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**Dealing with social threat: Examining behavioural responses
to anxiety-provoking situations for young adults with mild
intellectual disability**

and

Clinical Research Portfolio

Volume I

(Volume II bound separately)

Eleanor Jane Simpson

Institute of Health and Wellbeing

University of Glasgow

August 2013

***Submitted in partial fulfilment of the requirements for the
degree of Doctorate in Clinical Psychology (DClinPsy)***



University
of Glasgow

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CHAPTER ONE: SYSTEMATIC REVIEW

Impact of abuse on the wellbeing of adults with intellectual disabilities

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*Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology (DClinPsy)*

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Abstract

Although there exists a robust body of evidence concerning the negative impact of abuse upon mental health and functioning within the typically developing population, the research concerning the impact of abuse for adults with intellectual disabilities (ID) is scarce. High rates of mental health problems and vulnerability to abuse within this population indicate that this may be an important area for investigation and assimilation of existing research, in order to guide the direction and priorities of future research. The present review aims to draw together existing research on the impact of abuse experiences on the mental health and wellbeing of adults with ID. A total of 8 studies were included in the review, which were methodologically diverse and examined a range of outcomes. It was found that effects of abuse appear to be wide-ranging and broadly in line with what has been found within research on the general population. Methodological issues within this area of research are discussed and it may be that future research needs to explicitly delineate other pertinent factors known to be important in vulnerability and resilience, such as timing and extent of abuse, supportive relationships and other life events. There is also a need for high-quality longitudinal studies in this area, to offer a better insight into causal factors.

Introduction

Negative and stressful life events have an important influence on our wellbeing and experience of psychological problems, and it has been well documented through research into the impact of stressful experiences, that such life events have an impact on wellbeing and mental health (MH) within the typically developing population (Turner & Lloyd, 1995; Tennant, 2002). In recent years, impact of life events has been investigated within the intellectual disability (ID) literature. It appears from the research so far that, unsurprisingly, experience of negative life events can increase the risk of mental health problems for individuals with ID (Esbensen & Benson, 2006), and may be associated with behaviours such as self-harm (Brown & Baeil, 2009). Many studies in this area have examined the impact of life events generally, encompassing events such as bereavement, change of residence, and other life changes (Hastings *et al*, 2004; Gore, 2009).

Martorell *et al* (2009) conducted a study of the impact of life events on adults with ID, and found that traumatic events may be more important in predicting the development of mental health problems, when compared with other types of life event. One area which may be important to examine in this population is that of interpersonal traumatic life events, as individuals with ID can be particularly vulnerable to abuse by others (Brown & Craft, 1992), and some evidence suggests that the prevalence of abuse among the ID population may be particularly high (Levy & Packman, 2004; Horner-Johnson & Drum, 2006). This vulnerability to maltreatment is thought to be due to factors such as reliance on others for tasks such as personal care, and the imbalance of power that necessarily arises between those with ID and those who care for them (Cooke & Sinason, 1998). Individuals with ID may also be less able to prevent or to report abuse, due to difficulties in communication and understanding (Keating, 1998). Vulnerability to sexual abuse may be increased due to increased opportunity for sexual contact within group residential settings, and also lack of education about sex and sexual abuse (Tharinger *et al*, 1990).

There is some evidence to suggest that the patterns of outcome for abused individuals with ID may be similar to the general population (Sequeira *et al*, 2003),

and outcomes based on diagnostic criteria, such as Post Traumatic Stress Disorder (PTSD) have been used to try to establish if similar patterns of outcome emerge for abuse victims with ID (Davison, 1994). However, it may be that the ID population is differently affected by experiences of abuse compared to the typically developing population, due to a range of factors. Firstly, capacity to understand and process traumatic experiences may be impaired in various ways within this population, leading to potential differences in expression of distress or trauma from the PTSD model used for the typically developing population. Secondly, increased reliance on perpetrators for support and care may lead to repeated or prolonged experience of abuse, and ambivalence around reporting, and this may conceivably have an impact on trauma presentation. Also, the decreased ability of those with ID to prevent, disclose or escape abuse experiences may further influence the trajectory in terms of impact of abuse for this population. This unique set of circumstances faced by abused individuals with ID may conceivably lead to a different profile of abuse than that observed in the non-ID population.

Developmental factors may also exert an impact on outcomes of abuse. A recent review of the impact of traumatic life events on people with ID (Wigham *et al*, 2011) highlighted that impact of traumatic events could be mediated by developmental level, meaning that reactions to trauma within this population may manifest differently, such as through behaviour change (Moss *et al*, 2000). A comprehensive review by Kendall-Tackett *et al*, (1993) on the impact of abuse in the child population found a range of diverse psychological and behavioural sequelae. The review concluded that much symptomatology arising from abuse experience is developmentally specific and therefore difficult to profile across developmental stages. This finding has direct implications for examining the impact of abuse for individuals with ID, whose developmental profiles as a population could be expected to be heterogeneous. Responses to trauma and abuse in this group may therefore be expected to reflect this variability. In addition, difficulties with verbal reporting of psychological symptoms may cause methodological issues when trying to establish the presence of abuse outcomes across this population. The finding that behavioural outcomes are associated with abuse for this population may therefore also be a

partial reflection of the difficulty in reporting cognitive and emotional information for those with more severe ID.

It appears that there are various population-specific factors to consider when examining the mechanisms by which abuse experiences exert their impact on individuals with ID. Reviewing recent research on the impact of abuse experiences on mental health and wellbeing sequelae for adults with ID would help to determine whether these population specific factors do influence the outcomes for these individuals. To date there has not been a systematic examination on the literature regarding the impact of abuse. The proposed review will examine literature pertaining to the impact of abuse on mental health and wellbeing outcomes.

Review Questions

1. What is the impact of abuse experiences on the mental health and wellbeing of adults with ID?
2. Does the impact of abuse on adults with ID differ from the typically developing population?

Method

The review utilised online literature databases as the primary method of locating papers. Systematic searches of electronic databases were performed. The online search component utilised the following databases: Ovid Medline (1946 - 2012); EMBASE (1974 - 2012); PsycINFO (1987-2012), and ERIC (1965 – 2012). (Dates stated refer to the pre-set database parameters, and custom date parameters will be set based on the inclusion/exclusion criteria stated below).

The following search terms were used in order to locate relevant studies for potential inclusion: 'intellectual disability'; 'developmental disability'; 'learning disability'; 'mental retardation'; 'mental deficiency'; 'mental disability'; 'mental handicap'. Each of these terms were combined with one of each of the following: 'victim'; 'abuse'; 'violence', and with each of the following: 'impact'; 'outcome'; 'effect'; 'mental health'; 'sequelae'; 'behaviour'; 'disorder', using the Boolean

operator 'AND' to combine each possible set of three search terms. The search terms were truncated in order to include closely related terms. Preparatory searches were conducted to ensure these combinations of terms would capture relevant articles.

In addition, hand-searching was performed on the index pages of relevant journal publications to search for relevant articles that may have been omitted from the online search strategy. The proposed publications were as follows: Journal of Learning Disabilities (2001-2012), British Journal of Developmental Disabilities (1999-2012), Journal of Intellectual Disability Research (1991-2012), Journal of Applied Research in Intellectual Disabilities (2002-2012), and American Journal of Mental Deficiency (1980-2012).

Inclusion criteria

- Papers published in English language peer-reviewed journals
- Studies involving confirmed or alleged physical and sexual abuse experiences, explicitly examining impact of these experiences on wellbeing in individuals with ID
- Studies which examined the relationship between experiences of abuse and outcomes relating to mental health, behaviour and wellbeing
- Clinical and non-clinical ID populations

Inclusion criteria were set to reflect the relative paucity of literature in this area. Studies which were wider in scope and examined the impact of various factors on the wellbeing or mental health of individuals with ID were included if they explicitly examined experiences of abuse as part of the design. The proposed review was not limited to mental health outcomes alone, and included studies with a broad range of outcomes encompassing, but not limited to, quality of life and challenging behaviour, as well as measures of psychopathology, in order to examine impact on 'wellbeing' more broadly. Finally, all levels of ID severity were included, in order to explore the patterns found across this heterogeneous population.

Exclusion criteria

- Studies which examine other types of life events (such as bereavement)
- Studies which include abuse within a broader measure of 'life events' from which the impact of these specific experiences cannot be extracted
- Studies of abuse which did not explicitly examine impact of these experiences on wellbeing outcomes
- Studies on the child ID population
- Research on individuals 'with disabilities' as a wider group
- Studies where the target group has a diagnosis of Autistic Spectrum Disorder

In addition, political and cultural shifts over the last few decades in relation to support for individuals with ID, and in particular the shift away from institutional care, has meant that the nature of abuse and victimisation experienced by individuals with ID is likely to have changed. Studies published prior to 1995 were therefore excluded, in order to ensure the current review reflects contemporary issues and experiences in this area. Finally, studies which used qualitative methods were excluded, as were dissertation abstracts, book chapters and conference proceedings.

Article Selection

The abstracts of potentially relevant papers were read and full texts of all potentially relevant papers were then examined, and those which met criteria were identified. All unsuitable texts were discarded. Table 1, illustrating the selection process, is shown below.

Table 1: Article selection process

Source	Total results	Number of papers excluded by title (including duplicates)	Number of papers excluded by abstract	Number of articles excluded by full text	Number of papers included
Medline	133	126	3	1	3
Embase	104	90	12	1	1
PsycINFO	210	199	7	1	3
ERIC	390	375	13	1	1
Hand-searching	N/A	N/A	7	3	1
Total	837	790	42	7	9

Article Quality and Rating Criteria

Since the articles included in this review are not intervention studies, established guidelines such as those developed by the Critical Appraisal Skills Programme (CASP, 2013) and Consolidated Standards of Reporting Trials (CONSORT, 2010) have limited utility for informing the present review. The review proposes to examine the relationship between life events and subsequent wellbeing/mental health outcomes. Therefore, quality criteria were developed specifically for this review, based on strength of study design and methodology, including items concerning the quality of measures used to establish ID, abuse and wellbeing outcomes. Key criteria were referenced from established guidelines for observational studies, produced by the Scottish Intercollegiate Guideline Network (SIGN, 2008) when developing these quality criteria. The full quality criteria and scoring are shown below. Studies were then rated as ‘excellent’, ‘good’, ‘adequate’ or ‘poor’ according to their score on these criteria. The quality rating system was also devised specifically for the present review, and studies were ranked primarily on robustness of study design and clarity of the study question. Those studies ranking as ‘poor’ were excluded from the review. The full rating system is shown in Table 2, below.

Table 2: Quality Criteria for present review

Study question	<ul style="list-style-type: none"> • Focussed with clear aims • Partially focussed • Not clear 	2 1 0
Study design	<ul style="list-style-type: none"> • Longitudinal design • Cohort study/cross sectional study with control group/comparison group, or case-control study • Single sample study without control group • Case study 	4 3 1 0
Sample acquisition	<ul style="list-style-type: none"> • Geographical cohort • Convenience sample • Not clear 	2 1 0
Sample characteristics	<ul style="list-style-type: none"> • Sample characteristics reported: • Well addressed • Adequately addressed • Poorly addressed/not clear 	2 1 0
Measures of wellbeing/ mental health/quality of life	<ul style="list-style-type: none"> • Standardised and/or valid and reliable measure for use with ID population • Measure normed on non-ID population but appropriate to design and adapted for use with ID population • Non-standardised measure used but appropriate for use with ID population, including justification and specification of measure • Measure used not appropriate to design and/or population 	4 3 2 0
Acquisition of data on abuse/ victimisation experiences	<ul style="list-style-type: none"> • Standardised or appropriate structured self-report/ proxy reporting (where necessary and appropriate) – such as questionnaire or purpose-designed interview – with details of nature/duration of abuse experience reported • Standardised and/or appropriate structured self-report or proxy report with binary ‘yes/no’ response and/or without details of nature/duration of experiences • Casenote review/court report/other retrospective 3rd hand source • Unclear 	3 2 1 0
Measure of intellectual disability	<ul style="list-style-type: none"> • Wechsler Adult Intelligence Scale (WAIS) and a measure of adaptive behaviour used to assess for ID • WAIS only used • An alternative standardised IQ measure used, or only a measure of adaptive behaviour used • Case-note review/clinical opinion • Unclear 	4 3 2 1 0

Control/consideration for confounding factors (e.g. other life events/stressors unrelated to abuse, occurring in intervening time period) which may be associated with subsequent changes to wellbeing/ behaviour	<ul style="list-style-type: none"> • Explicit consideration given to possible presence of these factors and incorporated into design of study as covariates • Consideration given and discussed • No consideration of possible confounding factors reported 	4 2 0
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Table 3: Ranking system for quality ratings

Rating	Criteria
Excellent	score of at least 3 for study design, 2 for study question, score of 14 or higher for remainder of categories (Highest possible score = 25)
Good	score of at least 3 for study design, 2 for study question, score of 10 – 14 for remainder of categories
Adequate	score of at least 1 for study design, 1 for study question, and a score of 9 – 13 on remainder of categories
Poor	score of 10 or less in total

Data Extraction

Following the application of inclusion and exclusion criteria, nine papers were identified as being relevant to the systematic review question. The quality criteria above were applied to these studies by the author, in order to gain quality ratings for each study. One study was subsequently discarded due to receiving a ‘poor’ rating of quality, leaving eight papers for inclusion in the review. Details of these eight papers are summarised in data extraction tables in the following section.

Reliability of quality rating

All nine studies included for quality rating were independently rated by another researcher using the same rating scale. There was 100% agreement between raters using this rating scale.

Results

The narrative review below aims to provide an initial summary of the studies selected, followed by a distillation of the overall findings and a consideration of what each study contributes in reference to the research questions.

Overall study characteristics

Due to the paucity of research in this area, a range of studies was included for the present review which fulfilled the criteria for examining the impact of abuse experiences for adults with ID. Consequently, the included studies in this review were varied in terms of a) design and b) outcomes relating to mental health and/or wellbeing in the context of impact of abuse.

Of the included studies, sample size ranged from $n = 18$ -1202. Two studies utilised a forensic sample of males with ID, one study used a sample of women with ID and four studies used a mixed-sex sample of adults with ID. One study used a sample of children and adults.

Of the eight studies included in the review, only one was a longitudinal cohort study, conducted over a 2-year period and encompassing a range of predictors of mental ill-health. Four studies adopted a case-control design examining impact of abuse, between two ID groups where history of abuse was controlled for. One study was a case-control study examining differences in abuse-related outcomes between an ID and typically developing sample. One study used a retrospective cohort design to examine relationships between exposure to abuse and behavioural outcomes. One study used a retrospective case-series design without a control group.

Of these studies, three looked specifically at experience of sexual abuse, four examined abuse experiences more generally and one study looked at 'parental anger and assaultiveness' which included experience of parental physical abuse but no explicit measure of sexual abuse.

These studies were drawn from a range of geographically diverse populations. Four of the studies were carried out with groups of participants in the UK, two were conducted in New York, one in Sydney, and one study was conducted in Cape Town, South Africa. The included studies also comprised a range of participant groups drawn from inpatient, clinical and community populations.

Due to the breadth of designs and outcome measures utilised in the included papers, the results will be grouped in terms of primary outcome variables examined, and each paper will be discussed individually. Overall patterns across the studies will then be examined. Of the included studies, four studies looked at impact of abuse on mental health outcomes, one examined stress and coping, one examined adaptive behaviour and skills, and two studies examined aggression and violence as outcomes of abuse.

Since the scope of some of the papers was wider than examining the sequelae of abuse experience specifically, the papers will be discussed in relation to the present review question. Tables 4 to 7 present data extracted from the studies, to facilitate comparisons across study design, methodology, main findings and other aspects deemed important and relevant for the current review.

1. Impact of abuse on mental health outcomes

Four of the studies in the present review examined impact of abuse primarily on mental health outcomes. The studies will be discussed in turn and overall patterns of findings will be discussed with respect to the review question. Table 4 below outlines the main characteristics of these studies.

Table 4: Papers examining impact of abuse on mental health outcomes

4a.

