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Life events and psychological problems in people with intellectual disabilities

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Life events and psychological problems in people with intellectual disabilities

Stephen Lee Hulbert-Williams

A thesis submitted to the School of Psychology, Bangor University, in partial
fulfilment of the requirements of the degree of Doctor of Philosophy.

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Chapter 2, pages 15 – 32

Chapter 4, pages 51 – 67

Appendices A – Z, pages 93 – 158

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Table of Contents

| | Page |
|---|-----------|
| Summary | 1 |
| Chapter 1 – Introduction | 1 |
| Intellectual Disabilities | 2 |
| The Mental Health of People with Intellectual Disabilities | 4 |
| Methodological Issues In Life Events Research | 5 |
| Methodological Issues In Life Events Research with People with Intellectual Disabilities | 7 |
| Alternative approaches to stress research | 8 |
| The present thesis | 10 |
| Chapter 2 – Life Events as a Risk Factor for Psychological Problems in Individuals with Intellectual Disabilities: A Critical Review | 14 |
| Abstract | 15 |
| Background | 15 |
| Methods | 15 |
| Conclusions | 15 |
| Introduction | 15 |
| Critical Framework | 17 |
| Life Events as a Correlate of Psychological Problems | 18 |
| Specific Life Events | 18 |
| Cumulative Life Events | 20 |
| Life Events as a Risk Factor | 26 |
| Life Events as a Causal Risk Factor | 29 |
| Conclusions and Implications | 30 |
| Chapter 3 – Life Events and Psychological Problems in Adults with Intellectual Disabilities: Longitudinal Relationships | 33 |
| Abstract | 34 |
| Introduction | 34 |
| Method | 36 |
| Participants | 36 |
| Measures. | 37 |
| <i>Measures of life events.</i> | 37 |
| <i>Measures of psychological problems.</i> | 38 |
| <i>Physical Health and Adaptive Skills.</i> | 40 |
| Procedure | 41 |
| Results | 42 |
| Descriptive statistics | 42 |
| Correlates of life events exposure | 43 |

| | |
|--|-----------|
| Longitudinal analyses | 43 |
| Discussion | 46 |
| Chapter 4 – Self-reported Life Events, Social Support and Psychological Problems in Adults with Intellectual Disabilities | 50 |
| Abstract | 51 |
| Introduction | 51 |
| Materials and Method | 51 |
| Results | 51 |
| Discussion | 51 |
| Introduction | 51 |
| Materials and Method | 55 |
| Participants and Setting | 55 |
| Measures | 55 |
| <i>The Bangor Life Events Schedule for Intellectual Disabilities: Self-Report.</i> | 56 |
| <i>The Brief Symptom Inventory (BSI)</i> | 57 |
| <i>The Social Network Map</i> | 58 |
| Procedure | 59 |
| Results | 59 |
| Discussion | 64 |
| Chapter 5 – Life Events and Psychological Problems in Children with Intellectual Disabilities | 68 |
| Abstract | 69 |
| Introduction | 69 |
| Method | 71 |
| Participants and setting | 71 |
| Procedure | 72 |
| Measures | 73 |
| <i>The Behavior Problems Inventory (BPI).</i> | 73 |
| <i>The Reiss Screen for Maladaptive Behavior (RSMB).</i> | 73 |
| <i>The Nisonger Child Behavior Rating Form.</i> | 73 |
| Results | 74 |
| Discussion | 76 |
| Chapter 6 – Discussion | 79 |
| Life Events in Adults with Intellectual Disabilities | 80 |
| Life Events in Children with Intellectual Disabilities | 81 |
| Theoretical Implications | 82 |
| Implications for Policy and Practice | 84 |
| Methodological issues | 86 |
| Future directions for research | 89 |

| | |
|--|-----------|
| Conclusions | 92 |
| Appendices and References | 93 |
| Appendix A – The development of the BLESID | 93 |
| Appendix B – The BLESID-I | 97 |
| Appendix C – The BLESID-SR | 101 |
| Appendix D – Life Events List | 106 |
| Appendix E – Behavior Problems Inventory | 107 |
| Appendix F – PAS-ADD Checklist | 111 |
| Appendix G – Ward Anger Rating Scale | 113 |
| Appendix H – Physical Health Questionnaire | 115 |
| Appendix I – Adaptive Behavior Scales (Short Form) | 116 |
| Appendix J – Approval letters | 121 |
| Appendix K – Participant information sheet | 125 |
| Appendix L – Participant consent form and assessment | 126 |
| Appendix M – Advocate information sheet | 127 |
| Appendix N – Advocate assent form | 130 |
| Appendix O – Host organisation information sheet | 131 |
| Appendix P – Host organisation permission form | 134 |
| Appendix Q – Brief symptom inventory | 135 |
| Appendix R – Social network map | 144 |
| Appendix S – Approval letter | 146 |
| Appendix T – Information sheet | 147 |
| Appendix U – Host organisation permission form | 150 |
| Appendix V – Participant information sheet | 151 |
| Appendix W – Contextual assessment of capacity | 152 |
| Appendix X – Participant consent form | 154 |
| Appendix Y – Reiss Scales for Maladaptive Behavior | 155 |
| Appendix Z – Nisonger Child Behavior Rating Form | 156 |
| References | 158 |

List of Tables

| | Page |
|---|------|
| Table 3.1 – Events most commonly rated as having a negative impact | 42 |
| Table 3.2 – Results of longitudinal hierarchical regression analyses | 44 |
| Table 3.3 – Results of longitudinal hierarchical regression analyses, controlling for tertiary variables | 45 |
| Table 3.4 – Results of counterpart regression analyses | 46 |
| Table 4.1 – Number and percent of participants reporting each life event | 60 |
| Table 4.2 – Spearman’s correlation coefficients for associations between the BSI sub-scales, BLESID-SR, and SNM | 61 |
| Table 4.3 – Standardised beta coefficients for moderated regression analyses | 63 |
| Table 5.1 – Percent of children experiencing measured life events between Times 1 and 2 | 74 |
| Table 5.2 – Results of longitudinal hierarchical regression analyses | 75 |

Summary

This thesis presents a critical literature review and reports on the findings of three empirical studies, examining the relationship between life events and psychological problems in people with intellectual disabilities. An introduction is provided in Chapter 1. The critical review (Chapter 2) describes the current evidence base in relation to a critical framework that aims to establish life event exposure as a causal risk factor for psychological problems. Chapter 3 presents the results of a longitudinal study, using data from proxy informants, and begins to address the need for further longitudinal data in establishing life events as a risk factor. Chapter 4 presents the results of a self-report study of life events, psychological problems and social support, intended to establish whether valid data on life events could be obtained using self-report interviews with people with intellectual disabilities. The putative role of social support as a moderator in the relationship between life events and psychological problems is also examined. Chapter 5 presents the results of a longitudinal study of life events in children with intellectual disabilities, which begins to address the need for further studies of life events in children with intellectual disabilities, and in particular, the need for longitudinal evidence.

Chapter 6 draws together a number of conclusions from the present work, and provides a methodological critique. The findings in the reported studies are broadly consistent with published reports on life events in people with intellectual disabilities. Life events can be said to be a risk factor for psychological problems in adults with intellectual disabilities, though insufficient data has yet been gathered to establish life events as a *causal* risk factor. In children with intellectual disabilities, the data suggest a number of specific relationships between certain types of life event and psychological disorder, rather than global associations.

Chapter 1 – Introduction

Official estimates place the number of people with intellectual disabilities in England at 1.41 million (Department of Health, 2001). People with intellectual disabilities experience much the same range of psychological problems as their non-disabled peers (Tsakanikos, Bouras, Sturmey & Holt, 2006), though prevalence rates may be considerably higher (Borthwick-Duffy, 1994), and the nature of the symptoms presented may differ (Marston, Perry & Roy, 1997; Rush, Bowman, Eidman, Toole & Mortenson, 2004). In the general population, a large corpus of studies has accumulated since the 1960s, demonstrating strong associations between psychological problems and exposure to life events (Paykel, 2001). To date, very few of the findings of this work have been validated in people with intellectual disabilities.

The work presented in this thesis investigates the relationships between psychological well-being and exposure to life events in people with intellectual disabilities. This introductory chapter (Chapter 1) describes the context of the work and discusses a number of methodological issues in the study of life events generally, and specifically with people with intellectual disabilities. Towards the end of Chapter 1, a summary of the subsequent chapters is provided.

Intellectual Disabilities

Synonymous with the label 'mental retardation', which is used internationally, and 'learning disabilities', which is used in the UK (and which comprises a different set of diagnostic criteria to those used in North America), intellectual disability is a socially-constructed classification. The DSM-IV (APA, 1994) and ICD-10 (World Health Organisation, 1993) both provide tripartite diagnostic definitions including an IQ of less than 70, difficulties in domains such as self-care, communication, or social skills, and onset before the age of 18 years.

There are considerable methodological difficulties in establishing the incidence of intellectual disabilities, not least because a diagnosis may be made at any point during a person's first 18 years of life (Hatton, 1998). Numerous studies, however, have examined the prevalence of intellectual disabilities.

Reports typically range from 3.7 to 5.9 in 1,000 for mild intellectual disabilities and from 3 to 4 per 1,000 for severe intellectual disabilities (Hatton, 1998).

There is a wide range of genetic and other disorders which can affect development so as to render a person likely to attract a diagnosis of intellectual disability. These conditions can develop prior to, during, or after birth. Prenatal conditions include chromosomal disorders such as Down syndrome, which account for between 20% and 40% of live births of people with intellectual disabilities, other mono- and poly-genetic disorders, a range of multiply determined disorders such as spina bifida, and a number of disorders with environmental aetiology, such as foetal alcohol syndrome (McLaren & Bryson, 1987). Perinatal aetiologies include hypoxia during birth, and a range of infections such as bacterial meningitis (Hatton, 1998). Postnatal causes include high levels of environmental toxins such as lead or mercury, malnutrition, a range of childhood infections, and chronic social deprivation. The aetiology of mild intellectual disabilities is less well understood and has been hypothesised to be the result of interacting risk and vulnerability factors (Hatton, 1998). A number of other disorders and conditions are associated with intellectual disabilities including epilepsy, sensory impairments, and motor impairments (McLaren & Bryson, 1987).

The British legal system has held a category or classification approximately analogous to intellectual disabilities since medieval times, and has maintained this label as distinct from what we would now call mental health problems (Rushton, 1996). Social and medical changes during the Victorian period may have contributed to the considerable increases in the number of people with intellectual disabilities resident in institutions. The principal goal during this time was to provide training and education for a finite length of time (Gladstone, 1996). During the Edwardian period, and partly through the intervention of the eugenics movement, the goal of institutions became the permanent segregation of people with 'mental deficiency' (Jackson, 1996) who were then viewed as a difficult social problem. The number of people with intellectual disabilities living in institutions reached a peak in the 1950's and 1960's (Felce, 1996). In the early 1970's movement toward 'normalisation' took hold with a number of influential thinkers (e.g.

Wolfensberger, 1972) who propounded the view that people with intellectual disabilities should be considered valued citizens. Since the mid 1970's, a process of 'deinstitutionalisation' has taken place, although progress has been different across the geographical regions of the UK (Emerson & Hatton, 1994). This philosophy of 'normalisation' is now widely accepted and extends to clinical practice and research (e.g. Bannerman, Sheldon, Sherman & Harchik, 1990).

