

Life events exposure in people with intellectual disabilities

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Abstract

People with Intellectual Disabilities (ID), especially those living in residential settings, will likely experience one or more life events as they age through the lifespan. Relocation, personal illness, and losses were the most common life events in the ID population and have been implicated as risk factors for physical and mental health problems. A number of studies have reported a significant relationship between life events exposure and psychiatric problems in people with ID. When and where a life event occurs, and the ability to cope with an event(s) can have consequences on physical and emotional well-being. The impact of a life event as being positive or negative is also dependent upon how it is viewed by the person who experiences it. Multiple life events exposure was found to have a cumulative effect over time and increases the likelihood of emotional and behavioral problems. Within the ID population, moving (relocation) was a more frequent life event for adults with Down syndrome due to the higher incidence of functional decline and dementia. Further studies are needed that look at different age groups, living settings and sample grouping to better understand the effects of life events exposure in people with ID.

Keywords: Life events exposure, Intellectual disabilities, Relocation

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1. Introduction

Significant life events can have a direct as well as an indirect effect on physical and mental health. Negative life events have been associated with the onset of depression in both children and adults in the general population (Brilman & Ormel, 2001; Tiet, Bird, Hoven, Moore, Wu, Wicks *et al.*, 2001; Kraaji, Arensman, & Spinhoven, 2002; Muscatell, Slavich, Monroe, & Gotlib, 2009). Changes in routine or living situations were found to have a negative effect on physical health and mortality for people with dementia (Mirotznik & Kamp, 2000; Butler, Orrell, Ukoumunne, & Bebbington, 2004; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004).

People with ID respond to traumatic and significant life events in similar ways as in the general population. In an early study, Ghaziuddin (1988) reported that life events exposure was more associated with behavior problems in individuals with mild ID than for those with severe ID and behavior problems without a history of recent life events. Studies have consistently demonstrated a significant relationship between life events exposure and psychiatric problems in adults with ID (Hastings, Hatton, Taylor, & Maddison, 2004; Hamilton, Sutherland, & Iacono, 2005; Esbensen & Benson, 2006; Cooper, Smiley, Morrison, Williamson, & Allan, 2007). Robust associations were also found between specific adverse life events and psychiatric disorders among children with ID (Hatton & Emerson, 2004). A study of referrals to a mental health service revealed that depression, personality disorder, and adjustment reaction were reliably linked with multiple exposure to life events (Tsakanikos, Bouras, Costello, & Holt, 2007). Associations were also found between exposure to negative life events and an increased frequency of aggressive/destructive behavior and the presence of affective disorder (Owen, Hastings, Noone, Chinn, Harman, Roberts *et al.*, 2004).

People living in a residential setting were found to experience more life events than people living with natural or foster families (Hastings *et al.*, 2004; Hamilton *et al.*, 2005). When and where a life event occurs and the ability to cope with an event(s) can have consequences on a person's physical and/or emotional well-being and even influence their continued placement in a particular setting. The need to differentiate between traumatic experiences and life events as predictors of psychopathology was raised by Martorell and Tsakanikos (2008). They questioned whether such events served as risk factors or as triggering factors when mental health problems occur; however this has yet to be explored.

Specific life events such as moving to a new residence, experiencing a personal loss, and changing jobs have been implicated as risk factors for physical and

mental health problems. Moving to a group home or changing jobs may be a negative event for some individuals, whereas for others it can be a welcomed positive event. The impact of a life event is dependent upon how it is viewed by the person who experiences it. In a recent study, positive life events were not found to be associated with concurrent behavior problems, however, the frequency counts of life events and life events perceived as negative were reported to play a role in the development of behavior problems and depressive symptoms among adults with ID (Esbensen & Benson, 2006). In a critical review of the studies conducted with people with ID thus far, Hulbert-Williams and Hastings (2008) reported, “it appears likely that life events are causally related to subsequent psychological problems but further research is needed to establish the temporal precedence of life events and to build models of mechanisms by which this effect takes place”.

2. Issues in recording life events exposure

Currently, there is no gold standard in how investigators collect and record life events data in people with ID. From a review of the literature, different criteria have been used when analyzing and interpreting the data. In the seven studies reviewed in this report, the number and category of life events studied differed between the instruments used to measure them (see Table 1). The Psychiatric Assessment for Adults with Developmental Disabilities (PAS-ADD) (Moss, Prosser, Costello, Simpson, Patel, Rowe *et al.*, 1998) was used in three studies (Hastings *et al.*, 2004; Tsakanikos *et al.*, 2007; Martorell, Tsakanikos, Pereda, Gutiérrez-Recacha, Bouras & Ayuso-Mateos, 2009). The PAS-ADD is a semi-structured informant-based interview measure designed to identify psychiatric problems in people with ID; it includes a checklist of 17 negative life events which are not specific to people with ID. Two studies constructed their own life events checklists for research purposes which were tailored for people with ID (Owen *et al.*, 2004; Patti, Amble, & Flory, 2005). The remaining two studies used previously published questionnaires that included a variety of life events (Hamilton *et al.*, 2005; Esbensen & Benson, 2006).