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
Smiley, Cooper, Finlayson, Jackson, Allan, Mantry, McGrother, McConnachie & Morrison (2007) Longitudinal cohort study conducted over a 2 year period, examining incidence and predictors of mental ill-health among adults with ID	22 'Excellent'	Demographic information Personal history Mental health Adaptive behaviour Psychopathology Physical health Research aims: To determine the incidence of mental ill-health among adults with mild to profound ID and to investigate factors related to mental ill-health.	Identification of sample: All known adults with intellectual disability within the Greater Glasgow area were identified through GP registration or through social work or specialist health services. Characteristics of sample: n = 1202 at time 1, and 651 at time 2; age range 18.2 – 80.8. 355 male; 296 female. Dropout rates and reasons given: Cohort retention was 70% (n = 651 at time 2). Detailed reasons were given for all dropouts.	Interview with individual (where possible). Interview with relative. PAS-ADD, followed up with a psychiatric assessment if 2 or more symptoms present on PAS-ADD A purpose-designed semi-structured questionnaire of personal history was used. Vineland Adaptive Behaviour scale (Survey Form – Sparrow <i>et al</i> , 1984) to measure skills and ability level Physical health was assessed using the C21st Health Check.	Multivariate logistic regression analysis found that 'abuse, neglect or exploitation in adulthood' was independently related to incidence of mental ill-health (p = 0.04). Known abuse, neglect or exploitation during childhood did not emerge in the analysis as independently related to mental ill health or problem behaviours.	Unclear how and in what format the abuse data was gathered – may have been a single item. Lack of detail in terms of nature, severity and duration of abuse and support/action taken following abuse disclosure.

4b.

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
Matich-Maroney (2003) Case-control study of adults with ID with and without history of sexual abuse, examining mental health outcomes between groups.	18 'Good'	Abuse variables: Presence/absence of sexual abuse; nature and extent of sexual abuse Outcome variables: Emotional problems Behaviour problems Psychopathology Use of psychotropic medications Research aims: To examine how experiences of sexual abuse may affect the mental health of adults with ID.	Identification of sample: Sample drawn from those attending programs sponsored by a non-profit organisation in New York area. Individuals in research group identified by asking organisational staff to identify those they knew to have experienced sexual abuse, and to be functioning in 'mild to borderline' range of ID. Control group identified in same way, to be matched for functioning level but without history of sexual abuse. Characteristics of sample: N = 43; age range 23 – 52 Research group: 8 male and 10 female; control group: 10 male and 15 female. Of total sample, 58% living with family and 42% in residential care. No significant differences between groups for cognitive/adaptive functioning, gender, age, ethnicity (chi-square). ID status: 60% mild ID, 26% mild to moderate ID and 14% in 'borderline' range – included due to their lifelong involvement with ID services and socialisation as person with ID. Dropout rates: 1 participant declined to participate following initial interview.	Measures of ID: WAIS-R; also 'precise measures of cognitive and adaptive functioning' recorded on a personal data form Measures of abuse: Personal data form documenting nature, extent and details of the abuse history Measures of outcome: Personal data form documenting presence/absence of dual psychiatric diagnosis and present medication; Prout-Strohmer Assessment System (PSAS) to measure behavioural outcomes and pathology; Psychopathology Inventory for Mentally Retarded Adults to measure psychopathological behaviour. Both measures include a proxy report and self-report component.	Research group scored significantly higher on the PSAS behaviour rating scale ($p = 0.018$) Specifically the research group scored higher for 'sexual maladjustment' scale of the PSAS BRS ($p = 0.027$). Self-reported levels of depression and anxiety were higher for the group with a history of SA ($p = 0.023$; 0.043 respectively). Those in research group (50%) were more likely to be carrying a formal dual psychiatric diagnosis than the control group (11%) ($p = 0.002$). Significantly more research participants (50%) than control participants (20%) were prescribed medication for a psychiatric condition ($p=0.038$) Results expected but not found: No differences between groups for levels of aggression, self-esteem, somatisation or dissociation.	Not clear how adaptive functioning info derived/established for personal data form and for purposes of matching groups Source of ratings scales not made clear – references not given. Absence of inter-rater agreement for items on personal data form.

4c.

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
Sequeira, Howlin & Hollins (2003) A matched case-control study examining the association between sexual abuse and psychological disturbance in a community sample of adults with ID.	16; 'Good'	Abuse variables: Presence/absence of abuse history Nature of abuse; rate and duration of abuse; support/treatment following abuse; legal outcomes following abuse. Outcome variables: Fulfilment of psychiatric diagnosis Extent of challenging behaviour Extent of sexual behaviour Severity of depressive/anxiety symptoms and general psychiatric disturbance.	Identification of sample: Screening questionnaire given to managers of charitable ID organisations in Scotland and England. Characteristics of sample: Adults with ID living in community settings. Not necessarily involved with clinical services or identified as having history of mental illness. Those with dementia or psychotic disorder diagnoses were excluded. Sample n = 108; Abused group (n = 54), non-abused group (n = 54). Groups matched for gender, level of ID and communication ability. Age range: 16 – 44 years. Dropout rates not given.	Measure of ID: WASI or WAIS-R Measure of abuse: Unclear how this information was gathered but appear to be during interview with keyworkers and clients. Brown & Turk's (1992) definition of 'proved, highly probable or probable' cases of abuse were included in experimental group. Measure of impact: Aberrant Behaviour Checklist-Community (ABC-C – Aman <i>et al</i> , 1995) - a validated informant based measure of challenging behaviour Sexual behaviour domain from Adaptive Behaviour Scale (ABS-RC) used as a measure of sexual behaviour. PAS-ADD used to establish fulfilment of psychiatric diagnosis criteria. Where participants were unable to communicate sufficiently to complete the PAS-ADD respondent version, the informant interview was used for this purpose. PTSD Check List for Children/Parent Report (PCL-C/PR; Ford <i>et al</i> , 1999) was used to establish clinical symptoms for PTSD. This is an informant-based measure.	Scores on ABC-C subscales for irritability, lethargy, stereotypical behaviour and hyperactivity were significantly higher for the abused group. A higher proportion of those in abuse group engaged in self-injurious behaviour in previous 4 weeks. Higher scores for sexual behaviour in abuse group, as measured by ABS-RC domain. Proportion of those in abused group meeting psychiatric diagnostic criteria (as measured by PAS-ADD) was higher than control group. Scores for depression, neurotic, and total symptom scores on PAS-ADD also higher for abused group. Participants in abused group rated significantly higher for PTSD symptoms, according to PCL-C/PR. More severe forms of abuse were associated with greater severity of psychological disturbance.	Retrospective case-control, does not detect causal or temporal relationships between abuse and outcomes. Sample came from residential services only. No masking to purpose of study.

4d.

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
Shabalala & Jasson (2011) Case-control study comparing two groups of adults with ID to explore the presence of PTSD symptoms in victims of known sexual abuse.	15 'Good'	Abuse variables: Known history of sexual abuse Outcome variables: Symptoms of PTSD Research aims: To explore the presence of PTSD in a group of people with ID who were victims of sexual abuse.	Identification of sample: Sample recruited from a pool of Sexual Abuse Victim Empowerment clients awaiting assessment. Control participants were recruited through social workers at the Cape Mental Health Society. Characteristics of sample: n = 54: 27 people with ID and known history of abuse (3 males, 24 females; age range: 11 – 35 years, mean age = 18); and 27 people with ID and no known SA history (10 males, 17 females; age range: 14 – 52 years, mean age = 28). All participants lived with family members or in supported accommodation. None of the sample was in process of therapy, and none had any diagnosed mental disorder. Dropout rates were not reported.	Measure of ID: Unclear/not stated Measure of abuse: Experimental group recruited from complainants in sexual abuse court cases. No abuse measure stated. Measure of impact: The Child PTSD Checklist (Amaya-Jackson, 1995) was used and translated into isi-Xhosa and Afrikaans.	A higher percentage of people in the experimental group (n = 8; 30%) met diagnostic criteria for PTSD compared with the control group (n = 1; 4%). T-testing revealed that the experimental group were significantly more likely to score higher on self-reported PTSD symptoms than the control group. Experimental group reported higher frequency of some symptom items on the scale but not all.	Difficulty with criteria of 'no known abuse' and lack of clarity with how this was established – possibility of insufficient screening for undisclosed abuse within control group. Could confound outcome. Samples not well matched for age or gender. Children and adults included, makes it difficult to generalise effects or specify effects for adult population. Rationale for use of PTSD scale for children – a measure of verbal understanding could have been used to check if the measure was suitable for the population. Use of measure which has items relating to trauma – unclear what event the non-SA group are recalling when answering these items.

The 2007 study by Smiley *et al* (2007) achieved an 'excellent' quality rating. Details of this study can be found in Table 4a. The study examined a wide range of factors hypothesised to be related to mental ill-health and their predictive effect on mental health incidence in a Scottish ID cohort, using a prospective cohort design over a 2-year period. The study used the PAS-ADD and psychiatric assessment interviews to assess for mental health problems and problem behaviour. Abuse variables were measured via a single item on a semi-structured questionnaire. This study used multivariate logistic regression modelling to examine risk factors for incidence of mental ill-health within the follow-up period. In terms of the findings of the study relevant to the present review question, the study found that 'abuse, neglect and exploitation' during adulthood were independently related to experiencing an incident of mental ill-health, as measured by psychiatric assessment. Known abuse, neglect or exploitation during childhood, however, did not emerge as independently related to mental health problems. Neither adulthood nor childhood abuse were found to predict incidence of problem behaviour. A large sample size, prospective cohort design (allowing for causative conclusions to be drawn) and in-depth assessment of various aspects of mental health were strengths of this study. One limitation of the study was that the data collection method is unlikely to have captured the full extent of abuse experience in the sample, and this is acknowledged by the authors. Another limitation of the study in relation to the present review is that due to the wide-ranging scope of the study there is no detailed information present regarding the nature, frequency or duration of abuse experiences and how this may differentially impact on MH outcomes. The category of 'abuse, neglect or exploitation' is broad and may encompass a range of experiences which are not detailed. There is limited scope therefore for drawing conclusions about particular features of abuse experiences and their specific impact on subsequent incidence of MH problems.

Another study which examined mental health outcomes from abuse was the 2003 study by Matich-Maroney, shown in Table 4b. This study achieved a quality rating of 'good' in the present review. The study examined psychopathology and behavioural outcomes for adults, but this study focussed specifically on outcomes from sexual abuse. Two groups of adults with ID (with and without sexual abuse history) took

part in the study, and a data form was used to document details of sexual abuse history. Self and proxy-reporting were used on standardised measures of psychopathology outcome (Prout-Stromer Assessment System – PSAS; Psychopathology Inventory for Mentally Retarded Adults) to establish impact of abuse. A notable feature of this study is that those with borderline IQ were included in the sample due to their lifelong involvement with ID services and socialisation as individuals with ID. This study found that the group with reported abuse history scored higher on the PSAS measure of pathology than controls. Also the abuse group scored higher on ‘sexual maladjustment’ as well as self-reported depression and anxiety, and there was a higher likelihood of formal dual diagnosis of psychiatric disorder for the abuse group. In addition, there was a higher rate of prescribed psychiatric medications in the abuse group. Contrary to the expected outcomes of the study, no differences were found between groups for levels of aggression, self-esteem, somatisation or dissociation. Strengths of this study include use of measures with detailed subscales pertaining to different elements of mental ill-health and problem behaviour presentations, to allow for detailed examination of abuse impact on specific aspects of mental health outcomes. Also the measures used were specifically designed for an ID population. Weaknesses of the study were that it was unclear how adaptive functioning was established for the sample, and that there was an absence of inter-rater agreement for the data collected on functioning. In addition, the sample was relatively small and gathered via informant on individuals with and without known sexual abuse history, and consequently the sample is unlikely to be representative of the population or true unreported rates of abuse.

Sequiera *et al* (2003) similarly examined the impact of sexual abuse experiences specifically on mental health and behavioural outcomes. Their study achieved a ‘good’ rating in the present review and details are shown in Table 4c. The study used a community sample from across the UK. They used a case-control design to examine symptoms of ‘psychological disturbance’ in individuals with ID with and without a history of sexual abuse, using the Aberrant Behaviour Checklist and the PAS-ADD, and also a measure of PTSD was used to examine the presence of post-traumatic symptoms. This study found that the abused group scored higher for behaviour subscales of lethargy, stereotypy, and hyperactivity. Also there was a

higher rate of recent self-injurious behaviour in the abused group, and a higher rate of what was termed 'sexualised behaviour'. In terms of mental health outcomes, those in the abused group more frequently met criteria for psychiatric diagnosis, and had higher scores for depression, neuroticism and total PAS-ADD symptom-scoring than the non-abused group. In terms of PTSD symptoms, the abused group scored significantly higher than the control group. Importantly, this study found that more severe forms of abuse were associated with greater severity of psychological disturbance at the time of testing. However, the paper gave no information on how abuse severity was measured so it is difficult to interpret this result.

A strength of this paper is that no involvement with mental health or social services was required for inclusion in the study and therefore the data was obtained from clinical and non-clinical ID populations. One drawback with this study is that individuals with psychotic disorders were excluded from the sample, and this prevented examination of psychosis as a possible psychological sequela of sexual abuse. Another difficulty with this paper is that it uses 'sexualised behaviour' as a measure of pathology. This is potentially problematic since individuals with ID might understandably display sexual behaviour through lack of opportunity for sexual activity, or lack of education about appropriate sexual behaviour, so this may not always imply abuse-related pathology. It was unclear in this study how the information on abuse was gathered and categorised for analysis. Moreover, the retrospective nature of the design prevents the examination of clear patterns over time and the deduction of clear cause-effect relationships between abuse and outcomes.

The paper by Shabalala and Jasson (2011), which is detailed in Table 4d, also dealt with the sequelae of sexual abuse specifically, and was also rated as 'good' in the present review. This study was carried out in Cape Town, South Africa, and used a case-control design to examine presence of PTSD symptomatology in individuals with ID with and without history of known sexual abuse. This study reported no measures or guidelines used for defining or measuring presence or extent of abuse experiences, but the abused group were reportedly recruited through their involvement in sexual abuse court cases. One measure, the Child PTSD Checklist, a 28-item measure rating, was used in this study and administered to participants and

their caregivers in English, isi-Khosa or Afrikaans depending on the first language of the participants and caregivers. The measure gives a rating for each of the DSM-IV-TR (APA 2000) clusters of PTSD symptoms, namely re-experiencing, avoidance and hyperarousal, over the previous month.

Results from this study showed that there was a significantly higher likelihood within the abused group of meeting the PTSD diagnostic criteria, as measured by the checklist. In addition, when groups were compared on individual items on the measure, it was found that those with sexual abuse history were more likely to display avoidance 'all or most of the time'. It appeared that more respondents in the abuse group reported feeling upset more often by thoughts of the trauma, flashbacks and physiological reactions. However, those in the control group tended to report the presence of these symptoms 'some of the time'. The study also showed that more people in the abuse group reported a constant presence of anger and aggression compared with controls. A weakness in this study was the lack of agreement between participants and caregivers, and this may be due to different perceptions of abuse and impact. Also, researchers did not control for the experience of other trauma, and this is particularly salient in light of PTSD symptoms appearing to be present for the non-abused group. It would have been more useful to have information on the specific trauma experiences of participants in the control group when completing the PTSD measure. More information on other trauma and its differential impact would have improved this study greatly. Additionally, since both children and adults were included in this sample, it is difficult to generalise from the results found, as it is likely that developmental factors and other age-related variability could account for some variance in the findings. Finally, the sample was also predominantly female.

Discussion– Mental Health

It appears from the papers discussed above that overall there is an effect of abuse on mental health outcomes. In terms of specific patterns of outcome for mental health, two of the papers found links with higher rates of depression, and two found an effect on rates of PTSD symptomatology. In addition, behavioural measures taken in two of the papers found higher rates of sexualised behaviour in relation to sexual

abuse specifically (which is in agreement with the wider literature on sexual abuse impact (e.g. Browne & Finklehor, 1986). However, there is no clear pattern to indicate which specific clusters of mental health symptoms may emerge as a result of abuse. This variation in findings is likely to be as a result of the diverse designs used to tests for mental health outcomes.

In terms of depression and anxiety outcomes, the present findings would support the idea that abuse experiences can contribute to the emergence of these difficulties. This is in agreement with wider literature on abuse impact which has found consistently that abuse raises risk of later depression and anxiety problems (Penza *et al*, 2003).

In terms of conceptualising abuse sequelae as PTSD, only two studies used a specific measure for PTSD and both found that those individuals in the abuse group scored higher for PTSD symptomatology. However one of these studies used children and adults in the sample and did not control for the impact of other trauma experiences, which is likely to have confounded the data. Despite this it does appear that the application of PTSD criteria is useful to an extent in extracting at least some of the unique outcomes stemming from abuse experiences. There is a question in the literature currently around whether PTSD criteria can be directly applied to this population as a whole or whether the criteria would need to be modified to reflect the different ability of this group to experience and report the symptoms of PTSD as it is currently conceptualised. It seems likely from research into the typically developing population that PTSD may be useful, but could be seen as only one aspect of the wide range of sequelae found following abuse, including disturbance of mood, arousal, and behaviour, and in the case of sexual abuse, sexual problems (e.g. Cloitre *et al*, 2005). From the present review, it appears that using existing PTSD criteria may be a reasonable starting point, but that studies would need to be designed to take account of other possible confounding trauma.

