Bangor University

PROFESSIONAL DOCTORATES

The relationship between life events and challenging behaviour in people with intellectual disability : a preliminary study

Owen, Dawn

Award date:
2003

Awarding institution:
Bangor University

The Relationship Between Life Events And Challenging Behaviour In People With Intellectual Disability: A Preliminary Study.

Dawn Owen

University of Wales, Bangor

Thesis Submitted in Partial Fulfilment of the Requirement of the Degree of

Doctorate in Clinical Psychology (D.Clin.Psy)

July 2003

Summary

To date there have been few studies that have explored the relationship between life events and challenging behaviour (CB) in people with intellectual disabilities (ID). The present study is preceded by a literature review that first introduces the literature devoted to the understanding of risk factors associated with the development and maintenance of CB in people with ID. It then provides a flavour of the extensive general life events literature, by presenting meta-analytic and review studies that examine how life events impact on psychological well-being. It finally reviews life event studies that have so far occupied ID research. The literature review concludes with implications for future research and clinical interventions. This is followed by a research study that aims to i. explore the range of life events encountered by people with ID residing in a long stay residential hospital and ii. explore potential associations between life events and CB. To do this a correlational design was employed. Key respondents (nursing staff) well known to the participants provided information on known correlates of CB and life events experienced by the service-user over the previous 12 months. Results suggest that for the study population the life event domains of relationship issues and staff change provided a significant additional contribution to the prediction of CB once known correlates of CB were controlled. The results are discussed in light of the findings. Limitations of the study are also discussed together with the future clinical and research implications of such findings. Finally the research paper is followed by a critical review that outlines the strengths and weaknesses of the study, as well as the process issues arising during the course of the research. Clinical implications and future directions are further discussed.

Contents

Section – Page

Ethics Proposal

Section 1

Literature Review

Section 2

Research Paper Section 3

Appendix 1 Ethics Proposal

Appendices 2 Literature Review

Appendices 3 Research Paper

Appendices 4 Critical Review

Appendices 5 General Appendices

Acknowledgements

I would first like to thank my family and friends for all their support throughout my clinical training. Thanks also go out to Louise and John, Gwenan and Kevin and Kate Wheeler for their friendship and child-minding prowess. Further thanks to Fran and Kevin for rallying me along throughout the write-up period. I also need to thank Katie and Julie for supplying copious amounts of tea and empathy during the three years of training. Also thank you Mark for your love and unswerving belief in me that has picked me up at crucial points.

Secondly, many thanks to all the service users and staff from Bryn Y Neuadd Hospital involved in the study.

Finally, thanks to my supervisors Richard Hastings and Steve Noone.

I would like to dedicate this work to my daughter Poppy who catapulted into existence during my undergraduate studies and has therefore only known me with assignments and imminent deadlines. We've done it sweetie!

SECTION 1

ETHICS PROPOSAL

SECTION 2

LITERATURE REVIEW

Life Events and Challenging Behaviour in People With Intellectual Disability: A Review of The Literature.

Dawn M. Owen

Richard P. Hastings

Stephen J. Noone

School of Psychology, University of Wales, Bangor

Correspondence: Dawn Owen, School of Psychology, University of Wales, Bangor, Gwynedd, LL57 2DG, Wales, UK. E-mail: dawn.owen@bangor.ac.uk.

Short title: LIFE EVENTS AND CHALLENGING BEHAVIOUR

Paper written in accordance with author guidelines for the Journal of Applied Research in Intellectual Disabilities (see Appendix 2.1 for author guidelines).

Abstract

Background

This paper reviews the literature concerned with the impact of life events on the lives of people with intellectual disabilities (ID) and considers how this knowledge base can be linked to the challenging behaviour (CB) literature.

Materials and Method

A literature search was carried out using three approaches: the database PSYCH INFO, direct reference to main journals and scrutiny of reference pages of relevant articles.

Results

The review is divided into three main sections. First, there is an overview of the literature concerned with factors associated with the development of CB in people with ID. Second, the review presents a flavour of the general life events research area before reviewing how this has been applied to ID research. Third, the review critically appraises the present research.

Conclusions

It is the conclusion of the review that while there is a paucity of quality research demonstrating associations between life events and CB there is compelling evidence from the child literature that life events are associated with increased behavioural problems. The implications for future research are discussed.

Keywords

Challenging Behaviour, Life Events, Risk Factors, Intellectual Disability.

There is a wealth of literature pertaining to individual and environmental factors associated with the development and persistence of challenging behaviour (CB) in people with intellectual disabilities (ID). Such a literature creates a contextual framework from which a functional understanding of CB is facilitated. However one area less explored is that of how life events in the lives of people with ID might impact on CB. One reason for this is the methodological minefield encountered in this line of research. However it is widely accepted that people with ID are just as likely to encounter significant adverse events (Sobsey et al,1997) and that such experiences can impact on mental health and adaptive behaviours (Murphy & Razza,1998; Hastings et al, in press;Yoshihama,1998). If one then considers that the general psychological literature clearly illustrates the potential long-term impact of significant life events on the lives of people (Kraaj et al,2002; Sandberg et al,2001) it is apparent that this area of research needs further exploration. This paper will review the literature concerned with the impact of life events on the lives of people with ID and consider how this knowledge base can be linked to the CB literature.

Challenging Behaviour in People with Intellectual Disabilities

The most commonly accepted definition of CB is by Emerson (1995):
' *culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.* ' p3.

However the definition fails to specify how intense, frequent, enduring or restricting a behaviour must be to be reliably labelled as challenging. To further complicate the definitional process is the reality that behaviours occur in a social context and within different contexts will be varying capacities to effectively deal with the presenting behaviours. So the extent to which a behaviour is labelled as challenging is largely reflective of a services ability to cope with a given behaviour and adds little to our understanding of how that behaviour functions in the person adapting to their world (Cullen,1999; Elgie & Hastings,2002; Lowe & Felce,1995b).

The Extent of the Problem: Prevalence, Onset, Persistence and Co-existence

Prevalence rates for CB vary widely in the literature from between 61% (Jacobson,1982) to 1.5% estimated by Kushlik et al (1973). This variance is partly due to methodological and sampling problems and the problems of definition. Recent prevalence studies have reported rates of CB between 8 and 38% (Chung et al,1996) in a general ID population while Bruininks (1994) found higher rates in institutions compared to semi-independent group, family or foster homes. A recent U.K survey (Emerson et al,2001) reported figures on total prevalence rates as well as breaking down figures in order to identify the characteristics of individuals exhibiting CB. The study surveyed 2189 individuals in two areas of England. Two hundred and sixty four (10-15%) were identified, by a key informant, as having CB that was presenting a serious management problem to the local service provider. Within this population 4% self injured, 4-5% displayed destructive behaviours, 7% were aggressive, and 9-12% displayed 'other' behaviours.

In terms of onset the literature contains various retrospective studies that indicate that severe CB typically develops in childhood (Emerson,2001; Murphy et al,1993). However there are few long-term studies in the literature relating to the persistence of CB in individuals with an ID. A study by Kiernan et al (1997) suggested that over a seven year period 63% of 179 individuals identified as having an ID were still demonstrating equivalent levels of CB. Individuals are also likely to demonstrate more than one category of CB both across the four most prevalent topographies of aggression, self-injury, property destruction and 'other' behaviours, and within these behavioural categories (Emerson & Bromley,1995; Emerson et al, 2001). In Emerson et al's (2001) survey most of the identified participants demonstrated two or more of these four general topographies of CB.

Models of Challenging Behaviour

Historically there have been three main approaches that have dominated our understanding of CB. The most dominant approach has been in the area of applied behaviour analysis where CBs are conceptualised as being examples of operant behaviours. A second approach is the study of genetic syndromes and the neurobiology of learning disability. A further approach is to look at individual and environmental risk factors that increase the probability of the development of CB. The paper will now present a brief overview of these three areas.

Operant Account of Challenging Behaviour

A favoured model of CB's is to describe them as examples of operant behaviour, in that they are shaped and maintained by environmental contingencies (Emerson,2001).

An operant perspective is typified by three main characteristics:

i. it seeks to determine the functional relationships between behaviour and environmental factors
ii. the context in which a behaviour occurs is of primary interest
iii. it sees behavioural topographies as existing within a dynamic system

Consequently CB's are regarded as functional and adaptive, evolving through an individual's social and physical interactions, through positive, negative and automatic reinforcement contingencies (Joyce,1997). While reinforcers will vary according to the individual it is likely that behaviours occur in the context of certain setting conditions that act as a trigger for the behaviour. Historically CB was seen as 'attention seeking' but increasing sophistication in how CB is understood acknowledges the potential of social, tangible, sensory and demand avoidance mechanisms (Emerson et al,1987). Operant processes may interact with any number or combination of the outlined individual and genetic/biological risk factors that contribute to the development of CB in an individual's behavioural repertoire.

The literature demonstrates credible evidence for the contextual control of CB. Descriptive studies have looked at the social context in which CB occurs to support the idea that CB may be maintained by processes of positive and negative reinforcement (Emerson,1995,1996b; Hall & Oliver,1992,2000; Toogood & Timlin,1996). More scientifically rigorous studies have also supported the notion of the contextual control of CB for a wide array of behavioural topographies including self-injury (Iwata et al,1994); aggression (Derby et al,1992); destruction (Fisher et al,1998a); inappropriate social behaviour (Frea & Hughes,1997) and pica (Goh et al,1999). However the strongest evidence for the operant account of CB comes from studies that manipulate the reinforcing contingencies believed to be responsible for maintaining CB (Lovaas & Simmons,1969; Zarcone et al,1993).

Finally an operant model also has to account for how some behaviours are not reinforced by external contingencies. The operant approach to this has been to acknowledge the potential reinforcing powers of private/internal reinforcers that have been termed automatic/perceptual reinforcement. Evidence for this is compelling but circumstantial (Derby et al,1992; Iwata et al,1994; Ringdahl et al,1997).

Genetic Syndromes and Neurobiology.

There is a significant literature that demonstrates that CB is linked to particular genetic syndromes. For example, self-injury in the form of hand and lip biting is present in all individuals with Lesch-Nyhan syndrome (Anderson & Ernst,1994; Nyhan,1994). In Rett Syndrome the majority of individuals engage in stereotypical hand-wringing (Harris,1992). Harris (1992) also outlined that there is an above average occurance of self- injury in Cornelia de Lange, Riley-Day and Fragile X syndrome. Furthermore one encounters greater levels of CB in autistic spectrum disorders (Lewis & Bodfish,1998); Prader-Willi Syndrome (Holland,1998) and epilepsy (Kiernan & Kiernan,1994).

Neurobiological models of CB have primarily focused on the role of three classes of endogenous neurotransmitters that may modulate behaviour. For example, the D1 dopamine subsystem may be associated with the development of some forms of self-injury (Shroeder & Tessel,1994). A tenuous link has also been established between serotonin, aggression and some obsessional self-injurious behaviours (Bodfish et al,1995; Shroeder et al,1994). Finally Beta-Endorphin has been implicated in the processes of automatic reinforcement (Thompson et al,1995). As an opioid peptide neurotransmitter that is released following trauma, its analgesic and euphoric properties might lead to physical dependence. These associations have been supported by further psychological research that suggests that for some individuals neurobiological processes may be important in the maintenance of CB (Carr & Smith,1995; Mace & Mauk,1995).

Individual and Environmental Risk Factors

There is also a wealth of other established individual and environmental vulnerability factors associated with the development of CB in people with ID. The following list of factors is by no means exhaustive and categories are not mutually exclusive, as the function of topographically similar CB's will vary between individuals, and within an individual across contexts.

Individual factors that can predispose an individual with an ID to CB include the presence of additional difficulties such as the degree of ID (Hillery & Mulcahy,1997), and visual, hearing or mobility problems (Kiernan & Kiernan,1994). Di Terlizzi et al (1999) found that males were more often labelled as demonstrating CB than females. This relationship was particularly demonstrated in institutional establishments (Qureshi,1994); for more severe CB (Kiernan & Kiernan,1994) more likely in aggressive/destructive behaviours than self-injury (Borthwick-Duffy,1994); and in the years spanning age 15 to 24 (Kiernan & Qureshi,1993). Other individual factors associated with the development of CB include mental health problems (Borthwick-Duffy,1994; Joyce,1997); communication difficulties (Sigafoos,2001) and social interactional difficulties (Duncan et al,1999).

In terms of environmental factors, certain aspects of an individual's environment are understandably associated with the likelihood of the development of a challenging response. These factors would include the quality of the physical environment (Hewett,1998); the restrictiveness of residential environment (Borthwick-Duffy,1994; Emerson,1992); the quality of social environment (McGill & Toogood,1994).

Researchers have extensively explored those factors that may contribute to the emergence of CB in people with an ID. However one pertinent area that has received less attention is the extent to which life events impact on individuals with an ID and how this might be associated with the appearance of CB. There is an extensive general mental health literature concerned with the impact of life events and traumatic experiences. The paper will now present a brief introduction to the general life events realm to explore the possibility of integrating these two extensive literatures.

Life Events and Psychological Outcomes

The general theme of research on life events is that change can be stressful and might require adaptation (Cohen et al,1997). Furthermore, individuals recently experiencing life changes are more susceptible to illness and psychological difficulties than those with relatively stable lives (Brown & Harris,1989).

There are various definitions of what constitutes a life event. Kobasa (1979) suggested that a life event is considered stressful if '*it causes changes in, and demands readjustment of, an average person's normal routine*' p2. Paykel and Rao's (1984) working definition of a life event was '*a discrete change in the subject's social or personal environment. The event should represent a change, rather than a persisting state, and it should be an external verifiable change, rather than an internal psychological one*' p.2.

It was Holmes and Rahe's seminal paper in 1967 that catalysed a wealth of retrospective and prospective studies to establish a causal role for life events in almost every disease and psychological disturbance (e.g Dohrenwend & Dohrenwend, 1974; Faravelli et al,1997; Fitzpatrick,1998; McDaniel,1996; Paykel et al,1969). Given the enormity of the literature there are a wealth of meta-analytic and narrative review studies that consistently demonstrate that life events are associated with psychological problems. Recent studies have focused on a wide variety of issues.

Kraaj et al (2002) employed a meta-analytic methodology to review 25 studies exploring how the type and amount of negative life events experienced by older adults (65 years and older) might be related to depressive episodes. Studies included contained a clear operationalised definition of depression and negative life events. Negative life events further fell into the categories of: traumatic events, life events of a lesser extreme (divorce, financial difficulties) and daily hassles. The study indicated that life events such as the loss of a significant other; severe illness of self; severe illness of significant other; socio-economic factors and negative relationship issues were all modestly but significantly related to depression. Furthermore the meta-analysis indicated that total amount of life events (WAES $r = .150$, $p = .000$) and especially daily hassles (WAES $r = .408$,$p = .000$) were strongly associated with depression. It may be that such relationships are equally apparent in older adults with ID.