The Mental Health of People with Intellectual Disabilities

The understanding that people with intellectual disabilities can and do develop mental health problems is comparatively recent. Historically, clinicians and researchers either have denied the existence of mental health problems, attributing behavioural disturbances to the underlying intellectual disability (Schroeder, Mulick & Schroeder, 1979) or have maintained that there are qualitative differences and that mental health problems in people with intellectual disabilities are more likely to be of biological origin (Szymanski & Grossman, 1984). These views have been challenged and a number of psychological problems are now routinely researched, including depression (Marston *et al.*, 1997), anxiety (Mindham & Espie, 2003), post-traumatic stress disorder (Turk, Robbins & Woodhead, 2005), mania (Deb, Thomas & Bright, 2001), and psychosis (*ibid.*) amongst other disorders. Recently, the Royal College of Psychiatrists published a set of diagnostic criteria to aid in the assessment of mental health problems with people with intellectual disabilities (2001).

It remains likely that mental health problems are under-diagnosed in people with intellectual disabilities (Patel, Goldberg & Moss, 1993), largely due to three factors. First, carers and clinicians may attribute symptoms of mental health problems to a person's intellectual disability – a phenomenon referred to as 'diagnostic overshadowing' (Reiss, Levitan & Szyszko, 1982; Spengler, Strohmer & Prout, 1990). Second, assessment of mental health in people with intellectual disabilities presents a number of methodological challenges. Depending on the nature and extent of the intellectual disability, it can be difficult or even impossible to obtain reliable information by direct interview

with a person who has an intellectual disability (Finlay & Lyons, 2001). Third, a great deal of debate persists regarding the use of 'behavioural equivalents' – behaviours such as self-injury or aggression – in place of accepted diagnostic criteria for mental health problems (cf. Marston *et al.*, 1997; Tsiouris, Mann, Patti & Sturmey, 2003).

These issues also beset any attempts to study the epidemiology of mental health problems in people with intellectual disabilities. For these reasons, as well as slight differences in the diagnostic criteria adopted, estimates of the prevalence of mental health problems in people with ID vary widely (Borthwick-Duffy, 1994). Taking just studies where representative samples were subjected to a formal clinical evaluation, estimates range from 25% to 71% (*ibid.*).

Methodological Issues In Life Events Research

Whilst some reviewers (Brown, 1989) have traced the origins of life events research to studies on physiological stress by Cannon in the 1920's (e.g. Cannon, 1929), it wasn't until the middle of the century that the field gathered impetus (e.g. Hinkle & Wolf, 1952; Meyer, 1951). In particular, it was during the 1960's that substantial research interest came to focus on the associations between life events and mental, rather than physical, disorder (e.g. Brown & Birley, 1968; Paykel *et al.*, 1969).

A number of methodologies have been employed by life events researchers. Initially, researchers tended to adopt an unstructured interview approach to the study of life events (Hinkle & Wolff, 1958; Meyer, 1951), but a considerable number of structured and semi-structured measures have been developed since. Rahe, Holmes and colleagues (e.g. 1964) developed the Schedule of Recent Experience, a checklist measure comprising a range of events such as bereavement, pregnancy, moving home, and a change in personal habits. They later developed this checklist into the Social Readjustment Rating Scale (Holmes & Rahe, 1967) through the application of a scaling procedure wherein a panel of judges gave their opinions on how much life change might likely be entailed in the face of each life event type. The

assumption was made that multiple life events have additive effects, such that a total score of life stress could be derived (Holmes & Masuda, 1974).

There has since been some debate over the relative merits of 'life change' versus 'distress' as the dimension against which to weight different life event types (Paykel, 2001). Furthermore, a number of researchers have challenged the assumption that life events have a straightforward cumulative nature as regards the total stress a person has experienced (Brown, 1989; Paykel, McGuinness & Gomez, 1976). A wide range of alternative approaches have been propounded, a number of which entail the individual participant rating the stress or life change involved in his or her own experience of an actual event. Generally, these individualised techniques have proved more sensitive, though prone to more bias (Paykel, 1983).

Another issue that has repeatedly exercised life events researchers is the potential for a bi-directional relationship between life events and psychological problems (Paykel, 2001). A considerable proportion of the life events in which researchers have been interested, may in some cases represent an effect of psychological problems, rather than the cause. Examples include the loss of a job or the break-up of a marriage due to a person's depression or psychosis. Brown and colleagues (Brown, Sklair, Harris & Birley, 1973) developed the concept of rating life events for independence, that is, the probability, as assessed by the researcher, that the life event in question could not have been influenced by a person's psychological state. Examples of independent life events might include the contraction of a serious (physical) disease by a loved one.

Several life events scales have now been developed and widely used, with considerable variation in methodological approach, each striking a certain balance between sensitivity and brevity (Paykel, 1983). A number of psychological disorders have been examined with respect to any association they may have with life events, but there is particular consistency in the findings of a role for life events in depression and schizophrenia (Paykel, 1983; Tennant, 2002).

Methodological Issues In Life Events Research with People with Intellectual Disabilities

Conducting research into stressful life events, as experienced by people with intellectual disabilities, presents a number of specific further challenges. Unsurprisingly, given the wide number of aetiologies of intellectual disabilities, people with intellectual disabilities are not a homogeneous group (Hamilton, Sutherland & Iacono, 2005; Nadarajah, Roy, Harris & Corbett, 1995). In addition to individual differences in personality, environment and life history, considerable variation exists with regard to the severity of the disability and the relative severity of impairment in different domains. This heterogeneity places limits of the generalisability on findings. It is inherent to the nature of the diagnosis that people with intellectual disabilities often struggle with a range of cognitive and communicative tasks which can present methodological issues in gathering data on life experiences (Finlay & Lyons, 2001). These can include difficulties in receptive and productive communication, requiring careful interviewing to ensure comprehension (Prosser & Bromley, 1998), and difficulties with abstract or numerical concepts, including concepts relating to time (Finlay & Lyons, 2001). In particular, people with intellectual disabilities may report events from history as though they had occurred quite recently (Moss *et al.*, 1997). Such difficulties have typically lead researchers to the use of data gathered via professional or family carers, however, there are a number of disadvantages to the reliance on proxy informants, including decreased sensitivity to symptoms (Moss, Prosser, Ibbotson & Goldberg, 1996).

Besides these general methodological constraints, none of the measures of life events used in the general population have been validated for use with people with intellectual disabilities. Whilst 'ordinary living' is the guiding principle for services that support people with intellectual disabilities in the United Kingdom (Caine, Hatton & Emerson, 1998), there is still in many cases a restriction of life experiences. For example, the Social Readjustment Rating Scale (Holmes & Rahe, 1967), perhaps the most widely used scale of life events, includes *marriage, divorce, taking on a mortgage*, and a number of other life events which people with intellectual disabilities are less likely to experience than their

non-disabled peers. Contrarily, events pertinent to people with intellectual disabilities might be omitted.

Alternative approaches to stress research

For the sake of balance, it is worth noting some other broad approaches to the study of stress and its relationship with psychological disorder. A number of theorists have criticised the life events approach for its emphasis on observable phenomena. Selye (1956, quoted in Brown, 1989, p. 8) described the development of life events lists as arbitrary and claimed that "the stressor effects depend not so much upon what we do or what happens to us but on the way we take it". This conceptualisation, often referred to as 'transactional' for its entailment of a sophisticated relationship between the organism and its environment, has also attracted a good deal of support (e.g. Lazarus & Folkman, 1984; Temoshok, 1983). Two transactional approaches have gained most ground.

Lazarus and colleagues (Lazarus & Cohen, 1977; Lazarus & Folkman, 1987) began the development of a cognitive model of the transactional stress process. According to the model, individual variation in responses to stress are a symptom of underlying differences in the cognitive appraisal of both the stressor and the person's resources in meeting the demands of the stressor (Lazarus & Folkman, 1984). Outcomes, such as psychological problems, are also influenced by the efforts the person makes in coping with the stressor, and a number of competing attempts have been made to delineate different coping styles (Carver, 1997; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). The Lazarus model has been considerably revised over the years, with the addition of secondary appraisals, emotions, and core-relational themes (Lazarus, 1993, 1999), which it is beyond the scope of this brief review to cover. The resulting model is often expressed as a path diagram, with six constructs related by unidirectional, bidirectional and feedback mechanisms (Lazarus, 1999). Appraisal, like many other components in the model, has a number of sub-components and is intended to reflect cognitions about the current and future impact of the stressor, the extent to which the stressor might be controlled, and the resources available to cope with the stressor (Lazarus, 1991).

Hobfoll (1988) propounded a quite different model of stress, the Conservation of Resources model, which he claimed to be more parsimonious and potentially more accurately predictive of stress reactions. Psychological stress is said to occur in response to environmental changes involving (a) the threat of a loss of net resources, (b) the actual loss of net resources, (c) a lack of resource gain following resource investment (Hobfoll, 1989). Resources, in turn, are defined broadly as those characteristics, conditions and objects that are valued, or which help in the attainment of other valued characteristics, conditions or objects. Resources may thus be said to include socio-economic status, employment, self-esteem, social relationships amongst other things (Hobfoll, 1989). The model has subsequently been developed to describe a greater effect of resource loss as compared with resource gain, and to emphasise the relevance of resource investment in the context of those with limited resources (Hobfoll, 2001).

Both of these transactional models have lent considerable impetus to the field of stress research. However, there are methodological and other issues in applying these models to people with intellectual disabilities.

The transactional models are necessarily reliant on the measuring of cognitive processes such as primary and secondary appraisal (Lazarus, 1999). Testing these models in people with intellectual disabilities therefore requires the administration of self-report measures for appraisals, coping, core-relational themes, and so on. It is well recognised that there are significant methodological problems in obtaining self-report data with people with intellectual disabilities, most especially when the constructs under examination are highly abstract (e.g. Finlay & Lyons, 2001). Furthermore, the measures developed for the general population (e.g. Carver, 1997) are likely to be linguistically too complex for use. The development of suitable psychometric measures of the considerable number of constructs implicated in the transactional models will take considerable time. Attempts have been made to examine some of these constructs in people with intellectual disabilities, including attitudes to coping (Hartley & MaClean, 2005; Jahoda, Pert, Squire & Trower, 1998) and perception of control (Hartley & MaClean, 2005), through the use of novel approaches such as sentence completion tasks. This technique is a

useful pragmatic addition to the researcher's range of techniques, but relies entirely on retrospective coding of sentences and therefore offers no opportunity for the assessment of the usual psychometric properties such as validity, test-retest reliability and so on. Contrariwise, the life events approach, in concerning itself primarily with the occurrence or non-occurrence of events, limits the need for abstract cognitive constructs, though this also limits the nature of its conclusions.

Another body of research is developing alongside the literature on life events in people with intellectual disabilities, using many similar methods. A number of researchers have examined 'life stress' (e.g. Bramston, Fogarty & Cummins, 1999; Fogarty, Bramston & Cummins, 1997; Lunsky, 2003), a concept which has a number of overlaps with the 'daily hassles' often researched in the general population (see Kanner, Coyne, Schaefer & Lazarus, 1981). Rather than referring to significant and singular events, daily hassles include those undesirable aspects of life that are repetitive and chronic. A life stress inventory has been constructed for use with people with intellectual disabilities (Fogarty *et al.*, 1997), which includes such items as being regularly teased, bullied, or interrupted, and having a lack of choice in one's day-to-day business. This approach appears to be a useful contribution to the literature on the experiences of people with intellectual disabilities, however, the experiences examined are largely of a quite different nature from the life events examined in this thesis.

The present thesis

Historical attitudes to people with intellectual disabilities, discussed above, have traditionally lead to the exclusion of people with intellectual disabilities from research on stress, including life event stress. However, there is now a growing body of evidence that life events are associated with psychological problems in people with intellectual disabilities, just as in their non-disabled peers (reviewed in Chapter 2). To date, these studies have largely involved the assessment of life event exposure and the examination of direct concurrent relationships between life event exposure and psychological problems. The work presented herein was therefore developed to address a number of aims. The first aim was:

- To critically review the literature on life events in people with intellectual disabilities in order to establish a number of recommendations to lend impetus and give direction to the field.

