert response scale (never, sometimes, always). While overlapping with the construct of stress, the content of this scale incorporates more anxiety-specific symptoms (such as panic attacks) and is primarily a measure for individuals with mild intellectual disability, with no informant version. The other self-report scale was developed by Bramston and his colleagues, who conducted a series of focus groups amongst Australians with ID and from this developed a list of life events that typically bother, upset and frustrate individuals with ID. These were then refined into a self-report stress scale (the *Lifestress Inventory*) with accompanying normative self-report data from 459 people with mild or moderate intellectual disability (Bramston, Fogarty & Cummins, 1999). Subsequent use of the inventory confirmed that the subjective experience of the person with ID can be reliably and validly obtained, that it is predictive of depression and that this perspective is important to solicit (Esbensen, 2004; Hartley & MacLean., in press).

Previous research regarding perceived stress or negative life events in the ID population has focused on either exclusively on the perspective of caregivers or exclusively on individuals with ID. No studies thus far have obtained both perspectives. Whether the informant perspective can add further information beyond what we can learn from self-report has yet to be studied. Thus, the purpose of this study was to determine whether an informant version of the *Lifestress Inventory* could be a valuable parallel assessment tool to the existing self-report version of the *Lifestress Inventory* developed by Bramston and colleagues. Specifically, we sought to measure how informants (staff or family) perceive stress in people with intellectual

disability, how well informant perceptions correspond to self-reported stress, and how well an informant measure of stress is correlated with other informant measures of problematic life events and distress/depressive symptoms in the ID population.

Method

Participants

Ninety-nine adults with ID in Southern Ontario, Canada completed a study looking into “things in life that bother you”. For this study, each participant was asked to nominate someone “who knows you the best who might be willing to answer some questions about the same kinds of things we spoke about.” Seventy participants nominated an individual who agreed to participate and returned questionnaires (see Measures below). Findings here are based on these 70 self-report/informant pairs.

The average age of the 70 participants with ID was 38.7 years (range 20-63yrs) and 51% were male. The majority of individuals were between the ages of 36 and 50 (18 women and 13 men), 28 (18 men and 10 women) were 35yrs or below, and 11 individuals (5 men and 6 women) were older than 50. Participants came from a range of residential settings: 23% were living with family, 33% lived independently, 28% lived in supported independent living, and 15% lived in group homes. Twenty percent of the sample was working in community settings, 28% were in sheltered workshops, 33% attended educational or recreational day programs, and 19% had no daytime structured activities. On average, informants knew the participant for 14.6 years with 59% of the informants describing themselves as staff members (16 residential staff, 16 case managers or counsellors and 9 day program staff) and 41% identifying themselves as family (26 individuals) or unpaid caregiver/friend (3 individuals).

A standardised screening measure of intelligence (Wechsler Abbreviated Scale of Intelligence) was individually administered to each participant by the researcher (registered psychologist) so that any relationship between cognitive ability and performance on the dependent measures could be accounted for. Of the 65 individuals who completed the matrices and vocabulary WASI subscales, six individuals (1 woman and 5 men) had IQ screen scores between 76 and 86; 50 individuals had standardized scores between 56 and 75 (suggesting mild ID), and 9 individuals received a standardized score of 55 or below (the lowest score obtainable on the test, suggesting moderate ID). As WASI scores were not found to be related to scores on the dependent measures, and all individuals interviewed were receiving ID services, the six people who may have been functioning in the borderline range of intelligence were included in the study. (Correlations did not change significantly when these six pairs were excluded.)