Only one study in this section found links explicitly between severity of sexual abuse and severity of MH outcomes (Sequeira *et al*, 2003), and unfortunately this study used retrospective methods, meaning that the data on severity of abuse may not reliable.

The papers here broadly fit with the literature on impact of abuse on mental health and behaviour within the general population, in that there has been a wide range of sequelae found and the mechanisms which predict particular outcomes are still not well understood. More research is needed to establish whether differences do exist for the ID population in this respect.

2. Impact of abuse on skills and adaptive behaviour

Murphy *et al*(2007) examined the effects of abuse experiences on changes in skills and adaptive behaviour in adults with severe ID, using a retrospective case-series design, which gained an 'adequate' rating in the current review. This rating was due in part to the lack of control group and retrospective nature of the carer-report data on outcomes. Details of the study can be found in Table 5, below. This study was conducted in England, and used a small sample of 17 carers reporting on 18 individuals with severe ID. The authors hypothesised that sequelae of abuse in this more severely impaired group may be more usefully measured by examining change in skills and emergence of behavioural difficulties following abuse, rather than PTSD symptoms, which may not be easily measured in this group. Their study used an initial interview to establish nature and extent of abuse, as well as legal consequences of the abuse. Outcomes were measured using The Adaptive Behaviour Scale, used retrospectively for 3 time points: before the abuse, immediately after the abuse, and present day. This study found that there was a pattern in decline of skills immediately following abuse and some recovery towards baseline by the present day (time 3). This was a statistically significant change for the domains of independent functioning, self-direction, responsibility and socialisation. In terms of behavioural difficulties, the study found that behaviour problems were worse after abuse and somewhat recovered by time 3.

Table 5: Study examining impact of abuse on skills and behaviour

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
<p>Murphy, O'Callaghan & Clare (2007)</p> <p>Retrospective case-series study of the impact of abuse on the behaviour of adults with severe ID over 3 time points (before abuse; immediately after abuse; current)</p>	<p>17</p> <p>'Adequate'</p>	<p>Characteristics and disabilities of participants</p> <p>Nature and extent of abuse</p> <p>Support offered following abuse</p> <p>Life events</p> <p>Change in skills and adaptive behaviours over time</p> <p>Research aims: To find if there would be a change in a) skills and b) behavioural difficulties, following alleged abuse, for those with severe ID</p>	<p>Sample acquisition: Participants were recruited by approaching solicitors working in the field of abuse and ID.</p> <p>Sample characteristics: Participants were family members or carers for people with severe or profound ID who had allegedly been abused, where this resulted in police involvement (at least police interviews of perpetrators).</p>	<p>No measure used to establish ID since only carers were participating; however information on the aetiology of the ID was taken during the interview.</p> <p>Measure of abuse: Gathered during initial interview</p> <p>Measure of other life events: An adapted and extended version of the life events checklist from the mini PAS-ADD (Psychiatric Assessment Schedule for Adults with Developmental Disabilities) was used</p> <p>Measure of impact: The Adaptive Behaviour Scale (ABS – Residential and Community; parts I and II) was used, which is an informant based interview schedule. This was used for 3 retrospective time-points to reflect functioning before and immediately after the abuse and current functioning.</p>	<p>Non-parametric analyses of variance showed that there were significant changes over time for almost all factors of the ABS, with best scores at time 1, worst at time 2 and somewhat recovered by time 3 (all $p < 0.01$). The exception to this pattern was for factor A ('personal self-sufficiency') where the time 3 score was worse than time 2 (non-significant).</p> <p>Results appear to show that abuse has an impact on both skill levels and behavioural difficulties, which then improve somewhat over time but are not completely restored to pre-abuse levels.</p>	<p>Small sample size</p> <p>Unclear how ID status was confirmed</p> <p>Retrospective information gathering from an informant and difficulties in accuracy of memory and completeness of knowledge of skills at each time.</p> <p>Difficulty in retrospective rating in context of knowledge of abuse and beliefs about this could skew reports about functioning.</p> <p>A strength of this study was that other life events were recorded and timings taken to help control for other factors contributing to change in skills.</p> <p>The sample was not representative as it was drawn from those with solicitor involvement, although this is acknowledged by the authors.</p>

Discussion – Skills/Behaviour

Due to the retrospective design, the authors acknowledged that changes found in the study may not be entirely attributable to abuse. The carers completed the adaptive behaviour checklist in full knowledge of the target individuals' experiences of abuse. Consequently, the perceptions of the caregivers are likely to have been influenced by variables such as accuracy of recall, beliefs about likely impact of abuse and beliefs about the resilience or vulnerability of the target individual. A control group of individuals who had not been abused but had experienced another life change (such as a change of residence) might have helped to deduce which aspects of change in skills were due to the experience of abuse.

Unfortunately, the methodological limitations to this study make it difficult to draw even tentative conclusions about the impact of abuse on individuals' skills and this is an area which requires further research. For example, future studies could repeat assessments of adaptive behaviour that had been carried out with individuals prior to the abuse, as this approach may provide vital data on the topic.

3. Impact of abuse on stress and coping

Hickson *et al* (2008) examined psychological status, decision-making abilities and stress and coping in a sample of women with ID with and without documented abuse history within the last 5 years. The authors examined outcomes which would be relevant to planning intervention programmes for this group. This study achieved a 'good' rating in the present review, and is detailed in Table 6, below. The authors used a case-control design on a sample from the New York City area, to compare the groups on a range of measures that had been specifically developed for use with people with ID. The Decision-Making Video Scale (Khemka, 2000) uses video clip vignettes to simulate abuse scenarios, after which participants are asked to decide the best course of action in the situation. In addition, measures were taken using the Stress Management Survey – Revised, a measure of stress, the Coping Strategy Scale, assessing coping styles, and the Support Systems Scale, assessing participants' perception of their social support system. In addition the Risk Indicator Survey was used to gather information on current diagnosis, service involvement and social/community participation. This study found that, for the abused group, there

was a higher likelihood of responding to the abuse scenarios with 'passive/avoidant' decision-making responses. Those in the abuse group reported higher levels of stress, and there was a trend towards those in the abuse group reporting higher levels of emotional coping, although this was only approaching significance for the sample. In terms of information from the risk indicator survey, chi-square analysis showed that the abuse group was more likely to have a dual diagnosis, and more likely to be receiving group or individual counselling than the non-abuse group. In addition those in the abuse group were less likely to have as many friends at the agency, and less likely to go out into the community without others supporting them.

In relation to the present review question, it is not possible to draw conclusions about impact of abuse from the findings related to decision-making, level of community support or social support, since the direction of causality cannot be established. However, the authors reflect that levels of self-reported stress could be viewed as a consequence of abuse experiences, since this would be consistent with findings from other researchers (Ryan, 1994).

One issue with this paper is that it only examined experience of abuse within the last 5 years, and does not therefore look at the possible impact of earlier abuse. Also, the small sample size impacted on the power of this study and some of the trends may have reached significance with a properly powered study.

Discussion – Stress/Coping

Although again it is difficult to draw conclusions on broader patterns based on a single study, it does appear from this paper that there may be links between abuse experience and stress levels and coping style. In terms of fit with the wider literature, there is not a large number of studies looking at this type of outcome. However, a study by Leitenberg, Gibson & Novy (2004) did find an effect of more extensive abuse on the likelihood of endorsing more avoidant-type coping strategies. There is scope for more research into the impact of abuse on coping strategies, as this could prove potentially useful in developing interventions to reduce vulnerability to abuse.

Table 6: Study examining impact of abuse on stress and coping

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
<p>Hickson, Khemka, Golden & Chatzistyli (2008)</p> <p>A case-control study of women with ID, with and without a history of abuse, examining a variety of measures relevant to informing interventions.</p>	<p>16</p> <p>'Good'</p>	<p>Abuse variables: documented history of abuse in previous 5 years, Outcome variables: decision making, coping, stress management, social support</p> <p>Research aims: To compare women with and without abuse history within the past 5 years, on measures relevant to intervention development.</p>	<p>Sample acquisition: Recruitment from a clinic and 3 day service sites in New York City, conducted by staff members at the agency, based on selection criteria: female, IQ of between 35 and 75, aged between 22 and 55, not living in an agency-supervised residence.</p> <p>Sample characteristics: n = 36, of which 21 with documented abuse and 15 with no documented abuse within past 5 years; All female; Mean age: 33.3 years.</p>	<p>ID measures: Information on IQ appeared to be present for all participants but unclear how this was established – possibly existing case note information</p> <p>Risk Indicator Survey (Hickson, Khemka & Wills, 2002) used by case manager to give information on abuse history for previous 5 years</p> <p>Decision-Making Video Scale – modified from a scale developed by Khemka (1997; 2000) and used to assess independent self-protective decision making in response to simulated abuse situations.</p> <p>Self-report measures: Stress Management Survey – Revised (Khemka <i>et al</i>, 2005) – a self-report of stress Coping Strategy Scale – Revised (Hickson <i>et al</i>, 2002) – a self-report for coping. Support Systems Scale (Hickson 2002) – self-report of perceived support</p> <p>Risk Indicator Survey – a staff-based measure including information on abuse, mental health, current intervention, social contact and supervision by family/staff.</p>	<p>A significant difference between groups was found for likelihood of passive/avoidant responding to simulated abuse scenarios ($p = <0.01$). No other differences were found in response to the decision making task.</p> <p>The group with history of abuse reported significantly higher levels of stress ($p < 0.01$).</p> <p>Also, those with abuse history more likely to have dual diagnosis; to be receiving counselling; More likely to venture out with others accompanying them.</p>	<p>Unclear how IQ information was established.</p> <p>Difficulty in establishing 'impact' element as direction of causality/influence between decision making and abuse history is unclear</p>

4. Impact of abuse on violence and aggression

Two identified studies examined the impact of abuse on violence and aggressive behaviour, in the context of a forensic ID population. Details of these studies can be found in Table 7, below.

Novaco & Taylor (2008) used a relational design to examine exposure to parental anger and aggression (including experience of physical abuse from parents) in relation to current anger and assaultiveness, for a sample of 129 male forensic inpatients with ID residing in England and Wales. This study achieved an 'excellent' rating in the present review. Details of the study appear in Table 7a.

The study used structured interview schedules to ascertain details of parental anger and abuse. Comprehensive information on current anger, aggression and assaultiveness was gathered through the use of self-report and staff-rated measures, namely the Spielberger State-Trait Anger Expression Inventory (STAXI), the Novaco Anger Scale, the Provocation Inventory and the Ward Anger Rating Scale. In terms of results relevant to the current review, the study found that those patients who experienced physical abuse specifically from parents or carers were significantly higher in self-reported anger as assessed by the NAS ('Total' and 'All' subscales) and by the STAI 'Anger Out' subscale, but not on the other anger subscales. Also, physical abuse history was associated with higher rates of staff-reported anger as measured by the WARS. However in the final multivariate analysis, they found that the effect of childhood physical abuse was only significant for the ratings of antagonistic behaviour, therefore only partially confirming the hypothesis that physical abuse from carers would be related to anger and aggressive behaviour in hospital. This study used robust measures which were validated for this population, and was noted to possess a rigorous design and analysis section. Issues with the study included the fact that reports of family anger and abuse were based on self-report in a clinical setting and may not have always represented a reliable or accurate account. Non self-report measures showed differences between the abused and non-abused groups, but the self-report measures mostly did not, and this indicative of some lack of reliability between the forms of measures in this study.

Table 7: Studies examining impact of abuse on violence and aggression
7a.

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
<p>Novaco & Taylor (2008)</p> <p>A relational study on male forensic inpatients with ID, examining the relationship between exposure to parental anger/aggression and anger/assaultiveness in a ward environment</p>	<p>20</p> <p>‘Excellent’</p>	<p>IQ</p> <p>Length of stay in hospital</p> <p>Index offence</p> <p>Anger/aggression</p> <p>Family background/case history</p> <p>Research aims: To explore whether parental anger and aggression is related to individuals’ anger and aggression.</p>	<p>Sample acquisition: Sample was drawn from the inpatients in a specialist forensic ID hospital service in England.</p> <p>Sample characteristics: ; n = 107; mean age 33.2; All male; mean WAIS-R FSIQ score = 67.5. Of the sample, 36% had previous convictions for violent offending; 38% had no convictions for violence but documented history of violence/aggression; 26% had no documented history of violence/aggression.</p>	<p>ID measures: WAIS-R Full Scale IQ taken from case file.</p> <p>Abuse measures: Structured interview and case file information</p> <p>Outcome measures: Anger/aggression: Spielberger State-Trait Anger Expression Inventory (STAXI) (Spielberger, 1996) – an established and widely-used 44-item anger measure. Novaco Anger Scale (NAS) (Novaco, 2003) – developed for use with mentally disordered and normal populations and validated for use with forensic and clinical populations. Provocation Inventory (PI) (Novaco, 2003) – developed to accompany the NAS and provides an index of anger reaction in provocative situations.</p> <p>Ward Anger Rating Scale (WARS) – a 2 part scale completed by a member of ward staff as a measure of aggression/assaultiveness.</p> <p>*All measures were modified for use with an ID population and to be administered via structured interview.</p>	<p>45.8% of the sample reported having been physically abused at home.</p> <p>T-tests showed that those patients who were physically abused were significantly higher in self-reported anger as assessed by NAS Total ($p = 0.003$) and the STAXI ‘Anger Out’ subscale ($p = 0.038$). Patients with physical abuse history were also higher in anger and aggression as measured by the WARS ($p = 0.003$; $p = 0.032$) and by hospital reports of assaults ($p = 0.039$).</p> <p>Hierarchical regression with forced entry revealed that physical abuse is significant ($p = 0.009$) and accounts for 6.2% of variance in anger as measured by the NAS, but did not contribute significantly to the final model that included the witnessing of parental anger/aggression.</p> <p>Childhood abuse was significant in predicting antagonistic behaviour, as measured by staff ratings and hospital records.</p>	<p>Limited generalisability to other populations</p> <p>Retrospective self-report of abuse history so may not be accurate</p> <p>Individuals with ‘borderline’ ID included in sample</p>

7b.

Author(s); study design	Quality score and rating	Variables considered	Sample characteristics	Measures	Main Relevant Results	Methodological Issues
<p>Hayes (2009)</p> <p>Case-control study comparing sex offenders with ID to sex offenders without ID, using structured clinical interview to establish retrospective information on childhood abuse.</p>	<p>17; 'Good'</p>	<p>ID status</p> <p>Self-reported abuse history</p> <p>Previous psychiatric diagnosis</p> <p>Patterns of offending behaviour</p>	<p>Sample acquisition: Convenience sampling of male sex offenders referred to a forensic psychology clinic due to offending behaviour.</p> <p>Sample characteristics: 40 male participants; 20 with ID and 20 non-ID. Age range: 18 – 52; mean age 35.</p> <p>ID group: Mean K-BIT score = 55; mean VABS score = 50. Non-ID group: mean K-BIT score = 85; mean VABS score = 77.</p>	<p>ID measures: Kaufman brief Intelligence Test (K-BIT); Kaufman & Kaufman, 1990) Vineland Adaptive Behaviour Scales (Sparrow <i>et al</i>, 1984). IQ cut-off score = 70.</p> <p>Abuse measures: Structured clinical interview; Lindsay <i>et al</i>'s (2001) parameters for abuse were used.</p> <p>Outcome measures: Structured clinical interview; previous psychiatric disorders were defined using the DSM-IV.</p>	<p>Those in the ID group more likely to be diagnosed with depression ($p < 0.01$), PTSD ($p < 0.00$), and aggressive behaviour ($p < 0.02$).</p> <p>Within the ID group, those who demonstrated aggressive behaviour were more likely to have reported being the victim of childhood physical abuse ($p < 0.00$) and exposure to family violence during childhood ($p < 0.05$). For the non-ID group there was no such relationship between aggression and prior exposure to violence.</p> <p>For the ID group, prior sexual abuse was related to suicidal ideation ($p < 0.01$) and attempted suicide ($p < 0.00$).</p> <p>Those offenders with ID who had been physically abused were more likely to threaten violence during an offence ($p < 0.00$); to use violence during an offence ($p < 0.00$) or to use a weapon ($p < 0.01$) compared to the non-ID group.</p>	<p>Issues of using retrospective self-report data on abuse history – queried reliability of accounts of abuse.</p>

Another study the following year by Hayes (2009) also examined abuse experiences and impact on aggression within a forensic sample, this time in Sydney, Australia. Details of this study are shown in Table 7b. This study looked at sex offending behaviour and the relationship to childhood abuse in a sample of 20 male sex offenders with ID being assessed by community psychology services. This was a case control study which compared with a group of 20 non-ID sex offenders. This study gained a rating of 'good' in the current review, and can be found in Table 4b. Structured clinical interview was used in this study to gain information on prior abuse (which was categorised into physical or sexual abuse) and current and previous psychiatric disorders. Information on their offences was gained from police records and legal documents. The Vineland Adaptive Behaviour Scale was also used to gain a measure of skills and behavioural difficulties. The groups were compared, and it was found that within the ID group, those who demonstrated aggressive behaviour as adults were significantly more likely to have been the victim of childhood physical abuse and exposed to family violence, although this relationship was not found within the non-ID group. For the ID group, sexual abuse history was related to suicidal ideation, and child sex abuse was linked with attempted suicide for both groups. For the non-ID group, childhood physical abuse was related to depression and anxiety disorder and this was not found in the ID group.