From the results of this critical review, further aims were established:

- To contribute to the development of the field through the creation of a life events measure.
- To conduct longitudinal empirical work, to contribute to the establishment of life events as causal agents for psychological problems in people with intellectual disabilities.
- To examine the association between life events and psychological problems in people with intellectual disabilities using self-report data.
- To examine a range of other variables, including demographics, to begin to provide evidence that the relationship between life events and psychological problems in people with intellectual disabilities is not due to the influence of unmeasured tertiary variables.

The following is a brief overview of the structure of the thesis, which comprises a critical literature review and three quantitative empirical studies.

Chapter 2 presents a critical review of the literature on life events and psychological problems in people with intellectual disabilities. The small body of published work is set in context of a number of methodological issues. In particular, the current evidence base is assessed against a set of accepted criteria (Haynes, 1992; Kazdin, Kraemer, Kessler, Kupfer & Offord, 1997) for the examination of potentially causal relations in the social sciences. Whilst the reviewed literature provides reasonably consistent evidence for an association between life events and psychological problems, there is a need for further longitudinal data to establish the association as causal in nature.

The third chapter presents the results of a longitudinal study, using proxy reporting techniques and structured psychometric measures, of life events and psychological problems in 68 adults with intellectual disabilities. This study was intended to address the need for further longitudinal data in establishing life events as a risk factor. Life events are found to contribute to the prediction

of affective and neurotic symptoms, and of angry and aggressive behaviours, when earlier levels of these constructs are taken into account.

Chapter 4 presents the results of a self-report study of life events, psychological problems and social support in 38 adults with intellectual disabilities. This work was intended to establish whether valid data on life events could be obtained using self-report interviews with people with intellectual disabilities, and to examine social support as a potential moderator in the relationship between life events and psychological problems. Depression, anxiety, hostility and anger were all found to be positively associated with exposure to life events. Criticism from one's social circle was found to be associated with some types of psychological problem. No evidence was found to support the hypothesised moderating effect of social support on the relationship between life events and psychological problems.

Chapter 5 presents the results of an analysis of data originally obtained for the examination of the impact of caring for a child with intellectual disabilities. The data were collected longitudinally and therefore afforded the opportunity to contribute to the literature the first longitudinal examination of the association between life events and psychological problems in children with intellectual disabilities. As with the study reported in Chapter 3, this work begins to provide data on the longitudinal relationships between life events and psychological problems, which ultimately will be required to establish a clear causal link. The findings are somewhat surprising and afford limited support for the role of life events as a causal agent for psychological problems. A number of methodological issues are discussed with regard to future work on life events in children with intellectual disabilities.

The sixth chapter draws together a number of conclusions from the present work, provides a methodological critique and discusses implications for research and practice. One of the aims of this body of work was the development of a measure of life events suitable for use with people with intellectual disabilities. The Bangor Life Events Schedule for Intellectual Disabilities (BLESID) was developed for this purpose. Two versions have been developed, one for use with proxy informants and another for self-report use in a semi-structured interview setting. Data were collected using these measures

for the studies presented in chapters 2 and 3. The development of these measures is described in Appendix A, whilst copies of the measures can be found in Appendices B and C.

Chapter 2 – Life Events as a Risk Factor for Psychological Problems
in Individuals with Intellectual Disabilities: A Critical Review

The material presented in this chapter has been accepted for publication as:
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Chapter 3 – Life Events and Psychological Problems in Adults with Intellectual Disabilities: Longitudinal Relationships

The material presented in this chapter has been submitted for publication as:
Hulbert-Williams, L., Hastings, R. P., Owen, D. M., Burns, L., Day, J., Mulligan, J., *et al.* (2008). Life events and psychological problems in adults with intellectual disabilities: longitudinal relationships.

Abstract

There is gathering evidence for a link between psychological problems and life events in people with intellectual disabilities. We present findings from a three-and-a-half-year longitudinal study of life events in a sample recruited during a long-stay hospital resettlement. Professional carers provided data on 68 adults with intellectual disabilities with respect to life events and a range of psychological problems using structured psychometric instruments. Hierarchical linear regressions demonstrated a contribution of life events to the prediction of later psychological problems. Tentative evidence is presented that the relationship may be unidirectional and non-spurious. Results are discussed with respect to an established hierarchy of evidence. We assert that life events can be considered risk factors for psychological problems in people with intellectual disabilities.

Introduction

Estimates place the prevalence of psychological disorder between 10% and 71% of all people with intellectual disabilities (Borthwick-Duffy, 1994). The most prevalent types of psychological disorder, based on clinical diagnosis, are affective disorder (3.6-6.6%), anxiety disorders (2.4-3.8%), behavior problems (0.1-22.5%) and psychotic disorders (2.6-4.4%, Cooper, Smiley, Morrison, Williamson *et al.*, 2007a). It is widely hypothesised that people with intellectual disabilities are at a substantially higher risk for these and other types of psychological disorder compared to the general population (Clay & Thomas, 2005; Collacott, Cooper & McGrother, 1992; Gustafsson & Sonnander, 2004), a contention supported by the small number of studies that have drawn direct statistical comparisons and used population-based data (Emerson, 2003; Richards *et al.*, 2001).

There is also gathering evidence that psychological disorder is associated with the experience of stressful life events (such as moving home or being bereaved) in adults with intellectual disabilities (Esbensen & Benson, 2006; Chapter 2; Owen *et al.*, 2004). No data are available to draw direct comparisons between adults with and without intellectual disabilities as regards the number

of life events experienced, although evidence does suggest that children with intellectual disabilities experience a greater number of such events (Hatton & Emerson, 2004). This leads to the hypothesis that increased exposure to life events may explain some of the increased risk for psychological disorder in adults with intellectual disabilities. Given this possibility, and the fact that many life events can be predicted (e.g., bereavement after a long illness) and that a few can be prevented (e.g., moving home), there is considerable clinical and research interest in the examination of the putative impact of life events on the lives of adults with intellectual disabilities. Clinical interest may be driven by the possibility of developing support interventions that enable people with intellectual disabilities to cope effectively with anticipated life events.

Though there remains a dearth of studies in this area, and though there are considerable methodological difficulties, researchers have begun to move beyond the simple 'association' model. Earlier case report (e.g. Cook, Kieffer, Charak & Leventhal, 1993) and case series (e.g. Ryan, 1994) studies have given way to survey designs using statistical techniques to examine the relationship between life events and psychological disorder amongst adults with intellectual disabilities. A number of researchers have used measures of psychiatric symptoms to establish associations between life events and general psychological problems (Hamilton *et al.*, 2005) and between life events and affective disorder (Hastings *et al.*, 2004; Owen *et al.*, 2004). Using this method, no association has been demonstrated between life events and psychotic symptoms (Hastings *et al.*, 2004; Owen *et al.*, 2004). Owen and colleagues (2004) have examined the association between life events and measures of challenging behavior. Associations with life events have been demonstrated for aggressive behavior but not for self-injurious or stereotyped behavior. These patterns of results has been replicated where clinical diagnosis has been used in place of psychometric measurement (Cooper, Smiley, Morrison, Williamson *et al.*, 2007a; Cooper, Smiley, Morrison, Williamson *et al.*, 2007b; Cooper, Smiley, Morrison, Allan *et al.*, 2007).

Recently, data have been published (Esbensen & Benson, 2006) on the longitudinal relationships between life events and psychological problems, providing tentative evidence that life events may be a risk factor for

psychological problems. However, a number of gaps remain in the current evidence base. Measurement of life events, and indeed of psychological problems in people with intellectual disabilities is less well developed than in the general population. The current paper examines the research question using quite different measures to those employed by Esbensen and Benson (2006). Perhaps most importantly, further evidence is needed to establish whether life events are risk factors for, rather than correlates of, psychological problems in people with intellectual disabilities. To address this question, evidence is needed on the temporal relationship between psychological problems and life events (Chapter 2; Kraemer *et al.*, 1997). The current paper presents work similar in structure to that of Esbensen & Benson (2006) but with a more developed measure of life events, a longer period of time between measurements to capture more life events, and retrospective evidence relating to the occurrence of life events prior to Time 1. Furthermore, analyses have been conducted only rarely (e.g. Cooper, Smiley, Morrison, Williamson *et al.*, 2007a) to examine the extent to which the observed relationship between life events and psychological problems may be spurious, that is to say, the artefact of a correlation between each of the variables of interest and a further, tertiary variable. The present paper aims to present evidence relating to the temporal precedence of life events with respect to psychological problems (see Chapter 2). Through the treatment of demographic and etiologic variables, we aim to examine the evidence that the association between life events and psychological problems may be non-spurious.

Method

Participants

Informants provided data on 68 adults with intellectual disabilities. Diagnoses and etiological factors included cerebral palsy (11.8%), Down syndrome (5.9%), phenylketonuria (1.5%), pervasive developmental disorder including autism (26.5%), and perinatal complications (13.2%). For the remaining 55.9%, the intellectual disability was of unknown aetiology. Participants were 39 males (57.4%) and 29 females (42.6%), and ages ranged

from 27 to 82 years at the latest data collection point ($M=55.9$, $SD=11.7$). Whilst formal IQ test scores were not available, estimations from a measure of adaptive behaviour suggested that most adults were functioning with moderate to profound delays. Forty-two participants (61.8%) were living on a residential hospital site for adults with intellectual disabilities, and 26 (38.2%) had been resettled into smaller group homes in the community during the period between Times 1 and 2 of data collection. Forty-seven participants (69%) were reported to have sensory impairments. Five participants were reported to have no physical health problems, with the modal number of problems reported being three. Twenty-two participants (32.8%; one missing data point) were reported to be suffering regular seizures at Time 2. Informants were members of support staff who knew the participant well.

Measures.

A short questionnaire devised specifically for the demographic and personal data requirements of this study was administered alongside six other questionnaires at two points in time.

Measures of life events.

At Time 1, the Life Events List was used (Owen *et al.*, 2004; Appendix D). This measure was intended as a representative list of significant negative life events that a person with intellectual disabilities living in a long-term residential setting might experience. The list was not designed to be exhaustive in accordance with pilot data that showed that certain events (e.g., divorce) were extremely unlikely to occur in the population under study. Items were selected after a review of general population life events measures and canvassing the opinions of clinicians working with adults with intellectual disabilities. Ultimately, the measure comprised a checklist of 20 life events such as *change of staff in the residence, attacked by another resident and death of a first-degree relative*. Informants were asked to assess each event as present or absent in the 12 months prior to data collection at Time 1. A total number of unique events experienced was calculated for each participant as described in Owen *et al.* (2004).

At Time 2, life events were assessed using the Bangor Life Events Schedule for Intellectual Disabilities Informant Version (BLESID-I; Appendix B) devised

for use in the present research. The BLESID-I is designed to measure a wider range of life events than the Life Events List and offers a number of refinements. Like the Life Events List, the BLESID-I was developed using a multi-stage process. An item pool was generated by combining a number of published life events measures, and this was edited by three groups of professionals (clinical psychologists, intellectual disabilities nurses, and social workers). The pilot version thus generated was completed by 43 parents in respect of their adult sons and daughters. From the results of this pilot and further consultation, six events were added (*problem with alcohol or other drugs, permanent change in staffing, retired or stopped attending daytime activities, financial problems, serious illness of close relative, victim of sexual abuse*).