In their paper Tesser and Beach (1998) integrated the vast social judgement and life events literatures. Three studies and a mini meta-analysis were carried out to explore how low mood and negative life events impacted on an individuals' judgement of quality of intimate relationships. Studies either focused on mother-adolescent dyads or newlywed dyads. A general overview of results most pertinent to this review is that as negative life events accumulated the judgement of relationship quality in both dyads became less positive and continued to follow a negative trend. This negative spiral that can impact on mood and long-term relationship quality might be particularly pertinent in terms of the relationship dynamics encountered between carers and people with ID.

Davis et al (1999) also utilised meta-analytic principles in a review of 119 studies (83,559 participants) to explore gender differences in exposure and reaction to major and minor life events across the lifespan. Effect sizes were calculated using Cohen's *d*. Results suggested that females experienced more stressful life events than males ($d = .123$, $p<.001$). Furthermore, female appraisal of stress was elevated and this was particularly notable in adolescence (d=.121,p<.001). The study further found that females reported more symptoms of depression, anxiety and psychosomatic problems following a stressful life event (d = .282, p<.001).

The general literature further demonstrates how life events impact specifically on behavioural problems. This is particularly apparent in the child literature. In a longitudinal study of the early predictors of preadolescent internalising and externalising DSM-IV diagnoses, in 358 children, Mesman (2001) evaluated the independent predictive value of parent reported preschool individual and environmental factors, compared to parent reported outcomes (aged 10-11). In general early internalising and externalising difficulties predicted difficulties 8 years later. More specifically, of the environmental variables measured only exposure to life events provided a significant independent predictive value for later externalising difficulties.

Tiet et al's (2001) study examined whether certain psychiatric disorders were more closely associated with negative life events than others in a probability sample of 1285 youths (aged 9-17 years). Life events were measured using a 26-item Life Events Checklist (Brand & Johnson,1982) and psychiatric disorders occurring in the previous 6 months were assessed using the NIMH Diagnostic Interview Schedule for Children (Shaffer et al,1996). Bivariate and multivariate analyses suggested that Conduct Disorder, Oppositional Defiant Disorder and Dysthymia were closely associated with a broad range of negative life events.

Harland et al (2002) further sought to identify those children from a community-based national sample of 4480, that were at risk of developing behavioural and emotional difficulties. Information was collected on socio-demographic and family characteristics and life events as part of a routine preventative health screen carried out in schools. Child psychopathology was measured using the Child Behaviour Checklist (Achenbach,1991). Univariate analyses suggested that children who had recently experienced parental divorce/separation or unemployment were at greater risk of exhibiting externalising behaviours than internalising behaviours. This association was particular strong in 12 to 16 year olds. Findings also suggested that although children did recover over time from their experiences, recovery was not to pre-morbid levels.

These studies clearly provide a flavour of how life events impact on the psychological well-being of people across the lifespan. Moreover, there is compelling evidence that the exposure to a range of life events can be associated with the development of behavioural problems. What is clear is that this literature has a potentially huge relevance to how we understand CB in people with ID. The paper will now demonstrate the extent to which these 2 literatures have already crossed.

Life Events and People with Intellectual Disabilities

The bulk of life event research in ID has concentrated on specific areas such as the impact of bereavement (Day,1985; Hollins & Estehuysen,1997; MacHale & Carey,2002), abuse (Mansell & Moskal,1998; Sequeira & Hollins,2003), resettlement into community living (Bramston & Cummins,1998; Joyce et al,2001; Nottestad & Linaker,2002), and response to major traumas (Doyle & Mitchell,2003; Ryan,1994). However, the literature does also contain some investigation of broader life events (Hastings et al, in press; Monaghan & Soni,1992; Stack et al,1978).

Bereavement

Although specific interest has been taken in considering bereavement issues in people with an ID the literature is still slim and largely anecdotal (Bradford 1984;

Cathcart 1995; Oswin 1981, 1991, 1992).

The earlier literature on the impact of bereavement on people with an ID featured a number of case reports of loss and psychiatric illness. McLoughlin and Bhate (1987) reported on a woman with a moderate level of ID who following the death of her mother and later her father developed an affective psychosis. Anecdotal results suggest that these difficulties responded to psychopharmocological intervention enabling the woman to benefit from bereavement counselling. Then in 1988, Singh et al reported on a client, whose level of ID was not documented, describing a nine-day episode of mania experienced following bereavement

A study by Day (1985) compared psychiatric symptoms in 357 long-stay hospital residents, aged 40 plus, with retrospective data from 215 new admissions of people with ID to a psychiatric unit and a non-ID comparison group. Day (1985) proposed that people with ID lived more stressful lives in the community than their non-ID counterparts. This was due to exposure to an equivalent range of life events together with the added impact of the consequences and stigma associated with ID. The study further indicated that the death of a carer was a particularly traumatic event for a person with ID and might explain the higher levels of neurotic/affective difficulties in this group compared to other non-disabled users of mental health services.

Kloeppel and Hollins (1989) further explored this idea of the loss of a significant other highlighting the multiple losses experienced by an individual with ID on losing a primary caregiver. Such a loss may necessitate the person leaving their home for a residential placement. So the compound loss may equal loss of carer, friend, home, and possibly personal effects, social network, previous routine.

Hollins and Estehuysen's (1997) case controlled study compared a group of parentally bereaved adults with ID to a matched non- bereaved group. They found that the bereaved group attained higher scores on measures of psychopathology (Psychopathology Instrument for Mentally Retarded Adults, PIMRA, Matson et al, 1984) and behaviour problems (Aberrant Behaviour Checklist,ABC, Aman et al, 1985a,1985b) compared to the non-bereaved group. This study was followed up by one of the few longitudinal studies in the literature (Bonell-Pascual et al,1999). The five-year follow up set out to determine if psychiatric symptoms present two years after the bereavement had dissipated. Forty-one of the original sample of 50 were assessed using the same measures. While levels of psychopathology (especially anxiety) had reduced markedly there were increased levels of aberrant behaviour. The authors further concluded that ID is a strong predictor of mental health problems following bereavement. Lyons (2000) heavily criticised this unsubstantiated statement aswell as dubious methodological issues. The main issue being that in the follow-up study the control group were different to the original control group thus making a true comparison impossible.

More recently MacHale and Carey (2002) looked at how bereavement impacted on mental health difficulties and CB. They matched a group of adults with ID who had suffered the death of a primary carer in the two years prior to the study with a non- bereaved group of adults with ID. Using the PAS-ADD (Moss et al,1996c) and the ABC (Aman et al,1985a,1985b) as key measures they found that there were significant differences between groups on the affective neurotic and organic scales of the PAS-ADD and on the irritability, lethargy and hyperactivity scales of the ABC. The main criticism of this piece of work is that it did not take into account the multiple losses the death of a primary carer can have on an adult with ID.

Abuse

The research literature pertaining to abuse issues, in individuals with ID, has only recently gained momentum in the areas of physical and emotional abuse, with the area of sexual abuse still lagging (Moss 2001).

Most research is still concentrated on prevalence and incidence issues with data on the clinical effects of sexual abuse and intervention issues practically non-existent (Sequeira & Hollins,2003). Nevertheless, while research into the impact of sexual abuse is limited, it challenges the popular myth that individuals with ID are not as affected by sexual abuse as the general population (Sobsey,1994). Longitudinal research (Brown et al,1995; Turk & Brown,1993) has further established through key-worker/clinician report incidence levels of up to 70% in target populations. This is especially significant when one considers the methodological issue of under-reporting typically found in this area of research.

Mansel and Moskal (1998) compared the impact of sexual abuse between a group of 43 children with ID and 43 children without ID. Results indicated no significant differences in symptoms between the two groups with both groups displaying excessive anger and aggression and dominant behaviours, as well as poor self-esteem and nightmares. The main difference between the two groups was that the children with ID had a poorer sense of personal safety and poorer sexual knowledge.

Firth et al (2001) looked at the psychiatric sequelae of sexual abuse in children and adolescents with ID who had been victims and/or perpetrators. They were particularly interested in estimating the extent of Post Traumatic Stress Disorder (PTSD) from the 43 sets of case material (21 victims; 16 victims/ perpetrators; 6 perpetrators only). The study suggested PTSD was not common (cf Ryan,1994) and that among other findings sexual abuse of younger victims was associated with the perpetrator experiencing multiple forms of abuse as a child. Lindsey et al (2001) also compared the abuse histories of sexual and non-sexual offenders. Results suggested that 38% of sexual offenders had experienced sexual abuse compared to 12.7% in the comparison group. This might indicate that sexually abusive histories are a significant vulnerability factor for sexual offenders although Mansell et al's (2001) study data did not corroborate this.

Sequeira and Hollins (2003) in their critical review of the literature, spanning 1974 to 2001, found that of the 25 studies they encountered there were no controlled studies and only a few that had adopted a systematic approach to collecting data on the impact of abuse on people with ID. They further highlighted the methodological issues fraught in this area. A main issue was how to collect data, with methodologies complicated by factors including the lack of disclosure, unstandardised measures, under-reporting, definitional difficulties, the victim's lack of understanding, and the victim's communication difficulties. They concluded that while the evidence was currently inconclusive adverse psychiatric symptoms (depression, anxiety and traumatic reactions) and behavioural difficulties (aggression, sexual difficulties and self-injury) were consistently suggested in studies.

Resettlement

Emerson and Hatton (1994) reviewed all the research pertinent to the effects of resettlement between the years 1980 and 1993. This review looked at service user issues, such as quality of life and a range of psychological and behavioural outcomes. It also addressed outcome issues for carers and staff. In terms of the impact of resettlement on CB, the authors concluded that of the 25 studies reviewed there was little evidence of reductions in CB with the exception of stereotypy for people with ID.

Wertheimer (1997) proffered that it is not only the move into supported community living that is a huge transition for individuals with an ID. The whole process of community living can be fraught with ongoing change with individual's lives unsettled for significant amounts of time. Wertheimer (1997) further highlighted the dearth of literature pertaining to the stressors experienced by people with ID's in supported living placements and recommended that the first step was to understand the extent of 'daily hassles' and life events experienced by individuals with ID.

In their study, Bramston and Cummins (1998) employed a single case design methodology to explore the impact of various daily hassles and life events experienced by four individuals who had moved into supported community living. The methodology was used to capture general themes and individual experiences of four people adapting to community living. For the four people in this study it was not the move that they found difficult. Rather it was the daily hassles of independent living that eventually demoralised them.

Joyce et al (2001) then stumbled across the complexities of daily living for individuals with ID in a study that primarily focused on community service provision for CB. Many individuals with CB share residencies with other service users for whom the impact of daily living in such circumstances is unexplored. Informal communications with advocacy groups confirmed the notion that for non-challenging service users, the daily threat of violence or behaviours that markedly impacted on their quality of life was a significant daily worry. With the whole resettlement issue moving onwards this is an issue to be mindful of.

Nottestad and Linaker (2002) further explored individual and environmental factors associated with the emergence of aggression following resettlement. Participants were those individuals residing in an institutional setting who did not attack people prior to resettlement (n=64). This group was then divided to differentiate between those who started to attack following resettlement (n=22) and those who did not (n= 42). The authors concluded that the main predictors for starting to attack others following resettlement included self-injurious behaviour and more evidence of 'other' behavioural problems.

Traumatic Events and Post Traumatic Stress Disorder (PTSD)

The prevalence of PTSD in a general population is 1% (Helzer et al,1987) with 20-30 % of individuals who experience a traumatic event receiving a diagnosis of PTSD. Yet there is a dearth of literature on PTSD in ID despite the acknowledgement that traumatic events can impact on the psychological well-being of those who experience them (McCarthy,2001). In DSM-IV (American Psychiatric Association,1994) the definitional criteria for PTSD specifies '*the experiencing of a traumatic stressor as opposed to an ordinarily unpleasant stressor, which is a threat to life, or severe injury to self or others.*' The Royal College of Psychiatrists (2001) recently reviewed definitional criteria for PTSD in people with ID with definitional criteria remaining the same as for the general population.

One of the earliest studies of PTSD in ID, was carried out by Ryan (1994). Of 310 consecutive referrals to a community based clinic for individuals with developmental disabilities, 51 met diagnostic criteria for PTSD. In terms of exposure to life events Ryan (1994) reported that almost all 310 participants had traumatic/ abusive histories suggesting that 16.5% of individuals with ID who experience adverse events develop PTSD. Of the 310 participants surveyed, all had experienced at least two events with most experiencing five or more. The typical life events experienced included sexual, physical and emotional abuse including life-threatening neglect, although not all life events were abuse related.

Hardan and Sahl (1997) surveyed the incidence and symptomology of PTSD in 233 children and adolescents with an ID who attended a clinic over a one-year period. Results demonstrated that 1.5% met the diagnostic criteria for PTSD all of whom were considered as more able individuals (three had borderline ID and one had mild ID). The most common difficulties encountered in those diagnosed with PTSD compared to other disorders were oppositional disorder, suicidal behaviours, and depression.

Following these studies were three extended discussions of the assessment and treatment literature for people with ID (Doyle & Mitchell,2003; McCarthy,2001; Newman et al,2000).

McCarthy (2001) addressed issues such as misdiagnosis; co-morbidity with other mental health issues; developmental considerations of diagnosis in people with an ID; and treatment issues. To do this she drew extensively on the growing body of literature on PTSD in child and adolescent research (Cohen,1998; Yule et al,2000). She concluded that extensive work needs to be carried out to evaluate how valid the PTSD diagnostic criteria is for individuals with ID at different levels of functioning.

Newman et al (2000) concluded that the full spectrum of life events experienced by people with ID has not been examined sufficiently at this point in time. They particularly emphasised that this particular research agenda is long overdue in a population who are not only at greater risk of experiencing a plethora of adverse significant daily and life events, but who are also generally more susceptible to the psychological difficulties that can result from such experiences. Doyle and

Mitchell (2003) reiterated this statement, further adding that this area of research is potentially more of a methodological minefield, than the general life events literature, because of the difficulties the majority of individuals with ID have in communicating their feelings and emotions. The natural consequence may be that significant events in the life of a person with an ID can go unnoticed and unreported and the psychological sequelae of these experiences misdiagnosed (Doyle and Mitchell 2003).

General Life Events Research in People with Intellectual Disability

An early study by Stack et al (1987) looked at the relationship between admission into a psychiatric hospital for 19 people with an ID and the occurrence of life events compared to a non-ID control group of 19. Using a 30-item check-list, constructed for the study, the type and number of life events in the month prior to admission were examined. It was concluded that events surrounding conflict and loss precipitated admission onto the ward for the ID group. Furthermore, the ID group was less likely to reveal typical symptomology, such as feeling depressed in mood.

In a retrospective study Ghaziuddin (1988) analysed the clinical notes of 65 consecutive referrals for behavioural disorder to a community based service for people with ID using a revised version of Paykel's 64 item life events schedule (Paykel et al,1971). The half of the sample who experienced life events 12 months prior to the referral had a mild ID while those who had not experienced life events had a severe ID. Common life events identified in this study included leaving school, starting at a day placement, parental discord, issues of loss, and commencing relationships. This result may again suggest the methodological/diagnostic bias also apparent in Hardan and Sahl's (1997) later work where life events/trauma were only highlighted in those individuals who were in a position to report the issues.