In terms of the effects of abuse on offending behaviour, the authors found that ID offenders with physical abuse history were more likely to threaten violence, use violence or use a weapon during an offence, compared to the non-ID group. A strength of this study was the delineation of experiences of physical abuse and witnessing of family violence. This allowed for the examination of the effects of each type of experience. Issues with this study again included the use of retrospective self-report data for gathering information on abuse history, as this may not be reliable.

Discussion – violence and aggression

Both papers examining impact of abuse on aggression show consistent findings, and it appears that there is a link between experience of abuse in childhood and extent of aggression and assaultiveness within the forensic ID population. Issues within the

results of the Novaco & Taylor (2008) paper demonstrate the difficulties of discrepancies between staff and self-rated measures, and this paper also found that physical abuse only accounted for a small proportion of anger variability, which suggests that other factors are important in accounting for anger outcomes. Overall it appears again that these patterns of findings fit broadly with the wider literature which has found strong links between physical abuse experiences and later violence and aggressiveness (Malinosky-Rummell & Hansen, 1993). However further research in this area could focus on maximising reliability of data on abuse experiences rather than relying on retrospective self-report and casenote data.

Discussion

The papers will be discussed as a whole in the following section. Since many of the studies examined various mental health and behavioural outcomes as secondary measures, these outcomes will be discussed below with regard to patterns emerging across all of the included papers.

Overall Findings

Overall the literature regarding the impact of abuse on mental health (MH) and wellbeing for adults with ID is scarce, and limited by variability of measures used and issues with study design. Unsurprisingly, from the existing studies it appears that there is emerging evidence of wide-ranging psychological and behavioural sequelae related to experience of abuse in individuals with ID. In particular, a consistent finding across many of the studies appears to be the existence of a robust relationship between overall experience of abuse and experience of mental health problems, however these are conceptualised. When examining the impact of different types of abuse, it appears that experience of sexual abuse specifically may be a risk factor for the development of problems with sexual maladjustment, although these outcomes may need to be more carefully defined in future research. Studies examining physical abuse specifically found links with anger and aggression but this has so far only been examined in a forensic context with a male population. These findings would be in agreement with literature on the typically developing

population, which has found that experiencing physical and sexual abuse increases the risk of developing mental health difficulties (Breire & Elliott, 2003).

Mental Health and Wellbeing Outcomes

Specifically, the papers reviewed appear to show that experience of abuse is linked to the emergence of psychiatric problems as defined by current diagnostic criteria, and some of the studies specifically found a link with depression (Hayes, 2009; Matich-Maroney, 2003; Sequeira *et al.*, 2003), with anger (Novaco & Taylor, 2008), and with anxiety (Matich-Maroney, 2003), as well as PTSD (Sequeira *et al.*, 2003; Shabalala & Jasson, 2011). However many of these findings depend on specific measures used in individual studies, as no single study appeared to gather and report on a wide range of mental health outcomes. Dual diagnosis was found to be related to experience of abuse in two of the studies, and this may reflect the complex nature of abuse sequelae and its contribution to a MH presentation within ID.

The only study to make a direct comparison between ID and non-ID groups was the Hayes (2009) study, which did not find a link between childhood abuse and depression for the ID group but did for the ND group. It is difficult to generalise from a single study, but it appears that there may be differences in the sequelae between ID and non ID victims of abuse and this warrants further investigation to uncover these differences.

Another interesting finding across the studies was the disagreement in papers investigating childhood experiences of abuse, for which Smiley *et al* (2007) found no effect on MH outcomes, whereas the Hayes (2009) study found an effect of sexual abuse specifically on suicidal ideation and attempts at suicide. There is a methodological issue present here since some of the studies used 'previous abuse' as a criterion for inclusion in the study group. It may be more useful, given these mixed results, to separate out abuse experiences based on the point in the lifespan when they occurred, as this may influence their impact. The lack of impact on mental health outcomes found by Smiley *et al* (2007) for childhood abuse may reflect prospective changes across the life span or may be indicative that the measures used

were not sensitive enough to aspects of abuse and corresponding aspects of impact within current mental health, experience and quality of life.

Behavioural Outcomes

Overall, three of the papers in the review examined behavioural sequelae, and were not in agreement, as Smiley *et al* (2007) found no link from abuse to behaviour problems. However, Murphy *et al* (2007) found that behavioural difficulties became worse and then improved over a period of time following abuse. Unfortunately, the retrospective nature of the proxy reporting within the latter study makes it difficult to draw conclusions, since these carer reports will necessarily be influenced by subsequent knowledge of the abuse. Further evidence for the impact of abuse on behavioural outcomes, however, comes from the Sequeira *et al* (2003) study which found an effect of sexual abuse experiences specifically on the presence of behavioural problems such as lethargy, hyperactivity, self-injurious and sexualised behaviour. This finding was not replicated by the other studies included in the review. The two studies examining forensic ID populations both found a relationship between experience of childhood physical abuse and present-day rates of aggressive or antagonistic behaviour (Novaco & Taylor, 2008; Hayes, 2009).

It could be that effects of early abuse on behaviour outcomes were not captured by Smiley *et al* (2007), since these outcomes may have emerged before the 2 year 'incidence' period. Links between childhood abuse and aggressive behaviour may be particular to the forensic ID population. Alternatively, it may be that measures of aggression have been implemented more comprehensively within the forensic studies (particularly in Novaco & Taylor, 2008), and such links may also exist within the general ID population. Overall, behavioural outcomes appear to be important when assessing outcomes of abuse in an ID population, but since the findings are diverse, further research is required to extract information about which types/aspects of abuse experiences increase risk for particular behavioural outcomes.

Wider Implications

In terms of the wider body of research, the findings from the present review appear to be in agreement with literature in the non-ID population which has found that

although abuse experiences have an impact on mental health and behavioural outcomes (such as substance abuse), the experience of abuse does not predict lifetime incidence of mental ill-health, and that prospective change over the life course occurs in the context of other factors (Horwitz *et al*, 2001). In terms of the adult literature, recent reviews have found non-specific impact of abuse experiences on various wide-ranging axes of mental health and functioning (Hillberg *et al*, 2011; Jordan *et al*, 2010), which fits with what was found here in terms of the breadth of outcomes.

There also appears to be support for research in the area of child development, which concludes that it is not helpful to think of abuse sequelae in terms of one single symptom profile, and that differential effects may be understood in terms of developmental factors and factors associated with support, as well as the nature, severity, duration and consequences from abuse experience. It appears from developmental research that stage of development when abuse takes place is very important, and impacts on trajectory and skills acquisition, which will affect emotional and behavioural outcomes in the long term (e.g. Perry & Hambrick, 2011). A review into impact of childhood abuse also found that severity and circumstances of abuse were important in predicting symptomatology, but concluded that there was no evidence for a single traumatising process, rather a combination of factors which would contribute to severity of trauma (Kendall-Tackett *et al*, 1993).

Due to the breadth of sample characteristics and measures used in the reviewed papers, it is difficult to make broad conclusions regarding the impact of abuse on an ID population. There is a need for more high-quality longitudinal data examining the impact of abuse specifically on mental health and on other aspects of wellbeing such as behaviour problems, maintenance of adaptive skills and quality of life outcomes such as social interaction and community participation. There is also a need for replication of effects found in the present reviewed papers, using standardised measures to obtain a robust evidence-base for the profiles of difficulty that may arise as a result of abuse experiences. In addition, since the scope of this paper was to review impact of abuse generally, due to the dearth of literature, there is a need for investigation into the differential effects of sexual and physical abuse, and of other types of maltreatment such as neglect, so that the effects of these experiences

on this population can be better understood and effective interventions and prevention strategies can be developed.

Methodological limitations of included studies

There were methodological limitations to many of the studies included in the review, which may in part have been due to the sensitive nature of the information being obtained, and the issues around gaining consent from participants, carers and families. Convenience sampling was used for some studies, and the small sample sizes in some of the studies mean that clear patterns of sequelae are more difficult to ascertain. There appears to be a difficulty in establishing the presence of abuse and some of the methods used (e.g. use of court reports and case notes) can lead to sampling bias by only including those whose abuse had been widely known or had led to court action. There are clear ethical issues within this area of research, particularly around establishing the presence of abuse, and the handling of disclosure of alleged abuse which is not proven, or not investigated. Strategies therefore need to be developed to allow for standardisation of how such abuse data is handled and examined. Overall there has been a lack of studies with a longitudinal design, and it appears that research is required which will look prospectively at the impact of aspects of abuse experiences over time, within the context of community and inpatient ID populations.

Another limitation of the included studies was the broad range of geographical and cultural cohorts from which the samples were drawn. It is necessary to exercise caution when generalising across studies from different areas and populations since in this case particularly, cultural and social factors such as attitudes toward abuse and disability, as well as differences in legal and support services will have had an impact on how these studies were conducted, as well as on the outcomes found. Further work on standardisation of measures around abuse and outcomes would improve the generalisability of findings within this research area for the future.

Strengths, limitations and future research

The present review has drawn together recent research on the impact of abuse experiences within the adult ID population, which is an area of clinical importance, where there is a lack of high quality longitudinal data. This review has shown the

existence of wide-ranging and diverse psychological and behavioural sequelae stemming from abuse experience and has highlighted the need for further research in this area. The current review was limited to published research in the English language, and was limited in scope to examining the adult literature, so it has not been possible to draw broader conclusions concerning the possibility of changes in abuse impact over the lifespan.

Additionally, although some of the included studies in the present review examined specific types of abuse, the paucity of literature overall meant it was necessary to examine abuse studies as a whole. Clearly there will be distinct profiles of negative sequelae arising from different forms of abuse, and different abuse circumstances. Future research could focus on delineating these different abuse experiences to provide more information on the mechanisms which predict outcomes following abuse.

In terms of future areas of research, the present review has highlighted the need for high-quality, controlled longitudinal research into abuse impact within this population, along with standardisation of ways of measuring aspects of abuse such as a standardised structured interview, to allow for better comparison between studies, and to facilitate understanding of which aspects of abuse predict which outcomes for those with ID.

There is also a need to investigate protective factors which may buffer effects of abuse experiences, such as positive supportive relationships (e.g. Ludy-Dobson & Perry, 2010). Moreover, abuse experiences need to be understood within the likely context of wider experiences of maltreatment and adverse circumstances which often co-occur (e.g. Perry & Hambrick, 2011). It is this combination of factors that may all contribute towards developmental difficulties and lead to subsequent complex problems with emotional and interpersonal functioning (Cloitre *et al*, 2005).

Finally, it should be considered that as well as acting as a vulnerability factor for abuse, cognitive impairments, including learning disabilities, are known to arise as consequences of abuse, neglect and other adverse early experiences (Gaskill & Perry, 2011). This relationship was not explicitly explored in the included papers for the present review. It is clear however that future studies on the effects of abuse for

this population may need to encompass some understanding or awareness of the cognitive and developmental implications of abuse experiences (particularly early childhood abuse), to ensure that outcomes are measured in a way which reflects this. It may be difficult to separate vulnerabilities and consequences of abuse in this context, particularly in the adult population, which contributes to the argument for more longitudinal research in order to better understand these developmental factors.

Conclusions and Implications for NHS Policy and Practice

This review highlights the need for formulation led approaches to ID clients with complex presentation within services, since sequelae can be diverse and influenced by a range of factors. Abuse should 'held in mind' by professionals and carers, and individuals should be educated about their rights and the reporting of abuse, to reduce risk. Also, this review highlights the importance of the continuation of a qualitative research stream, particularly in establishing the elements of abuse experience which are perceived as difficult to overcome, and an understanding of changes in life quality and wellbeing following abuse. Greater insights into individual experiences may contribute to more sensitive interventions targeted at the particular needs of people with ID.

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CHAPTER TWO: MAJOR RESEARCH PROJECT

Dealing with social threat: Examining behavioural responses to anxiety-provoking situations for young adults with mild intellectual disability

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Doctorate in Clinical Psychology (DClinPsy)*

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Plain English Summary

To date, there has not been much research looking at how young adults with intellectual disabilities (ID) cope in difficult social situations. 'Intellectual disability' is a term used in psychology to mean a significant difficulty with learning and with everyday skills, where people often need support to live independently. People with ID often have different social experiences from other people, because of their difficulties, and some studies have found that people with ID might find social situations (such as meeting new people) very stressful when compared with people who are not disabled. We thought it might be useful to look at social worries in college-aged people, since leaving school is a time when many people have to deal with new social situations. The study we did was designed to see if college students with ID worry more about social things than the non-disabled students, and whether they have different ways of coping in stressful social situations.

In the study we asked young people (between 16 and 22 years old) about their worries and then asked them what they would do in some different stressful social situations. We recruited a group of 21 people who had ID and 20 people who didn't have ID, from local colleges. We used photographs to help people talk about their different worries, and asked them to pick their 'top 4' biggest worries. We then asked people what they would do in 6 different social situations (such as if they were asked to stand up and demonstrate a cooking technique in front of a college class). We used photographs to help make the situations seem 'real'. We audio-recorded what the students said and looked at their responses to see if they were different between the two groups, for each of the two tasks.

We found that the two groups worry about some similar things such as money and death, but also that lots of their worries are different. For example the non-ID group worried more about things to do with planning for their future and becoming independent. The ID group worried more about the past deaths of loved ones in their family, and worried more about bullying, as many of the ID group said they had

been bullied in the past. Results from the coping task showed that again, there were some differences and similarities between groups in their ways of coping. Those students without ID tended to talk slightly more about trying to hide their feelings and changing other people's feelings. Students with ID talked slightly more about concentrating on the task and about avoiding the stressful situation. However, overall the coping strategies were similar for the two groups, and both groups found situations involving possible rejection from others particularly uncomfortable. This suggests that young adults with ID don't appear to be more troubled by social stress, and don't seem to react hugely differently to difficult social situations, compared with those without ID.

The results of this study will be useful for helping those who work with young adults to understand what kinds of worries they have. Also it will help to know which types of coping might be more difficult for students with ID to learn, so that they can be supported to develop useful coping strategies.

Abstract

Background

People with intellectual disabilities (ID) may respond differently to social stressors due to differences in social conditioning and acquisition of skills. The present study examined whether social worries are more salient for young people ID than their non disabled peers, and whether there are differences in their responses to socially stressful situations.

Method

Forty-one participants aged 16 to 22 took part in this study; 20 typically developing young adults and 21 with mild ID were recruited through local further education colleges. The groups participated in an open-ended 'worry' interview where they described their worries and rated them in terms of salience. They were then asked how they would cope in a series of 6 'social threat' scenarios, using pictorial vignette stimuli. Responses for worries and coping were content analysed and categorised.

Results

It was found that there were some differences between the groups in terms of content of worries reported, with the ID group reporting more worries about maintaining friendships and being bullied, whereas the non-ID group worried more about future aspirations and gaining independence. In terms of coping styles, the control group endorsed more sophisticated responses involving management of social and emotional presentation, but overall coping between the groups was broadly similar. Finally, both groups reported a high rate of 'emotion-focussed' responding in response to situations involving risk of social rejection, and this appears to reflect that these situations may be particularly stressful for both groups.

Discussion/Implications

This study contributes to the literature on transition and social coping for those with ID, and in particular adds weight to the idea that young adults with ID have a different profile of worries at this life stage, but this does not appear to impair social coping, and those with ID possess a variety of strategies to utilise in situations of social stress, although these strategies may be less sophisticated at times than non-disabled peers.

Keywords: intellectual disabilities; young adults; worries; social coping; transition; stress

Introduction

Transition to adulthood is a key stage for developing social contacts beyond the family context, and it is a stage when broader social relationships take on greater importance (Elias *et al*, 1985). Adolescence has been shown to be a stressful time for many young people (Eccles *et al*, 1995), and it seems likely that this may also be the case for individuals with intellectual disabilities (ID), who may struggle with achieving life goals ordinarily expected of young people when they leave school, and may have to negotiate new and unfamiliar social situations at this time. There are, to date, few studies examining the specific stresses and coping styles of young people with ID negotiating the transition to adulthood.