Measures

Informants were asked to complete the *Lifestress Inventory* for informants (*Lifestress-Inf*), which is a new inventory compiled specifically for this study and designed to enable informants to quantify the number of potentially stressful life events being experienced by people with ID (see Appendix A). The *Lifestress-Inf* was

derived from the *Lifestress Inventory* (Bramston, Fogarty & Cummins, 1999) which is a self-report stress scale comprised of a list of 30 life events which people with ID reported (in focus groups) to most often bother or upset them (for details on scale construction, see Bramston, Bostock and Tehan, 1993). The original *Lifestress Inventory* (self-report) has been shown to be reasonably reliable, valid and factorially stable (Bramston, Fogarty, & Cummins, 1997) and clinically useful in understanding the pressures experienced by young adults moving into community accommodation (Bramston & Cummins, 1998). For comparative purposes with the new *Lifestress-Inf*, the *Lifestress Inventory* (self-report) was also administered in this study.

The *Lifestress-Inf* slightly adapts the wording of items from the original *Lifestress Inventory* (self-report) to suit the perspective of a rater. For example, the self-report item “Do you get to choose things that are important to you?” was changed to “Does he/she get to choose things that are important to him/her?”. Informants were asked to score each item on a 0-2 scale Likert scale with 0 = ‘No, not at all’; 1 = ‘Sometimes or somewhat’; and 2 = ‘Yes, most definitely’. This three-point scale was also used for the self-report *Lifestress Inventory* in this study in order to facilitate comparisons between the two scales. The original *Lifestress Inventory* (self-report) uses a 4-point Likert Scale to measure stress impact, but this was considered unsuitable for the current study because informants cannot reasonably be expected to so finely quantify the personal impact on another of experiencing various life events. It was anticipated that this change would not alter the number of reported life events (frequency score) but would restrict the range of Impact totals. To minimise response sets, 17 of the 30 items on both scales are worded positively and require reversing prior to analysis so that higher scores reflect more stress.

On both the self-report and the informant scales a frequency score represents the total number of life events that have happened recently in the individual’s life (Frequency score: maximum of 30 events). The impact of those events on the individual is estimated by adding the ratings (0, 1, 2) on the endorsed items (Impact score: maximum score of 60). These scoring procedures are in accordance with the processes set out in the original *Lifestress Inventory* (Bramston, Cummins, & Fogarty, 1999).

An additional measure of stressful life events, a short form of the *Inventory of Negative Social Interactions* (INSI; Lakey, Tardiff & Drew, 1994) was included in this study as a measure of convergent validity of the *Lifestress-Inf*. The INSI focuses on stressful interpersonal interactions and is structured identically to the *Inventory of Socially Supportive Behaviours* (ISSB; Barrera, Sandler, & Ramsey, 1981). The INSI has 40 items where the respondent rates the frequency of specific types of interactions that have occurred in the last month. For individuals with intellectual disabilities, the instrument is presented verbally, rather than in written form, and there are only three response options (not at all, sometimes, and a lot) and items are modified slightly to be better understood. For example, instead of “criticized you” the item is reworded as “said bad things about you”. This scale was modified by Lunsy and Benson (2001) with demonstrated reliability and validity. For the purposes of this study, the 25 items most commonly endorsed by adults with intellectual disability in that study were

administered. The informant version of this questionnaire was modified similarly to the *Lifestress-Inf*, substituting “s/he” for “you”.

The Birleson Depressive Short form Self- Rating Scale (BDS-S) was included in this study to further assess convergent validity of the *Lifestress-Inf* and was administered as a self-report and an informant scale. The BDS-S is an 18-item measure, based on a 37-item questionnaire developed for 7 to 12-year-old children (Birleson, 1981). There are three response categories: “Most of the time,” “Sometimes,” and “Never.” These are scored 0, 1 or 2 with the higher score reflecting depression. This scale was adopted in Benson and Ivins’ 1992 study involving adults with ID, where scores on it correlated significantly with informant ratings. The informant version of the Birleson consists of 5 items scored on a 3 point Likert scale (Benson & Ivins, 1992).