According to Owen *et al.* (2004), adults with ID residing in an institutional setting are exposed to a range of potentially negative life events over the course of a typical year.

However, the impact of a life event as being positive or negative can be different based upon how it is perceived by the person who experiences it (Esbensen & Benson, 2006).

The nature of an event as having a positive, neutral or negative impact on the individual may be more important than the frequency of events (Stack, Haldipur, & Thompson, 1987).

Variables such as the age of the person and the location where a life event occurs can have a bearing on its impact especially for adults with Down syndrome (see Patti *et al.*, 2005). Other factors to take into account are the sample size and grouping, and the age-range of a study cohort which can have a bearing on a study’s findings and conclusions. Only one study conducted thus far was population-based in its scope (Hastings *et al.*, 2004). The age-range and mean age also varied across the seven studies; only one (Patti *et al.*, 2005) focused on life events exposure in an “over age 50” adult cohort (see Table 1). Therefore, studies on life events exposure need to include a number of factors when exploring the effect(s) of one or more life events on the individuals who experience them.

Table 1- *Studies and instruments used to record life events exposure in people with ID*

| <i>Authors, year</i> | <i>Instrument Used</i> | <i># Life events</i> | <i>Type of events</i> | <i>Cohort size^a</i> | <i>Study duration</i> |
|-----------------------------------|---|----------------------|---|---|-----------------------|
| Owen <i>et al.</i> , (2004) | <i>Life Events List (LEL)</i> (developed by authors) | 20 | only negative events listed | 93 <i>M</i> = 55.2 yrs <i>R</i> = 24–93 yrs | previous 12 mos. |
| Hastings <i>et al.</i> , (2004) | <i>PAS-ADD</i> (Moss <i>et al.</i> , 1998) | 17 | only negative events listed | 1155 <i>M</i> = 43.9 yrs. <i>R</i> = 17-92 yrs. | previous 12 mos. |
| Hamilton <i>et al.</i> , (2005) | <i>Life Quality and Health for Adults with DD</i> (1999) | 37 | events not rated | 624 <i>M</i> = 34.2 yrs. <i>R</i> = 18-76 yrs. | previous 24 mos. |
| Patti <i>et al.</i> , (2005) | <i>Life Events and Changes Checklist</i> (developed by authors) | 33 | events not rated | 211 <i>M</i> = 69.3 yrs. <i>R</i> = 50-86 yrs. | previous 60 mos. |
| Tsakanikos <i>et al.</i> , (2007) | <i>PAS-ADD</i> (Moss <i>et al.</i> , 1998) | 17 | only negative events listed | 281 <i>M</i> = 34.5 yrs. <i>R</i> = 16-86 yrs. | previous 12 mos. |
| Esbensen & Benson (2006) | <i>Life Experiences Survey</i> (Sarason <i>et al.</i> , 1978) | 45 | events rated as positive, negative or no impact | 104 <i>M</i> = 42.0 yrs. <i>R</i> = 21-79 yrs. | two 4 mo. intervals. |
| Martorell <i>et al.</i> , (2009) | <i>PAS-ADD</i> (Moss <i>et al.</i> , 1998) | 17 | only negative events listed | 177 <i>M</i> = 29.6 yrs. <i>R</i> = not listed | previous 12 mos. |

^a*M* = mean age of study cohort; *R* = age range in study cohort

3. Multiple exposure to life events over time

Half the studies listed in Table 1 investigated life events exposure over a 12-month period which may limit assumptions when attempting to explain their long-term effects. Owen *et al.* (2004) reported long-term hospital residents to have encountered an average of 3.50 negative events (range 0-8) in the previous 12 months. The most frequently reported were staffing and residence changes, conflicts with staff/other residents, death of a close friend/relative, and personal injury/illness. Analyses revealed that individuals exposed to more recent (negative) life events were also rated as displaying more aggressive/destructive behavior and were at increased risk for affective/neurotic disorder.