A recent study by Forte *et al* (2011) found that for a sample of young people with and without ID, the content of their worries was different, with a larger proportion of social worries reported by the ID group. This is in agreement with other literature which has found that individuals with ID find social stress particularly upsetting compared with other types of stress (Bramston, Fogarty & Cummins, 1999; Hartley & MacLean, 2005) and that people with ID can experience particular difficulties in forming and maintaining peer relationships (Carison 1987; Hoyle and Serafica 1988). It appears not only that the profile of worries at transition may be different for young people with ID, but that social worries are a particularly salient source of stress for people with ID in general.

Successful negotiation of social stressors during the transition to adulthood requires the development and utilisation of adaptive strategies for coping with these stressors. Lazarus & Folkman (1984) have defined 'coping' as 'cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'. Since social concerns appear to be particularly stressful for those with ID, it may be important to investigate the nature of social coping styles adopted in response to these social stressors. Little research has been done into coping strategies used by adults with ID, and to date there are no studies which investigate social coping specifically for this population. However, clues from the wider literature on coping has shown that social coping styles change with age and become more sophisticated during

development to adulthood (Losoya *et al*, 1998). One study with adults found differences in coping strategies between ID and non-ID groups on 'choice-making' tasks; ID participants appeared to make more unconsidered, 'knee-jerk' responses to unfamiliar decisions, in a seeming effort to avoid or escape the choice-making process as quickly as possible (Jenkinson & Nelms, 1994). Nevertheless, these findings were not explicitly linked to anxiety or to social concerns specifically. Another study by Hartley and McLean (2005), concerning the coping styles of people with ID, found a propensity towards 'problem focussed' rather than 'emotion focussed' active coping styles. A drawback to this study was that a control group was not used to allow comparison with non-ID individuals. In terms of coping with anxiety specifically, a study by Kindt *et al* (1997) on childhood anxiety found that developmental factors may be important, since the ability to inhibit anxious responses develops with age, and older children may be better able to inhibit their own anxiety and subsequent anxious responding. This may have some relevance to the current area of investigation, given the unique developmental trajectory of individuals with ID; research indicates that the skills required for social and emotional understanding may develop differently within the mild to moderate ID population (Thirion-Marissiaux & Nader-Grosbois, 2008).

The literature on social coping in ID appears therefore to be somewhat inconclusive thus far due to lack of high quality controlled studies. There are, however, various factors which provide good rationale for why individuals with ID may have a unique profile in terms of their perception of social stress and subsequent coping.

Firstly, the social experiences of those with ID are known to differ from the typical population. This is partly due to a need for additional support. For example, individuals with an ID may attend ID-specific services, and may live with family or in residential settings, socialising mainly with carers and other clients with ID (Robertson *et al*, 2001). Studies into the social networks of those with ID suggest this group may encounter fewer opportunities to develop informal social relationships (Rosen & Burchard, 1990) and tend to rely more on paid staff for emotional support (Lunsky & Benson, 1999). These differences might lead to a relative lack of experience in negotiating certain social situations independently, and the emotional responses and coping styles of individuals with ID may reflect this lack of experience.

As well as a lack of opportunity to experience certain social scenarios, it appears that those with ID may also experience differences in the quality of their interactions with others. This has been examined in the literature concerning *stigma*. There is evidence that having an ID confers a stigmatised social status, or means having a 'culturally judged negative evaluation of a difference or impairment' (Goffman, 1963). People with ID are often subject to high levels of stigmatising behaviour by others (e.g. Jahoda & Markova, 2004), and studies (Dagnan & Sandhu, 1999; Dagnan & Waring, 2004; Paterson *et al*, 2011) have pointed to a possible process whereby awareness of stigmatised status may lead to a sensitivity to stigma. This may, in turn, lead to an increased risk for becoming socially anxious through a process of self-monitoring, in an effort to manage this stigma (Dagnan & Jahoda, 2006).

In terms of how these differences in experience may impact on social coping, some work has been done previously on social threat negotiation within the child ID literature (Carison, 1987). Differences were found between groups in terms of how children with and without ID responded to difficult social situations, with the ID group using less sophisticated strategies. There is ambiguity around whether social or developmental factors (i.e. lack of development of necessary socio-cognitive skills) are responsible for these differences. Yet the high levels of perceived external locus of control and powerlessness found in responses from the ID group point to the possible significance of social and contextual factors during development, which may impact on expectations of social interaction.

It appears therefore that specific investigation of the presence and nature of differences in social stress and social coping between ID and typically developing groups may be an important area for investigation. Exploring the nature of these differences at transition to adulthood may help to highlight how developmental and experiential factors contribute to different patterns of coping with social stressors. Previous work by Forte *et al* (2011) used a sample of young adults with mild to moderate ID and examined worry content. The present study aims to expand on these findings to investigate whether differences in the nature of social worries impacts on coping within social 'threat' situations. In light of the dearth of literature in this area, the current study will therefore be exploratory, and will consist of two parts, investigating:

- A) the content of worries of young college-age adults with and without ID, and specifically the presence of social worries within and between groups;
- B) The social coping strategies employed by each group in response to social 'threat' situations.

Method

Design

The present study utilised a between-groups design, since the primary focus was on the differences between ID and non-ID groups. The study took an exploratory approach, with two distinct phases:

Part 1: Worries

Part 1 investigated worry content and salience, using semi-structured interview and content analysis of verbatim worry data, which was categorised, summed and compared descriptively. Sums of worry salience ratings were also used to investigate quantitative differences in worry between groups.

Part 2: Social Coping

Part 2 investigated the nature of coping responses, between groups, again using verbatim verbal responses on coping, which were analysed via content analysis and categorised and summed for comparison between and within groups.

Participants

Twenty participants with ID and twenty-one typically developing young people were recruited from two separate Further Education (FE) colleges in the West of Scotland. Those students with Autism Spectrum Disorder (ASD) were excluded, due to differences in social responding within this group (World Health Organisation, 2010), which would have served as a confounding factor in the present study.

Interviews, tasks and measures

The following materials were used to examine the participants' worries, and then to investigate their social coping strategies.

Background Information

For each participant, information on age, gender and postcode was recorded by the interviewer. The Carstairs Index (Carstairs & Morris, 1991) was also used as a measure of socio-economic status. The Carstairs Index is an index of socio-economic deprivation which uses postcode area to calculate a single deprivation score based on census information.

Glasgow Anxiety Scale – Intellectual Disability (GAS-ID)

The GAS-ID is a 27-item scale, developed by Mindham and Espie (2003) as a measure of anxiety specifically in those with ID. The scale was developed using existing research data and focus group discussion and has been shown to have good test-retest reliability ($r = 0.95$), good internal consistency (Cronbach's $\alpha = 0.96$) and an acceptable correlation with the Beck Anxiety Inventory ($\rho = 0.75$).

Part 1: ID worry interview (IDWI)

This is an interview framework previously developed by Forte *et al* (2011) to elicit salient worries across young ID and non-ID individuals. It was shown to be a sensitive and effective method of engaging participants and eliciting information about worries across the ID and non-ID populations. Worry topics for this interview (as developed by Forte *et al.*) were derived from the main areas of worry thought to be salient for adolescents in the general population, as identified by Millar & Gallagher (1996), namely: decision-making; work; family; relationships; money; home; college; friends; family; death; loneliness.

The interview process was explained to each participant before beginning the task (i.e. 'Today I want to talk to you about your worries. I have some pictures here that represent different areas of worry. For each picture, I will ask you what you think it is a picture of, and then I will ask you whether it's something that you worry about, and you can tell me, yes, it's a worry for me, or no, it's not a worry for me'). Participants were then presented with photographs representing the 11 areas of worry outlined above (examples of photographs are shown in Appendix 2.2). Participants were presented with each photograph in turn, and asked 'What does this picture make you think of?'. If the participant identified the topic, they were asked 'Is that something you worry about?' at which point their verbatim response was recorded. If the participant did not identify the worry topic from the picture,

prompts were given by the interviewer (e.g. 'this is a picture of a college. Some people have worries about college. Is college something that you worry about?'), in order to allow discussion around this topic. The participant was then asked to indicate whether the topic is a worry by placing the picture in a pile marked either 'Yes' or 'No'. The 11 worry topics were addressed in this way, and presented in randomised order to each participant to avoid ordering effects.

After completing this process for all the photographs, participants were asked if they had any other worries not discussed within the topic areas. Finally, participants were shown the worries which they had placed in the 'yes' pile, and asked to identify their 'top 4 worries', beginning with their 'biggest worry'. A 4-point visual analogue scale was used to illustrate the task. Participants were engaged in conversation at the end of the task, to ensure there was no residual distress from talking about their worries. Materials used in the Worry Interview task can be found in Appendix 2.2.

Part 2: Socially Anxious Situations Task (SAST)

This measure was developed specifically for this study by adapting existing vignettes from the literature on aggression in ID (e.g. Pert *et al*, 1999; Jahoda *et al*, 2006; Larkin, 2011) and on social threat (e.g., Bögels & Zigterman, 2000). Vignettes have been shown to be an effective way of examining individuals' response to social provocation. The vignettes were 'stories' concerning situations of 'social threat'. Each vignette was illustrated by two photographs depicting the situation being described, to aid the participants' engagement and understanding. The stories were told from the point of view of the participant, and the photographs were designed to be from the viewpoint of the protagonist, meaning the protagonist does not appear in the photograph. This was to allow the participants to imagine themselves in the situation. Six 'socially threatening' stories were used in the current study, to represent two areas of social threat thought to be salient based on previous research in this area:

1. Situations related to '**social evaluation**' concerns (i.e. performing a task in front of others). An example 'story' would be:

'You go to a new computing class. Everyone is being shown a new way to search for information. You have never done this before. The tutor asks you a question about it. Everyone turns round to listen to what you have to say'.

2. Situations involving '**social acceptance**' concerns (i.e. threat of rejection by peers). An example:

'You are in town. You see some people that you know from college. They walk past you and don't say anything. When they have walked past, two of the people in the group start laughing.'

Three vignettes were devised for each of the two types of threat scenario. The pictures and stories were presented one by one and participants were asked to imagine being in the situation. They were then asked 'What would you do?' and their verbal response was recorded by the researcher, in order that responses could be content analysed and categories of responses compared between the two groups. Materials for the task are included in Appendix 2.3.

The Wechsler Abbreviated Scale of Intelligence (WASI-II) (Wechsler, 1999)

The WASI-II is an abbreviated version of the Wechsler Adult intelligence Scale (WAIS-III) and was used in this study as a formal measure of cognitive ability. Correlations between the WASI and WAIS-III are reasonable, at 0.88 for Vocabulary, 0.66 for Matrix Reasoning and 0.87 overall. For the present study, the two-subscale version (FSIQ-2) was used.

Pilot phase

This was for the purpose of confirming that the vignettes developed represented meaningful social threat for the two groups of young people. A small group of young adults (n = 3) with mild ID were presented with the series of vignettes and accompanying photographs, to check comprehension of the vignettes and the overall 'threat vignette' task. The pilot phase demonstrated the understandability of the social vignette materials for an ID population, and also confirmed that the vignettes represented situations that were recognised as socially stressful for this population.

Procedure

Ethical approval for the present study was gained from the University of Glasgow Ethics Committee (See Appendix 2.5 for ethical approval documentation), and permission was gained from the colleges prior to commencing recruitment.

Participants were recruited via staff members at the colleges. To ensure students would be able to complete the interview tasks, tutors were advised of the level of receptive and expressive language required to complete the tasks, based on guidance from the Adaptive Behaviour Scale (ABS-RC:2, Nihira, 1993). Staff were then able to select potential classes of participants based on this information. Prior to participation, participants were given information on the study and asked to provide consent in the presence of a member of staff, in order to check comprehension. Information sheets and consent forms are included in Appendix 2.4. Participants were all interviewed individually in a room within the college that afforded privacy. Data collection sessions with each participant lasted around 1 hour and participants were also asked for their consent to audio-record the interview session. Participants' responses were recorded onto response sheets by the researcher during the tasks. Audio-recordings of interviews were checked against the recorded response sheets for accuracy. For one participant who did not consent to audio-recording, responses were written down verbatim during the interview.

Participants were engaged in conversation before beginning the task, to help build rapport and ensure they were relaxed. Explanation was given as to the purpose of the study and all participants were advised that there were no 'right' or 'wrong' responses for the main tasks, before proceeding. Measures were administered in the order stated above. The WASI-II was administered last since it is the only measure to have 'right' and 'wrong' responses and is therefore inconsistent with the 'spirit' of the verbatim tasks which were focussed on eliciting the participants' perspectives. The researcher spent time speaking with the participants at the end of the session to ensure residual anxiety was not carried over from the tasks.

Sample size considerations

A sample size of 50 participants, (25 with mild intellectual disabilities and 25 without disabilities) was considered sufficient for this exploratory and mainly qualitative

study, as this sample size was successfully used in a previous study comparing the participants' open ended views about their worries (Forte *et al*, 2011). However, difficulties with recruitment within the term-time timeframe and within the constraints of the exclusion criteria (particularly the exclusion of those students with ASD) meant that the final sample obtained was 41 participants.

Results

After describing the socio-demographic characteristics of the participants, part 1 of the results will describe the data on the four 'top' worries reported by each of the two groups during the Worry Interview task, along with descriptive data on the content of these worries. Part 2 will then outline the results from the Socially Anxious Situation Task, and will compare the frequency of different styles of coping response reported by the two groups in response to the social threat vignettes.

Background Information

The ID and non-ID groups were matched as closely as possible for age, gender and for socio-demographic status. Details of participant characteristics are shown in Table 1. WASI-II scores were not available for one of the students in the control group, as she was not available to complete the cognitive assessment following participation in the experimental tasks.

Table 1: Characteristics of Sample

<i>Characteristics</i>	<i>ID Group</i>	<i>Non-ID Group</i>
<i>Mean age (SD)</i>	<i>18.7 (1.42)</i>	<i>18.7 (1.49)</i>
<i>Age range</i>	<i>16 - 22</i>	<i>16 - 22</i>
<i>Male (%)</i>	<i>12 (57.1%)</i>	<i>7 (35%)</i>
<i>Female (%)</i>	<i>9 (42.9%)</i>	<i>13 (65%)</i>
<i>Mean Carstairs Score (SD)</i>	<i>1.03 (3.38)</i>	<i>1.24 (2.48)</i>
<i>Range</i>	<i>-5.44 – 8.18</i>	<i>-3.25 – 4.94</i>
<i>Mean WASI-II FSIQ-2 (SD)</i>	<i>64.1 (8.75)</i>	<i>99.05 (10.21)</i>
<i>Range</i>	<i>45 - 78</i>	<i>77 - 118</i>
<i>GAS-ID (SD)</i>	<i>19.62 (7.72)</i>	<i>23.0 (5.57)</i>
<i>Range</i>	<i>6 – 33</i>	<i>11 – 34</i>

As shown in the table, the group were well-matched for age. Participants within the ID group were well-matched for gender but the non-ID group had a somewhat higher proportion of female participants. The range of Carstairs Index scores shown here demonstrates that there is a larger range of variability in the ID group in terms of socio-economic status. The presence of higher scores in the ID group indicates that some individuals came from more deprived areas than controls, but overall the spread of scores was broader for the ID group and reflects the fact that students came from a range of backgrounds. The spread of scores for the non-ID group was smaller, but the similar means between groups indicate that overall these groups were relatively well-matched in terms of deprivation.

As shown by the mean and range of IQ scores shown here, there was a clear difference in levels of ability between groups, as measured by the WASI. The inclusion of one individual with an IQ score of 78 in the ID group was felt to be appropriate due to a) the large confidence intervals given for the WASI-II FSIQ-2, and b) his lifetime socialisation and education as a person with additional support needs.

Notable within the background information for this sample is the high overall level of anxiety reported by both groups of participants. The guideline cut-off score for clinically significant anxiety on the Glasgow Anxiety Scale (GAS-ID) is between 13 and 15 (Mindham & Espie, 2003), hence the mean scores for both groups are within the clinically significant range. An independent-samples t-test revealed no significant differences between the groups on GAS-ID scores [$t(39) = 1.61, p = 0.12$].

Part 1: Worry Interview

Worries were recorded verbatim, transcribed, and analysed using a content analysis approach. Content analysis is a flexible method for analysing text data, with attention paid to the content or contextual meaning of the text (Hsieh & Shannon, 2005). For the present study, a 'conventional' content analysis approach was used, where the codes developed were driven by patterns found within the data itself. In the present study, the text data was examined under the 12 pre-defined worry topic areas (as described in the previous section). Codes for categorising responses were developed based on the key ideas and concepts reported within each topic. In a small number of cases, where people had produced responses that clearly belonged in a different topic area (e.g. discussing family worries within the 'friends' topic), these were re-assigned to the appropriate topic. An independent rater was asked to group the participants' responses into the 12 topic areas developed for the interview, to check they had been appropriately assigned. Inter-rater agreement for categorising the worries was 90%. Disagreements were resolved via discussion.