Procedures

Potential participants were contacted by their service providers from 15 agencies who provide residential, therapeutic or vocational services to adults with ID and asked about the project and for permission to be contacted by the researcher, who then telephoned them and explained the study in greater detail and arranged a meeting date. Interviews occurred in settings comfortable for the person with ID, following an oral and written consent procedure. To minimize response sets, prior to administration of each self-report scale, participants were given two to three training items using the same response choices as those used with the scale. These response choices were presented both verbally and visually, with coloured symbols/words. If the participant appeared to answer each item in the same way (e.g., always picking the last option), response choices were presented in varied order. At the end of this interview, participants with ID nominated a caregiver informant. With participants’ consent, the researcher then contacted the nominated caregivers by telephone, explained the study and asked if they would be willing to complete several questionnaires. The questionnaires were then mailed to the informants, with a postage-paid return envelope. Informants were telephoned twice following the mailing of the questionnaires if they were not returned within a month. All questionnaires reported here were returned within 8 weeks of the initial participant interview. This study received ethics approval from the University of Toronto Department of Psychiatry Institutional Review Board.

Results

In order to reveal how many of the 30 potentially stressful life events were endorsed as occurring in participants’ lives, a frequency analysis was conducted. Results revealed that 14.76 (SD 4.34) life events occurred according to informants and 12.45 (SD 5.17) events according to participants with ID. This suggests that on average, nearly half the potentially stressful events listed in the scale did actually occur in participants’ lives. Using the same 30 life events, Bramston et al found the number of events self-reported as occurring by 459 people with mild or moderate intellectual disability was 8.59 (SD 6.14) (Bramston, Fogarty & Cummins, 1999), a

mean difference of less than one SD from the current study (that is not statistically significant). In the current study, adding the Likert scale ratings (maximum possible score of 60) produced a mean Impact score of 21.21 (SD 7.12) according to informants and 20.78 (SD 8.67) according to self-report.

Mean Frequency and Impact scores were compared according to the age and tested intelligence level of the participants with ID and were found to be unrelated. However, women were rated as having higher stress Frequency scores than men according to informants [$t(69) = 2.27, p < .05$] and higher stress Impact scores according to both informants [$t(69) = 2.96, p < .05$] and self report [$t(69) = 2.21, p < .05$].

Relationship between responses of informants and people with ID

Impact scores on the informant and self-report versions of the scale were modestly correlated ($r(70) = .41, p < .005$) suggesting a total of 16% of the variance is shared. Interestingly, Impact scores of family member informants and self reports were strongly correlated ($r(29) = .70, p < .001$) and Impact scores on the staff and self report versions were only modestly correlated ($r(41) = .34, p < .05$). This difference in strength of correlations was statistically significant ($z = 2.02, p < .05$). Mean Frequency scores of informants were significantly higher than mean Frequency scores of self reports ($t(69) = 3.282, p < .01$), but there were no differences between the groups according to mean Impact scores ($t(69) = 0.35, p > .05$). Again, we see a different relationship between scores of family members compared to self and scores of staff compared to self in this regard. Families gave significantly higher scores than self reports for both Frequency ($t(28) = 4.85, p < .001$) and Impact of stress ($t(28) = 3.67, p < .005$). Staff, in contrast, did not give significantly higher scores for Frequency ($t(40) = -.95, p > .05$) or stress Impact ($t(40) = 1.63, p > .05$) than their clients.

The most common and least common items/events reported by self and informant are presented in Table 1. Of the four most frequently reported items, only one was common to both self-report and informants (hearing others argue), and two items were in common amongst the least often reported items (not getting enough privacy and not making own choices).

Reliability

Initial reliability was calculated for the present sample, with a recognition for the need to test again in a larger sample. The *Lifestress-Inf* had a Cronbach's alpha of 0.77, which is comparable to the .80 of the *Lifestress Inventory* (self-report) in this study, suggesting adequate internal reliability for both versions.

Validity

In order to estimate the convergent validity of the *Lifestress-Inf*, the mean Impact score was compared to the mean total score for the *Inventory of Negative Social Interactions* (INSI). Both the self-report and informant versions were significantly correlated with the INSI ($r(69) = .64, p < .001$ and $r(57) = .58, p < .001$

respectively) and the *Birleson Depression Scales*, self-report and informant versions ($r(70) = .78 p < .001$ and $r(65) = .31 p < .05$ respectively).