In a population-based sample of adults with ID who were receiving community and residential services ($N = 1155$), 46% encountered at least one significant life event and over 17% had two or more life events in the previous 12 months (Hastings *et al.*, 2004). Significant relationships were found between life events exposure and psychiatric problems. Similar to the findings of Owen *et al.* (2004), the most frequent events were moving residence, illness of close relative/friend, conflicts with others, illness/injury to self, and death of close friend/relative. It was found that those living in an institution were more likely to have experienced at least one recent event in the previous 12 months than those residing in a community setting indicating location to be an important variable.

For 281 adults with ID seen in a mental health clinic, an average of 1.17 life events (range 0-7) was reported during the last 12 months (Tsakanikos *et al.*, 2007). Events such as moving out of house or residence and bereavement were associated with some form of psychopathology. The study findings indicated that depression, personality disorder and adjustment reaction were reliably associated with the multiple exposure to life events. In a study of 177 adults with ID living in the community, 75% had experienced at least one traumatic event during their lifespan, and 50% had experienced at least one negative life event in the previous 12 months (Martorell *et al.*, 2009).

Others have investigated life events exposure over different time periods. Esbensen and Benson (2006) studied the life events (both positive and negative) in 104 adults with ID over two 4 month periods. An average of 2.6 life events (range 0-13) were reported with 0.8 rated as negative and 1.3 rated as positive. Individuals with major depression were found to experience a significantly greater number of all life events and more events perceived as negative in the prior four months. It was proposed that experiencing life events in general and negative life events can predict the development of behavior problems and depressive symptoms among individuals with higher-functioning levels of ID.

Over a 2 year period, an average frequency of 4.68 life events (range 0-16) was reported in 624 adults with ID living in family/foster care or a residential setting (Hamilton *et al.*, 2005). Associations were found between emotional and behavioral problems and life events exposure; the frequency of life events varied according to the type of residence where the individual resided. Regarding location, people living in a residential setting were found to encounter more life events than those living with family or a foster family which supports the findings of Owen *et al.* (2004).

The number and types of life events over a 5 year period in an older cohort of 211 adults with and without Down syndrome (DS) living in community group homes were reported by Patti *et al.* (2005). Life events were divided into four distinct categories: 1) relocations (i.e., moving to a new residence or living setting), 2) environmental/social changes (i.e., change in day program, bedroom, social relationships), 3) losses/separations (i.e., death of a parent/family member/peer, change or loss of a roommate), and 4) medical events (i.e., hospitalization(s), surgery, onset of seizures, sustaining a fracture, pneumonia, other medical changes). The DS adults were found to experience more life events in all four categories than those without DS. The differences in life events exposure for those with and without DS are highlighted in Table 2.

Table 2 - Mean number of life events by category in a cohort of older persons with and without Down syndrome* (N = 211)

| Life events category | DS Group (n = 108) (50-59 years) | NDS Group (n = 103) (50-86 years) |
|------------------------------|-------------------------------------|--------------------------------------|
| Home Changes | 1.06 (1.11)* | .25 (.54)* |
| Environmental/Social Changes | .45 (.63)* | .14 (.35)* |
| Loss/separation | .45 (.72)* | .12 (.39)* |
| Medical events/changes | 1.35 (1.21)* | .56 (.85)* |

*taken from Patti *et al.* 2005

* The number in parenthesis is the standard deviation for each calculated mean. For all four categories, significant differences between the DS and NDS groups were found ($p < .001$).

Due to the nature of an intellectual disability and the need for some form of support, it is very likely that people with ID, especially those living in residential settings, will experience one or more life events and changes (positive

and negative) as they age through the lifespan. Most research has focused on negative or adverse events, however specific events such as relocation (e.g., moving to a group home, transferring from one group home to another group home) and changing jobs (e.g., a new job placement) may not be a true negative event as such a change may actually be anticipated or desired by the person and result in a more positive outcome for them. What seems to be more important is the occurrence of multiple life events (both positive and negative) and the inability to cope with their cumulative effect that can cause some form of psychopathology.

From the cited studies, both the occurrence and frequency of life events were associated with physical and mental health changes, but the degree of their impact can vary based the person's level of functioning, and on where they reside. Additionally, the effect of one or more specific life events (e.g., relocation, death of a relative/friend, physical illness) may not be fully manifested within a certain time period (e.g., 12-months) as the consequences of multiple events have been found to be cumulative but may take a longer time period before an effect occurs.

Studying life events exposure over longer time periods (>12 months) may provide more information to better predict the onset of depressive symptoms and behavior problems in people with ID. Following this approach in future studies, preventative efforts could then be developed to intervene with people who have experienced one or more life events in order to reduce or prevent behavior problems, symptoms of depression or other psychiatric conditions.