Nevertheless, this study still reported a 50% incidence of life events in the group studied. This possibly suggests that life events may play a role in the onset of behavioural problems and as such is an area necessitating research.

Cooper (1991) found a relationship between the frequency and types of life events experienced by individuals with Down's Syndrome and relapses in depression. Of the 56 episodes of depression jointly accrued by the 42 participants, 22 of the episodes were preceded by a life event. The study further divided the group into two (34 with single episodes of depression compared to eight experiencing recurrent depression). For the single episode group there was an identifiable life event preceding the depression on 19 occasions compared to the recurrent group where only three life events were experienced across the 22 bouts of depression. It was further identified that these three life events occurred before the initial episode of depression in a recurrent cycle.

Monaghan and Soni (1992) studied the effects of significant life events on the behaviour and self-help skills of a community sample of 27 adults with ID living at home. The Mental Handicap Assessment Schedule (MHDAS) was used as the pre and post study measure, re-administered six months later together with a measure of life events (Social Readjustment Scale - Holmes & Rahe 1967). Results suggested that an increase in life events scores over a six-month period was associated with a deterioration of self-care and increased behavioural difficulties.

Using data from a UK national survey of mental health issues in 10,438 children and adolescents (aged 5 to 15), Emerson (2003), looked at the prevalence of psychiatric difficulties in this sample. In terms of this review the most noteworthy findings were that children with increased exposure to life events were more likely to have been diagnosed with a conduct disorder (Mann-Whitney $z = 3.16, p<.01$), anxiety disorder (Mann-Whitney z =3.14,p<.01) and emotional disorders (Mann-Whitney z =3.55,p<.001).

Hastings et al (in press) employed a correlational design with a population based sample to explore the range of life events experienced by individual's with ID, and the potential associations between life events and psychiatric symptoms in adults with ID. Key informants provided information on 1155 using the PAS-ADD checklist (Moss et al,1996c) that collects information on psychiatric symptomology and recent life experiences. Results suggested that in the previous 12 months 46.3% had experienced one or more life events and 17.4% had experienced two or more. The most common life events experienced were moving residence (15.5%); serious illness of close relative or friend (9%); serious problems with close friend, neighbour or relative (8.8%); serious illness or injury to self (8.5%);and death of a close family friend or relative (8.3%). Further analyses also indicated associations between the experience of one or more life events with psychiatric caseness, specifically affective neurotic disorder.

A review of methodological issues in life events research literature, in ID, was also carried out by Nadarajah et al (1995). The main methodological issues raised in this review included the paucity of control groups in research; the time interval studied (between the life event and onset of difficulties); issues of heterogeneity in the sample groups; issues of validity in the measures used and choice of instruments (checklists versus interview methods). They concluded that no ideal method had yet been established for ascertaining the impact of life events on the lives of people with ID and highlighted the importance of comparing various methods of data gathering through prospective and controlled research.

Conclusions and Directions for Future Research

CB is a major clinical problem in ID. Multi-determined in nature, CB has been extensively researched. However, the study of life events as aetiological variables of CB has been largely overlooked to date.

The general mental health literature clearly illustrates how life events can be predictive of psychological problems, including behaviour problems, in general populations. The extension of life events research to ID has demonstrated that people with ID certainly experience life events and are possibly at increased risk of exposure to certain events (e.g abuse and violence). The reality of resettlement has also been to increase exposure to a range of events not found in institutions. Furthermore, exposure to both specific and general life events has been associated with the development of psychological problems in ID.

However despite compelling evidence to support the impact of life events on the psychological well-being of people with ID, less focus has been leant to how life events might impact on CB. What little the literature presents tells us that there are increased episodes of CB following a bereavement (MacHale et al,2002) and some general life events (Monaghan & Soni,1992). While there is also some tentative evidence suggesting people who have CB have experienced higher rates of significant life events (Ghaziuudin,1988) prevalence rates may not be any different than for people with ID in general (see Hastings et al,in press).

A critical appraisal of the life events research reviewed highlights the potential methodological considerations necessary for future research integrating the CB and life-events literatures. In terms of the measurement of life events there is still a dearth of normative data concerning the range of experiences encountered by people with ID across different contexts. This problem is not only compounded by the limited range of life events measures suitable to use in this field of research but that those available do not take into account the nature of the lives of people with ID. Without normative data it is difficult to know when individuals are at increased risk.

Of those studies that have attempted to integrate the two literatures the measures of CB used either had poor psychometric properties or were more akin to psychiatric symptomology (e.g ABC, Aman et al,1985a,1985b). The necessity for utilising measures that operationalise CB into clear behavioural topographies is essential.

With construct validity taken care of a further weakness of previous studies has been the lack of control. The exploration of possible associations between life events and CB needs to confront the problem of conceptually and operationally disentangling life events from other factors that may impact on the development of CB in individuals with ID (e.g demographics, mental health issues, quality of life, adaptive behaviour).

Finally, people with ID's are a heterogenous group of individuals. As such one can't apply general findings to all individuals with ID. Consequently more population based research is necessary to ensure that when collecting data the variance in the range of life events experienced may be more typical and less extreme to allow the possibility of a theoretically and clinically meaningful integration of these two literatures.

References

Aman M.G. Singh N.A. Stewart A.W. & Field C.J. (1985a) The Aberrant Behavior Checklist. A behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency* 89, 485-491.

Aman M.G.Singh N.A. Stewart A.W. & Field C.J. (1985b) Psychometric Achenbach T.M. (1991) *Manual for the Child Behavior checklist/4-18 and 1991 Profile.* University of Vermont, Burlington,VT

Characteristics of the Aberrant Behavior Checklist. *American Journal of Mental Deficiency* 89, 492-502.

American Psychiatric Association. (1994) *Diagnostic and Statistical Manual of Mental Disorders (4th ed.): DSM-IV.* American Psychiatric Association, Washington DC.

Anderson L.T. & Ernst M.(1994) Self- Injury in Lesch-Nyhan Disease. *Journal of Autism and Developmental Disorders* 24, 67-81.

Bodfish J.W. Crawford T.W. Powell S.B. Parker D.E.Golden R.N. & Lewis M.H. (1995) Compulsions in adults with mental retardation: prevalence, phenomenology and co morbidity with stereotypy and self-injury. *American Journal on Mental Retardation* 100,183-192.

Bonell-Pascual E. Huline-Dickens S. Hollins S. et al (1999) Bereavement and grief in adults with learning disabilities. A follow-up study. *British Journal of Psychiatry* 175, 348-350.

Borthwick-Duffy S.A. (1994) Prevalence of destructive behaviours. In: *Destructive Behaviour in Developmental Disabilities: Diagnosis and Treatment (Eds T. Thompson & D.B Gray),* pp.3-23.Sage Publishers, Thousand Oaks.

Bradford J. (1984) Life after Death. *Parents' Voice* 34, 6-7.

Bramston P. & Cummins R.A. (1998) Stress and the Move into Community Accommodation. *Journal of Intellectual and Developmental disability* 23, 295-308.

Brand A. & Johnson J. (1982) Note on reliability of the Life EventsChecklist. *Psychological Report* 50, 1274.

Brown G.W. & Harris T. (1989) *Life Events and Ill*ness. London: the Guilford Press.

Brown H. Stein J. & Turk V. (1995) The Sexual Abuse of Adults with Learning Disabilities: Report of a Second TwoYear Incidence Survey. *Mental Handicap Research* 8, 3-24.

Bruininks R.H.Olsen K.M. Larson S.A.& Lakin K.C. (1994) Challenging Behaviours among people with mental retardation in residential settings.In: *Destructive behaviour in Developmental Disabilities: Diagnosis and Treatment (Eds T. Thompson & A.B.Gray). pp.24-48.* Sage Publishers, Thousand Oaks.

Carr E.G. & Smith C.E. (1995) Biological Setting Events for Self-Injury. *Mental Retardation and Developmental Disorders Research Reviews* 1,94-98.

Cathcart F. (1995) Death and people with learning disabilities: interventions to support clients and carers. *British Journal of Clinical Psychology* 34, 165-175.

Chung N.S. Cumella S. Bickerton W.l. (1996) A preliminary study on the prevalence of challenging behaviours. *Psychological Reports* 79,1427-1430.

Cohen J.A. (1998) Summary of the practice parameters for the assessment and treatment of children and adolescents with post-traumatic stress disorder. *Journal of the American Academy of Child and Adolescent Psychiatry* 37, 997-1001.

Cohen S. Kessler R.C. & Underwood-Gordon L. (1997) *Measuring Stress. A Guide for Health and Social Scientists.* Oxford University Press, Oxford.

Cooper S.A. (1991) Aspects of affective disorders in adults with Down Syndrome. *Psychiatric Bulletin Supplement* 4,33-34.

Cullen C. (1999) *A review of some important issues in Research and Services for People with Learning Disabilities and Challenging Behaviour. Report to Social Work Services Inspectorate of the Scottish Office (Home Department).*

Davies M. Matthews K. & Twamley E. (1999) Is life more difficult on Mars or Venus? A meta-analytic review of sex differences on major and minor life events. *Annals of Behavioural Medicine* 21, 83-97.

Day K. (1985) Psychiatric disorder in the middle aged and elderly mentally handicapped. *British Journal of Psychiatry* 147, 660-667.

Derby K.M. Wacker D.P. Sasso G. Steege M. Northup J. Cigrand K. Asmus J. (1992) Brief functional assessment techniques to evaluate aberrant behaviour in an outpatient setting: a summary of 79 cases. *Journal of Applied Behavior Analysis* 25,713-721.

Di Terlizzi M. Cambridge P.& Maras P. (1999) Gender, Ethnicity and challenging behaviour: a literature review and exploratory study.Tizard Learning Disability Review 4,33-44.

Dohrenwend B. & Dohrenwend B. (1974) *Stressful life events: Their nature and effects.* Wiley, New York

Doyle C. & Mitchell D. (2003) Post-traumatic stress disorder and people with learning disabilities. A literature based discussion. *Journal of Learning Disabilities* 7, 23-33.

Duncan D. Matson J.L. Bamburg J.W. Cherry K.E. & Buckley T. (1999) The relationship of self-injurious behaviour and aggression to social skills in persons with severe and profound learning disability. *Research in Developmental Disabilities* 20, 441-448.

Elgie S. & Hastings R. (2002) Staff definitions of challenging behavior. *Education & Training in Mental Retardation & Developmental Disabilities* 37, 202 –208.

Emerson E. (2003) Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research* 47, 51-58.

Emerson E. (2001) *Challenging Behaviour.Analysis and Intervention in people with severe intellectual disabilities(2nd ed.).* Cambridge University Press, Cambridge.

Emerson E. (1995)*Challenging Behaviour:Analysis and Intervention in People with Learning Disabilities.* Cambridge University Press, Cambridge.

Emerson E. (1992) Self-injurious behaviour: an overview of recent developments in epidemiological and behavioural research. *Mental Handicap Research* 4,49-81.

Emerson E. Alborz.A. & Kiernan C. (2001) Predicting the persistence of severe self-injurious behaviour.*Research in Developmental Disabilities,*22,77-93.

Emerson E. Barrett S. Bell C. Cummings R. McCall C. & Toogood A. (1987) *Developing Services for People with Severe Learning Difficulties and Challenging Behaviour.*Institute of Social and Applied Psychology, University of Kent, Canterbury

Emerson E. & Bromley J. (1995) The form and function of challenging behaviour. *Journal of Intellectual Disability Research* 39, 388-398.

Emerson E. & Hatton C. (1996b) In practice: provocations from the 'new genetics'. *Tizard Learning Disability Review* 1,31-33.

Emerson E. & Hatton C. (1994) *Moving Out. Relocation from Hospital to Community.* HMSO, London.

Emerson E. Kiernan C. Alborz A. Reeves D. Mason H. Swarbrick R. Mason L. & Hatton C. (2001) The prevalence of challenging behaviours: a total population study. *Research in Developmental disabilities* 22, 77-93.

Favarelllli C. Paterniti S. Servieta P. (1997) Stressful life events and panic disorder. In*: Press Stress and Health Series, Monograph 4. (Ed T.W Miller).* International Universities Press Inc, Madison,CT,US:

Firth H. Balogh R. Berney T. Bretherton K. Graham S. & Whibley S.(2001) Psychopathology of sexual abuse in young people with intellectual disability 45, 244-252.

Fisher W. Adelinis J.D. Thompson R.H. Worsdell A.S. & Zarcone J.R. (1998a) Functional Analysis and treatment of destructive behaviours maintained by termination of 'don't' (and symmetrical 'do') requests. *Journal of Applied Behavior Analysis* 31, 339-356.

Fitzpatrick T. (1998) Bereavement events among elderly men. *The effects of stress and health* 17, 204-228.

Frea W.D. & Hughes C.H. (1997) Functional analysis and treatment of social communicative behaviours of adolescents with developmental disability. *Journal of Applied Behavior Analysis* 30, 701-704.

Ghaziuddin M.(1988) Behavioural disorders in the mentally handicapped. The role of life events. *British Journal of Psychiatry* 152,683-6.

Goh H.L. Iwata B.A. & Kahng S.W. (1999) Multicomponent assessment and treatment of cigarette pica. *Journal of Applied Behavior Analysis* 32, 297-316.

Hall S. & Oliver C. (1992) Differential effects of severe self-injurious behaviour on the behaviour of others. *Behavioural Psychotherapy* 20, 355-365.

Hall S. & Oliver C. (2000) An alternative approach tot eh sequential analysis of behavioural interactions. In: *Computer Assisted Behavioural Observations. Methods for Developmental Disabilities.* (Eds T.Thompson, D.Felce, & F.Symons). Paul H. Brookes, Baltimore.

Harden A. & Sahl R. (1997) Psychopathology in Children and Adolescents with Developmental Disorders. *Research in Developmental Disabilities* 18, 369-382.

Harland P. Reijneveld S. Brugman E. Verloove-Vanhorick S. & Verhulst F. (2002) Family factors and life events as risk factors for behavioural and emotional problems in children. European Child and Adolescent Psychiatry,11,176-184.

Harris C.P. (1992) The nature and extent of aggressive behaviour among people with learning difficulties in a single health district. *Journal of Intellectual Disability Research* 37,221-42.

Hastings R. Hatton C. Taylor J.L. & Maddison C.(in press). Life Events and Psychiatric symptoms in Adults with Learning Disabilities. *Journal of Intellectual Disability Research.*

Helzer J.E. Robbins L.N. & McEvoy L. (1987) Post-traumatic stress disorder in the general population. *New England Journal of Medicine* 317, 1630-1634.

Hewett D. (1998) *Challenging Behaviour.Principles and Practice.* David Fulton Publishers, London.

Hillery J. & Mulcahy M.(1997) Self-injurious behaviour in persons with mental handicap: an epidemiological study in an Irish population. *Irish Journal of Psychological Medicine* 14,12-15.