Discussion

This study examined the qualities of the *Lifestress-Inf*, an informant version of the *Lifestress Inventory*, a self-report scale designed to measure stress in people with ID. The self-report nature of the *Lifestress Inventory* has restricted its use to people with higher-level communication skills, whereas the informant version enables clinicians and researchers to quantify the stress from another important perspective: the caregiver. In the present study, both scales were related to reports of interpersonal difficulties and depressed mood. However, there were some differences between caregiver and self-report perspectives. Given the modest but far from perfect relationship between the two perspectives, it is important to examine both sides and attempt to understand differences in perspectives when they do exist.

The items on the *Lifestress Inventory* that were most commonly self-reported in this Canadian study were largely the same as items most frequently reported in an earlier study amongst a large Australian sample of people with mild or moderate levels of intellectual disability (see Bramston, Fogarty and Cummins, 1999) and a recent study with an American sample (Sigan & MacLean, in press). Hence, it would seem that across different nations people with ID consistently report as stressful: hearing other people argue, death or serious illness of someone close, constantly being interrupted, and not being quick enough. Apart from the latter event, these common stressors are 'other oriented' involving interpersonal relationships and networks. This finding can be understood in the light of research literature showing that disruption of the social environment and relationships are known to be highly stressful because attachment to others and the social support gained from such attachment is a fundamental human need (O'Leary, 1990).

According to the results of this study, on average, participants experienced almost half of the 30 potentially stressful listed items/life events. It is interesting that women were reported to experience stressors more frequently than men, and that their impact was perceived as more severe according to both self-report and informants. Higher reported stress by women has also been reported in the general research literature (Mazure & Maciejewski, 2003). Women with intellectual disability have also been found to report higher levels of depressed mood than men (Lunsky, 2003), as have women in the general population (McGrath et al., 1990). Higher levels of stress in women may be one explanation for gender differences in the onset of depression in the general population and in those with ID (see Mazure & Maciejewski, 2003 for further discussion on link between stress and depression in women in the general population).

The *Lifestress-Inf*, as used by 70 informants with respect to a person with disability known well to them, was shown to have adequate reliability and modest correlations with an informant measure of negative social interactions and an informant measure of depression. The *Lifestress-Inf* also showed modest correlations

with the equivalent self-report stress scale. However, some informants may be better able to rate stress in those that they care for better than others. Specifically, findings from this study suggest that family member ratings were more highly correlated with self report ratings than were ratings of staff. Only 14 (48%) of these family members were living with the individuals they rated. Whether informants (family or staff) can accurately report stress of individuals who are non-verbal is a separate issue that was not addressed by this study. Clearly, the informant can provide some information, but their perspective cannot replace the perspective of the person with ID and should not be adopted on its own as a proxy measure.

The items/events most often and least often thought by informants in this study to be troublesome for people with ID differed appreciably from the self-report. This suggests that the orientation or focus of an informant may differ from the self-focus of the individual, a finding replicating earlier research (Bramston & Fogarty, 2000). In this study the informants seemed to focus more on inadequacies or coping deficits in the people with disability, for example, not being able to find or maintain a job or getting 'stuck' in a difficult situation and not knowing what to do. Interestingly, in this sample such issues were not as highly emphasized in the ID group. It may be that such stressors are a greater concern for the agencies that serve these individuals than the individuals themselves.

In contrast to the deficit orientation of caregivers, people with ID focused on current challenges in their interpersonal relationships as their greatest stress. It may be that caregivers are more aware of skill deficits because that is what they see and that is often the very reason caregiving is needed, while relationship difficulties are less obvious and less well understood. The obvious implication here is that informant and self-report scales should not be considered interchangeable. Self-report has the clear advantage of being able to potentially access feelings and attitudes not available to informants (see also Bramston et al., 2000; Cummins, 2002 for review on proxy measures).