In addition to the content analysis, each participant identified their 4 top worries and ranked them from 1 – 4 in order of which was the 'biggest worry' for them currently. For the identified top rated worries, rankings were summed over the sample to gain an overall 'salience' rating for each worry topic. Figure 1 below shows the patterns of salient (top-rated) worries for the two groups.

Both the pattern of salient worries and content of worry topics between groups will be described in more detail below.

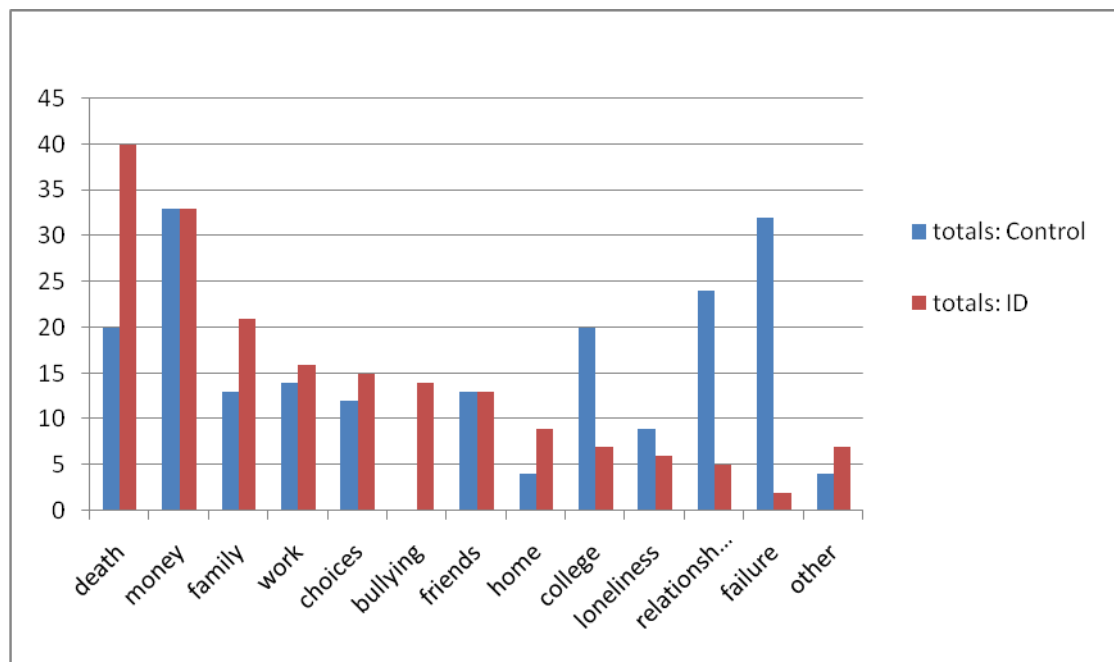


Figure 1: Summed rankings for top rated worries

Patterns of worry

As can be seen in Figure 1 above, salient worries reported were different between the ID and control groups, although both groups commonly reported that death and money were salient worries. The greatest worry within the ID group was about death, followed by worries about money, family and work. The greatest worry within the ND group was money, followed by worries about failure, relationships, and also worries about death and college which were equally highly rated. Participants in the ID group reported fewer salient worries about failure, relationships and college than controls. Those in the ID group reported more salient worries about death than controls. Also of note in terms of patterns of worry was the fact that although ‘bullying’ was ranked as a salient worry for the ID group, none of the control group ranked this as a top worry. There were no differences between groups in terms of salience ratings for worries about money, or about friends.

As well as differences in patterns of worry salience, the groups also differed in terms of the content of their worries. In the following section, the content of worries for each group will be summarised and compared.

Content of worries

Content analysis of verbatim worry data allowed for exploration of the content of worry within each of the 12 topic areas. The results are discussed below with reference to commonalities and differences between the groups. Examples of worries for each topic, by group, are shown in Table 2.

Death: The most common type of worry for the ID group was worry about past experience of the death of loved ones, and memories of the bereavement and attending the funeral. Worries about death in the control group tended to reflect either worries about a loved one who was currently ill or elderly, or else ‘existential’ fear about one’s own death which was usually not related to any experience of ill-health.

Money: The most common money worries for the ID group were those which centred on the practicalities of handling cash, such as not being able to count money for payment in shops. Worries about money for the controls tended to reflect concerns about not having enough money for various expenses, and this included concerns about budgeting.

Family: There were commonalities between groups in terms of family worries, as participants in both groups most commonly reported worries about either past or present illness of a family member, as well as some worries about relationships or conflict in the family.

Work: Worries about work were also similar between groups, with both groups reporting worries about either difficulties in finding a job currently, or worries about not getting a job after their college course finished. However, the control group also reported some distinct worries about wanting to be able to support others and oneself in the future by getting a good enough job.

Choices: Those in the ID group reported worries about choice making which were diverse, but some were to do with making a choice about what job or course to do in the future, and some to do with making everyday choices such as activities and picking clothes. For the control group, worries about ‘choices’ mainly reflected concerns about choices to do with life progression, such as education, employment and where to live.

Bullying: For the ID group, worries about bullying were mainly concerned with current experience of perceived bullying or rejection by peers, and some participants mentioned past experiences of bullying at school. There were also some reported worries about friends being bullied. There were no worries about bullying which were rated as top worries for the ND group.

Friends: Some of the worries about friends for the ID group reflected concerns about difficulty making and maintaining friendships, and also some worries around the change in friendships following progression to college. For the control group, concern around changes and 'drift' in friendships following transition from school was the most common topic, but there were some concerns also around maintaining friends.

Home: Worries about home for the ID group were not commonly reported and were varied in nature, including concerns about moving house to live with another family member and worries about home security. For the control group, worries about home tended to reflect concerns about living independently, either currently or in the future.

College: Worries about college for the ID group were not commonly reported, but reflected concerns around getting into mainstream courses and progressing out of supported learning. For the control group, worries about college tended to centre around workload, and keeping up with the level and volume of coursework.

Loneliness: For the ID group, loneliness was not commonly reported as a salient worry. Some of the concerns in this group reflected worries about being lonely in the future. There were also concerns about being left out by peers, and about past loneliness. For the control group, the most commonly reported worry was around loneliness as a result of changes in social landscape following school, although there were also some worries about disliking being alone.

Relationships: Relationship worries in the ID group were not commonly reported, but tended to reflect concerns about past break-ups, or worries about the likelihood of forming a romantic relationship in the future. Worries for the control group mainly reflected concerns about problems in relationships, and worries about the future of their current relationships.

Failure: For the ID group, worries about failure tended to reflect concerns about failing assessments in college, or failing more globally in terms of future opportunities. There were also some worries about poor school performance in the past. For the control group, worries tended to reflect failure in the context of education, such as failing exams and courses, and failing to achieve career goals. Some control participants also expressed worries about failing in other pursuits such as driving tests.

Other: Other areas of worry outwith the 11 topic areas were not frequently reported, but included diverse concerns such as independence, worries about falling (ID group), and in addition two participants reported worries about physical appearance, and others' responses to this (both groups).

Table 2: Examples of worry content for both groups

Topic	Example quotes from ID group	Example quotes from control group
Death	<i>'it's like I worry about my gran and my auntie and one of my dogs... like seeing them in their coffins'</i>	<i>'and like old grandparents, I think everybody has that though when you get to this age your grandparents are always kinda old when you get to this age in life...'</i>
Money	<i>'I'll get mixed up, and if the guy is looking for change, and you're trying to count it'</i>	<i>Just trying to get to college from the house, trying to have fun as well at the same time, just everything, but like money I just, I seem to realise I've got less than I want hehe'</i>
Family	<i>'Just, like, my mother, just her health'</i>	<i>'Like, I, my Dad's like em, got a lot of health problems and things like that...'</i>
Work	<i>'because it's just trying to get a job out there at the moment it's kinda hard and it's, something I worry... it's just hard out there (laughs)'</i>	<i>'Well em I'm worried I can't get one and if I can't get one then I'm not going to be able to get other things, like my own house and be able to support em, myself or like marriage, kinda thing...'</i>
Choices	<i>'Worry about what to choose....at college...Choose what, choosing what to do, what tasks to do'</i>	<i>'...em, what kind of life I want to go down, like what kind of route I want to go down, with work and business and where I want to live, just stuff like that'</i>
Bullying	<i>'Cos it's happened that many times to me so... like you go into a new class and they go "can she do this or can she do that", and you go... try it and you can't do it, and they go and they laugh about you or something'</i>	(no salient worries reported)
Friends	<i>'I mean I've had ups and downs with friends, I fall out with them and you fall back in, em...'</i>	<i>It's a bit hard to, well, because we've all kinda moved on and gone our separate ways we're all in different colleges and Uni's, it's hard to kinda keep in touch...'</i>

Home	<i>'Aye, cos in case any gangs break in'</i>	<i>'Well yeah cos I mean I live with my mum right now so I mean it's kinda getting to that age where it's, gotta move out and get my own home'</i>
College	<i>'Cos I've moved from learning support into mainstream...and I want to keep into that and I just, I just want to do my next level...'</i>	<i>'Eh, the stress of getting your course done...and moving on and all that. Eh, homework, sometimes I don't hand in homework, then it piles up...'</i>
Loneliness	<i>'Maybe like what the future holds, like will you be happy or will you be lonely?'</i>	<i>'...my mates are like, some of them have got weans and that... and cannae really, turn up at their house every day...'</i>
Relationships	<i>'...I feel I don't know how to make a boyfriend or girlfriend... how to make a relationship with folk'</i>	<i>'...and em, normally, like I'm in college three days and then I normally work three days so then, if we don't see each other much then that can cause like... arguments and stuff, and whatever else'</i>
Failure	<i>'... if I, trying to get a job at the end of it, I would worry about failure and not getting a job and stuff...'</i>	<i>'like I'm learning to drive and like I keep worrying I'm not doing things right...'</i>
Other	<i>'I don't like people staring at me, I find it's quite cheeky sometimes'</i>	<i>'..it's not just what you're gonna wear, it's not just how you look, but it's also like...are you gonna fit in with people that are there...'</i>

In conclusion, the overall gross patterns of 'top worries' observed between groups appear on the face of it to be similar, with overlap between groups in terms of worry topics reported. However, on closer examination with the use of content analysis, it appears that there are some quite distinct differences in terms of the content of worries reported between groups, and specifically it appears that indeed, social concerns may play a part in distinguishing worries between groups. For example, in the case of money worries, the dominant concerns in the ID group (looking after money; counting out money and change correctly) may have reflected concerns about task performance and associated social evaluation from others. Also, worries about bullying were salient for the ID group and not for the ND group, reflecting more worry about peer rejection and victimisation, some of which was linked to past experience. Finally, worries about friendships tended to be more heavily weighted towards making and keeping friends and negotiating conflict within the ID sample, rather than about 'drift' following school, which was the dominant worry for ND students. These patterns, although derived from small numbers of participants in the present study, nevertheless provide good reason to think that social concerns may be more salient for the ID group, and that there may be differences in social coping between the groups. Part 2 will therefore explore the differences between the

groups' social coping responses within situations which may evoke social anxiety/threat.

Part 2: Social Coping

Data analysis

To examine patterns of social coping between the groups, a content analysis approach was again used, this time to analyse verbatim responses given in the Socially Anxious Situation Task (SAST).

Verbal responses given by participants in the task were transcribed and analysed for the presence of words and phrases representing different types of coping, and the responses were grouped together to establish codes based on what type of coping was represented. Codes emerged through the examination of the content of responses (as per guidance on 'conventional' content analysis, e.g. Hsieh & Shannon, 2005). Responses to each vignette were assigned a single code to reflect the main content of the response. If responses reflected more than one type of coping response, the first response given by the participant was coded, and the remainder of the response was disregarded, in order to allow single codes to be assigned.

Initial analysis revealed 12 categories in total (included in Appendix 2.7), which were then collapsed into 6 broader categories to reflect different 'styles' of coping, and to facilitate single codes being assigned to each response. Assignment to categories was checked by an independent rater following analysis. Agreement was 87.6% and disagreements were resolved via discussion.

Coping categories

The final categories generated by the analysis process are shown in Table 3, along with descriptions and example quotes from each group.

Table 3: Final coping categories derived from content analysis

Coping category	Description of features to fulfil code	Example – ID group	Example – Non-ID group
Assertive/ problem solving	<i>An attempt to address the situation directly using a non aggressive style</i>	<i>'Go and try to talk to them'</i>	<i>'Probably just ask them about it, cos there'd be no point overreacting to something if it was nothing'</i>
Emotion- focussed: anxious/ avoidant/ passive	<i>Response based on initial emotional reaction which reflected an anxious or avoidant response, or no action to directly address the situation</i>	<i>'Get dead nervous and tense and shaky. Probably walk out of the class'</i>	<i>'I'd probably just shut down, I'd be like 'ehh'. I'd go bright red, just say anything. I'd say something along the lines - try and answer it. Just to stop them paying attention to me'</i>
Emotion- focussed: aggressive/ vengeful	<i>Action based on initial emotional reaction which reflected an aggressive or angry response or an intention to 'get back at' the protagonist</i>	<i>'punch her in the face'</i>	<i>'tell them to f*** off'</i>
Competence- focussed	<i>Attempt to manage situation by presenting self as competent</i>	<i>'try and do as good as you can'</i>	<i>'just do exactly what she told me, really carefully so I don't make a mistake'</i>
Managing social impact	<i>Attempt to manage social or emotional aspects of the situation, using 'higher-order' awareness of existing or predicted responses to the situation. This would include appeasement of others, using humour to diffuse, or managing one's own presentation to overcome initial stress response.</i>	<i>'sometimes walk away and calm myself down. Come back and say "ok"'</i>	<i>'I could laugh along with it, to show I'm not being too "up myself"'</i>
Support- seeking	<i>Looking for emotional support from others (friends, teachers, carers)</i>	<i>'phone a family member like your brother, and take it from there'</i>	<i>'I'd probably just speak to someone about it - my friends or my boyfriend'</i>
Footnote: To ensure that 'higher-order' aspects of coping were recognised within the analysis process, responses containing explicit references to managing social or emotional aspects of the situation were always coded as 'managing social impact' (even if the response also contained elements that were assertive, avoidant, etc.).			

Coping responses by scenario type

The 6 vignettes were developed to reflect two types of social concerns thought to be salient for this population, namely:

- a) Social evaluation scenarios (such as performing a task in front of others);*
- b) Social acceptance scenarios (such as experience of conflict or rejection with peers).*

The vignettes were therefore collapsed into these two scenario types (with three vignettes representing each distinct type of scenario) for the purpose of analysis. Occurrences of each type of coping category were summed for each group, for each of the two types of scenario. Overall frequencies were also obtained for coping styles reported across the two types of scenario (evaluation/acceptance). These summed frequencies for coping responses are described in the following sections.

‘Social evaluation’ scenarios

Figure 2 below shows a graphic representation of summed coping responses for the ‘social evaluation’ scenarios.

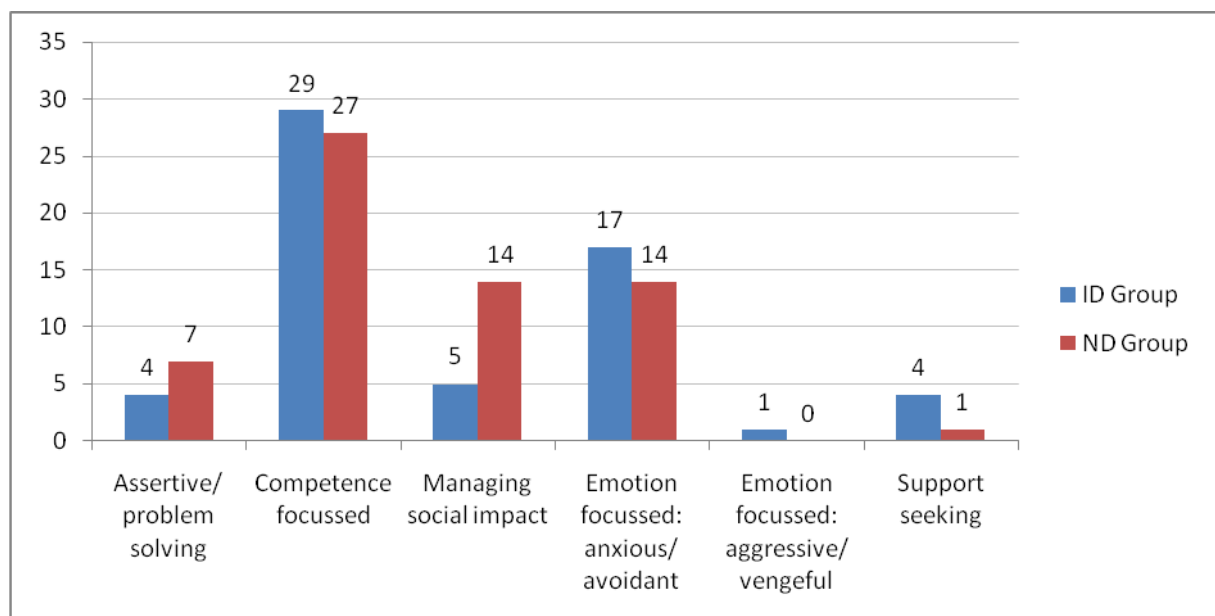


Figure 2: Summed coping styles for social evaluation scenarios by group

For both groups, in the ‘social evaluation’ scenarios (involving performance of a task in front of others), coping strategies which reflected attempts to manage competence and perceptions of competence (‘competence focussed’) were the most commonly endorsed. As detailed in Appendix 2.7, this category included ‘task focussed’ approaches (deliberately focussing on the task to maximise competence), but also responses which reflected attempts to manage how their competence was perceived by others (such as making up an answer in order to seem competent). Emotion-focussed responses reflecting anxiety/avoidance were the next most frequent type of response provided by both groups. The ID group were slightly more

likely to endorse an anxious/avoidant response than the controls. The control group were slightly more likely to endorse an 'assertive/problem solving' approach than the ID group.