Holland A.J. (1998) Understanding the eating disorder affecting people with Prader-Willi syndrome. *Journal of applied Research in Intellectual Disabilities* 11,192-206.

Hollins S. & Esterhuyzen A. (1997) Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry 170, 497-501.*

Holmes T.H. & Rahe R.H. (1967) The Social Readjustment Rating Scale. *Journal of Psychosomatic Research* 11,213-18.

Iwata B.A. Pace G.M. Dorsey M.F. Zarcone J.R. Vollmer T.R. Smith R.G. Rodgers T.A.Lerman D.C. Shore B.A. Mazaleski J.L.Goh H.L. Cowdery G.E. Kalsher M.J. McCosh K.C. & Willis K.D. (1994) The functions of self-injurious behaviour: an experimental epidemiological study. *Journal of Applied Behavior Analysis* 27, 215-248.

Jacobson J.W. (1982) Problem behaviour and psychiatric impairment within a developmentally disables population. *Applied Research in Mental Retardation* 3,121-139.

Joyce T. (1997) Challenging Behaviour.In: *Mental Health in Learning Disabilities (2nd ed.)(Eds G.Holt & N.Bouras).* Pavilion Publishing, Brighton.

Joyce T. Ditchfield H. & Harris P. (2001) Challenging behaviour in community services. *Journal of Intellectual disability research. Special Issues: Mental Health and Intellectual Disability VIII* 45, 130-138.

Kiernan C. & Kiernan D. (1994) Challenging Behaviour in schools for pupils with severe learning difficulties.*Mental Handicap Research* 7,117-201.

Kiernan C. & Qureshi H. (1993) Challenging Behaviour.In: *Research to Practice?Implications of research on the challenging behaviour of people with a learning disability (Ed C. Kiernan).* British Institute of Learning Disabilities Publications, Avon.

Kiernan C. Reeves D.& Halton C. (1997) *The HARC Challenging Behaviour Project. Persistence and change in the challenging behaviour of people with learning* *disability.*Hester Adrian Research Centre,University of Manchester.

Kloeppel D.A. & Hollins S. (1989) Double Handicap: Mental retardation and death in the family. *Death Studies* 13, 31-38.

Kobasa S. (1979) Stressful life events, personality and health: An inquiry into hardiness. *Personality and Social Psychology* 37,1-11.

Kraaj V. Arensman E. & Spinhoven P. (2002) Negative life events in depression in elderly persons: A meta-analysis. *Journal of Gerontology: SeriesB. Psychological Sciences and Social Sciences* 57B, 87-94.

Kushlik A. Blunden R.& Cox G. (1973) The Wessex Social and Physical Incapacity (SPI) Scale and the Speech, Self-help and Literacy Scale (SSL). *Psychological Medicine* 3,336-378.

Lewis M.H. & Bodfish J.W. (1998) Repetitive behaviour disorders in autism. *Mental Retardation and Developmental Disabilities Research Reviews* 4,80-89.

Lindsey W.R. Law J. & Quinn K. (2001) A comparison of physical and sexual abuse: histories of sexual and non-sexual offenders with intellectual disability. *Child Abuse and Neglect* 25, 989-995.

Lovaas O.I.& Simmons J.Q.(1969) Manipulation of self-destructive behaviour in three retarded children. *Journal of Applied Behaviour analysis* 2,143-57.

Lowe K. & Felce D. (1995b) The definition of challenging behaviour in practice. *British Journal of Learning Disabilities* 23, 118-123.

Lyons C. (2000) Studying grief in adults with a learning disability. *British Journal of Psychiatry* 176, 297.

Mace F.C. & Mauk J.E. (1995) Biobehavioural diagnosis of treatment of self-injury. *Mental Retardation and Developmental Disabilities Research Reviews,*1,104-110.

MacHale R. & Carey S. (2002). An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities*, 30, 113-117.

Mansell S. & Moskal R. (1998) Clinical findings among sexually abused children with and without developmental disabilities. *Mental Retardation* 36,12-22.

Matson J.L. Kazdin A.E. & Senotore V. (1984) Psychometric Properties of the Psychopathology Instrument for Mentally Retarded Adults. *Applied Research in Mental Retardation* 5, 881-889.

McCarthy S. (2001) Post-traumatic stress disorder in people with learning disabilities. *Advances in Psychiatric treatment* 7,163-169.

McDaniel J.S. (1996) Stressful life events and psychoneuroimmunology. In: *Theory and Assessment of stressful life events. International University Press Stress and Health Series.pp.3-36* (Ed T.W Miller). International University Press, Madison,CT,US.

McGill P.& Toogood S. (1994) Organising community placements.In: *Severe Learning Disabilities and Challenging Behaviour.Designing High Quality Services* (Eds E.Emerson,P.McGill& J.Mansell). Chapman&Hall, London.

McLoughlin I.J. & Bhate M.S. (1987) A case of affective psychosis following bereavement in a mentally handicapped woman. *British Journal of Psychiatry* 151, 552-554.

Mesman J (2001) Early preschool predictors of preadolescent internalising and externalising DSM-!V diagnoses. *Journal of the American Academy of Child & Adolescent Psychiatry* 40, 1029-1036.

Monaghan M.T. & Soni S. (1992) Effects of significant life events on the behaviour of mentally handicapped people in the community. *The British Journal of*

Mental Subnormality XXXVIII, 114-21.

Moss J. (2001) Working with issues of sexual abuse. In: *Clinical Psychology and People with Intellectual Disabilities.* (Eds *E.Emerson, C. Hatton, J. Bromley & A. Caine).* Wiley, Chichester.

Moss S.C. Emerson E. Kiernan C. Turner,S. Hatton C. Alborz A. (2000) Psychiatric Symptoms in Adults with Learning Disability and *Challenging Behaviour. British Journal of Psychiatry* 177, 452-454.

Moss S.C. Prosser H. Costello H. Simpson N. & Patel P.(1996c) *PAS-ADD Checklist. Manchester:* Hester Adrian Research Centre, University of Manchester.

Murphy G.H. Hall S. Oliver C. & Kissi-Debra R.(1999) Identification of early self-injurious behaviour in young children with intellectual disability. *Journal of Intellectual Disability Research* 43,149-163.

Murphy G.H. Oliver C.Corbett J. (1993) Epidemiology of self-injury, characteristics of people with self-injury and initial treatment outcome.In: *Research to Practice?Implications of research on the challenging behaviour of people with a learning disability.* (Ed *C. Kiernan).* British Institute of Learning Disabilities Publications, Avon.

Murphy L. & Razza N. (1998) Domestic Violence against women with mental retardation. In: *Battered women and their families(2nd ed.). (Ed A.Roberts).* pp.271-290. Springer, New York.

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

Newman E. Christopher S.R. & Berry J.O. (2000) Developmental Disabilities, trauma Exposure and Post-traumatic Stress Disorder. *Trauma, Violence and Abuse* 1, 154-170.

Nottestad J.A.& Linaker O.M. (2002) Predictors for attacks on people after deinstitutionalisation. *Journal of Intellectual disability Research* 46, 493-502.

Nyhan W.L. (1994) The Lesch-Nyhan Disease. In: *Destructive Behavior in Developmental Disabilities: Diagnosis and Treatment. (Eds T.Thompson & D.B.Gray).* pp.181-97. Sage, Thousand Oak.

Oswin M. (1981) *Bereavement and mentally handicapped people.* King's Fund Report. Kings Fund Centre, London.

Oswin M. (1991) *Am I Allowed to Cry? A Study of Bereavement Amongst People who have Learning disabilities.* Human Horizons, London.

Oswin M. (1992) *Don't Ask Us to Dance. Some aspects of bereavement for people who have learning disabilities.*

Paykel E.S.& Rao B.M. (1984) Methodology in studies of life events and cancer. In: *Psychosocial Stress and Cancer.(Ed C.L Cooper.).* John Wiley & Sons, Chichester.

Paykel E.S. Prusoff B.A. Uklenhuth E.H. (1971) Scaling of Life Events. *Archives of General Psychiatry* 25, 340-347.

Paykel E.S. Meyers J.K. Dieneit M.N. Kiernan J.L. Lindenthal J.J. & Peffer M.P. (1969) Life Events and Depression. *Archives of General Psychiatry* 21, 753-760.

Qureshi H. (1994) The size of the problem. In: *Severe Learning Disabilities and Challenging Behaviours:Designing High Quality Services(Eds E.Emerson, P.McGill & J.Mansell).* Chapman & Hall, London.

Ringdahl J.E.Vollmer T.R. Marcus B.A. Roane H.S.(1997) An analogue evaluation of environmental enrichment: the role of stimulus preference*Journal of Applied Behaviour Analysis* 30,203-16.

Royal College of Psychiatrists.(2001) *DC-LD: Diagnostic Criteria for Psychiatric Disorders foe use with Adults with Learning Disabilities/Mental Retardation.* Gaskell, London.

Ryan R.(1994) Post-traumatic stress disorder in persons with developmental disabilities. *Community Mental Health Journal* 30, 45-53.

Sandberg S.Rutter M. Pickles A.McGuinness D. & Angelo A. (2001) Do high-threat life events really provoke the onset of psychiatric disorder in children? *Journal of Child Psychology and Psychiatry* 42, 5233-532.

Sequeira H. & Hollins S. (2003) Clinical Effects of Sexual Abuse on People with learning disability. Critical literature review. *British Journal of Psychiatry* 182,13-19.

Shaffer D. Fisher P. Dulcan M. Davies M. Piacentini J. Schwabstone M. Lahey B. Bourdon K. Jensen P. Bird H. Canino G. Regier D. (1996) The NIMH Diagnostic Interview Schedule for Children Version 2.3: Description, acceptability, prevalence rates and performance in the MECA study. *Journal of the American Academy of Child & Adolescent Psychiatry* 35, 865-877.

Shroeder S.R. & Tessel R. (1994) Dopaminergic and serotinergic mechanisms in self-injury and aggression. In: *Destructive Behavior in Developmental disabilities: Diagnosis and Treatment*. (Eds *T.Thompson & D.B. Gray).* Sage, Thousand Oaks.

Sigafoos J.Tucker M (2001) Brief assessment and treatment of multiple challenging behaviours. *Behavioural Interventions* 16, 111-125.

Sobsey D. (1994) *Violence and Abuse in the Lives of People with disabilities. The End of Silent Acceptance?* P.H Brookes, Baltimore, MD.

Sobsey D. Randall W. & Parrila R.K. (1997) Gender differences in abused children with and without disabilities. *Child Abuse and Neglect* 21,707-720.

Stack L.S.Haldipur C.V. & Thompson H. (1987) Stressful life events and psychiatric hospitalisation of mentally retarded patients. *American Journal of Psychiatry* 144, 611-13.

Tesser A. & Beach S.R. (1998) Life Events, Relationship Quality, and Depression. An Investigation of Judgement Discontinuity in Vivo. *Journal of Personality and Social Psychology,* 74, 36-52.

Tiet Q. Bird H. Hoven C. Moore R. Wu P. Wicks J. Jensen P. Goodman S. & Cohen P. (2001) Relationship Between Specific Adverse Life Events and Psychiatric Disorders. *Journal of Abnormal Child Psychology*,28,153-164.

Thompson T. Symons F. DelaneyD. & England C. (1995). Self-injurious behaviour as endogenous neurochemical self-administration. *Mental Retardation and Developmental Disabilities Research Reviews,* 1, 137-148.

Toogood S. & Timlin K. (1996) The functional assessment of challenging behaviour. *Journal of Intellectual Disability Research 9,206-222.*

Turk V. & Brown H. (1993) The Sexual Abuse of Adults with Learning Disabilities. Results of a Two Year Incidence Survey. *Mental Handicap Research* 6,193-216.

Wertheimer A. (1997) *Great Expectations: Experiences of Community* Living. National Development Team, Manchester.

Yoshihama M. (1998) Domestic violence in Japan: Research, program developments and emerging movements. In: *Battered women and their families(2nd ed.) (Ed A. Roberts). pp. 405-447.* Springer, New York.

Yule W. Bolton D. Udwin O. et al (2000) The long-term psychological effects of a disaster experienced in adolescence. 1: The incidence and course of PTSD. *Journal of Child Psychology and Psychiatry* 41, 503-511.

Zarcone J.L. Iwata B.A. Vollmer T.R. Jagtiani S. Smith R.G. & Mazaleski J.L.(1993) Extinction of self-injurious escape behaviors with and without instructional fading. *Journal of Applied Behavior Analysis* 261,353-60.

Appendix 2.1

Author Guidelines

SECTION 3

SCIENTIFIC PAPER

Life Events as Correlates of Challenging Behaviour: A Preliminary Study.

Dawn M. Owen

Richard P. Hastings

Stephen J. Noone

Jo Chinn

Julia Roberts

Katie Harman

Kelly Taylor-Dodd

School of Psychology, University of Wales, Bangor

Correspondence: Dawn Owen, School of Psychology, University of Wales, Bangor, Gwynedd, LL57 2DG, Wales, UK. E-mail: dawn.owen@bangor.ac.uk.

Short title: LIFE EVENTS AND CHALLENGING BEHAVIOUR

Paper written in accordance with author guidelines for the Journal of Intellectual Disability Research (see Appendix 3.1 for author guidelines).

Abstract

Background

An extensive literature exists around factors associated with the development and maintenance of challenging behaviour (CB) in people with intellectual disabilities (ID). However few studies have explored specifically how life events may be associated with CB.

Method

Key informants provided information on basic demographics, mental health, adaptive behaviour, quality of life the frequency and severity of CB, and life events experienced in the previous year, for 93 adults with ID residing in a long-stay residential setting in North Wales.

Results

Overall, 90% had experienced one or more significant life events in the previous 12 months. In terms of life event domains the most prevalent experiences were: bereavement (39%), change in living circumstances (78%), relationships (38%), staff issues (90%) and health issues (62%). Correlational analyses suggested that relationship difficulties and staff issues, experienced in the previous 12 months, added significantly to the prediction of CB once known correlates of CB were controlled.

Conclusions

In this study, life events such as relationship difficulties and staff change were found to be associated with CB. The potential for such events to affect CB should be considered in clinical work, and further research is required to explore the causal direction of this relationship.

Keywords: Life Events, Challenging Behaviour, Adults, Intellectual Disability.

Background

There is a large research literature exploring the many different factors, contributing to the development and persistence of challenging behaviour (CB) in people with intellectual disabilities (ID). The most commonly accepted definition of CB is: ' *culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.*'p3. (Emerson,1995). As such CB is a global term for a wide class of topographically and functionally distinct behaviours that are generally catergorised as self-injurious behaviour (e.g head banging, scratching, pica, eye poking); aggression/ destructiveness (e.g, hitting, kicking, verbal abuse; throwing items); and stereotyped mannerisms (e.g screaming, spinning, smearing, regurgitation). These behaviours can be a substantial clinical management issue as recent prevalence research suggests that between 10-15% of people with ID engage in CB (Emerson et al,2001).