Parallel versions of the *Lifestress Inventory*, given their relationship to self reported and informant rated depressed mood, have potential clinical utility, particularly when the two perspectives differ. For example, if a clinician relies primarily on the caregiver to report on relevant life events that may have contributed to the current problems and the caregiver fails to report on significant interpersonal issues or losses to the individual with ID, the clinician might not intervene accordingly. Alternatively, the clinician could rely exclusively on the self-report of an individual with ID who is very concerned about how others perceive him. Such an individual might not report that he is experiencing stressors at work or that he is worrying about how to complete work tasks because of fears that his job could be in jeopardy, but a caregiver might be able to offer this perspective. The process of caregivers and individuals with ID talking together about the kinds of things they think are stressful to the person with ID might help them to better understand and support one another. The clinician, having obtained both perspectives through the *Lifestress Inventory*, could easily facilitate such a discussion.

This study has a number of limitations that must be taken into consideration when interpreting its results. First, it is difficult for informants to rate impact of stressful events on the life of a person with ID. While potentially stressful events can readily be rated by informants as occurring/not occurring in someone's life, expecting informants to detect how much stress each event induces is difficult. Thus, while the *Lifestress-Inf* extends our ability to quantify life-event stress in people with disability, there remain some good reasons to use of self-report if at all possible. A second important limitation of this study is its small sample size, with only a minority of individuals having moderate ID. If informant ratings of stress are to be adopted in the future for individuals with a broader range of disabilities, then we need to study informant ratings of more severely impaired individuals. It may be that some stressors from the *Lifestress Inventory* are less relevant to individuals with more severe disabilities, and that indices such as the *Stress Survey Schedule* (Grodin et al., 2000) or the *Life Events List* (Owen et al., 2004) may be more appropriate.

In summary, the results of this study suggest that the *Lifestress-Inf* can be a useful supplement to the *Lifestress Inventory* (self-report). It seems that an informant nominated by the individual can make a reasonably good estimate of the occurrence of such events, and their perceptions of stress are related to their perceptions of interpersonal difficulties and depressed mood. However, our results suggest that there may be a tendency for informants to focus on skill deficits and lack of coping and self-report to focus on interpersonal difficulties. In addition, some caregivers offer more consistent reports to self reports than others. Clearly, there can be advantages in sourcing both perspectives when assessing stress. Future research should explore whether similar categories of stress are found for individuals with more severe disabilities, and how well caregivers can assess stress in such individuals.