The BLESID-I thus comprises 38 life events in five general sections: Health (8 events), support and living arrangements (10 events), crime (6 events), occupational and financial (6 events), and relationships (8 events). Each life event is scored against two scales: The Frequency scale has three response options according to the events having been absent, present once, or present more than once. The Impact scale is a five-point Likert type scale with response options of *considerable negative impact, some negative impact, no impact, some positive impact, considerable positive impact*. A number of scoring algorithms can be used to create total scores relating to frequency of events, impact of events, and a combination of the two. The principal measure adopted for the analyses reported herein is the number of events experienced and rated as having a negative impact, weighted for how many times they have occurred. This method of scoring allows for a single metric that combines both frequency and impact scales of the BLESID-I, and consistently yields the strongest correlations with data on psychological problems. This scoring process takes into account the distinction between positive and negative life events discussed by Esbensen and Benson (2006).

Measures of psychological problems.

The Behavior Problems Inventory (Appendix E) is a respondent-based rating instrument for use with individuals with an intellectual disability and other developmental disabilities (Rojahn *et al.*, 2001). The measure comprises 15 items on self-injurious behavior (e.g., self scratching, hair pulling), 25 items on

stereotypic behaviours (e.g., repetitive hand movements, rocking back and forth) and 12 items on aggressive/destructive behavior (e.g., hitting others, being verbally abusive). Items are rated on a frequency scale (never, monthly, weekly, daily, or hourly) and a severity scale (no problem, slight, moderate, or severe problem). The Behavior Problems Inventory was designed to be administered to support staff working with individuals with behavior problems and has been found to have good psychometric properties including internal consistency (Cronbach's alpha = .61 - .82), test-retest reliability (intraclass correlation coefficients = .64-.76), and inter-rater reliability for the three sub-scales (Esbensen *et al.*, 2003). As is commonly reported, the frequency and severity scales were highly correlated in the current sample ($.76 < r < .86$). Analyses reported here were thus restricted to the use of the frequency scale. The internal consistency of these scales was good with Cronbach's alphas of .68, .87, and .79 for the self-injurious behavior, stereotyped behavior, and aggressive/destructive behavior sub-scales respectively.

The Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (Appendix F; Moss *et al.*, 1998) is a screening and research tool based on the ICD-10 clinical interview (World Health Organisation, 1992). This 29-item measure is usually completed in respect of the four weeks prior to measurement with the aid of an informant who knows the individual well. Scores are derived from the measure on three scales: affective/neurotic disorder (e.g., repeated checking behaviours, loss of energy); possible organic disorder (e.g., confusion, forgetfulness, loss of self-care skills); and psychotic disorder (e.g., strange experiences or beliefs). Only the affective/neurotic and psychotic sub-scales were used for the current study as the organic sub-scale is designed to screen for behavioural symptoms of physiological aetiology. These sub-scales demonstrated adequate internal consistency with Cronbach's alphas of .73 and .59 respectively.

The Ward Anger Rating Scale (WARS; Appendix G; Taylor, DuQueno & Novaco, 2004) is a 25-item informant-rated scale of anger and aggression. It comprises two sub-scales, both completed by a carer with reference to the previous week. The first includes 18 dichotomous (yes/no) ratings of a person's verbal and physical aggressive behavior such as *shouted or yelled* and

physically attacked someone. The second sub-scale measures anger and related emotions. It comprises seven items (e.g., *angry or annoyed, bitter or resentful*) scored on a Likert type scale from zero (not at all) to four (very often). The WARS has been found to have high internal consistency and inter-rater reliability, and has shown robust concurrent and discriminant validity with comparison measures completed by independent raters. In the current sample, Cronbach's alpha was calculated at .83 for the aggressive behavior scale and .92 for the anger scale.

Physical Health and Adaptive Skills.

Physical health at Time 2 only was measured using the Physical Health Questionnaire (Appendix H; Robertson *et al.*, 2005). This brief measure of physical health was devised for a large study of Person Centred Planning and comprises a list of 19 types of medical complaint (e.g., stomach trouble, persistent trouble with teeth) endorsed on a yes/no basis. This measure was included at Time 2 only, as a potential tertiary variable.

Adaptive skills were assessed using the Adaptive Behavior Scale, Short-Form (Appendix I; Hatton *et al.*, 2001). This is a 24-item reduced version of the 73-item Adaptive Behavior Scale –Residential and Community (Part 1; Nihira, Leland & Lambert, 1993). The measure is usually completed by a carer. Items are of two types, some requiring a rating of the highest level of adaptive behavior achieved with reference to the area described, others having dichotomous sub-items. As with the original form, the short form is scored into three factors: personal self-sufficiency, community self-sufficiency, and personal-social responsibility. The short-form version was developed based on data from two diverse UK samples of adults with intellectual disabilities living in residential services through the use of an item reduction technique. Adaptive Behavior Scale (Short Form) factor and total scores showed good internal reliability in both samples and were highly correlated with their Adaptive Behavior Scale (full version) Part 1 equivalents. While further work continues to establish reliability and cross-cultural validity of the instrument, it is a useful research tool.

Procedure

A total population study of the residents of a medium-sized residential hospital was conducted as a prelude to an anticipated program of community resettlement. At Time 1, the entire population of the hospital, 100 adults, was approached (Owen *et al.*, 2004). Three people were resettled into the community before data could be collected, one person withheld consent to take part, and three more died. By Time 2 (42-48 months later), 39 had moved out to supported settings in the community, 45 remained at the hospital and a further 9 had passed away. In following up the participants at Time 2, access to 13 participants was denied to researchers by their care provider organisations, either at initial contact (N=8) or in practice through multiple cancelled meetings and other difficulties (N=5). Two participants refused consent, and one was in the district general hospital and too ill to be included, resulting in a longitudinal sample of 68 participants, 73.1% of the original sample. The ages of participants in the sample at Time 2 (M=55.9, SD=11.7) was not much changed from Time 1 (M=55.2, SD=12.7). There was no evidence that attrition of the sample as described above had led to any changes in the proportion of males and females, level of disability, or other demographics when compared against the Time 1 sample.

A protocol was devised for obtaining informed consent where possible, and a best interests decision otherwise. Ethical approval was sought and a favourable opinion given from the University and health service ethics boards. Nurses in charge of each unit at the hospital identified 14 residents who might be able to give informed consent. Only one person declined. Appropriate advocates gave their opinion for the benefit of those who lacked capacity. Support staff members who worked most closely with each participant were approached and given information about their potential role as informants. Where potential informants declined, alternative informants were identified and approached. Once an informant had been identified, a data collection meeting was scheduled and held in a private room at the hospital or at the participants' homes. The measures described above were completed by one of the researchers using information provided during the meeting. At Time 2, the entire process of obtaining consent and collecting data was repeated. (See

Appendices J to P, for approval letters, information sheets, and consent forms used at Time 2.)

Results

Descriptive statistics

Analyses were conducted to explore data distributions. Using graphical analyses of residuals, all life events variables were found to conform approximately to Normal distributions whilst some psychological variables were found to diverge significantly, resulting in our use of some non-parametric inferential statistical tests. Comparisons were made, using Time 1 data, between those participants who did and did not remain in the study at Time 2. No differences were found with respect to age, gender, or adaptive behavior. Descriptive statistics were prepared on exposure to life events. Seventy percent of participants experienced 1 or more life events rated as negative in the twelve months prior to Time 2 data collection. Fifty percent had experienced two or more. The ten most frequently experienced of these life events rated as having some negative impact are listed in Table 3.1.

Table 3.1: Events most commonly rated as having negative impact

| Event | Number of participants |
|---|------------------------|
| Permanent change in staffing | 24 (35.3%) |
| Other person moved into or out of house/flat/unit | 16 (23.5%) |
| Period of cover by non-regular carer | 15 (22.1%) |
| Serious illness or injury not requiring hospitalization | 13 (19.1%) |
| Separation from friend/family/long-term carer | 11 (16.2%) |
| Moved house | 9 (13.2%) |
| Change in daily routine | 8 (11.8%) |
| Subjected to verbal abuse | 8 (11.8%) |
| Witnessed physical attack or verbal abuse of another | 8 (11.8%) |
| Moved room, change in decoration/furniture | 7 (10.3%) |
| Victim of violence | 7 (10.3%) |
| Introduction/change/withdrawal of medication | 5 (7.4%) |
| Being physically restrained | 5 (7.4%) |
| Death of close friend or relative | 5 (7.4%) |
| Increased arguments with others | 5 (7.4%) |

Correlates of life events exposure

A number of correlation analyses and t-tests were performed to investigate potential relationships between exposure to life events prior to Time 2 and a number of demographic variables, including age, sex, type of residence, sensory impairments, current receipt of psychoactive medication, epilepsy, variables relating to aetiology of intellectual disabilities (e.g., autism, Down syndrome), and physical health. Of these variables, only type of residence was significantly associated with life event exposure with participants still resident at the long-stay hospital experiencing significantly more negative life events ($M=7.6$, $SD=3.9$) than those who had been resettled ($M=4.8$, $SD=2.4$, $t(66)=3.26$, $p=.002$).

Longitudinal analyses

In the general population, life events are hypothesised to be a risk factor for psychological problems; experiencing life events increases the likelihood of subsequent psychological problems. To address the question of the impact of life events on various types of psychological problems a series of hierarchical regression analyses was conducted. In the first step of each analysis, a Time 2 measure of psychological problems was predicted from the Time 1 measure of the same construct. In the second step, the total negative impact score of the BLESID-I was added to the model. Recent life events, as measured by the BLESID-I Weighted Negative Total were found to predict scores on the Psychiatric Assessment Schedule's Affective/Neurotic and Psychotic sub-scales, as well as the Ward Anger Rating Scale sub-scales (Anger, and Aggressive behavior) after controlling for the measure of the same construct three years earlier. Behavior Problems Inventory Aggression/Destruction sub-scale scores were also predicted by life events, though less strongly. Results are displayed in Table 3.2.

Table 3.2: Results of longitudinal hierarchical regression analyses

| Criterion variable | Step 1 R ² | Step 2 Δ R ² | F of change | Step 2 predictors (beta) | |
|--------------------------------|-----------------------|--------------------------------|-------------|-----------------------------------|----------|
| | | | | Time 1 Measure of Criterion | BLESID-I |
| PAS-ADD Affective/ Neurotic | 0.039 | 0.228 | 20.16*** | 0.075 | 0.492 |
| PAS-ADD Psychotic | 0.180 | 0.269 | 31.66*** | 0.248 | 0.548 |
| WARS Aggression | 0.197 | 0.313 | 40.82*** | 0.362 | 0.565 |
| WARS Anger | 0.134 | 0.092 | 7.57** | 0.298 | 0.310 |
| BPI Self Injury Freq. | 0.208 | 0.006 | 0.49 | 0.448 | 0.077 |
| BPI Stereotypy Freq. | 0.166 | 0.000 | 0.03 | 0.405 | 0.018 |
| BPI Aggression Freq. | 0.260 | 0.062 | 5.99* | 0.487 | 0.251 |

* p<.05, ** p<.01, *** p<.001

Next, a set of analyses were run to ascertain whether the relationships demonstrated in Table 3.2 might be spurious. For each criterion variable in Table 3.2 a set of t-tests and non-parametric correlations were conducted to look for associations between each construct and a range of demographic variables measured at Time 2 including physical health, adaptive behavior, age, sex, sensory impairments, epilepsy, urinary incontinence, faecal incontinence, etiological variables, and three items from the Short Adaptive Behavior Scale relating to mobility, receptive language and expressive language. Though the literature on correlates of psychological disorder in people with intellectual disabilities is not well developed, many of these variables have been implicated to some degree (Chapter 2; Cooper, Smiley, Morrison, Williamson *et al.*, 2007a; Deb *et al.*, 2001; Emerson *et al.*, 2001; McClintock *et al.*, 2003). Where any of these tertiary variables were associated with the criterion variable, the regression analysis in Table 3.2 was repeated with the relevant tertiary variables also included in the first step of the regression. As can be seen in Table 3.3, the contribution made by the BLESID-I as a predictor of psychological problems remains strong in these revised analyses, suggesting that the relationships are non-spurious. It might be argued that the Time 1 measure of the criterion

variable comprises any contributions made by tertiary variables to that construct, rendering such analyses unnecessary. There are a limited number of cases however, where tertiary variables may render their effects subsequent to Time 1 measurement. The analyses presented in Table 3.3 therefore represent the most conservative approach.