The risk factors for CB include various individual and environmental characteristics. In terms of individual risk factors, increased risk for CB has been shown to be associated with: genetic syndromes (Harris,1992; Holland,1998; Lewis & Bodfish,1998); neurobiological processes (Bodfish et al,1995; Shroeder & Tessel, 1994; Thompson et al,1995); degree of ID (Borthwick-Duffy,1994; Hillery & Mulcahy,1997; Qureshi,1994); gender (Di Terlizzi et al,1999; Kiernan & Kiernan, 1994; Qureshi,1994); age (Kiernan & Qureshi,1993); mental health problems (Borthwick-Duffy,1994; Joyce,1997; Reid,1982); communication difficulties (Hewett,1998); social interactional difficulties (Duncan et al,1999). Environmental factors that have been shown to be associated with CB include the quality of the physical environment (Hewett,1998); restrictivness of residential environment (Borthwick-Duffy,1994; Emerson,1992); quality of social environment (McGill & Toogood,1994); reinforcement contingencies (Joyce,1997).

Despite such a broad range of factors identified in previous research one line of enquiry attracting less attention is that of how life events in the lives of people with ID might impact on CB. There is a general consensus that people with ID are likely to encounter significant adverse events in their lives (Sobsey et al,1997; Valentine, 1990; Zirpoli et al,1987) and that such experiences can impact on mental health and adaptive behaviours (Hastings et al, in press; Howlin & Clements,1995; Murphy & Razza,1998; Yoshihama,1998). The focus of the present paper is to explore any evidence for an association between exposure to life events and the expression of CB.

Outside of the ID field there is an extensive literature concerned with the impact of life events and traumatic experiences. The general theme of this research area is that change can be stressful and might require adaption (Cohen et al,1997). Furthermore, individuals recently experiencing life changes are more susceptible to illness, psychological and behavioural difficulties than those with relatively stable lives (Brown & Harris,1989). To support this is a wealth of meta-analytic (e.g Davis et al,1999; Kraaj et al,2002), narrative review (e.g Tennant,2002) and empirical studies (Chahraoui et al,1999; Faravelli et al,1997; McDaniel,1996; Nott & Vedhara, 1999; Petticrew et al,1999) exploring associations between life events and areas such as Depression, Post Traumatic Stress Disorder (PTSD), Panic Disorder, cancer and psycho-neuroimmunology.

There has been some interest in life events in ID research with the majority of studies focusing on specific experiences such as the impact of bereavement (Day, 1985; Hollins & Estehuysen,1997; MacHale & Carey,2002; McLoughlin & Bate, 1989), abuse (Mansell & Moskal,1998; Sequeira & Hollins,2003), resettlement into community living (Bramston & Cummins,1998; Joyce et al,2001; Nottestad & Linaker,2002), and response to major traumas (Ryan,1994; Doyle & Mitchell,2003). For example, MacHale & Carey (2002) looked at how bereavement impacted on mental health difficulties and CB. They matched a group of adults with ID who had suffered the death of a primary carer in the two years prior to the study with a non-bereaved group of adults with ID. Using the The Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD;Moss et al 1996c) and the Aberrant Behavior Checklist (ABC; Aman et al 1985a,1985b) as key measures they found that there were significant differences between groups on the affective neurotic and organic scales of the PAS-ADD and on the irritability, lethargy and hyperactivity scales of the ABC.

The literature does also contain some investigation of broader life events (Hastings et al,in press; Monaghan & Soni1992; Stack et al,978) that generally explore the impact of life events on mental health and adaptive behaviour. For example, Hastings et al (in press), recently employed a correlational design with a population based sample to explore the range of life events experienced by individual's with ID, and the potential associations between life events and psychiatric symptoms in adults with ID. Key informants provided information on 1155 participants residing in the North East of England using the PAS-ADD (Moss et al,1996c) that collects information on psychiatric symptomology and recent life experiences. Results suggested that 46.3% had experienced one or more life events in the previous 12 months with 17.4% experiencing two or more life events in the prior year. The most common life events experienced were moving residence

(15.5%); serious illness of close relative or friend (9%); serious problems with close friend, neighbour or relative (8.8%); serious illness or injury to self (8.5%); and death of a close family friend or relative (8.3%). Further analyses also indicated associations between the experience of one or more life events and psychiatric caseness, specifically affective neurotic disorder.

The general theme of findings from existing research is that people with ID are at as great a risk of experiencing a plethora of adverse significant daily and life events but are also generally more susceptible to the psychological difficulties that can result from such experiences. As with the general mental health literature the methodology employed in studies has restricted the generalisability of findings. Nadarajah et al (1995) discussed some of the methodological issues inherent in this area of ID including definitional dilemmas, measurement issues (e.g small sample sizes, paucity of control groups, heterogeneity in the sample groups, validity of measures and choice of instruments) through to generalisability of findings and establishing causal pathways. Doyle and Mitchell (2003) further suggest that because of the difficulties the majority of individuals with ID have in communicating their feelings and emotions, significant events in the life of a person with an ID can go unnoticed and unreported and the psychological sequelae of these experiences overlooked.

The purpose of the current study was to address some of these methodological problems and to focus specifically on associations between life events and CB. As there is a dearth of information on normative exposure to life events in the lives of people with ID one aim of the study was to extend this knowledge base specifically in relation to individuals with ID living in long-term residential settings where day to day issues such as residence events, staff turnover and the behaviour of other clients might hugely impact on an individual's life. Furthermore, as the lack of control in studies may explain associations found between CB and life events (e.g Ghaziuddin, 1988; Cooper,1991) population based research could address this by reducing the variance in the sample data to elicit meaningful findings relevant to the population of study.

This research was conceived as an exploratory study. Although it is expected that there will be an association between life events and CB we cannot be sure what those associations might be. Therefore, no specific predictions are made.

Method

Participants

Key informants provided data on 93 adults with ID living in a long stay residential hospital in North Wales that provides health and day service provision to all residents. Participants were 61 males and 32 females, with a mean age at the time of the study of 55.2 years (SD = 12.7, range = 24 – 93 years). Table 1 presents further demographic details of the study population who can be described as being over-represented by people with severe to profound ID (60%), compared to those with mild to moderate ID (34%) and by people with multiple disabilities (visual disability 18%; hearing problems 14%; mobility problems 41%; physical health problems 72%; epilepsy 35%). Key informants were members of nursing staff who knew the participant well.

---- Insert Table 1 about here ----

Design

As a preliminary investigation to establish whether life events are associated with CB, data from a total population survey were analysed using a correlational design. A subsidiary inter-rater reliability study of the short form version of the

Adaptive Behaviour Scale- Community and Residential (Hatton et al,2001; SABS) was also included, where two different staff members reported on 30 participants.

Materials

The measures were chosen because of their ability to capture a wide range of information on known correlates of challenging behaviour. Additionally the majority of these measures were identified as widely used in ID research and as such had reasonable amounts of psychometric data available on them.

Demographic Questionnaire. A short questionnaire was devised specifically for the demographic and personal data requirements of this study. The questionnaire collected information on age, gender, length of residence at the hospital, additional disabilities, physical health problems, epilepsy, other diagnoses and family contact.

The Behaviour Problems Inventory (BPI). The BPI (Rojahn et al,2001) is a 52 item respondent based rating instrument for measuring self-injury (14 topographics e.g self-biting, head-hitting), stereotypy (24 topographies e.g rocking, screaming) and aggressive/ destructive behaviour (11 topographies e.g hitting, destroys). The BPI was chosen for this study because it clearly operationalises CB into distinguishable topographies. Items are rated on a five-point frequency scale (never = 0, monthly = 1, weekly = 2, daily = 3, hourly = 4) and a four-point severity scale (0 = no problem, 1 = slight problem, 2 = moderate problem, 3 = severe problem). Rojahn (2001) present strong psychometric properties for the BPI including internal consistency (.61-.82), retest reliability (.64 - .76) and inter-rater reliability (.58 -.75) for the three domains. The scale is administered to care-staff working with individuals with behavioural problems.

The Adaptive Behaviour Scale- Short Form (SABS). The SABS (Hatton et al,2001) is a 24 item short form of the 73 item Adaptive Behaviour Scale-Residential and

Community - Part 1. (Nihira & Nihira,1993a,b). The questionnaire is usually completed by a carer. Part 1 of the full version is grouped into 10 domains: Independent Functioning (24 items);Physical Development (6 items); Economic activity (6 items); Language Development (10 items); Numbers and Time (3 items); Domestic Activity (6 items); Prevocational/Vocational Activity (3 items);Self-Direction (5 items); Responsibility (3 items) and Socialisation (7 items).The 73 items in Part 1 have also been factor analysed into 3 factors: Factor A: Personal Self-sufficiency(18 items); Factor B: Community Self-Sufficiency (38 items); and Factor C: Personal-Social Responsibility (17 items). Responses to items take two forms, either a rating of the highest level of adaptive behaviour exhibited on an item or a checklist of yes/no responses that are summed to form the item and factor scores. Factor items are then converted to scaled scores based on age ratios, which can then be compared to normative data.

The rationale for developing the Short Form was to attain a less time consuming measure of adaptive behaviour for use in research and was the key determinant in its selection for this study. Selection of items for the Short Form was based on data from two diverse U.K samples of adults with ID in residential services (n=560 and 254). Hatton et al (2001) first calculated item-total correlations for each long form item. Those with an item-total correlation of >0.7 were selected. Final items were then chosen on their representativeness of the range of ABS-RC2 domains so that domains were equally represented to the original questionnaire (Factor A= 6 items from 18; Factor B = 11 items from 38; Factor C = 7 items from 17). SABS scores are derived by adding all items in that factor. Conversion to full-scale equivalents is achieved through regression equations described by Hatton et al (2001). SABS factor and total scores showed good internal reliability in both samples

(0.84 –0.98) and were highly correlated with their full ABS-RC2 Part 1 equivalents (r = 0.97 -.99). Given the lack of psychometric data for the SABS a small inter-rater reliability study was included in the present research. Inter-rater reliability for the SABS, was very strong for Factor A (r = .92, p<.000), reasonable for Factor B (r=.57, p<.001) but poor for Factor C (r = .14, p<.48). Given the poorer performance of the SABS Factor C scale, these data were excluded from the analysis.

The Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD). The PAS-ADD (Moss et al,1996c) is a semi-structured questionnaire based on the ICD-10 clinical interview (World Health Organisation 1994). The checklist aims to help staff and carers to decide whether a full assessment of an individual's mental health may be helpful. The questionnaire can be used with an individual with ID or a key informant. The PAS-ADD is made up of 29 symptom items that are rated on a four-item likert scale. Symptoms are aggregated to elicit three domain scores: Affective Neurotic Disorder (maximum score = 28, threshold = 6, e.g loss of energy, repeated actions); Possible Organic Condition (maximum score = 8, threshold = 5, e.g more forgetful or confused, decrease in self-care skills); and Psychotic Disorder (maximum possible score = 6, threshold = 2, e.g strange beliefs, strange experiences). Reliability and validity data were provided by Moss et al (1998). Internal consistency for the three domains was respectively (.84, .63, and .51). Inter-rater reliability was measured at .55 and greater. Validity was measured in terms of case identification between untrained raters and full psychiatric assessment. Here there was an 83% concordance with diagnosis.

The Life Experiences Checklist (LEC). The LEC (Ager,1998a,b) is a brief checklist comprised of 50 structured items evenly distributed between the life domains of quality of home environment (e.g my home is carpeted), leisure opportunities (e.g there is lots for me to do at home), relationships (e.g I have several close friends), freedom/rights (e.g I can spend time by myself when I want to), and general opportunities (e.g I am being taught some new skill). It can be completed by the individual concerned or a key informant. Item selection was based on the premise that everybody has equal accessibility to each experience and as such the scale is designed to be equally relevant to any group. Scoring is on the basis of a dichotomy (whether or not the person rated has access to the experience described). Items are totalled to produce subtotals and a total score. Test-retest data on the LEC total score (Ager,1998a,b) was .93 with domain scores ranging between .91 (opportunities) and .96 (relationships). Inter-rater reliability of the total score was .96 with domain specific reliability in the range of .93 - .97 (Ager,2001). Ager (2001) also measured validity of LEC against the Index of Community Involvement (Raynes & Sumpton, 1986), with correlations ranging between .72 (post move) to .78 (pre move).

Life Events List. The Life Events List (LEL; Appendix 3.2) is a checklist of life events constructed for the purpose of this piece of research to try to provide a representative list of possible life events that a person with ID living in a long-term residential setting may encounter. To do this items were taken from the Psychiatric Epidemiology Research Interview (PERI; Dohrenwend et al,1978); Paykel's 61 item life events scale (Paykel, 1974); life events outlined in the PAS-ADD check-list (Moss et al,1996); and by canvassing the opinions of clinicians working in the ID sector. The checklist is comprised of 72 items divided into nine domains: bereavement (8 items e.g death of first degree relative), change in living circumstances (12 items e.g change of residence), relationships (13 items e.g trouble with other resident), health (10 items e.g minor physical illness), work (7 items e.g change in work conditions), criminal legal issues (7 items e.g trouble with the police), financial issues (3 items e.g lost sum of money), staff issues (3 items e.g change of staff) and miscellaneous/ other (6 items e.g holiday cancelled). A full list of items experienced is shown in Table 4. The scale is scored by summing the number of events experienced in each of the domains described. A total score and sub domain scores are derived. In the present study, the scale was completed by staff, detailing events that have occurred in an identified individuals life, in the previous 12 months. A 12 month period was chosen to try and reduce difficulties associated with memory accuracy.

Procedure

Ethical consent was sought from the University and local NHS ethics boards. Prior to this permission was sought from the local ID management team to carry out research in a long-stay residential hospital for people with ID. Following approval from these three sources the main researcher then disseminated the details of the research to relevant personnel in the hospital. There followed a period of recruitment to the study.

One hundred service users were initially identified as potential participants. Charge nurses then identified all those service-users who might be in a position to give consent. In total, 14 service users were approached by the main researcher, to give individual consent. At a time convenient to the service user, the study was explained and their rights to consent or decline carefully outlined. Initially information was read from a prepared script in order to ensure all key points of informed consent were covered. However the researcher also repeated and rephrased and translated information into Welsh to facilitate understanding. This process was witnessed by a member of staff. Of the 14 service users approached, one declined to take part. Of the remaining 99 service users three resettled into community placements, and three died before data could be collected.

Charge nurses then identified those members of staff who were judged to be in the best position to answer questions on behalf of a service user. Identified staff members were approached and their potential role in the study was explained. A minimum of one week was provided for potential key respondents to make their informed decision. If consent was declined then charge nurses identified an alternative staff member and the process of recruitment was repeated until a suitable key respondent was identified. Once consent was established, a data collection meeting was arranged at a time that suited the staffing demands of the hospital residential unit and the key respondent.

In the meeting, a battery of measures were completed on an identified service user by the key respondent. Interviews were carried out in a private room so that interruptions were kept to a minimum. The researcher remained with the key respondent throughout the process so that support was on hand to complete all the measures as quickly as possible.