References

- Annison, J.E. (2000). Towards a clearer understanding of the meaning of "home." *Journal of Intellectual & Developmental Disability, 25*(4), 251-262.
- Barrera, M. Jr., Sandler, I.N., & Ramsey, T.B. (1981). Preliminary studies of a scale of social support: Studies on college students. *American Journal of Community Psychology, 9*, 435-447.
- Benson, B.A., & Ivins, J. (1992). Anger, depression and self-concept in adults with mental retardation. *Journal of Intellectual Disability Research, 36*, 169-175.
- Birleson, P. (1981). The validity of depressive disorder in childhood and the development of a self-rating scale: A research report. *Journal of Child Psychology and Psychiatry, 22*, 71-88.
- Bradley, E., & Lofchy, J. (2005). Learning disability in the accident and emergency department. *Advances in Psychiatric Treatment, 11*, 45-57.
- Bramston, P., & Bostock, J. (1994). Measuring perceived stress in people with intellectual disabilities: The development of a new scale. *Australia and New Zealand Journal of Developmental Disabilities, 19*, 149-157
- Bramston, P., Bostock, J., & Tehan, J. (1993). The measurement of stress in people with an intellectual disability: A pilot study. *International Journal of Disability Development and Education, 40*, 95-104.
- Bramston, P., & Cummins, R.A. (1998). Stress and the move into community accommodation. *Journal of Intellectual and Developmental Disability, 23*, 295-308.
- Bramston, P. & Fogarty, G. (1995). Measuring stress in the mildly intellectually handicapped: The factorial structure of the Subjective Stress Scale. *Research in Developmental Disabilities, 16*, 117-131.
- Bramston, P., & Fogarty, G. (2000). The assessment of emotional distress experienced by people with an intellectual disability: A study of different methodologies. *Research in Developmental Disabilities, 21*, 487-500.
- Bramston, P., Fogarty, G., & Cummins, R. A. (1999). The nature of stressors reported by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 12*, 1-10.
- Cummins, R.A. (2002). Proxy responding for subjective well-being: A review. *International Review of Research in Mental Retardation, 25*, 183-207.
- Esbensen, A.J. (2004). Depression in individuals with mental retardation: An evaluation of cognitive theories. *Unpublished doctoral dissertation*, Ohio State University, Columbus, OH.
- Fogarty, G. J., Bramston, P., & Cummins, R. A. (1997). Validation of the Lifestress Inventory. *Research in Developmental Disabilities, 18*, 435-456.
- Ghaziuddin, M. (1988). Behavioural disorder in the mentally handicapped: The role of life events. *British Journal of Psychiatry, 152*, 683-686.
- Groden, J., Diller, A. Bausman, M., Velicer, W., Norman, G., & Cautela, J. (2001). The development of a stress survey schedule for persons with autism and other developmental disabilities. *Journal of Autism and Developmental Disorders, 31*, 207-217.

Hartley, S.L. & MacLean, W.E. (In press). Perceptions of stress and coping strategies among adults with mild mental retardation: Insight into psychological distress. *American Journal on Mental Retardation*.

Hastings, R.P., Hatton, C., Taylor, J.L., & Maddison, C. (2004). Life events and psychiatric symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 48*, 42–46.

Hatton, C., & Emerson, E. (2004). The relationship between life events and psychopathology amongst children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 109-117.

Jahoda, A., Cattermole, M., Markova, I. (1988). Stigma and the self-concept of people with a mild mental handicap. *Journal of Mental Deficiency Research, 32*, 103-115.

Lakey, B., Tardiff, S., & Drew, B. (1994). Negative social interactions: Assessment and relations to social support, cognition, and psychological distress. *Journal of Social and Clinical Psychology, 13*, 42-62.

Lazarus, R. S., & Folkman, S. (1984b). *Stress, appraisal, and coping*. New York: Springer.

Lunsky, Y. (2003). Depressive symptoms in intellectual disability: Does gender play a role? *Journal of Intellectual Disability Research, 47*, 417-427.

Lunsky, Y., & Benson, B.A. (1999). Social circles of adults with mental retardation as viewed by caregivers. *Journal of Developmental and Physical Disabilities, 11*, 115-129.

Lunsky, Y., & Benson, B.A. (2001). The association between perceived social support and strain and positive and negative outcome for adults with mild intellectual disabilities. *Journal of Intellectual Disability Research, 45*, 106-114.

Lunsky, Y., & Neely, L. (2000, August). Interpersonal conflict in a relationships context. *Paper presented at International Association for the Scientific Study of Intellectual Disability World Congress*. Seattle, W.A.

McGrath, E., Keita, G.P., Strickland, B., & Russon, N.F. (1990). *Women and depression: Risk factors and treatment issues*. American Psychological Association, Washington, DC.

Mazure, C.M. & Maciejewski, P. K. (2003). The interplay of stress, gender, and cognitive style in depressive onset. *Archives of Women's Mental Health, 6*(1), 5-8

Mindham, J., & Espie, C.A. (2003). Glasgow Anxiety Scale for people with an intellectual disability (DAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research, 47*(1), 22-30.

Moss, S., Prosser, H., Costello, H., Simpson, N., Patel, P., Rowe, S., Turner, S., & Hatton, C. (1998). Reliability and validity of the PAS-ADD checklist for detecting psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research, 42*, 173-183.