4. Life events exposure in subgroups of the ID population

A review of the literature revealed few studies that looked at life events in children with ID. In an early study, Ghaziuddin, Alessi and Greden (1995) found children with pervasive developmental disorder (PDD) and depression to experience significantly more life events in the 12-months preceding evaluation than children with PDD alone. Coe, Matson, Russell, Silfer, Capone, Baglio *et al.* (1999) found that children with Down syndrome (ages 6–15) experienced fewer life events in the preceding 12 months, but had more behavior problems than typically developing (TD) children of the same age. This differed somewhat from Hatton and Emerson, (2004) who reported that children with ID were more likely to experience a greater number and a wider range of negative life events (e.g., losses, separations) than TD children.

It was also found that there was an association between some life events and emotional disorders, and that the effect of the events appears to be cumulative.

Life events research has mainly focused on the general adult ID population; most studies did not single out any special subgroups (e.g., people with Prader-Willi and Fragile X syndromes, autism). Some studies, however, did investigate life events exposure in people with Down syndrome. Hamilton *et al.* (2005) included 129 DS adults in their sample of 624 adults with ID (mean age 34.2 years) but presented only frequency data on life event exposure. A strong relationship between the frequency of life events and emotional/behavioral problems was found for DS adults who were functioning in the mild range but not for those in the moderate to severe range of ID. Owen *et al.* (2004) had only 6 DS adults in their residential sample of 93 adults; as a result no distinctions could be made with such a small number.

In the study by Patti *et al.* (2005) comparisons were made between the number and types of life events experienced by older adults with and without DS. The findings revealed that DS adults in the sixth decade of life experienced a significantly greater number of relocations and medical events than their non-DS counterparts of similar or older ages. A follow-up study focused on the number of relocations that occurred in an older cohort of 140 adults with and without DS over a 5 and 10 year period (see Patti, Amble, & Flory, 2010). Data on 61 DS adults (mean age 61.8 years) was compared with 79 non-DS adults (mean age 70.7 years). The DS group encountered significantly more relocations (i.e., changing group homes, nursing home placements) than the non-DS group over both time periods which were attributed to age-related functional decline and presence of dementia that was more prevalent in the DS group. A mean of 1.07 and 1.26 relocations respectively occurred during the 5 and 10 year periods in the DS group compared to a mean of 0.59 and 1.00 respectively in the non-DS group. Nursing home placement for end-of-life care was significantly higher in the DS group (39% versus 9%) whereas the majority (91%) in the non-DS group remained in a group home setting. Mortality differences were also significant between the two groups. Of the 44 DS adults who died, the locations were nursing home 46%; hospital 39% and group home 16%; for the 25 who died in the non-DS group it was group home 52%, hospital 28% and nursing home 20% (Patti *et al.*, 2010).

5. Conclusions

Life events exposure can have a direct as well as an indirect influence on physical and mental health of people with ID. Caregivers and health care professionals need to monitor both young and older people with ID who have experienced one or more life events (both positive and negative) because they are at risk for a consequential change in their behavior or functioning.

Studies have demonstrated that multiple life events can have a cumulative effect; can have an impact on behavior, health and stability; and result in some form of psychopathology. In addition, a medical event (e.g., a new illness or medical condition), can further contribute to a change in a person's emotional well-being and affect quality of life.

Relocation (e.g., moving/changing residences), personal illness and personal losses were reported to be the most common life events experienced in the adult ID population. Often an older person with ID who is displaying age-related functional decline needs to be moved to another setting for increased care and/or for safety management issues. Within the ID population, moving (relocation) was reported to be a more frequent occurrence for older adults with DS due to the higher incidence of functional decline and dementia which necessitates placing them in an alternative residence or health-related facility for an increased level of care and supervision. It was suggested by Patti *et al.* (2005) that the cumulative exposure of one or more life events with the additional onset of medical frailties associated with aging and dementia can combine to create a stressful period for older adults with Down syndrome.

Further studies are necessary to better identify and evaluate the effects of life events exposure in people with ID. Few studies to date have focused on life events exposure in children, teenagers and the elderly as well as studying life events in different subgroups of the ID population. These remain important areas for future research. In addition, studying different living settings where people with ID reside and including more population-based samples should also be done. By tracking the occurrence of significant life events and developing proactive coping strategies, we may be able to minimize or prevent the display of behavioral problems and any associated psychiatric disorders. Also significant to take into account is the impact of medical events on the physical and mental health of older adults with ID, especially for those with DS, as they can present challenges for caregivers on future placement and the delivery of care and services.

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