Following the main data collection period a fifth data gatherer was recruited to an inter-rater study where a second key respondent completed a SABS for an identified service user (N=30). Service users were randomly picked from each hospital residence and the key respondent was the nurse in charge of the hospital residence (who had not participated in stage one). The time between each completion of the SABS ranged from 1 week to 6 weeks.

Results

Descriptive Data

Preliminary analyses were carried out to check the normality of the data collected across all measures using the Kolmogorov-Smirnov goodness-of-fit test. The majority of computations were significant indicating that data was not normally distributed. Consequently further analyses were carried out using non-parametric statistics.

Mean scores for the BPI, PAS-ADD, Life Experiences Checklist and SABS are displayed in Table 2.

----Insert Table 2 about here ----

BPI data indicated that the percentage of participants engaging in one or more acts of CB within the 3 behavioural domains was 74% (self-injury), 80% (stereotypy) and 77% (aggression/destruction). Mean scores across those domains were elevated compared to Rojahn et al's (2001) normative sample suggesting that the present sample seemed to have more CB. Mean PAS-ADD scores in this study indicated that 15% of participants crossed the clinical cut-off for affective/neurotic disorders, 2% for possible organic conditions and 8% for possible psychotic disorder. Compared to normative data (Moss et al,2001) these data suggested lower mean levels of mental health difficulties. The overall LEC mean was 24.3 (SD = 5.69) compared to 30.8 (SD = 6.1) in Ager's (2001) hospital sample. Compared to population norms (Ager,1998,2001) for the subsections home (8.6,8), leisure (4.6, 4.2), relationships (6.6, 4.5), freedom (8, 6.4), and opportunities (7.5, 7), LEC subsection scores in this study were lower. The range of SABS scores further suggested that the population surveyed represented the full range of ID. However, despite a wide range of adaptive behaviour scores the pattern of scores indicate that in the present study participants generally exhibited lower average levels of adaptive behaviour than in other samples (e.g Nihira & Nihira,1993; Hatton et al,2001) with mean Factor A and Factor B quotients in the 45th and 6th percentile, respectively.

Analysis of the life events data established the range and amount of life experiences typically experienced by the study population over the previous 12 months. Table 3 presents data on the range of experiences encountered. In terms of the amount of life events encountered all participants had experienced at least one event with the mean amount of experiences estimated at 6.88 (sd = 3.35, range 1-18).

---- Insert Table 3 about here ----

Correlates of Challenging Behaviour

Spearman's Rho and Mann-Whitney tests were computed to ascertain whether CB as measured by the six dimensions of the BPI was associated with the demographic variables of age, gender, length of residence, other specified disabilities (visual, mobility, hearing), physical health problems, epilepsy, quality of life, mental health issues and adaptive behaviour. Table 4 summarises the results of these tests.

---- Insert Table 4 about here ----

These data suggest that for the present sample CB was generally associated with longer time spent in hospital and increased levels of other disabilities (visual, hearing and mobility), physical and mental health difficulties. Lower levels of adaptive behaviour and quality of life were also associated with CB.

Contribution of Life Events to the Prediction of Challenging Behaviour.

Spearman correlation coefficients were computed to establish if any of the life events scores were correlated with CB as measured by the six dimensions of the BPI. Out of the possible 42 correlations, only four reached significance at $p<0.05$. Table 5 displays the matrix of bivariate correlations between the life events subscales and the dimensions of the BPI.

---- Insert Table 5 about here ----

Of these the life events subscale *relationships* was associated with BPI subscales *Self-Injury-degree of pro*blem and *Aggression/Destruction-frequency* and *degree of problem.* The life events subscale *staff issues* was associated with BPI subscale *Aggression/Destruction-frequency.* Specifically increased exposure to life events in these domains was associated with increased levels of CB.

Given the large number of correlational analyses, there was a high chance of Type I errors. Thus further exploratory analysis was conducted. Hierarchical multiple regression analyses were used to explore whether life events found to be associated with CB added to the prediction of CB once other factors with potential to affect ratings of CB were taken into account. In total four regression analyses were conducted. In the first step of each analysis correlates of CB from Table 4 were entered. In the second step, the life events scores identified in Table 5 were entered. The results of these analyses are summarised in Tables 6-8.

----- Insert Tables 6 through 8 about here ------

Table 6 suggests that the life events variables *relationships* and *staff issues* made a significant additional contribution to the prediction of the frequency of aggressive/destructive behavioural topographies after other factors were taken into account. Table 7 shows that the variable *relationships* made a marginal contribution, approaching significance, to the prediction of the severity of aggressive /destructive behaviours but had no predictive value for the frequency of self-injury (Table 8).

Discussion

The results of this preliminary study suggest that exposure to a range of life events in the previous 12 months was associated with CB in adults with ID. Bivariate analyses identified the life event domains of relationship issues and staff issues as significantly associated with CB. Regression analyses confirmed that these experiences added significantly to the predictive value of CB once other correlates were taken into account. Given that 90% of participants had experienced one or more significant events in their lives over the previous 12 months these findings are worthy of further explorations. However, due to various limitations of design and measurement in the present study, the above conclusions require some further explanation.

The first obvious design issue in the present study is the extent to which a correlational design can afford generalisable conclusions. In this study the apparent presence of an association between life events and CB does not offer clues to the direction of causality. In the absence of causality information one has to consider alternative interpretations. It is possible, for example that CB places individuals at risk of exposure to certain life events. In the broader ID literature for example, CB is a predictor of out-of-home placement (Blacher & Baker,1994;Hanneman & Blacher, 1998).

A further issue is the consideration of potential confounding factors impacting on the associations found. For example, with the life domain areas of *relationships* and *staff* it is necessary to acknowledge that for service users residing in the long-stay setting a large proportion of their social interactions and hence daily relationships are with staff members. However, this cross-over of staff/relationship issues is not necessarily an artefact of residential living as it is potentially a confounding factor in the community setting where individuals with ID will spend a significant proportion of their time with carers. A further confounding influence of the life event domains of staff issues and relationships is that these are also two variables that are potentially most reactive to exposure to challenging behaviour (Hastings & Remington, 1994; Bromley & Emerson, 1995). To unravel these bidirectional influences further research needs to consider the merit of collecting data that is temporally related and that also attends to staff issues.

A further measurement consideration is also extended to the potential bias encountered from key informant report. On the whole key staff knew the service users well and had typically known the service user for many years. However, despite an inclusion criterion, for key informants, specifying that they should have known the client well for 12 months or more, there were four occasions where due to staff sickness a key respondent (typically a newly appointed key worker) was nominated who did not meet the inclusion criteria. While their responses were corroborated by the nursing file and other staff members, the quality of the data still has to be questioned. This is particularly pertinent in an area where inaccurate memory and a failure to attach significance to events in the life of a person with ID have already been identified as shortcomings of measurement (Doyle & Mitchell, 2003)

A further bias one must acknowledge in this study is the collection of data on CB and life events from the same informant. This approach is acknowledged to potentially increase the likelihood of finding associations in research (Hastings et al., in press). In this study one mechanism that might contribute to this bias is key informant causal attributions of CB in general and specifically for the identified service user. There is an extensive literature that attends to staff attitudes to CB (e.g.

Bromley & Emerson,1995; Hastings,1997; Hastings et al 1997; Hastings & Remington 1994b). It is possible that individual or wider system beliefs held by staff might influence the quality of the data collected. As staff were aware of the focus of the study it may be that preconceptions, of what causes CB, may have elicited information that more closely reflected the informants attributional bias.

An additional consideration when interpreting these findings is that the Life Events List (LEL), developed for the purposes of this study, lacked data pertaining to its reliability and validity. Although beyond the scope of this study, further work needs to be carried out to establish the psychometric value of this checklist. A potential methodology for this pursuit can be found in Bramston & Bostock's (1994) study.

A further issue with the LEL is that it represented a wide array of life events including one off or chronic interpersonal difficulties, tiresome daily routines and daily irritants and major events. Although the questionnaire served a purpose for this exploratory study responses to more specific questions about life events that figure most apparently in CB are required.

The present data suggest that people with ID living in a long stay setting experience a range of significant events in their lives that potentially impact on levels of CB. Whether the way forward is to establish causal pathways, examine the consequences of major life events, chronic adversity, daily irritants encountered, or the mediating influences between life events and well-being, a prospective daily design as promoted by West and Hepworth (1991) may offer numerous advantages in the field of ID research.

The measurement of these processes in 'real time' may help reduce the bias encountered from the retrospective bias of poor memory, temporal distortions in measuring cause and effect, which is compounded as a result of reliance on key informant report. The analysis of within persons sequencing of variables over an extended time period using meta-analytic statistical procedures might allow stronger conclusions to be drawn. In this respect a prospective daily design might improve the conditions for causal inference by creating associations and temporal precedence and ruling out other confounds, unlike traditional field designs historically used in this field of research (West & Hepworth,1991).

At present the clinical implications of this piece of work might be to raise awareness to staff teams, carers and clinicians about the potential impact of major and minor life events on the well-being of individuals with ID. This might be especially important in the ongoing resettlement process of individuals with ID into community placements, where exposure to a plethora of new demands and experiences is likely.

In summary this preliminary study has contributed to understanding the range of issues impacting on the lives of individuals with ID in long stay residential settings and indicated associations between certain life event domains and CB. Such research has huge theoretical and clinical implications that if pursued may afford an increased awareness of our understanding of CB.

References

Aman M.G. Singh N.A. Stewart A.W. & Field C.J. (1985a) The Aberrant Behavior Checklist. A behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency* 89, 485-491.

Aman M.G.Singh N.A. Stewart A.W. & Field C.J. (1985b) Psychometric Characteristics of the Aberrant Behavior Checklist. *American Journal of Mental Deficiency* 89, 492-502.

Ager A. (1998) *The Life Experiences Checklist (2nd edn.).* NFER-Nelson, Windsor.

Ager A. Myers F. Kerr P. Myles S. & Green A. (2001) Moving home: community integration achieved with varying forms of reprovision for adults with learning disabilities. *Journal of Applied Research in Intellectual Disabilities* 14, 392-400.

Blacher J. & Baker B. (1994) Out-of-home placement for children with retardation: Family decision making and satisfaction. *Family Relations: Interdisciplinary Journal of Applied Family Studies* 43,10-15.

Bodfish J.W. Crawford T.W. Powell S.B. Parker D.E.Golden R.N. & Lewis M.H. (1995) Compulsions in adults with mental retardation: prevalence, phenomenology and co morbidity with stereotypy and self-injury. *American Journal on Mental Retardation* 100,183-192.

Borthwick-Duffy S.A. (1994) Prevalence of destructive behaviours. In: *Destructive Behaviour in Developmental Disabilities: Diagnosis and Treatment(Eds T. Thompson & D.B Gray).* pp.3-23. Sage Publishers, Thousand Oaks.

Bramston P. & Bostock J. (1994) Measuring perceived stress in people with intellectual disabilities: the development of a new scale. *Australia & New Zealand Journal of Developmental Disabilities* 19, 149-157.

Bramston P. & Cummins R.A. (1998) Stress and the Move into Community Accommodation. *Journal of Intellectual and Developmental disability* 23, 295-308.

Bromley J. & Emerson E. (1995) Beliefs and emotional reactions of carestaff working with people with challenging behaviour. *Journal of Intellectual Disability Research* 39, 341-352.

Brown G.W. & Harris T. (1989) *Life Events and Illness*. TheGuilford Press, London.

Chahraoui K. Benomy H. Bingener C. & Jebrane A. (1999) Cumulative aspects of life events and depression. *European Review of Applied Psychology* 49, 183-189.

Cohen S. Kessler R.C. & Underwood-Gordon L. (1997) *Measuring Stress. A Guide for Health and Social Scientists.* Oxford University Press, Oxford.

Cooper S.A. (1991) Aspects of affective disorders in adults with Down Syndrome. *Psychiatric Bulletin Supplement* 4,33-34.

Davies M. Matthews K. & Twamley E. (1999) Is life more difficult on Mars or Venus? A meta-analytic review of sex differences on major and minor life events. *Annals of Behavioural Medicine* 21, 83-97.

Day K. (1985) Psychiatric disorder in the middle aged and elderly mentally handicapped. *British Journal of Psychiatry* 147, 660-667.

Di Terlizzi M. Cambridge P.& Maras P. (1999) Gender, Ethnicity and challenging behaviour: a literature review and exploratory study.*Tizard Learning Disability Review* 4,33-44.

Dohrenwend B.S. Krasnoff L. Askenasy A.R. & Dohrenwend B.P. (1978) Exemplification of a method for sealing life events. The PERI Life Events Scale. *Journal of Health and Social Behaviour 19, 205-220.*

Doyle C. & Mitchell D. (2003) Post-traumatic stress disorder and people with learning disabilities. A literature based discussion. *Journal of Learning Disabilities* 7, 23-33.

Duncan D. Matson J.L. Bamburg J.W. Cherry K.E. & Buckley T. (1999) The relationship of self-injurious behaviour and aggression to social skills in persons with severe and profound learning disability. *Research in Developmental disabilities* 20, 441-448.

Emerson E. (2001) *Challenging Behaviour.Analysis and Intervention in people with severe intellectual disabilities(2nd ed.).* Cambridge University Press, Cambridge.

Emerson E. (1995)*Challenging Behaviour:Analysis and Intervention in People with Learning Disabilities.* Cambridge University Press, Cambridge.

Emerson E. (1992) Self-injurious behaviour: an overview of recent developments in epidemiological and behavioural research. *Mental Handicap Research* 4,49-81.

Favarelllli C. Paterniti S. Servieta P.(1997) Stressful life events and panic disorder. In: *International Universities Press Stress and Health Series, Monograph 4. (Eds T.W Miller).* International Universities Press Inc., Madison,CT,US.

Ghaziuddin P. (1988) Behavioural disorders in the mentally handicapped. The role of life events. *British Journal of Psychiatry* 152,683-6.

Hanneman R. & Blacher J. (1998) Predicting placement in families who have children with severe handicaps: A longitudinal analysis. *American Journal on Mental Retardation* 102, 392-408.

Harris C.P. (1992) The nature and extent of aggressive behaviour among people with learning difficulties in a single health district *Journal of Intellectual Disability Research* 37,221-42.

Hastings R.P. (1997) Staff disbeliefs about the challenging behaviour of children and adults with mental retardation. *Clinical Psychology Review* 17 775-790.

Hastings R. Hatton C. Taylor J.L. & Maddison C.(in press). Life Events and Psychiatric symptoms in Adults with Learning Disabilities. *Journal of Intellectual Disability Research.*

Hastings R.P. Reed T.R. & Watts M.J. (1997) Community staff causal attributions about challenging behaviour in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 10, 238-249.

Hastings R. & Remington B. (1994b) Staff behaviour and the implications for people with learning disabilities and challenging behaviour. *British Journal of Clinical Psychology* 33, 423-438.