The biggest difference observed between groups within the evaluation scenarios was the increased tendency of the control group to produce responses which attempted to 'manage social impact'; that is, the tendency to explicitly report awareness of and attempts to predict and manage the emotional or social responses of the self or others. This category included appeasement of others, managing one's own emotions and managing one's own social presentation. The ID group were much less likely to report these types of responses, but they did report slightly more responses which involved seeking support from others.

'Social acceptance' scenarios

Figure 3 below shows the summed coping responses for the 'social acceptance' scenarios.

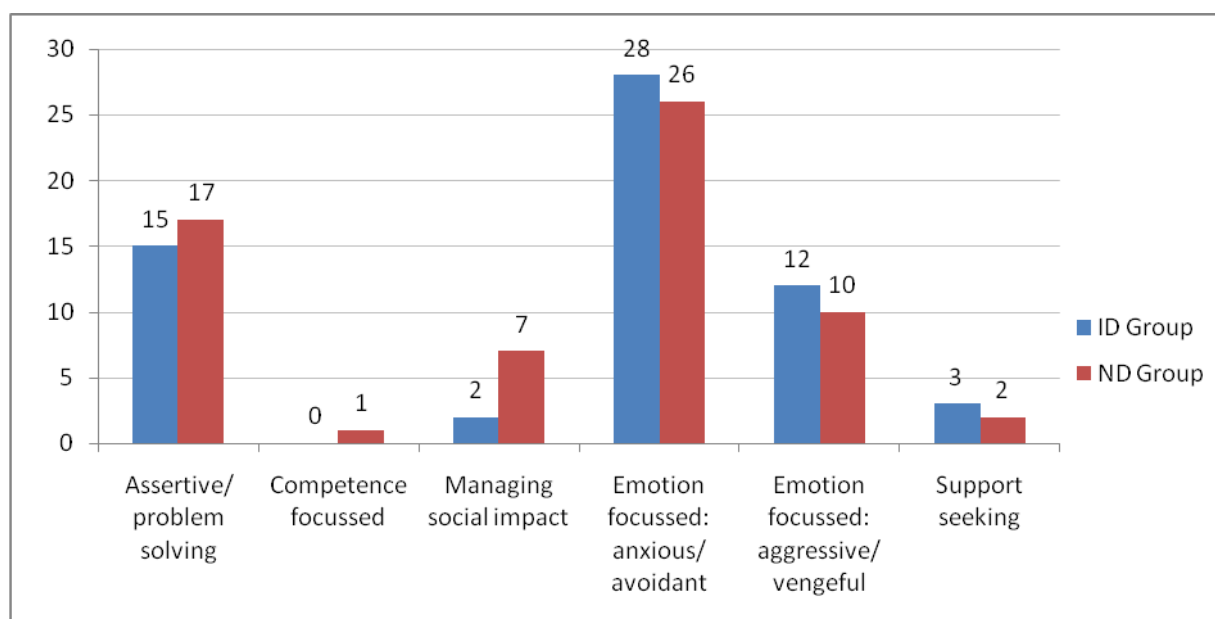


Figure 3: Summed coping styles for social acceptance scenarios by group

For the scenarios involving social acceptance (threat of rejection from peers), there were also commonalities and differences observed between groups. Overall patterns of coping were broadly similar between groups, for these scenarios. Notably, a high level of emotion-focussed coping and particularly anxious/avoidant responding was

reported by both groups, compared with the evaluation scenario. Both groups also proved equally adept at producing assertive/problem solving approaches and few participants from either group said that they would seek support from others. Once again, slightly more of the non-ID participants said they would use the higher-order strategy of 'managing social impact'. Overall, coping responses between groups were observed to be largely similar, as reflected in Table 3.

Discussion

This was an exploratory investigation examining the presence of social worries between ID and non-ID college students, to see whether students with ID would be more sensitive to social stressors and therefore respond differently in simulated situations of social threat. Overall it was found that although there was overlap in the worries reported by both groups, the ID group notably reported worries specifically about fear of rejection from peers and also worries around social evaluation related to task performance. This was in contrast to the non-ID group in which the worries reported mainly reflected concerns about life changes, future planning and independence. These findings gave rationale for investigating whether the ID group would be more sensitive to social stressful situations and therefore would cope differently. In fact, results from the vignette task revealed that largely the coping responses between groups were similar, and there was not a sense from the patterns that emerged that different types of coping were present for the two groups, although the non-ID group unsurprisingly endorsed more sophisticated forms of coping at times. Both groups appeared in particular to be largely emotionally reactive to the 'social acceptance' scenarios, which simulated risk of social rejection.

Worries about bullying have been previously reported as an area of concern for young adults with ID (Forte *et al*, 2011), and were indeed present as a salient concern for the ID group and not for the controls in the present study. Additionally, examination of worries about friendship showed that although concerns were similar between groups, the control group tended to report more worries specifically about 'drift' in friendships following the transition from school, and less about

making and maintaining friendships. Lastly, worries about money were highly salient for both groups and content analysis revealed that for the ID group these tended to reflect underlying concern about task performance in terms of handling and counting money, which can be viewed as an evaluative concern around others' perceptions of competence. This would be in agreement with Forte *et al* (2011) who found that worries about task performance featured more prominently for the ID group, although in the previous study these worries were mainly reported within the context of the 'failure' category.

The findings in the present study provide support for the idea that worries at this stage of transition may differ between young people with and without ID. A noticeable pattern overall was the presence in the control group of more salient worries pertaining to adopting an independent adult role, such as further education, career, and planning for independent living arrangements. This is in agreement with Forte *et al* (2011) whose study also found more worries relating to future choices within the control group.

When talking about their lives more generally, the ID students in the present study often reported that they previously had more worries about friendship and social interaction (with frequent reports of previous bullying) when at school, but that their social network was much improved now at college. It appears possible that the difference in patterns of worries in this study compared with that found by Forte *et al* (2011) may reflect the high level of support and social facilitation offered by the college departments for this sample. It may be that for these young people, transition to college represented an opportunity for more successful peer interactions within a somewhat protected environment.

Interestingly, the finding that death and money were particularly salient for the whole sample was not found in Forte *et al*'s previous research using this model, but may reflect social and economic features of the sample. The present sample was taken from areas of Scotland with high levels of socio-economic deprivation (as reflected by the Carstairs scores) and these concerns may be a reflection of associated experience of adversity.

The second part of the study examined coping styles chosen in response to social threat between the two groups, in the context of expected differences in worry

salience and content. The differences found between groups in terms of social concerns provided some rationale for investigating subsequent differences between the groups in terms of social coping.

Content analysis of the coping responses for the social threat scenarios also revealed interesting patterns of commonalities and differences between groups. Perhaps unsurprisingly, competence-focussed approaches were highly endorsed by both groups in response to the 'evaluation' vignettes which were centred on performing a task in front of others. Perhaps more notably, the higher number of 'managing social impact' responses endorsed by the control group may be suggestive of the idea that social acceptance concerns (such as making sure of being liked or being viewed a particular way, unrelated to competence in the task) are still in play for the control group during times of social task evaluation, whereas for the ID group, the task competence elements perhaps took a more central role when deciding how to cope. This finding would make sense in the context of possible differences in experiences of task failure between the groups (Zigler *et al*, 2002), and findings from this and the previous worry study (Forte *et al*, 2011) suggest that competent task performance may be a more salient concern for the ID group. Also the finding may be a reflection of the fact that the ID group lacked the higher-order skills necessary to manage social elements during an evaluation scenario.

The overall finding that management of social and emotional presentation and complex 'deceptive' forms of coping are more prevalent within the controls may be related to the fact that social coping becomes more sophisticated during development and people with ID may fail to acquire these skills (Carison, 1987). There is some evidence that social information processing, required for complex social negotiation, requires the development of 'advanced executive function' capacities such as interpretation, working memory, and inhibition, and that these executive functions may be less well developed in young people with ID (van Nieuwenhuijzen & Vriens, 2012). The literature on the comparative development of social and emotional understanding for ID and ND individuals is complex and nuanced, but Jervis & Baker (2004) have suggested that social and environmental factors may play an important part in influencing the development, maintenance and expression of these abilities within the ID population. It may be that a relative

lack of social experience in the ID group (Rosen & Burchard, 1990) plays a part in the acquisition of coping strategies specifically. Investigation into the trajectory of these coping profiles over the life span would help to clarify the mechanisms underlying these differences.

The higher level of unregulated emotional responses and support seeking reported by the ID group may be indicative of this group finding social stress more difficult to cope with, which would be in agreement with previous literature in this area (Bramston *et al*, 1999). It is perhaps unsurprising that 'support-seeking' responses are more prevalent within the ID group and this may reflect of differences in social conditioning within this group who typically receive a higher level of support from others such as family and carers, for assistance with everyday tasks (Lunsky & Benson, 1999). Avoidance and support seeking were by no means the only strategies employed by the ID group however, and this exploratory investigation of coping shows that young adults with ID do possess a range of different coping strategies for dealing with social threat. Interestingly, aggressive responses were not higher for the ID group which is in agreement with recent literature (Larkin *et al*, 2012) which found that high rates in aggressive responding to conflict were not found when using self-report methods, even in a group identified to be high in aggression. The study also found that interpersonal conflict situations can be perceived as more threatening and aggravating for people with ID, which may imply that the lack of aggression reported may be a result of self-censure when responding, due to perceived scrutiny. It may be therefore that self-report alone may not be the most accurate way to gain information on aggressive responding specifically.

Across groups, the higher rate of 'emotion-focussed' (both avoidant and aggressive) responding for the scenarios concerning social rejection may suggest that they were particularly stressful for both groups. There was also a relatively high rate of passive/avoidant responses across groups overall, and this may be influenced in part by the finding that anxiety levels were high within the control group. The participants without ID were recruited shortly before their end of term exams, meaning that their anxiety levels were probably particularly high. Moreover, there may have been a recruitment bias, with more anxious or worried individuals volunteering to take part because of the research topic. It may also be that

avoidance is a natural immediate response to situations which are aversive, and the results found here possibly reflect this tendency across groups. There is some evidence to suggest that avoidance tends to be utilised in situations where there is low perception of control over the situation (Hartley & Maclean, 2005), and therefore the finding may be a reflection of the use of vignettes (where participants may have felt they had little familiarity and mastery over the 'scenario'). Alternatively, it may reflect a lack of internal locus of control within the sample. Previous research has found evidence for high perceptions of social 'powerlessness' within ID groups (Carison, 1987), so this pattern may conceivably have been present (as reflected by high avoidance in both groups) but was possibly 'masked' by the unusually high anxiety within the control group.

Finally, it appears from the results that overall level of anxiety did not differ between groups and therefore the differences found in coping between groups were not due to differences in overall state anxiety. This is notable as it implies that there may be quantitative differences in coping that exist between ID and non-ID groups, as opposed to differences which merely reflect different levels of anxiety in the two groups.

Methodological Strengths and Limitations

The present study was an exploratory study using a relatively small sample to examine differences in worry content and coping styles between groups of ID and non-ID college students. A strength of the present study was that it provided further evidence for the use of the worry interview technique developed by Forte *et al* (2011) in engaging students and eliciting information about salient worries. Vignettes were also developed to stimuli to simulate situations of social threat concerning social evaluation and social acceptance, and this may prove useful clinically, although the method needs further investigation.

This was exploratory and the nature of the convenience sample may have been biased in particular ways. For example, due to the timing of recruitment, students were interviewed during exam time, which may have had an impact on anxiety levels and responses on the worry and coping tasks. Also due to sample size, it was not possible to further examine the differences in coping strategy between groups using

quantitative methods. Further investigation of these differences would appear to be an important area for future research, based on current findings.

It may also be that individuals' responses within the vignette task were influenced by social desirability and the participants' views about the researcher's expectations regarding 'acceptable' behaviour. The piloting of materials (such as video-based vignettes) which may further enhance the ecological validity of coping responses could be a valuable addition to this area of research.

It may also be the case that, since the concerns reported were different for the two groups during the worry task, the coping vignettes may not have been equally salient for both groups. Hence, perhaps a future study about social coping would require a more extensive preparatory stage to develop salient 'social threat' scenarios pertaining to each group, based on their particular social concerns. Future research improve on this design by using information on salient worries to guide the nature of social threat tasks, to ensure they are salient and relevant for that group.

This study used content analysis and descriptive exploratory analysis to investigate overall patterns of worry and coping. It would be useful to investigate mechanisms around social coping in more detail in future research, in order to examine the emotional and cognitive predictors of coping decisions for this population, and how this directly relates to worry content. Further research using statistical between-groups comparisons and examining predictive relationships between anxiety, attributions and social coping would be useful to this area of research.

Clinical implications/applications

The current research contributes to the literature on young adults with and without ID in terms of worries, social stress and social coping, and in particular highlights the ability of young adults with ID to use a variety of strategies to cope with everyday social stress. The study appears to show that, overall, threat of social rejection is particularly stressful, and likely to lead to avoidance in both ID and non-ID groups, which may help to inform educational support around social anxiety and proactive coping. The design of the present study highlights that there may be more subtle aspects of coping (such as managing social and emotional presentation in front of

others) that young people with ID may require more specific tailored support in order to develop.

The current study also highlights the influence of examinations on stress levels for non-ID students at this life stage, as future aspirations become more important. The evidence here that academic and vocational worries feature highly could be useful for informing educational support services, in terms of developing resources for students to access at such times.

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CHAPTER THREE: REFLECTIVE ACCOUNT

Advanced Clinical Practice 1:

CBT and beyond: Confidence, mentalisation and integration in the process of the journey through placement

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*Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology (DClinPsy)*

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Abstract

In the following reflective account, I consider my changing relationship with the CBT model of working throughout my experience of placement so far, and how this relates to my confidence as a practitioner and my ability to integrate approaches in a useful and formulation driven way. The reflections in this account are guided by the Gibbs (1988) model of reflection, which suggests a process where evaluation and change in knowledge and behaviour can emerge as a result of reflection and understanding of experiences. I pay particular attention to process issues as they have pertained to my own experience of placement and in relation to my work with clients. I attempt to reflect on my development of clinical skills throughout each of my placements, and how the learning of new models and the emergence of challenges has enhanced and developed my practice, and my ability to work flexibly with different presentations and settings.

Appendices

Appendix 1.1: Application of quality and ranking criteria for included studies

Study	Study question	Study design	Sample acquisition	Sample characteristics	Measures of MH/ wellbeing	Acquisition of data on abuse experiences	Measure of ID	Control/ consideration of confounding factors	Total score & quality rating
Smiley <i>et al</i> (2007)	2	4	2	2	4	3	1	4	Excellent
Murphy <i>et al</i> (2007)	2	1	1	2	4	3	0	4	Adequate
Sequeira <i>et al</i> (2003)	2	3	1	1	4	0	3	2	Good
Hayes (2009)	2	3	1	2	2	3	2	2	Good
Hickson <i>et al</i> (2008)	2	3	1	2	2	1	1	4	Good
Matich-Maroney (2003)	2	3	1	2	4	3	1	2	Good
Shabalala & Jasson (2011)	2	3	1	2	3	1	1	2	Good
Novaco & Taylor (2008)	2	3	2	2	4	2	3	2	Excellent

Appendix 2.1: Guidelines for submission to the Journal of Applied Research in Intellectual Disabilities

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Appendix 2.2: Materials for the ID Worry Interview (IDWI)

2.2.1: Interviewer guide script

Today I'm going to talk to you about your worries. I will show you some pictures to help you think about different types of things people worry about. Ask you if it's something you worry about and you can tell me yes or no. Then I will ask you about how much of a worry each one is. Does that make sense? Do you have any questions?