Table 3.3: Results of longitudinal hierarchical regression analyses, controlling for tertiary variables in Step 1, adding life events in Step 2.

| Criterion variable | Step 1 R ² | Step 2 ΔR^2 | F of change | Tertiary variables as additional predictors |
|--------------------------------|-----------------------|------------------------|----------------|---|
| PAS-ADD Affective/ Neurotic | - | - | - | No tertiary variables. |
| PAS-ADD Psychotic | 0.230 | 0.232 | 27.58*** | Receptive language |
| WARS Aggression | 0.393 | 0.228 | 35.56*** | Age, sex, mobility, adaptive behavior total, receptive language |
| WARS Anger | - | - | - | No tertiary variables |
| BPI Aggression Freq. | 0.292 | 0.053 | 5.04* | Age, sex, mobility |

* p<.05, *** p<.001

To address the possibility that observed associations might be bidirectional, that is to say, the possibility of psychological problems also increasing subsequent exposure to life events, a series of counterpart analyses was conducted. For each of the relationships found to be significant in Table 3.2, a counterpart regression model was constructed. These counterpart models were partly the reverse of the models reported in Table 3.2, though the temporal direction is maintained such that prediction is always from the earlier time point to the later one. With this set of models, Time 1 life events were not included, however, as data at Time 1 were obtained using a different life events scale. These results are displayed in Table 3.4. None of the psychological variables were found to predict significantly the subsequent occurrence of life events in the sample, suggesting that the observed relationships are unidirectional.

Table 3.4: Results of counterpart regression analyses, predicting subsequent life events

| Predictor variable | BLESID-I Events Total | | |
|----------------------------|-----------------------|----------------|------|
| | Beta | R ² | F |
| PAS-ADD Affective/Neurotic | 0.140 | 0.020 | 1.33 |
| PAS-ADD Psychotic | 0.173 | 0.030 | 2.04 |
| WARS Aggression | 0.209 | 0.044 | 3.01 |
| WARS Anger | 0.057 | 0.003 | 0.22 |
| BPI Aggression Freq. | 0.215 | 0.046 | 3.21 |

A final set of exploratory analyses was conducted to look for any measurable effect of life events that preceded Time 1 on Time 2 psychological variables. These hierarchical regression analyses again begin as in Table 3.2, and Time 1 life events (scored using the Life Events List) was added in the second step. In the main, Time 1 life events were not found to contribute significantly to the models and the initial pattern of results was maintained. However, life events prior to Time 1 did have a small measurable effect on the psychotic sub-scale of the Psychiatric Assessment Schedule (R^2 change = .036, F of change (1, 64) = 4.53, $p = .037$).

Discussion

The data we have presented add to the evidence base for an association between life events and psychological problems in people with intellectual disabilities. Our results identify associations between life events and affective, neurotic and psychotic problems, and with anger and aggression. In adopting a systematic approach to identifying and controlling for potential tertiary variables identified in previous research (Chapter 2) we have also shown that the observed associations between life events and psychological problems are non-spurious. Further, the longitudinal approach adopted for the current study has yielded evidence of temporal precedence. Life events significantly predict subsequent psychological disorder, though psychological disorder does not significantly predict subsequent life events. We also provided unique results to demonstrate that these temporal relationships between life events and psychological problems are not accounted for by exposure to life events

preceding the first data collection point in the research. Thus, these results present the most robust evidence to date that negative life events may constitute a risk for psychological problems in adults with intellectual disabilities.

A number of cautionary comments need to be made about the interpretation of the present results. First, the sample size was moderate and thus statistical power was likely limited. With a larger sample, bidirectional effects (e.g., psychological problems as a risk for life events exposure) may have been observed as statistically significant. However, the proportion of explained variance in these analyses (Table 3.4) was low and thus unlikely to be clinically meaningful in comparison to the effect of life events on psychological problems. Second, the delay between the two data collection points was not coextensive with the period of reference for the measurement of life events; only those life events that occurred in the 12 months prior to Time 2 were recorded. The distance in time between the initial measures of psychological problems was therefore greater than the distance between the recorded life events and subsequent psychological problems. This introduced a potential source of bias. A further study is warranted where all life events in the interim between Time 1 and Time 2 measurements are included, though this is likely to restrict the maximum latency between time points due to practical considerations in asking informants or participants with intellectual disabilities to recall life events over a longer period.

A third cautionary note relates to the new measure of life events, the BLESID-I, and the lack of information about its properties. The observed effect sizes for associations between life events and psychological disorder compare favourably with previous studies (e.g. Esbensen & Benson, 2006; Owen *et al.*, 2004) and the pattern of findings is also similar to that observed in previous research (Chapter 2). Thus, there is some evidence for the convergent validity of the BLESID-I in addition to strong face validity as a result of the measure development process. The principal advancements in this new measure are an increased range of included life events, and a method for recording, for each event, the observed impact on the individual. Whilst the BLESID-I is promising as a measure of life events, the current research afforded no opportunity to

examine inter-rater reliability or short term test-retest reliability. Such properties need thorough exploration in future.

Professionals providing support and clinical services to adults with intellectual disabilities should be aware that some variability in presenting psychological problems, including aggressive behavior, may relate to recent life events. It may be important to consider life events in the diagnosis and treatment of psychological problems in people with intellectual disabilities. In considering treatment implications, it is important both to understand the nature of risk variables and the importance of identifying the mechanisms by which risk variables have their effects.

Kraemer *et al.* (1997) have proposed a nomenclature to distinguish between *correlates* (variables which significantly correlate to the phenomenon of interest, but where no conclusion can be drawn as to temporal or directional relation), *risk factors* (for variables which precede the outcome of interest) and *causal risk factors* (indicates evidence that the risk factor has a causal role with respect to the outcome). For the latter denomination, a plausible, and preferably established mechanism must be demonstrated (Haynes, 1992; Kazdin *et al.*, 1997). The application of this systematic approach may help to provide direction for future research in the area (Chapter 2). Evidence from cross-sectional studies (e.g. Owen *et al.*, 2004) establishes life events as a correlate of psychological problems. The current data add to previous longitudinal data (Esbensen & Benson, 2006) in establishing temporal precedence of life events in respect of psychological problems and thus in upgrading life events to a 'risk factor'. To demonstrate that life events are causal in the development or maintenance of psychological problems, evidence is needed for a mechanism by which life events contribute to the causation of psychological disorder. Whilst there are a number of theoretical approaches to understanding such stressful events in the general population (e.g. Hobfoll, 1989; Lazarus, 1999; Lazarus & Folkman, 1984), to our knowledge no systematic research has yet been done to demonstrate the validity of these models in people with intellectual disabilities.

Thus, a research priority is to explore how life events have their impact on people with intellectual disabilities and lead to vulnerabilities resulting in psychological problems. Once these mechanisms are understood, treatment and

support implications will be identified. For example, if the cognitive appraisal of a stressor, as described by Lazarus (1999) were found to be of considerable importance, the development of acceptance might be a priority for intervention. The role of multiple risk and protective factors also needs to be explored within intellectual disability research. For example, social support may act to protect against the emergence of depression in individuals exposed to negative life events (Myers, Lindenthal & Pepper, 1975; Paykel, 1994). However, individuals with intellectual disability often have relatively small and impoverished social networks (Lunsky & Benson, 1999; Rosen & Burchard, 1990) and so they might be especially vulnerable to the impact of negative life events.

Chapter 4 – Self-reported Life Events, Social Support and Psychological Problems in Adults with Intellectual Disabilities

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Chapter 5 – Life Events and Psychological Problems in Children with Intellectual Disabilities

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Hulbert-Williams, L. & Hastings, R. (2008). Life Events and Psychological Problems in Children with Intellectual Disabilities.

Abstract

There is considerable evidence that life events are associated with psychological disorder in children without intellectual disabilities. To date, the literature on this association in young people with intellectual disabilities is under-developed. We present data from 113 children with intellectual disabilities in England and Wales, across two times points, twelve months apart. Participants were exposed to a mean of 0.54 life events (range = 0–2 life events) in the twelve month reference period. Life event exposure was found not to contribute to regression models to predict psychological well-being when prior levels of well-being has been controlled for, in most of the analyses. However, total life event exposure was found to predict subsequent anger scores, and loss-related life events were found to predict subsequent depression scores. The need to develop studies to examine the differential associations between life events types and psychological syndromes is discussed.

Introduction

There is robust evidence of an association between psychological problems and adverse life events, such as bereavement and moving home, in children without intellectual disabilities (for a review, see Sandberg & Rutter, 2002). This field of enquiry is beset by methodological complexities, however the evidence points to a number of conclusions. First, recent life events are associated with a number of different psychological disorders across a range of ages (Goodyer, Wright & Altham, 1990; Goodyer, 1993; Tiet, Bird, Hoven, Moore *et al.*, 2001; Tiet, Bird, Hoven, Wu *et al.*, 2001). Second, life events may be more strongly associated with affective disorders, oppositional defiant disorder and conduct disorder than with attention deficit hyperactivity disorder and social phobias (Tiet, Bird, Hoven, Moore *et al.*, 2001). Third, different life event types may be associated with specific syndromes. For example, loss-related life events may be more closely associated with affective disorders whilst threat-related life events may be associated more with anxiety disorders (Eley & Stevenson, 2000; Goodyer, 1993).

There is limited evidence that intellectual ability affords children a greater degree of resilience in situations where they are at high risk for psychological disorder (Tiet, Bird, Hoven, Wu *et al.*, 2001). It is surprising then, that to date, there has been very little research interest in the impact of life events on children with intellectual disabilities. Life events studies of the type cited above include a range of life events as a checklist and derive a cumulative score in order to draw conclusions about life events as a broad category of experience. We are aware of only one study of this sort to date involving children with ID. Dekker and Koot (2003) have presented an analysis of longitudinal predictors of DSM-IV disorders in children (N=474) with intellectual disabilities. Recent life events were found to predict child psychological disorders, after controlling statistically for prior levels of behavioural problems.

A further study has examined a range of life events, treating each individual life event type as a predictor. Hatton and Emerson (2004) conducted a secondary analysis of a large national sample of children, in which a sub-set with intellectual disabilities could be operationally defined using demographic and educational parameters (N=264). Odds ratios were calculated to measure the association between exposure to each life event type and emotional and conduct disorder. A number of life events, including the death of a close friend and parental separation were found to be significantly associated with these types of psychological problem. In a sample of children with Down syndrome, Coe *et al.* (1999) reported that number of life events was not significantly associated with problem behavior measures, however, positive associations were found with *life change units* (life events totals weighted with respect to the supposed impact of life event types Coddington, 1972). A number of related studies have also been published. Ghaziuddin (1995) has reported on significant associations between life events and depression in a case-control study of children with developmental disorders (a diagnostic category that overlaps with but which is not contiguous with intellectual disability). Several studies have also been published on specific life event types such as bereavement (for a review, see Everatt & Gale, 2004), and abuse (Benedict, White, Wulff & Hall, 1990; Jaudes & Diamond, 1985; Mansell, Sobsey & Moskal, 1998).