Hatton C. Emerson E. Robertson J. Gregory N. Kessissoglou S. Perry J. Felce D. Lowe K. Noonan Watosn P. Linehan C. & Hillery J. (2001) The adaptive behaviour scale-residential and community (part 1). Towards the development of a shortform. *Research in Developmental Disabilities* 22,273-288.

Hewett D. (1998) *Challenging Behaviour.Principles and Practice.* David Fulton Publishers, London.

Hillery J. & Mulcahy M.(1997) Self-injurious behaviour in persons with mental handicap: an epidemiological study in an Irish population. *Irish Journal of Psychological Medicine* 14,12-15.

Holland A.J. (1998) Understanding the eating disorder affecting people with Prader-Willi syndrome. *Journal of applied Research in Intellectual Disabilities* 11,192-206.

Hollins S. & Esterhuyzen A. (1997) Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry* 170, 497-501.

Howlin P. & Clements J. (1995) Is it possible to assess the impact of abuse on children with pervasive developmental disorders. *Journal of Autism and Developmental Disorders* 25, 337-354.

Joyce T. (1997) Challenging Behaviour.In: *Mental Health in Learning Disabilities (2nd ed.)*. (Eds *G.Holt & N.Bouras)*. Pavilion Publishing, Brighton.

Joyce T. Ditchfield H. & Harris P. (2001) Challenging behaviour in community services. *Journal of Intellectual disability research. Special Issues: Mental Health and Intellectual Disability VIII* 45, 130-138.

Kiernan C. & Kiernan D. (1994) Challenging Behaviour in schools for pupils with severe learning difficulties.*Mental Handicap Research* 7,117-201.

Kiernan C. & Qureshi H. (1993) Challenging Behaviour.*In C. Kiernan. (Ed.).Research to Practice?Implications of research on the challenging behaviour of people with a learning disability.* British Institute of Learning Disabilities Publications, Avon.

Kraaj V. Arensman E. & Spinhoven P. (2002) Negative life events in depression in elderly persons: A meta-analysis. *Journal of Gerontology: SeriesB. Psychological Sciences and Social Sciences* 57B, 87-94.

Lewis M.H. & Bodfish J.W. (1998) Repetitive behaviour disorders in autism. *Mental Retardation and Developmental Disabilities Research Reviews* 4,80-89.

MacHale R. & Carey S. (2002) An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities* 30, 113-117.

Mansell S. & Moskal R. (1998) Clinical findings among sexually abused children with and without developmental disabilities. *Mental Retardation* 36,12-22.

McDaniel J.S. (1996) Stressful life events and psychoneuroimmunology. In: *Theory and Assessment of stressful life events. International University Press Stress and Health Series. (Ed T.W Miller). pp.3-36.* International University Press Madison,CT,US.

McGill P.& Toogood S. (1994) Organising community placements.In: Severe Learning Disabilities and Challenging Behaviour.Designing high quality services. (Eds E.Emerson P.McGill & J.Mansell). Chapman Hall, London.

McLoughlin I.J. & Bhate M.S. (1987) A case of affective psychosis following bereavement in a mentally handicapped woman. *British Journal of Psychiatry* **151**, 552-554.

Monaghan M.T. & Soni S. (1992) Effects of significant life events on the behaviour of mentally handicapped people in the community. *The British Journal of Mental Subnormality* XXXVIII, 114-21.

Moss S.C. Prosser H. Costello H. Simpson N. & Patel P. (1996c) *PAS-ADD Checklist. Hester Adrian Research* Centre. University of Manchester, Manchester.

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

Murphy L. & Razza N. (1998) Domestic Violence against women with mental retardation. In: *Battered women and their families(2nd ed.). (Ed A.Roberts).* pp.271-290. Springer, New York.

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

Nihira K. Leland H. & Lambert N. (1993a) *Adaptive Behaviour Scale-Residential and Community(Second Edition): examination booklet.* PRO-ED, Austin,TX.

Nihira K. Leland H. & Lambert N. (1993b) AAMR Adaptive *Behaviour Scale-Residential and Community(Second Edition):examiner's manual.* PRO-ED, Austin,TX:

Nott K.H. & Vedhara K. (1999) Nature and consequences of stressful life events in homosexuals HIV-positive men. A Review. *AIDS Care* 11 235-243.

Nottestad J.A. & Linaker O.M. (2002) Predictors for attacks on people after deinstitutionalisation. *Journal of Intellectual disability Research* 46, 493-502.

Paykel E.S. Prusoff B.A. Uklenhuth E.H. (1971) Scaling of Life Events. *Archives of General Psychiatry* 25, 340-347.

Petticrew M. Fraser J.M. & Regan M.F. (1999) Adverse life events and risk of breast cancer. A meta-analysis. *British Journal of Health Psychology* 4, 1-17.

Qureshi H. (1994) The size of the problem. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*. (Eds E.E*merson P.McGill & J, Mansel.).*Chapman & Hall. *London.*

Raynes N., & Sumpton R. (1986) *The Index of Community Involvement.* Unpublished Manuscript.

Reid A. (1982) *The Psychiatry of Mental Handicap.* Blackwell, Oxford.

Rojahn J. Matson J.L. Lott D. Esbensen A.J. Smalls Y. (2001) An Instrument for the Assessment of Self-Injury, Stereotyped Behaviour and Aggression/ Destruction in Individuals with Developmental Disabilities. *Journal of Autism and Developmental Disabilities* 31, 577-587.

Ryan R.(1994) Post-traumatic stress disorder in persons with developmental disabilities. *Community Mental Health Journal* 30, 45-53.

Sequeira H., & Hollins S. (2003) Clinical Effects of Sexual Abuse on People with learning disability. Critical literature review. *British Journal of Psychiatry* 182,13-19.

Shroeder S.R. & Tessel R. (1994). Dopaminergic and serotinergic mechanisms in self-injury and aggression. In: *Destructive Behavior in Developmental disabilities: Diagnosis and Treatme*nt. (Eds *T.Thompson & D.B. Gray).* Sage, Thousand Oaks.

Sobsey D. Randall W. & Parrila R.K. (1997) Gender differences in abused children with and without disabilities. *Child Abuse and Neglect* 21,707-720.

Stack L.S.Haldipur C.V. & Thompson H. (1987) Stressful life events and psychiatric hospitalisation of mentally retarded patients. *American Journal of Psychiatry* 144, 611-13.

Tennant C. (2002) Life Events, Stress and Depression. A Review of the Findings. *Australian and New Zealand Journal of Psychiatry* 36, 173-182.

Thompson T. Symons F. Delaney D. & England C. (1995) Self-injurious behaviour as endogenous neurochemical self-administration. *Mental Retardation and Developmental Disabilities Research Reviews* 1, 137-148.

Valentine D.P. (1990). Double jeopardy: child maltreatment and mental retardation. *Child and Adolescent Social Work Journal* 7,487-499.

West S.G. & Hepworth J.T. (1991) Statistical issues in the study of temporal data: Daily experiences. *Journal of Personality* 59, 649-662.

World Health Organisation. (1993) *ICD-10: International Statistical Classification of Diseases and Related Health problems.10th Revision.* WHO, Geneva.

Yoshihama M. (1998) Domestic violence in Japan: Research, program developments and emerging movements. In: *Battered women and their families(2nd ed.)(Eds A. Roberts). pp. 405-447.* Springer, *New York.*

Zirpoli T.J. Snell M.E. & Loyd B.H. (1987) Characteristics of persons with mental retardation who have been abused by caregivers. *Journal of Special Education* 21, 31-41.

Table 1. Demographic Details of Study Population

Demographics	Number
Degree of ID.	
Borderline or above	2
Mild ID	7
Moderate ID	23
Severe ID	53
Profound ID	5
Unknown	3
Other Diagnoses	
Autism	13
Down's Syndrome	6
Cerebral Palsy	5
Encephalitis	3
Other	5
Communication	
Non-verbal	11
Non-verbal + gesture	34
Verbal + gesture	23
Verbal	25
Other Disabilities	
Visual disability	17
Hearing Problems	13
Mobility Problems	38
Physical Health Problems	67
Epilepsy	33
Other	
Family Contact	58

Table 2. Descriptive Data for Measures Administered

Mean Scores on Measures (N=93)			
Scale	M	(SD)	Range
BPI			
Self Injury - Frequency	4.20	4.11	0-17
Self Injury - Degree of Problem	2.76	3.75	0-17
Stereotypy - Frequency	11.57	11.60	0-46
Stereotypy - Degree of Problem	3.08	5.38	0-30
Aggression/Destruction Frequency	4.76	4.81	0-21
Aggression/Destruction Degree of Problem	5.40	6.57	0-30
LIFE EXPERIENCES CHECKLIST			
Total Score	24.43	5.67	12-39
Home	7.00	1.44	3-10
Leisure	3.64	1.83	0-8
Relationships	3.95	1.44	1-8
Freedom	5.29	1.72	1-8
Opportunities	4.55	1.84	1-9
PAS-ADD			
Affective Neurotic Disorder	2.36	3.59	0-15
Possible Organic Condition	.63	1.16	0-6
Psychotic Disorder	.33	.83	0-5
SABS			
Factor A – Quotient	98.47	16.32	73-145
Factor B – Quotient	77.46	16.82	56-144

Table 3. Proportion of Sample Exposed to Each Life Event in Previous 12 Months

Life Event	% of sample
Bereavement/Loss	**39**
Death of first degree relative	5
Death of close family friend/carer	16
Serious illness of injury	10
Serious illness of close relative or carer	4
Something valuable lost or stolen	1
Separation from significant person	9
Change in living circumstances	**78**
Fellow resident moved to another room	5
Fellow resident moved to another villa	23
Change of daily routine	27
New person in villa	33
Change of décor/furniture	29
Move of house or residence	8
Move to another room	13
Friend moved to another room	9
Friend moved to another villa	4
Furniture rearranged	32
Relationships	**38**
Break up of steady relationship	2
Increased arguments with friends	2
Increased arguments with staff	6
Broke up with old friend	1
Change in frequency of visits from/to family	5
Change in frequency of trips out with friends	5
Trouble with other resident	17
Trouble with member of staff	4
Trouble with stranger	1
Health Issues	**17**
Sexual problem	4
Major physical illness	1
Minor physical illness	34
Injury	12
Accident with no injuries	3
Menopause	8
Work	**6**
Change in work conditions	3
Change in line of work	2
Returned to work after long absence	1
Staff	**90**
Change in male/female staff ratio	33
Loss of keyworker	25
Change of staff	82

Table 4. Correlates of Challenging Behaviour in Present Study.

	Correlates of Challenging Behaviour					
	Self-Injury - Frequency	Self-Injury Degree of Problem	Stereotypy – Frequency	Stereotypy- Degree of Problem	Aggression/ Destruction Frequency	Aggression/ Destruction- Degree of Problem
Age	-.29**	-.22*	-.25*		-.258*	-.6**
Length of time at hospital	-.30**	-.22*			-.28**	-.29**
Quality of Life			-.32**	-.28**		
Factor A – SABS					.23*	.28*
Factor B – SABS			-.34*			
Affective/ Neurotic issues				-.25*		-.26**
Physical Health Problems				-.1.96*	-1.95*	
Mobility Problems	-2.16*	-2.88**	-3.02**	-3.89**		-2.05*
Hearing				-1.96*		
Gender			-3.02**	-3.64**		

* Association significant at the .05 level (2 tailed)

** Association significant at the .01 level (2 tailed)

Table 5. Correlation Matrix Displaying Associations Between Life Events and Challenging Behaviour

	Life Events as Correlates of Challenging Behaviour					
	Self-Injury – Frequency	Self-Injury – Degree of Problem	Stereotypy - Frequency	Stereotypy – Degree of Problem	Aggression/ Destruction – Frequency	Aggression/ Destruction – Degree of Problem
Bereavement/Loss	-.09	-.10	-.18	-.09	-.05	-.11
Change in Living Circumstances	-.14	-.17	.09	.03	.06	-.00
Relationship Issues	.17	**.26**	.17	.19	**.23**	**.23**
Health Issues	.07	.08	-.04	-.01	-.03	-.02
Work Issues	-.04	-.06	.16	.12	.14	.16
Staff Issues	.02	-.07	.18	.11	**.25**	.13
Total Life Experiences	.01	-.03	.13	.07	.19	.12

Coefficients in bold type, $p<.05$

Table 6. Stepwise Regression Analysis: life event variables = relationships and staff issues

	BPI Subscale - Aggression/ Destruction Frequency						
Regression Model/ Predictor Variable	β	p	ΔR^2	F change	df1	df2	Sig. F Change
Model 1			.20	5.48	4	88	.001
Age	-.21	.05					
Length of Residence	-.25	.02					
Physical Health Problems	-.13	.21					
Factor A Scaled Score	.10	.32					
Model 2			.12	7.88	2	86	.001
Age	-.13	.20					
Length of Residence	-.25	.01					
Physical Health Problems	-.15	.11					
Factor A Scaled Score	.11	.24					
Relationships	.22	.02					
Staff	.25	.01					

Table 7. Stepwise Regression Analysis: life event variable = relationships

	BPI Subscale – Aggression/Destruction: degree of problem						
Regression Model/ Predictor Variable	β	p	ΔR^2	F change	df1	df2	Sig. F Change
Model 1			.32	8.02	5	87	.000
Age	-.23	.02					
Length of residence	-.37	.00					
Mobility Problems	.03	.78					
Factor A scaled scores	.15	.16					
Affective/Neurotic Disorder	.15	.12					
Model 2			.02	3.58	1	86	.062
Age	-.22	.02					
Length of residence	-.35	.00					
Mobility Problems	.03	.78					
Factor A scaled scores	.14	.19					
Affective/Neurotic Disorder	.14	.15					
Relationships	.17	.06					

Table 8. Stepwise Regression Analysis: life event variable = relationships

	BPI Subscale – Self-Injury: degree of problem						
Regression Model/ Predictor Variable	β	p	ΔR^2	F change	df1	df2	Sig. F Change
Model 1			.15	5.10	3	89	.003
Age	-.13	.22					
Length of residence	-.29	.01					
Mobility Problems	-.12	.23					
Model 2			.02	2.09	1	88	.152
Age	-.12	.24					
Length of residence	-.27	.01					
Mobility Problems	.11	.26					
Relationships	.14	.15					

Appendix 3.1

Author Guidelines for The Journal of Intellectual Disability Research

SECTION 4

CRITICAL REVIEW

Challenging Behaviour and Life Events: A Critical Review

The inspiration for carrying out research in the area of intellectual disability (ID) research came from the researcher's commitment to applying clinically meaningful research to the understanding of the psychological issues faced by people with ID.

The researcher was particularly keen to carry out a piece of research that would also make a contribution to local ID services, particularly in relation to the provision of challenging behaviour (CB) services. Following much trial and error in crystallising a realistic research protocol the researcher was introduced to the concept of life events research and the apparent dearth of it in relation to individuals with ID who have CB.