Nadarajah, J., Roy, A., Harris, T.O., & Corbett, J.A. (1995). Methodological aspects of life events research in people with learning disabilities: a review and initial findings. *Journal of Intellectual Disability Research, 39*, 47-56.

O'Leary, A. (1990). Stress, emotion and human immune function. *Psychological Bulletin*, 108(3), 363-382.

Owen, D.M., Hastings, R.P., Noone, S.J., Chinn, J., Harman, K., Roberts, J., & Taylor, K. (2004). Life events as correlates of problem behavior and mental health in a residential population of adults with developmental disabilities. *Research in Developmental Disabilities*, 25, 309-320.

Reiss, S., Benson, B.A. (1984). Awareness of negative social conditions among mentally retarded, emotionally disturbed outpatients. *American Journal of Psychiatry*, 141, 88-90.

Stack, L.S., Haldipur, C.V., & Thompson, M. (1987). Stressful life events and psychiatric hospitalisation of mentally retarded patients. *American Journal of Psychiatry*, 144, 661 – 663.

Author Note

This project was funded by a postdoctoral fellowship from the Social Sciences and Humanities Research Council of Canada, and a research grant from the Scottish Rite Foundation, awarded to the first author. No restrictions on access to or publication of data were imposed by these two granting agencies. The authors have no financial or non-financial conflicts of interest regarding this study.

Table 1: Percentage of the sample reporting most and least common life events

| Most Commonly Reported - Informant Report | % | Most Commonly Reported - Self-Report | % |
|---|----------|--|----------|
| No job | 88 | Death of someone close | 83 |
| Difficult situation and not knowing what to do | 85 | Hearing others argue | 79 |
| Being in crowds | 84 | Not being quick enough | 74 |
| Hearing others argue | 81 | Others think you cant do things | 73 |
| Least Commonly Reported - Informant Report | % | Least Commonly Reported - Self-Report | % |
| Not getting enough help | 18 | Not getting enough privacy | 12 |
| Not getting enough privacy | 19 | Not getting on with special friend | 17 |
| Not making own choices | 21 | Not making own choices | 20 |
| Not liking where you live | 27 | Getting into trouble | 24 |

Appendix A: Lifestress Informant

1. Does s/he get to choose things that are important to him/her?
2. Does s/he get enough privacy and time to him or herself?
3. Has s/he heard people s/he knows arguing?
4. Do people treat him/her as though s/he is different?
5. Do people respect his/her rights?
6. Has someone s/he knows been seriously ill or died?
7. Has s/he been getting along with his/her partner/boyfriend/girlfriend?
8. Does s/he get along well with his/her family?
9. Do people listen to him/her when s/he has something to say?
10. Does s/he feel s/he can't do things properly or quick enough?
11. Can s/he understand other people's instructions or directions?
12. Can people understand him/her?
13. Does anybody bully or hurt him/her?
14. Do people interrupt him/her when s/he is busy?
15. Do people tease him/her or call him/her names?
16. Does s/he get on well with his/her supervisor or teacher?
17. Do people make him/her do things s/he doesn't really want to do?
18. Have s/he had any arguments or fights with anyone?
19. Can s/he do the things people want him/her to do?
20. Can s/he get enough help when s/he wants it or needs it?
21. Has s/he recently been in any really crowded places?
22. Has s/he ever been in a difficult situation where s/he didn't know what to do?
23. Do people around him/her let him/her know what's going on?
24. Will s/he always be able to have or find a job?
25. Does s/he feel confident handling money and counting change?
26. Does s/he like living where s/he lives at the moment?
27. Has s/he been in trouble lately?
28. Does s/he have enough friends?
29. Do people think s/he can't do things when s/he thinks s/he can?
30. Do people like talking to him/her?

Scoring:

| | |
|-------------------------------|----------|
| <i>Yes, most definitely=</i> | 2 |
| <i>Sometimes or somewhat=</i> | 1 |
| <i>No, Not at all =</i> | 0 |