A larger body of evidence exists in regard of life events in adults with intellectual disabilities. As in the child literature, concurrent associations have been demonstrated for both mental health (Cooper, Smiley, Morrison, Williamson *et al.*, 2007a; Hamilton *et al.*, 2005; Hastings *et al.*, 2004) and behaviour problems (Owen *et al.*, 2004). However, recent developments have not yet been applied in the child literature, such as the application of longitudinal research designs (Chapter 3 ; Esbensen & Benson, 2006). The primary interest in life events for clinical psychology research lies in the extent to which life events may be said to *cause* psychological problems. It has long been acknowledged (e.g. Brown & Harris, 1978) that the relationship between a person's physical or psychological well-being and the life events they experience may run in either causal direction: a depressed person may lose his job as a result of his symptoms, just as losing a job may cause or worsen a person's depressed state. In establishing a phenomenon as causal, it is necessary to measure a range of variables which may be related to the phenomena of interest in order to rule out spurious associations, and to examine the central relationship over time to establish a causal direction (Haynes, 1992; Kazdin *et al.*, 1997). We present data on a number of measures of psychological well-being including psychopathology, challenging behaviour, and positive aspects of behaviour. The aim of the present study was to examine the association between cumulative life events and psychological well-being in children with intellectual disabilities, using a longitudinal approach, and thereby establish evidence in regard of the criteria of association and temporal precedence established in Chapter 2.

Method

Participants and setting

The present data were collected as part of a larger study of psychological aspects of caring for a child with ID (Hastings, Beck & Hill, 2005). One hundred and thirty-eight parents responded at Time 1, providing data on their children. At Time 2, twelve months later, the parents were again sent a measures pack, and 114 parents responded, representing a retention rate of 82.6%, though life events data were incomplete in one case. Thus, participants were 113 school-

age children (37 girls and 76 boys) with intellectual disabilities living in England and Wales, ranging in age from three-and-a-half to 18 years ($M=10.44$, $SD=4.2$). A normed measure of adaptive skills was used to establish the severity of developmental delay for each child, using the standard categories of borderline (5.3%), mild (11.5%), moderate (31.0%), severe (37.2%), or profound (13.3%). Such data were not available for two participants.

Additional diagnoses included autism spectrum disorder (42%), Down syndrome (20.4%), cerebral palsy (12.4%), ADHD (5.3%), and epilepsy (13.3%). Thirty-one percent had concomitant physical health problems, 30.1% had problems with mobility, and 22.1% had at least one sensory impairment.

All of the children in the sample lived at the parental home, though 31.1% also made use of respite care facilities. Information was collected from mothers, who ranged in age from 23 to 57 years ($M=40.0$, $SD=7.3$). The modal level of education amongst mothers was a high-school level certificate, though 21.1% had a university education. The majority of mothers were married (66.4%), though a sizeable proportion were cohabiting (12.4%) or divorced (21.2%). There was a comparatively even split between mothers who were employed (15.9% full-time, 34.5% part-time) and those who were not employed (49.6%). Family income was established using a categorical scale (in Pounds Sterling): under 15k (23.9%), 16-25k (24.8%), 25-35k (18.6%), 35-50k (15.0%), 50-75k (4.4%), 75-100k (0.9%).

Procedure

Information about the project was disseminated through schools for children with intellectual disabilities. Parents were asked to opt-in by mail. Once parents had opted into the study, they were sent a questionnaire pack including the three principal psychological measures described below. At Time 1 the postal questionnaire pack also included a demographic questionnaire designed specifically for this sample, and the Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984) were completed via telephone interview with the primary carer as an indirect measure of the severity of ID. These measures were repeated 12 months later, at Time 2, with the inclusion of a life events checklist, also described below.

*Measures**The Behavior Problems Inventory (BPI).*

The BPI (Appendix E) is designed to be completed by a carer of a person with an intellectual disability or other developmental disability (Rojahn *et al.*, 2001). The measure comprises 15 items on self-injurious behaviour (e.g. self scratching, hair pulling), 25 items on stereotypic behaviours (e.g. repetitive hand movements, rocking back and forth) and 12 items on aggressive/ destructive behaviour (e.g. hitting others, being verbally abusive). Behaviours are rated for frequency (never, monthly, weekly, daily, or hourly) and severity (no problem, slight, moderate, or severe problem). The sub-scales have good internal consistency (alpha = .61 - .82), test-retest reliability (intraclass correlation coefficients = .64-.76), and inter-rater reliability (Rojahn, Aman, Matson & Mayville, 2003). The degree of problem ratings on the BPI have been demonstrated to be highly correlated with the frequency ratings (e.g. Rojahn *et al.*, 2001). In the present sample these two response scales were found to correlate at both Time 1 ($.95 < r < .97$) and Time 2 ($.92 < r < .97$). To reduce the potential for error associated with multiple comparisons, only the frequency ratings were used in the analyses.

The Reiss Screen for Maladaptive Behavior (RSMB).

The RSMB (Appendix Y; Reiss, 1988), a commonly used screening tool on which a carer rates the severity of each of 36 symptoms, was used to measure psychological disorder. The RSMB has been shown to have adequate psychometric properties including inter-rater and test-retest reliability (Havercamp & Reiss, 1997), and good convergent validity with independent clinical diagnosis (Steven Reiss & Valenti-Hein, 1994). Items are scored into sub-scales for attention deficit, anger, anxiety, conduct disorder, depression, autism, psychosis, self-esteem, somatoform behaviours, and withdrawn behaviour.

The Nisonger Child Behavior Rating Form.

The parent version of this scale (Appendix Z; Nisonger CBRF; Aman, Tassé, Rojahn & Hammer, 1996; Tassé, Aman, Hammer & Rojahn, 1996) was also adopted as it contains two sub-scales relating to social competence, labelled

compliant/calm and *adaptive social*. Only the questions relating to these subscales were administered. The Nisonger CBRF has adequate inter-rater reliability (Aman *et al.*, 1996) and some data have been published on its concurrent validity, which appears unproblematic (Aman *et al.*, 1996).

A checklist of life events was constructed using events common to many life events scales (e.g. The Social Readjustment Rating Scale, Holmes & Rahe, 1967) and studies (e.g. Hatton & Emerson, 2004). These events, such as parental marital separation and moving home, were chosen to be uncontroversial exemplars of significant life events in children. The full list of events measured is presented in Table 5.1.

Results

Table 5.1 presents the full list of life events measured for the study with the proportion of children who experienced each life event type in the period between Time 1 and Time 2. The table is ordered by overall frequency. In the 12 months prior to Time 2, children experienced a mean of 0.54 life events ($SD = 0.69$, range = 0-2), with modal exposure being one event in 12 months. Loss-related life events were less common ($M = 0.31$, $SD = 0.54$, range = 0-2), with the modal number experienced being zero. Direct comparisons cannot be drawn with the findings of Hatton and Emerson (2004) as to the number of life events experienced by children with intellectual disabilities as life events were measured over the lifetime of the child in their sample.

Table 5.1: *Percentage of children experiencing measured life events between Times 1 and 2.*

| Event | No. of Children | Percent of Sample |
|----------------------------------|-----------------|-------------------|
| Death of close family member | 10 | 8.8 |
| Hospital visit | 8 | 7.1 |
| Moved home | 8 | 7.1 |
| Family discord with grandparents | 8 | 7.1 |
| Gaining a family member | 8 | 7.1 |
| Mother becoming pregnant | 3 | 2.7 |
| Death of close friend | 6 | 5.3 |
| Parental marital separation | 4 | 3.5 |
| Parental divorce | 3 | 2.7 |
| Suffered an accident | 1 | 0.9 |
| Parental marital reconciliation | 1 | 0.9 |
| Parental marriage | 0 | 0 |

To establish whether any particular demographic profile was associated with higher prevalence of life events, such as would require attention in later statistical analyses, a number of tests of difference and a correlation analysis were performed. No statistically significant differences were found in the prevalence of life events with respect to sex; mother's or father's marital status; mother's or father's employment status; family income; numbers of children or adults in the family; parental age; diagnoses of autism, cerebral palsy, or Down syndrome; sensory impairments; mobility or other health problems; or extent of developmental delay. Child age was not found to correlate with life event exposure.

To examine longitudinal associations between life events and psychological well-being, hierarchical linear regression was applied. A model was developed for each sub-scale in turn. In step 1, the Time 2 measure of psychological well-being was predicted from the Time 1 measure on the same sub-scale. In step 2, total number of life events in the intervening period (measured retrospectively at Time 2) was included. A similar set of models was developed using the total number of loss-related life event as the additional predictor in Step 2 in place of total life events. Results of both types of analysis are displayed in Table 5.2. Graphical analysis of residuals suggested that these

analyses were sound despite the skewness present in the life event data. The addition of the total life events score was not found to contribute significantly to the prediction of psychological well-being in any of the models. Similar non-significant results were found with regard to loss-related life events, however, the addition of these life events at Step 2 did add significantly to the model to predict depression (RSMB).

Table 5.2: Results of longitudinal hierarchical regression analyses. Control variables entered in Step 1, life events in Step 2.

| Criterion variable | Step 1 R ² | Total Life Events | | Loss-related Life Events | |
|---|-----------------------|--------------------------------|-------------|--------------------------------|-------------|
| | | Step 2 Δ R ² | F of change | Step 2 Δ R ² | F of change |
| <u>Nisonger</u> | | | | | |
| Compliant/calm | .43 | .00 | 0.03 | .00 | 0.44 |
| Adaptive/social | .50 | .00 | 0.11 | .00 | 0.10 |
| Total | .54 | .00 | 0.13 | .00 | 0.12 |
| <u>Behaviour Problems Inventory</u> | | | | | |
| Self-injurious behaviour | .68 | .00 | 0.02 | .00 | 0.20 |
| Stereotype behaviour | .74 | .00 | 0.75 | .00 | 1.42 |
| Aggressive/destructive | .63 | .01 | 2.75 | .00 | 0.79 |
| <u>Reiss Scales of Maladaptive Behavior</u> | | | | | |
| Attention deficit | .551 | .01 | 1.20 | .00 | 0.44 |
| Anger | .60 | .02 | 5.00* | .01 | 1.46 |
| Anxiety | .66 | .00 | 0.12 | .00 | 0.64 |
| Conduct disorder | .45 | .00 | 0.38 | .00 | 0.03 |
| Depression | .45 | .02 | 3.21 | .04 | 8.09** |
| Autism | .61 | .00 | 3.31 | .01 | 2.00 |
| Psychosis | .44 | .00 | 0.08 | .00 | 0.04 |
| Self-esteem | .57 | .00 | 0.25 | .00 | 0.04 |
| Somatoform | .42 | .00 | 0.66 | .00 | 0.32 |
| Withdrawn | .63 | .00 | 0.61 | .00 | 0.18 |

* p<.05, ** p<.01

Discussion

Children with intellectual disabilities experience a range of life events, exposure to which may be associated with psychological well-being in rather specific ways when prior levels of psychological well-being are taken into account. Total life event exposure was found only to predict subsequent scores on the anger sub-scale of the RSMB, whilst loss-related life events were found to be associated selectively with depression scores on the same instrument. These findings are in line with those reported by Hatton and Emerson (2004), where

some life events such as the break-up of a steady relationship, and parental financial crisis were found to be selectively associated with emotional disorder but not conduct disorder.

This pattern of results is consistent with those reported by Hatton and Emerson (2004) for children with intellectual disabilities. That there should be specific relationships between life events of certain types, such as those involving loss, and specific types of psychological disorder is consistent with the literature on life events in children without intellectual disabilities (Eley & Stevenson, 2000; Goodyer, 1993). It is perhaps surprising how few associations were found between life events and subsequent changes in psychological well-being. There appears to be reasonable evidence for concurrent and longitudinal relationships between life event exposure and psychological problems in children without intellectual disabilities, including studies using a cumulative approach and including a range of life events (for a review, see Goodyer, 1993). There are two primary explanations for the present pattern of results. It may be that associations between life events and psychological problems are more specific in children with intellectual disabilities. Alternatively, it may be that some of the life event types measured in the present sample are not particularly pertinent to children with intellectual disabilities. Effect sizes for associations between life events and psychological problems are generally small (Chapter 2) and these effects might be undetectable if life event scores include irrelevant life events, thereby increasing measurement error.