While there is evidence in the literature that life events theory has been applied to some aspects of ID research (Cooper,1991; Ghaziuddin,1988; Hastings et al, in press; Stack et al,1987) there is little evidence of how this can be applied to the understanding of CB in people with ID. As with all research, finding a place to start was a huge consideration. However the methodological minefield that is encountered in life events research made this decision easy. Start from the beginning!

Thus the main methodological issues influencing this piece of work included the paucity of knowledge regarding the range of life events potentially faced by people with ID and the lack of appropriate measures with which to collect this information. Furthermore, the need for research that could explore this question, while attempting to exert control of the plethora of known correlates of CB.

Consequently the present study set out to determine the range of life events experienced by people with ID and examine how these might be associated with CB.

Methodology

Sample

The first task was to identify a sample population to survey. As the researcher's clinical placement was based in a large residential hospital for people with ID, there were some logistical reasons for targeting this population. The researcher was also aware that with the resettlement initiative underway the prospect of a thorough battery of psychological measures taken on all hospital residents would also contribute to a mental health assessment, informing current and prospective service care-planning as well as providing a baseline dataset with which to track how well service users adjust to community living. However, from a methodological perspective the prospect of a total population survey and a significant 'n' offered the potential advantages of reducing the variance of data thus providing more meaningful outcomes. However, the disadvantage of this sample was the compromise encountered in the generalisability of findings to a community population. To address this threat to external validity a replication of the study recruiting participants from different populations (community versus residential) and different lifespan ages (children versus adults; adults versus older adults) would help ascertain whether these effects still proved to be important.

Recruitment

Recruitment was also an important issue in this study. The recruitment process took time and negotiation.

i. Prior to ethical approval from the local NHS trust an outline plan of the required research was presented to the local ID hospital management team for permission to carry out research in the hospital.

ii. Then meetings with individual residential charge nurses were organised by the main researcher. Here the research protocol was explained in detail and charge nurses identified members of staff who were best suited to provide detailed accurate information on each service user.

iii. The researcher then approached each staff member individually with a letter explaining the study and followed this letter up a week later with a phone call to establish whether they were happy to take part in the study.

iv. A meeting was then set up with each key respondent where consent was collected and the research interview was carried out (subject to informed or proxy consent from the service user).

The researcher had anticipated problems in recruitment due to strained rotas and the study being perceived as irrelevant. However, the take-up rate on the study was high with all but one member of staff agreeing to take part. Feedback during the study suggested this high compliance rate was partly due to the fact that everybody felt informed and consulted during the planning process. So while the amount of time initially spent with managers, charge nurses, service users and potential key respondents delayed the start of data collection, this process of consultation communicated the relevance and importance of the research and how it would directly benefit the service user. Good will was further maintained by the research team remaining respectful of ward routines and rota pressures by carrying out lots of out of hour work to meet the demands of the wards.

One might therefore speculate that a replication study in the community might prove more difficult and certainly occupy a wider time frame. To begin with one might be dealing with different health, social services and housing association management strata who have varying policies with regard to research. Rodgers (1999) found this in her study. More practically the rural area that serves the local community would mean that travelling to each household, to cover the preliminary recruitment issues and later data collection, would take time and possibly restrict the flexibility of data collection times.

Consideration of consent

The issue of gaining consent was a huge issue in this study and was not undertaken lightly. Very simply the process of seeking consent is considered part of a respectful relationship in everyday decision-making. While there are those who have a reduced capacity to make decisions on behalf of themselves, statute in Wales and the England does not permit another adult to make a decision on their behalf (Holland 2001). While there are clearer parameters outlined for issues concerning medical treatment the law relating to research where consent is unattainable is currently unclear (Department of Health,2002). Consequently the main researcher familiarised herself with the main issues to consider in determining a sensitive, appropriate way forward.

In the Department of Health (2002) document 'Seeking Consent: working with people with learning disabilities' it outlined 5 main issues of consideration.

----- Insert Figure 1 about here -----

Armed with all these considerations the process for informed consent was undertaken. Once information had been presented in the recommended format (Department of Health,2002) service users were asked to explain the key issues back to the researcher to ascertain how well they understood what had been asked of them. Arscott et al (1998,1999) would argue that this is not sufficient to fully determine the extent to which a service user understands the implications of what they are agreeing to. In their studies, focusing on people with ID providing informed consent for medical intervention (Arscott et al,1999) and research participation (Arscott et al, 1998), they suggested that people with ID struggle most to comprehend the consent issues of individual rights, options and the impact of their choices. Arscott et al (1999) further found verbal ability and memory to greatly influence ability to consent. They recommended that over-reliance on one measure of ability to consent (e.g asking questions) was inadequate and that assessment required use of vignettes and formal evaluation of an individuals receptive language and memory abilities. The advantage of such an approach is that once undertaken there remains on file a clear indicator of whether an individual is in a position to potentially consent to further medical or research issues. However it does not necessarily tell us whether an individual does eventually provide informed consent. Ultimately the way to establish that is through questioning the individual. Furthermore Arscott et al (1998,1999) provided little guidance as to who should and should not be assessed. Such a lack of clarity simply results in subjective cut-off points decided by research teams. For this exploratory piece of work it is argued that a comprehensive assessment as outlined above would have been time consuming, over-intrusive and ultimately as subjectively defined as the process followed. However, there is no doubt that the routine assessment of people's potential ability to give consent is an issue that local services need to seriously consider.

So the question still remains could the researcher have attended to the issues of consent any further? As a psychologist it is necessary to say 'probably.' However, mindful of current guidance on issues of consent the researcher is hopeful that she tackled this ethical minefield with appropriate respect and sensitivity.

Design

Having established the participant group and recruitment issues the next issue was to consider the design of the study. As the study was a preliminary study to explore the range of life events experienced by people with ID, and to tentatively tease out possible associations between CB and the occurrence of life events in people with ID, a correlational design was considered a realistic starting point. In pursuing such a design the researcher was aware of the immediate limitations of such a design. It was clear that a causal pathway could not be established nor could we be clear as to the extent to which life events impacted on individuals. However this was never the focus of the study. For added scientific value this study collected a wealth of information on known correlates of CB in order that multiple regression analyses could be used to tease away at the research question.

Future research would also benefit from utilising a prospective design that can track life events as they occur while capturing temporally related data on CB. This method was utilised in a study of individual and environmental moderators of daily stress reactivity (Affleck et al 1994) whereby the sample population of 74 became a series of single case studies tracked over a 75-day period. Principles of meta-analytic statistics were then used to compute the effect size. Here each subject constituted an independent replication of the design with the number of studies equivalent to the number of participants (n=74). The study sample size was equivalent to the number of days (n=75) that the individuals were followed (West & Hepworth 1991). Such an approach would reduce reporter bias and allow stronger conclusions to be drawn from the analysis of sequentially related variables, measured within persons over time.

Data Collection

As the potential study population was originally 100, careful consideration was taken about how to gather such information in such a small space of time. Each interview took 45-60 minutes on average, so it was envisaged that a minimum of 100 hours of data gathering would be needed to complete the task. As it was also necessary to realistically consider staff/service user variables that can impact on data collecting, a data collection period of four months from January to April seemed a tall order for one person to overcome. Therefore it was decided prior to obtaining ethical consent that other postgraduate psychology students would be approached to help with data gathering. This was achieved and in total there were five data gatherers (including the main researcher, two clinical psychology trainees and two MSc students) involved in the process. In practice this meant one student gathered the inter-rater reliability data and the other three students collected between 15 and 20 sets of data each. The main researcher retained the majority of the workload taking sole responsibility for the construction of measures; all aspects of recruitment and consent; collection of 38 sets of data; and the scoring and data input of all 93 data sets

While the addition of extra data gatherers hugely facilitated the feasibility of the data gathering process once underway the process introduced the researcher to the complexities of managing and training up a research team to assure the integrity of the data. The main issues considered here were:

Training on the measures being used. The researcher met several times with the other data gatherers to introduce the research measures, explain their objective and issues around administration. Any difficulties encountered with the research measures were identified and rectified before the data process commenced through a process of mock administration. However, as the study did not obtain formal inter-rater reliability data no objective measure of the merit of this process was available. A future replication of this study would benefit from a more objective measure of inter-rater reliability.

Familiarity with the research protocol. During the training sessions, data gatherers were provided with a protocol to follow for each interview, to ensure that interviews were carried out as uniformly as possible. This included the ethical consideration of dealing with potential issues that could be raised by staff in response to participating in this research. Data gatherers were clear to report and refer any issues back to the main researcher who would then deal with issues as outlined on the ethics form.

Monitoring the integrity of data as it came in. The researcher was also keenly aware of the importance of keeping on top of the data mass to ensure that data sets were returning complete. To do this the researcher took on the task of scoring all the measures in each dataset. This allowed the main researcher to eyeball the data to ensure all information was collected. Furthermore, the main researcher also took responsibility for coding and inputting the data into the database to keep tabs on the developing database.

On reflection while the requirements of managing the data capture team at times seemed more time consuming than the actual data collection, it was nevertheless an invaluable experience that ran reasonably smoothly. In some ways that is possibly attributable to the sense of ownership that all data gatherers had of the project. As each one was to use data for smaller projects there appeared to be an increased drive to maintain the integrity of the project.

Measures

When deciding on the main measures to be used in the study it was relatively straightforward to find measures of mental health, CB, adaptive behaviour and quality of life that are widely used in ID research. The task of deciding how to capture life events was a much trickier task. The study needed an easy to complete, checklist method that could be filled in by key respondents. Having reviewed the literature it was clear that were a wealth of checklist and interview based measures out there (Brown & Harris,1979; Dohrenwend & Dohrenwend,1974) some of which had been used in ID research (Holmes & Rahe,1967; Paykel,1969). However, the literature also suggested that such research should concurrently explore life events and daily hassles that in themselves can be significant (Newman et al,2000). While all had their strengths and weaknesses there wasn't a scale that met all the criteria. Consequently the decision was made to construct a check-list of life events to try and provide a representative list of possible life events that a person with a learning disability living in a long-term residential setting might encounter.

In doing this, the researcher was aware that the study was compromised from an inability to compare to other relevant research using more common measures. However, the list was never meant to be an exhaustive measure of all the possible experiences an individual with a learning disability may encounter. Nor was it meant to contribute to a discussion on the cumulative impact of life events or to differentiate between the impact of various life events on an individual.
Rather it was regarded as a tool/aid memoir by which the research team could gather information relevant to the research question that focused on the range and amount of life events a service user had encountered in the previous twelve months. In that sense the compromise was rationalised and justified.

Future Research

Forward progression is required on a number of fronts. Methodologically, having discovered initial associations between some life event domains (relationships and staff change) and CB, the next step is to determine how to establish causal links. One way forward may be to explore the viability of prospective within and between subjects daily event studies over time that then utilise meta-analytic procedures to tease away at causal links. This approach in ID population based research, that covers a wide range of abilities, may be a way of ensuring that key informants are providing information that more closely reflects cause and effect.

On a theoretical front, child literature clearly demonstrates how reactions to trauma and life events are to some extent mediated by developmental level. As such it is possible that this also applies to adults with different levels of ID. Placing an emphasis on a lifespan developmental perspective might facilitate an understanding of how life events impact on people with ID. Such a perspective acknowledges that life events research has typically collected data at few and brief temporal points and not considered how relentless and/or dynamic life events can be. Furthermore, environmental demands and role definition alter over the course of development and the way one deals with 'life' is partly defined by previous experience. A longitudinal approach with emphasis on developmental/lifespan change might be particularly suited to the area of CB that does appear to have a developmental trajectory that peaks then declines. Such an approach may indeed permit more realistic representations of how life events impact on CB in the lives of people with ID.

References

Affleck G. Tenner H. & Urrows S. (1994) Person and contextual features of daily stress reactivity: individual differences in relations of undesirable daily events with mood disturbance and chronic pain intensity. *Journal of Personality and Social Psychology* 66, 329-340.

Arscott K. Dagnan D. & Stenfert Kroese B. (1999) Assessing the ability of people with a learning disability to give informed consent to treatment. *Psychological Medicine* 29, 1367-1375.

Arscott K. Dagnan D. & Stenfert Kroese B. (1998) Consent to Psychological Research by People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 11,77-83.

Brown G.W. & Harris T.O. (1979) *The Bedford College Life Events and Difficulty Schedule: Directory of severity for long-term difficulties.* University of London, London.

Cooper S.A. (1991) Aspects of affective disorders in adults with Down Syndrome. *Psychiatric Bulletin Supplement* 4,33-34.

Department of Health. (2002) *Seeking Consent: working with people with learning disabilities.* DoH, London.

Dohrenwend B. & Dohrenwend B. (1974) *Stressful life events: Their nature and effects.* Wiley, New York

Ghaziuddin M.(1988). Behavioural disorders in the mentally handicapped. The role of life events. *British Journal of Psychiatry* 152,683-6.

Hastings R. Hatton C. Taylor J.L. & Maddison C.(In Press). Life Events and Psychiatric symptoms in Adults with Learning Disabilities. *Journal of Intellectual Disability Research.*

Holland A. (2001) Common Legal Issues in Clinical Practice. *In E Emerson, C Hatton, J Bromley, & A Caine (Eds.). Clinical Psychology and People with Intellectual Disabilities.* John Wiley & Sons, Chichester.

Holmes T.H. & Rahe R.H. (1967) The Social Readjustment Rating Scale. *Journal of Psychosomatic Research*11,213-18.

Newman E. Christopher S.R. & Berry J.O. (2000) Developmental Disabilities, trauma Exposure and Post-traumatic Stress Disorder. *Trauma, Violence and Abuse* 1, 154-170.

Paykel E.S. Meyers J.K.Dieneit M.N. Kiernan J.L. Lindenthal J.J. & Peffer M.P. (1969). Life Events and Depression. *Archives of General Psychiatry* 21, 753-760.

Rodgers J. (1999) Trying to Get it Right: undertaking research involving people with learning difficulties. *Disability and Society* 14, 421-433.

Stack L.S. Haldipur C.V. & Thompson H. (1987). Stressful life events and psychiatric hospitalisation of mentally retarded patients. *American Journal of Psychiatry* 144, 611-13.

West S.G. & Hepworth J.T. (1991) Statistical issues in the study of temporal data: Daily experiences. *Journal of Personality* 59, 649-662.

Appendix 4.1

Diagrammatic Summary of Guidelines for Obtaining Consent.

Figure 1. DoH (2002): Guidelines for Obtaining Informed Consent

Appendix 5.1

Statement of Word Count

Statement of Word Count

Thesis Component	**Words**
Title	16
Main Abstract (summary)	287
Ethics Proposal	4836
Literature Review	6141
Research Paper	4067
Critical Review	2857
Total	19204
Components of Appendices	**Words**
Contents Section (excluding abstract)	380
Tables (section 3)	887
References:	
Ethics Proposal	720
Literature Review	2908
Research Paper	1821
Critical Review	363
Appendix 1	9465
Appendix 2	1450
Appendix 3	1230
Appendix 4	19
Appendix 5	68
Total	19311