The approach taken in the present study, in computing total scores for life event exposure, rather than studying one life event type (e.g. bereavement) is standard in life events research (Paykel, 1983) and allows researchers to draw conclusions about general stress responses. This approach has a number of disadvantages associated with it however. Such an approach may lead to assumptions being made about individual life event types due to their inclusion in standard life events measures, rather than sound evidence of an association with specific psychological problems. Furthermore, the inclusion of life event types which are not pertinent for the population under study can considerably reduce observed effect sizes. Given that the life events checklist used for the present study was chosen through a rather pragmatic process in the absence of

any developed measure for use with children who have intellectual disabilities, such an effect might account for the number of non-significant results presented here.

A possible solution to this problem has already been demonstrated. Hatton and Emerson (2004) present data in regard of a range of life events in the same sample of children, but render separate analyses for each event type. With such studies, researchers can easily compare and contrast between different life events. However, such analyses typically require large samples, due to the low prevalence of significant life events. The present data set was not large enough to power such analyses, especially considering the need to control for variables across time. It is necessary also to note the possibility of a Type I error with regard to the two predictive models where life events were found to be a significant additional predictor. Given the difficulties in obtaining sufficient power to conduct analyses of this sort, where highly stable psychological characteristics must be controlled for, corrections for multiple comparison were not applied.

Whilst it is difficult to draw firm clinical implications from such a small evidence base, it appears likely that there are a number of specific relationships between individual life event types and different patterns of psychological disorder. Given the longitudinal relationships observed, it is likely that some life events are a risk factor for one or more types of psychological problems in children with intellectual disabilities. There remains insufficient evidence to establish life events as a causal risk factor however. Further research is needed to address the possibility of more specific relationships between certain life event types and specific types of psychological disorder, as described above, and to establish the putative causal relationship between life events and psychological problems.

Chapter 6 – Discussion

The examination of life events in relation to psychological problems in people with intellectual disabilities is important for a number of reasons. People with intellectual disabilities experience higher rates of a wide range of psychological problems (Borthwick-Duffy, 1994). There is some evidence that children with intellectual disabilities may also be at increased risk of experiencing life events (Hatton & Emerson, 2004), though data are not currently available to draw a similar comparison for adults. And there is some evidence that intellectual ability is positively associated with resilience to adverse life events (Tiet, Bird, Hoven, Wu *et al.*, 2001).

Chapter 2 of this thesis critically reviewed the literature on life events in people with intellectual disabilities and established a number of gaps in the evidence base. The empirical studies reported in Chapters 3, 4 and 5 were designed to provide some of the evidence required to address these gaps.

This chapter (Chapter 6) will provide a discussion of the forgoing reports of empirical work, with reference to the critical framework established in Chapter 2. Findings will be reviewed, and linked to a number of theoretical and practical implications. The chapter will also provide a critique of the methodological issues encountered in the execution of this work. Finally, a number of directions for future research will be discussed.

Life Events in Adults with Intellectual Disabilities

Both Chapter 3 and Chapter 4 present the results of empirical studies on life events in adults with intellectual disabilities. The study presented in Chapter 3 relied on proxy informants' reports and included both measures of mental health (PAS-ADD; Moss *et al.*, 1993) and challenging behaviour (BPI; Rojahn *et al.*, 2001; and WARS; Taylor *et al.*, 2004). Data were collected across two time points. Hierarchical linear regression techniques were employed so that earlier measures of psychological problems could be controlled for in the analyses. Life event exposure was found to significantly add to the prediction of subsequent psychological problems, providing evidence for the temporal precedence of life events. This finding was further bolstered in that longitudinal analyses to predict subsequent life events from earlier measures of

psychological problems indicate no significant relationships, suggesting that the relationship may be unidirectional.

The study presented in Chapter 4 used self-report data, and was collected in a single time point. The Brief Symptom Inventory (Derogatis, 1993) was used in an assisted completion format (Kellett *et al.*, 2003) to measure depression, anxiety, hostility and anger. All four constructs were found to be positively and significantly associated with self-reported life events exposure. Data were also collected on social support using the Social Network Map (Tracy & Abell, 1994; Tracy & Whittaker, 1990), though participants struggled with some aspects of the measure. No evidence was found to support the hypothesis that social support might moderate the relationship between life events and psychological problems in adults with intellectual disabilities, but reported criticism from one's social network was associated with higher anxiety and hostility.

The data presented in both of these chapters also permitted a basic analysis of the prevalence of life events in adults with intellectual disabilities. Whilst direct comparisons with other samples reported in the literature are difficult to make, due to the different lists of life events included, the present data appear to have a broad agreement with the published data. Life events often considered to have a negative impact, according to proxy informants, included permanent changes in staffing, another person moving into or out of shared accommodation, and periods of cover by non-regular carer. Life events frequency rated as negative in self-report data included being subject to verbal abuse, the serious illness of close relative, bereavement, and changes in one's finances. Changes in staffing, including temporary cover, were reported to occur quite often, and were quite frequently rates as undesirable by adults with intellectual disabilities.

Life Events in Children with Intellectual Disabilities

Chapter 5 presented data on life events and psychological problems in children with intellectual disabilities. The analyses were conducted in order to begin to address the need identified in Chapter 2 for further research on childhood life events. Three measures of child behaviour were included, and data were gathered across two time points, via primary carers. Data were thus

collected on challenging behaviour (the BPI, Rojahn *et al.*, 2001), psychological disorders (RSMB, Reiss, 1988) and positive aspects of behaviour – adaptive social behaviour and calmness (Nisonger CBRF; Aman *et al.*, 1996; Tassé *et al.*, 1996). Data on prevalence were prepared, and were similar to published data in a much larger sample of children both with and without life events (Hatton & Emerson, 2004).

Life event exposure was found to be a longitudinal predictor of psychological problems, when earlier measures of these constructs were taken into account, but only in rather specific ways. Total life event exposure was found to predict subsequent anger scores. A sub-set of life events which had to do with the loss of a situation, object, or loved one, were analysed separately, and were found to predict subsequent depression scores. This finding provides evidence for the temporal precedence of life events in regard to psychological problems, albeit in a restricted fashion where only certain relationships between life events and psychological problems pertain. Overall, these findings agree with similar reports on children with intellectual disabilities (Hatton & Emerson, 2004). Whilst specific associations, especially with life events which represent a loss, have been noted in the child literature generally, total number of life events has generally been correlated with a wider range of outcome variables (e.g. Goodyer, 1993; Goodyer, 1996). It may be either that children with intellectual disabilities differ somewhat from their non-disabled peers with respect to the specificity of relationships between life events and psychological problems, or that the range of life events measured in the present data did not comprise the most pertinent life events for children with intellectual disabilities.

Theoretical Implications

Taken together, the data presented in this thesis have a number of implications for the development of theory in relation to life events and people with intellectual disabilities. It is worth re-stating that research on life events falls within a broader field of research, namely, that of stress research. All research in this field has as its aim the examination of human responses to stress. As discussed in Chapter 1, life events researchers have typically

restricted themselves to externally verifiable phenomena to a far greater extent than is true of the transactional models of stress (Brown & Harris, 1989; Hobfoll, 1989, 2001; Lazarus, 1999; Lazarus & Folkman, 1984). This emphasis has both benefits and risks for the development of the field.

The data presented in this thesis contribute to a progressive body of evidence on the impact of life events on people with intellectual disabilities. Indeed, it is important to emphasise that life events researchers generally (Paykel, 2001), and those who work with people with intellectual disabilities (e.g. Esbensen & Benson, 2006; Hamilton *et al.*, 2005; Hatton & Emerson, 2004) do tend to regard life events as a risk factor for psychological disorder. Often, this assumption is implied, for example through the use of unidirectional regression techniques (e.g. Hamilton *et al.*, 2005) or use of concepts such as “risk” even in the absence of longitudinal data (e.g. Hatton & Emerson, 2004). Whilst this assumption is not unreasonable, given the considerable literature on life events in the general population, it is indeed an assumption, in that it goes beyond the data. It is clearly of considerable practical importance to establish evidence for the putative role of life events in psychological problems.

Non-experimental approaches are not ideally suited to providing evidence for causality. Practical and ethical considerations preclude the possibility of conducting experimental manipulations of life events however, and so researchers must infer causality by establishing evidence that the relationship of interest meets four criteria (Haynes, 1992). First, there must be evidence of association, that the two phenomena reliably co-vary; second, reasonable attempts must be made to establish the relationship as non-spurious, that is, that the relationship is direct and not reliant on other variables; and third, the causative phenomenon must occur before the effect, a criterion referred to as temporal precedence. The fourth criterion might be considered more strict, and involves the identification of a plausible mechanism whereby the causal phenomenon comes to affect the caused phenomenon (Haynes, 1992). Life events research, as usually conducted (for reviews, see Brown & Harris, 1989; Paykel, 2001) is capable of providing evidence to meet the first three of these criteria. Indeed, with the addition to the literature of longitudinal data (Chapter 2; Esbensen & Benson, 2006), the association between life events and

psychological problems in adults with intellectual disabilities might be said to have addressed each of these criteria to a considerable extent.

The fourth criterion, however, that of mechanism, is fundamentally beyond the scope of the life events method. Researchers and clinicians must decide the importance of the failure to address this fourth criterion. To use the nomenclature of Kazdin, Kraemer and colleagues (Kazdin *et al.*, 1997; Kraemer *et al.*, 1997), the life events approach can produce evidence that life events are a risk factor for psychological problems. Establishing life events as a *causal* risk factor, however, necessitates evidence to address Haynes' (1992) fourth criterion, through the examination of psychological mechanisms.

Widely differing models (Hobfoll, 2001; Lazarus, 1999) are propounded in the general psychological literature to explain the psychological mechanisms of stress. These models, as discussed in Chapter 1, are highly reliant on cognitive psychological theories and methods of self-report. The difficulties in using self-report methods with people with intellectual disabilities, especially in regard of complex abstract concepts such as 'congruence with goals' (Lazarus, 1999) are well established (Finlay & Lyons, 2001) and rehearsed here (Chapter 4). Tentative efforts have been made to examine relevant constructs such as coping and perceptions of control (Hartley & MaClean, 2005; Jahoda *et al.*, 1998) in people with intellectual disabilities, but without the development of self-report measures with sound psychometric properties, progress in this area will be limited. Whilst the possible application of these models should not be ruled out, the life events approach may afford the best chance possible, in the medium term, of ensuring a sound evidence base for practice in regard of people with intellectual disabilities who experience stressful life events.

Implications for Policy and Practice

The empirical findings reported here, taken together with findings already published on life events in people with intellectual disabilities, have a number of implications for policy and practice.

It is clear that people with intellectual disabilities experience a wide range of life events, from bereavement to moving house, from being physically restrained, to changes in support staffing arrangements. This finding adds

greater emphasis to the acknowledged need for well-designed mental health services for people with intellectual disabilities.

There is also a need to revisit the well-worn discussion over the choices people with intellectual disabilities have in the running of their own day-to-day lives. A number of life events were commonly rated as having a negative impact (on the BLESID-I impact scale), including changes in staffing, other people moving into and out of the home, and periods of staff cover. Participants in the self-report study were, on the whole, able to make their feelings about events quite clear. Whilst these events may occasionally be unavoidable in busy and under-funded services, it is important for service providers and commissioning agencies fully to appreciate the impact such service changes may have on the psychological well-being of their clients. There is currently no evidence for whether it might be possible to help people with intellectual disabilities prepare for unavoidable life events such as these.

Clinical psychologists, psychiatrists and other diagnosticians will need to be mindful of the role life events can play in psychological problems, including challenging behaviour. Whilst the evidence is not yet sufficient to conclude unequivocally, it appears highly likely that exposure to life increases subsequent risk for psychological problems. Given similar findings in the more developed general literature, clinicians may wish to consider brief routine screening for recent life events as part of the diagnostic interview.

The self-report data presented in Chapter 4 reveal associations between life events and psychological problems, with greater effect sizes than are typically reported in studies using proxy-informant reporting. This is suggestive of greater sensitivity in the detection of life events, psychological symptoms, or both. Clinicians may therefore wish to consider the possibility that diagnostic assessment may be considerably aided by the increased use of self-reporting techniques wherever feasible.

It is noteworthy that many of the participants involved in the self-report study commented, without having been asked, that they felt positively about taking part in the study. This was somewhat surprising given the sensitive nature of the topics under discussion. A number of participants said that it was

nice to talk to someone, while several others asked whether the researchers would return so that they might talk again.

Research conforming to the life events tradition is not well placed to make recommendations regarding psychological treatment. The emphasis is on the association between observable events and subsequent disorder. Little consideration is paid to the psychological processes underlying the stress reaction. It will be necessary to further research these psychological processes, however, in the meanwhile, with no evidence to the contrary, the safest assumption is that people with intellectual disabilities share the same set of cognitive process as have been researched in the general population. Treatments, therefore, should be broadly similar.

Methodological issues

Whilst the empirical work included in this thesis makes a contribution to addressing the gaps in the evidence base as identified by the critical review in Chapter 1, it is subject to a number of methodological limitations. First, there are a number of issues which limit somewhat the generalisability of the findings. People with intellectual disabilities are not a homogeneous group. Individual differences exist in a wide range of domains, not least in regard to the severity of disability.

The two adult samples recruited differ in a number of regards. The participants of the longitudinal study in Chapter 3 were long-term residents of an institution for people with intellectual disabilities, during a time when a programme of resettlement was taking place. As expected, individuals in this sample covered a broad range of levels of severity, and some regularly engaged in very challenging behaviour. The self-report study in Chapter 4 was conducted with a considerably more restricted sample. The nature of intellectual disabilities is such that individuals with a more severe disability are proportionately less able to communicate and to comprehend. Though formal IQ testing was not employed, to ensure a reasonably minor degree of participant burden, it was felt likely that all the participants in this sample fell in the mild-borderline range. There is some evidence that people with intellectual disabilities of differing severity or aetiology may differ in their

responses to life events (Hamilton *et al.*, 2005). The present findings cannot be taken to apply equally to all sub-groups therefore.

Second, there is an issue with the life events approach generally taken in studies with people with intellectual disabilities. Most studies conducted to date use a checklist approach for the measurement of life events (e.g. Esbensen & Benson, 2006; Hamilton *et al.*, 2005; Hastings *et al.*, 2004; Owen *et al.*, 2004). Such an approach is also extremely common in life events research with people in the general population (Miller, 1996). The alternative approach involves conducting an in-depth interview in a relatively unstructured manner (e.g. Dohrenwend, Raphael, Schwartz, Stueve & Skodol, 1993). These methods each have a number of strengths and weaknesses, and a recent review has concluded that neither method is clearly better (Gorman, 1993).

Whilst life events checklists afford a greater degree of standardisation, and ensure that a set number of life events are considered by participants responding to questions, the fact that a range of life events is established prior to the data collection means that it is the responsibility of the researcher to include relevant events. Furthermore, most life events checklists (e.g. Holmes & Rahe, 1967) do not afford the possibility to record multiple occurrences of the same life event type. Both versions of the Bangor Life Events Schedule for Intellectual Disabilities (BLESID; Appendices B and C, see Appendix A for information on development) attempt to address these shortcomings. The development of the item pool was not entirely reliant on the researcher (Appendix A), the impact scale allows the participant to indicate that the event had no personal relevance, the frequency scale is used to record information about repeated events, and space is provided at the end for life events not included in the list.

Despite these developments, it is by no means certain that all of the disadvantages of the checklist approach have been fully ameliorated. The inclusion of an *impact* scale, which allows participants or informants to rate the personal relevance of each life event type, was a pragmatic development intended to compensate for any possible over-inclusion of life event types that rarely affect people with intellectual disabilities. The data presented in Chapter 5 were collected as part of a larger study which was underway concurrently

with the development work on the BLESID and so a standard life events list was used. This study likely suffers from the disadvantages of the checklist approach to a greater degree.

Third, the studies reported here had small to moderate samples sizes. Whilst in most cases, there was clearly sufficient statistical power to identify effects and label them as significant, there are two particular areas where sample sizes may have been too small. The longitudinal study on childhood life events reported in Chapter 5 found mostly non-significant results, contrary to concurrent analyses presented by Emerson and Hatton (2004). Whilst there are reasons to think it unlikely (discussed in Chapter 5), it remains possible that these results suffer from a Type II error, due to a lack of statistical power. Similarly, the analyses presented in Chapter 4 regarding the direct and indirect effects of social support may suffer from a lack of power.

Fourth, we must return to the issue of non-spuriousness discussed in Chapter 2. Whilst attempts were made to measure a wide range of relevant variables, including demographics, it is beyond the scope of a set of three empirical studies to establish non-spuriousness for the association between life events and psychological problems. In particular, the self-report study reported in Chapter 4 is the first study of life events in adults with intellectual disabilities to rely entirely on self-report data, however this important contribution comes at a price. Most participants were unable to answer the researcher's many questions about demographics. It is impossible to provide any data on the spuriousness or otherwise of the associations found in these data therefore.

Fifth, we must consider the way data are collected in relation to time. A balance must be struck between the inclusion of life events from a period so long as to greatly increase inaccuracies of recall, whilst including a period sufficiently long to ensure an appreciable number of life events have occurred in the study period. The study of childhood life events in Chapter 5 conforms to standard practice in life events research in that life events are measured retrospectively over a twelve month period. Data on psychological problems were collected immediately before and after this period. Participants in the self-report study (Chapter 4), however, had some difficulties in relation to instructions about timeframes. This may have led to the inclusion of less recent

life events. Since data were gathered from carers for the longitudinal study of life events in adults (Chapter 3), there were no appreciable problems in holding to the 12-month timeframe, however, for practical reasons the time between the two data collection time points was considerably greater than 12 months. Though psychological problems were largely stable over time, the Time 1 measures of psychological problems used as control variables may have been less than ideal.

Furthermore, all the data collected on life events for studies presented here, and for studies reviewed in Chapter 2, were collected retrospectively at the end of a period of time. In this sort of retrospective study, participants may provide biased responses due to a phenomenon sometimes referred to as 'effort after meaning' (Paykel, 1983, 1997, 2001). This bias arises when participants hold views about the extent to which individual life events affect their lives (or, by extension, the lives of the people for whom they are caring), and are more likely to recall and report events that hold personal meaning. To some extent, the use of a checklist approach ameliorates this issue, as respondents are less likely to forget a life event if directly prompted from a list (Gorman, 1993). Researchers in the field of intellectual disabilities may be at an advantage in this connection, due to the high dependence on record-keeping, such as daily diaries, in some supported living settings. It may prove possible to conduct prospective studies of life events using repeated measures of psychological problems, with retrospective analysis of daily diaries to establish the occurrence of life events.

Future directions for research

A number of directions for future work can be identified, partly from the evidence base gaps identified by the critical review in Chapter 2, but also to build on the findings of the empirical studies.

The principal focus of the present thesis has been the life events of adults with intellectual disabilities, however, it has been noted that very little has yet been published on life events in children with intellectual disabilities. Whilst a number of researchers have examined individual life events types, such as bereavement (Everatt & Gale, 2004), there are benefits in establishing general

modes of response to stressful life events, rather than particular responses to well-defined experiences. Clearly, there is a need for further studies on life events in children with intellectual disabilities, not least to test the possibility that loss-related life events are the most pertinent life event types for children with intellectual disabilities.

As acknowledged above, there may be differences in the association between life events and psychological disorder according to level of intellectual disability and syndrome (Hamilton *et al.*, 2005). Whilst such differences were not found in the present data, future studies should be designed with sufficient power to detect differences between sub-groups in the sample. There are a number of reasons why such differences might be expected. For example, people with autism tend to have a considerable preference for routine. It is likely that life events which impact on daily routine would be more pertinent, perhaps more stressful, for people with autism therefore.

Measurement of life events is a business fraught with methodological issues (Gorman, 1993; Zimmerman, 1983). Whilst a great deal of effort has gone into the development of both checklist measures and interview schedules for the general population, these are generally not suitable for use with people with intellectual disabilities. The BLESID has been developed as part of the work presented in this thesis (see Appendix A and B) to provide a flexible research and clinical tool for use both in a self-report format and with proxy informants. The development of the BLESID (described in Appendix A) included the canvassing of opinions from professionals with a great deal of experience working with and caring for people with intellectual disabilities. However, the self-report version of the measure is based directly on the proxy-informant version. Given the importance of including only highly relevant life events in a checklist for use in life events research, it may be helpful to develop a self-report measure from the ground up, perhaps using qualitative interviews with people with intellectual disabilities to establish a range of life events that have most pertinence.

Future studies must include a range of variables, such as demographics, both to progressively rule out alternative hypotheses and thus demonstrate the non-spuriousness of the relationship between life events and psychological

problems, and to test for moderating effects. In particular, phenomena and constructs which may ameliorate or protect against the effects of stressful life events should be considered and tested in order potentially to inform intervention work.

Finally, as discussed, the life events approach is not well placed to describe the psychological processes that give rise to stress reactions. To date, no attempts have been made to test the transactional models of stress (e.g. Hobfoll, 2001; Lazarus, 1999) in people with intellectual disabilities. The methodological difficulties in doing this have been discussed. However, there is a clear trend in intellectual disabilities research toward the inclusion of self-report methods, and sound psychometric properties have been demonstrated for a number of self-report measures for cognitive phenomena (Dagnan & Waring, 2004; Kellett *et al.*, 2003; Nezu, Nezu, Rothenberg, DelliCarpini & Groag, 1995; Wadsworth & Harper, 1991).

The importance of testing the transactional models in people with intellectual disabilities may be decided from a clinical standpoint. The evidence base does not currently allow us to conclude as to any differences in the cognitive reactions to stress of people with intellectual disabilities, as compared with people who don't have intellectual disabilities. Currently, therefore, treatment approaches should be similar to those used with the general population, notwithstanding any accommodation for communication difficulties and the like. It may be useful to examine the efficacy of therapies for people with intellectual disabilities whose psychological problems are linked to life events. Any evidence that success rates are lower in people with intellectual disabilities may give increased impetus to any attempts to test out cognitive models such as the transactional models in people with intellectual disabilities. The first step would be to develop appropriate self-report measures for the most pertinent variables from these cognitive models (e.g. appraisals, Lazarus, 1999), and test these as mediators for the association between life events exposure and psychological problems.

Conclusions

Life events are associated with psychological problems in people with intellectual disabilities. In adults, there is evidence that life event exposure is a risk factor for subsequent psychological problems. To date, there is insufficient evidence that life events play a causal role in the development or maintenance of psychological problems. The evidence base for the effects of life events in children with intellectual disabilities is less well developed. Whilst evidence has been presented in the literature for the concurrent association of life events with psychological problems, data presented here on the longitudinal relationship between these variables suggest that further work is needed to establish which types of life events are associated with which types of psychological disorder. Further work is clearly needed to examine the causal hypothesis in both adults and children with intellectual disabilities. A range of other variables need to be taken into account, both as potential tertiary variables in a spurious association, and as potential moderators of the relationship between life events and psychological problems.

Appendices and References

Welsh language versions of the information sheets, consent forms, and similar materials in these appendices were prepared for use, but were never requested or used, and are therefore not included here.

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