(present first materials)

What is this a picture of?
What does this picture make you think of?

(opportunity to discuss)

Is this a worry for you right now? If it is, you can put it in the yes pile. If it isn't a worry just now, we can put it in the no pile.

If yes pile:
for this worry (name it) – can you tell me how often you worry about this? Here is a scale to help. Is it (proceed with 3-point rumination scale)
Okay, great. Now for this worry (name) can you tell me about how upset you feel when you think about it? Do you feel (proceed with 3-point distress scale)

(repeat for all 11 topic areas)

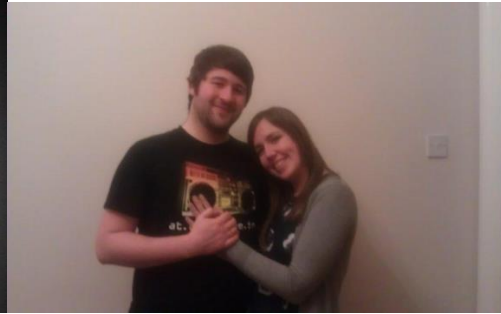
Now, we've talked about different worries you might have. Are there any other worries you have that we might not have talked about?
(opportunity to discuss)

Now from this pile that you said were worries for you, can you tell me which ones would be your 4 *biggest* worries?
Which would be the biggest worry? (repeat for all 4 – using visual analogue)

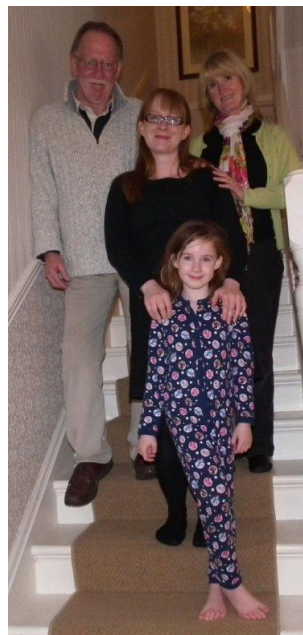
2.2.2: Examples of photographic stimuli for ID Worry Interview



'Money'



'Relationships'



'Family'



'Work'



Appendix 2.3: Materials for Socially Anxious Situation Task (SAST)

2.3.1: Interviewer guide script

Now the next part is a bit different. We have talked about the things that you worry about. Now I would like to talk you about some different situations that might happen in life, and what you might do in each situation. I have got some pictures to help me explain. I will read out each situation, and I would like you to imagine it is happening to you. Then I will ask you what you think about the situation, and what you would do. Do you understand? Shall we try the first one?

(read vignette and show photographic stimuli)

How do you feel?

What do you think?

What do you do?(repeat x6)

2.3.2: Vignettes for the Socially Anxious Situation Task (SAST)

(Adapted from Bögels&Zigterman, 2000; Larkin,2011)

‘Social Evaluation’ vignettes

You go to a new computing class. Everyone is being shown a new way to search for information. You have never done this before. The tutor asks you a question about it. Everyone turns round to listen to what you have to say.

You are at a new cookery class and the tutor shows the class how to make a new type of cake. The tutor asks you to show the class how to do the mixing. You try your best. While you’re doing it everyone is watching you.

It is your first day at a new job, with some other new people. Your boss is telling you all about what you’ve got to do. She asks you a question. You give an answer and she says ‘no that’s wrong’ and looks annoyed.

‘Social acceptance’ vignettes

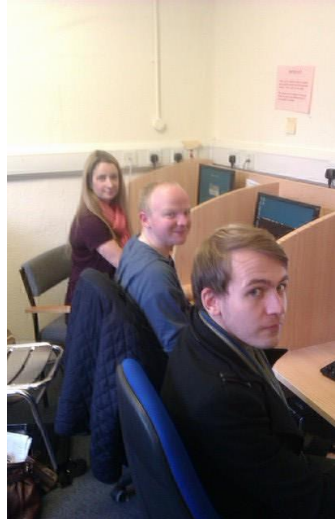
One of your close friends tells you that another friend is having a party next Saturday. He received an invite in the post. You have not yet received an invite.

You are in town. You see some people that you know from college. They walk past you and don’t say anything. When they have walked past, two of the people in the group start laughing.

You’ve arranged to meet your friend at the cinema and you’re really excited about seeing the movie. You are waiting outside the cinema but your friend’s about half an hour late and hasn’t been answering their phone. Then, your friend calls you and says that they don’t want to meet you today because they’re staying in to watch a DVD with a different friend.

2.3.3: Examples of photographic stimuli used in the SAST

Computing (social evaluation)



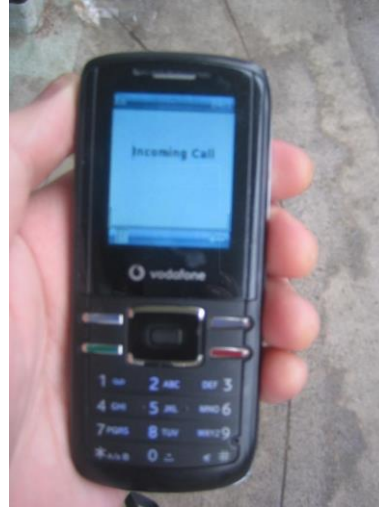
Cookery (social evaluation)



Walking (social acceptance)



Cinema (social acceptance) (used with kind permission from Larkin, 2011)



Appendix 2.4: Participant information sheets and consent forms as follows:

2.4.2: Information sheet for ID group

2.4.3: Information sheet for non ID group

2.4.4: Consent form

My name is Eleanor. I am at university.



I am interested in finding out **what type of worries people have when they are at college**. I want to speak to people aged between 16 and 22 years old. I want to ask about peoples' experiences of what worries them, and how they might act in different life situations.



What this study is about: This study is about understanding the types of things people worry about when they are at college. The study is also about how people react to different life situations. This will help us to understand about the kinds of things young people think about, and how this might affect how they act. This is important as it will help people like college tutors to understand young people like you.



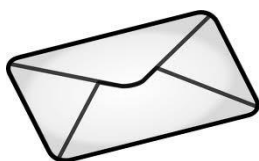
What is involved? I would ask to meet you for around 1 hour at your college to talk about the types of things you worry about. I would also ask you to speak about how you would act in some different life situations. Then, at the end I would ask you to do some word and picture puzzles. If you find an hour is too long I could come back to finish the interview, with your consent. There are no right and wrong answers. If you say it is ok I would tape record your answers. It is ok if you tell me you do not want me to record you. I can write your answers down instead.

If you want, you can have someone come into the room with you, like a support worker or someone from your family.



If you take part...

If you do decide to take part, you can change your mind at any time and stop. You do not have to say why. If you take part, we will use the interviews to write a report. The report might get put into a journal that people can read. Your name will not be in this. Nobody will know that it is your information.



If you are interested in taking part...

If you would like to take part please complete the tear-off slip below, and return it to me or your class tutor in the stamped addressed envelope provided. You can choose if you want to take part.

Your tutor will have a box in the classroom labelled 'Research study tear-off slips'. Thank you for reading this information sheet and I do hope I have the chance to find out more about your worries and how you act in different situations. Please complete the tear-off slip if you are happy for me to contact you.

Eleanor Simpson, Trainee Clinical Psychologist, Dept of Health & Wellbeing, Admin Building, Gartnavel Royal Hospital, G12 0XH. Telephone: (mobile)

Signature:

Name:

Address

Telephone (optional):



My name is Eleanor. I am a postgraduate clinical psychology student at Glasgow University. I am interested in finding out **what type of worries people have when they are at college**. I want to speak to people aged between 16 and 22 years old. I want to ask about peoples' experiences of what worries them, and how they might behave in different life situations.

What this study is about: This study is about understanding the types of things people worry about at college. The study is also about how people react to different life situations. This will help us to understand about the kinds of things young people think about, and how this might affect their behaviour. This is important as it will help people such as college tutors to understand the concerns of young people like you.

What is involved? I would ask to meet you for around 1 hour at your college to talk about the types of things you worry about. I would also ask you to speak about how you would behave in some different life situations. If you find an hour is too long I could come back to finish the interview, with your consent. There are no right and wrong answers. If you agree I would tape-record your answers. If you do not wish to be recorded I can write your answers down instead.

If you take part...

If you do decide to take part, you can change your mind at any time and stop. You do not have to give a reason for this. If you agree to take part, we will use the interviews to write a research report. The report may be published in a journal that can be accessed in print and online. Your information will be anonymous within this report, and you will not be identifiable.

If you are interested in taking part...

If you would like to take part please complete the tear-off slip below, and return it to me or your class tutor in the stamped addressed envelope provided. You can choose if you want to take part.

Your tutor will have a box in the classroom labelled 'Research study tear-off slips'. Thank you for reading this information sheet and I do hope I have the chance to find out more about your worries and how you act in different situations. Please complete the tear-off slip if you are happy for me to contact you.

Eleanor Simpson: Trainee Clinical Psychologist (address and contact number)
Signature
Name
Address
Telephone (optional)

Dealing with social threat

A research study

CONSENT FORM

My name is_____.

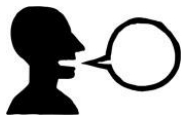


I have read and understood

the information sheet



I have had a chance to ask questions



My questions have been answered



I have got all the information I need





I know that I can change my
mind or stop at any time



I want to take part in the study



I agree to the meeting being
tape recorded



I agree to you using things I have said
in your report without my name on it



Participant signature:.....

Date:

Researcher signature:.....

Date:

Appendix 2.5: Ethical approval documentation

2.5.1: Evidence of departmental approval to proceed to ethics



University of Glasgow | College of Medical,
Veterinary & Life Sciences

TMcM/ST

1st October 2012

Eleanor Simpson
Flat 1/0
27 Athole Gardens
Glasgow
G12 9BB

Dear Eleanor,

Doctorate in Clinical Psychology Major Research Project
Dealing with social threat: Examining behavioural responses to anxiety-provoking situations for young adults with mild intellectual disability

The above project has been reviewed by your University Research supervisor and by a member of staff not involved in your project and has now been deemed fit to proceed to ethics.

Congratulations and good luck with the study.

Yours sincerely,

T M McMillan
Professor of Clinical Neuropsychology
Research Director

Doctorate in Clinical Psychology
Programme Director: Dr Hamish McLeod

Mental Health and Wellbeing
Admin Building, Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW G12 0XH
Direct line: +44(0) 141 211 3920/0607 Fax: +44(0) 141 211 0356
Email: mhwb-dclnpsy-students@gl.ac.uk

The University of Glasgow, charity number SC004401

2.5.2: Ethical approval documentation



University of Glasgow | College of Medical,
Veterinary & Life Sciences

21 March 2014

Dear Eleanor SIMPSON

MVLSCollege Ethics Committee

Project Title: Dealing with social threat: Examining behavioural responses to anxiety-provoking situations for young adults with mild intellectual disability

Project No: 2012086

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. They are happy therefore to approve the project, subject to the following conditions

- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- If the study does not start within three years of the date of this letter, the project should be resubmitted.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Andrew C Rankin
College Ethics Officer

Professor William Martin
Professor of Cardiovascular Pharmacology

R507B Level 5
School of Life Sciences
West Medical Building
Glasgow G12 8QQ Tel: 0141 330 4489
E-mail: William.Martin@glasgow.ac.uk

Appendix 2.6: Independent-samples t-test for scores on the Glasgow Anxiety Scale (GAS-ID) between groups

Independent Samples Test									
	Levene's Test for Equality of Variances		t-test for Equality of Means						
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower	Upper
GAS_ ID	2.114	.154	1.601	39	.117	3.381	2.111	-.890	7.652
Equal variances assumed									
Equal variances not assumed			1.614	36.408	.115	3.381	2.095	-.866	7.628

Appendix 2.7: Table of categories generated by initial content analysis of coping data from SAST

Coping category	Description of features to fulfil code	Example
<i>Aggression</i>	<i>Intention to behave in an aggressive or violent way towards another</i>	<i>'punch her in the face'</i>
<i>Unregulated emotional response</i>	<i>action based on initial negative emotional reaction without inhibiting this</i>	<i>'I'd probably just shut down, I'd be like 'ehhh'. I'd go bright red'</i>
<i>Assertive confrontation</i>	<i>Some attempt to address the situation directly using a non aggressive style</i>	<i>'Go and try to talk to them'</i>
<i>Assertive information seeking</i>	<i>Actively seeking information from another in order to address situation</i>	<i>'ask for information'</i>
<i>Task-focus</i>	<i>Deliberately bringing attention to the task as a way to manage situation</i>	<i>'try and do as good as you can'</i>
<i>Managing social presentation</i>	<i>Explicitly reported attempts to manage own social presentation to others</i>	<i>'I could laugh along with it, to show I'm not being too "up myself"'</i>
<i>Managing perceptions of competence</i>	<i>Explicitly reported attempts to manage own presentation to others in terms of task competence</i>	<i>'act confident, like you know what you're doing'</i>
<i>Appeasement</i>	<i>Attempts to appease others as a way to address situation</i>	<i>'do it with a smile on my face and be polite' 'just charm her'</i>
<i>Support-seeking</i>	<i>Looking for emotional support from others (friends, teachers, carers)</i>	<i>'phone a family member like your brother, and take it from there'</i>
<i>Passive/avoidant</i>	<i>No action which directly addresses situation, or action which is designed to escape/avoid situation</i>	<i>'I would just keep walking, just don't look at them'</i>
<i>Revenge</i>	<i>Some explicit statement related to punishing another or 'getting someone back' for a perceived wrongdoing</i>	<i>'I wouldn't invite them back!'</i>
<i>Manage emotional response</i>	<i>Efforts reported around managing one's own emotional state</i>	<i>'walk away and calm myself down'</i>
<i>Focus on others</i>	<i>Statement of focus of attention on feelings/experiences of others in the situation</i>	<i>'just show them how to do it and if they're stuck, you can show them'</i>

Appendix 2.8: MRP proposal including addendum

UNIVERSITY OF GLASGOW

Dealing with social threat: Examining behavioural responses to anxiety-provoking
situations for young adults with mild intellectual disability

Supervisor: Professor Andrew Jahoda

Major Research Project: Proposal

Word count: 3,261

Eleanor Jane Simpson

26/9/12

Abstract

Background

People with intellectual disabilities (ID) may be more likely to face social stressors due to their marginalized social status and differences in development of social skills. This might be predicted to lead to greater sensitivity to social threat, and different coping styles in response to social threat when encountered.

Present Study

The present study will:

- i) Examine the nature of worries reported by young people with and without ID to establish whether they report more worry about potential social stressors.
- ii) Examine whether those with ID predict responding differently from their non-disabled peers to potential social stressors.

Method

Fifty participants will take part in this study, 25 typically developing young adults and 25 individuals with mild ID, between the ages of 16 and 22. Participants will be recruited through local further education colleges. As far as possible, participant groups will be matched for age, gender and socio-demographic status. Participants will take part in an open-ended 'worry' interview and will complete a measure of distress in relation to each worry, as well as an overall measure of anxiety. They will be asked about their coping in 'social threat' scenarios, using specifically developed vignette stimuli. Responses will be rated and categorised.

Data Analysis

The differences in content and salience of worries between ID and non-ID groups will be compared. Predicted responses to social threat will be descriptively explored using content analysis and also compared across groups. Also of interest will be the relationship between salience of social worries and likelihood of endorsing a particular coping response to social threat.

Practical Applications

This study will contribute to literature on transition and social coping for those with ID, and will help to inform cognitive-behavioural approaches to social anxiety for those with ID by providing insight into coping strategies used at times of social stress.

Background

Whilst there has been investigation into social threat and social coping within the general population (e.g. Bögels&Zigterman, 2000), to date little research has been done on the social coping strategies of individuals with intellectual disabilities (ID).

There are various ways in which individuals with ID may experience and respond to social stressors differently from the general population, and there is some research to suggest that people with ID can experience difficulties in forming and maintaining peer relationships (Carison 1987; Hoyle and Serafica 1988), and can find social situations particularly stressful and anxiety-provoking (Bramston, Fogarty and Cummins, 1999; Forte, Jahoda&Dagnan, 2011). One reason for these differences may be that the social experiences of those with ID are known to differ from the typical population, due to a need for additional support. For example, individuals with an ID may attend ID-specific day services, and may live with family or in residential settings, socialising mainly with carers and other clients with ID (e.g., Robertson *et al*, 2001). Studies into the social networks of those with ID suggest this group may encounter fewer opportunities to develop informal social relationships (e.g. Rosen & Burchard, 1990) and tend to rely more on paid staff for emotional support (Lunsky& Benson, 1999). One may expect that these differences would lead to a relative lack of experience in negotiating particular social situations independently, and therefore emotional response and coping style may reflect this discrepancy of experience.

As well as a lack of opportunity to experience certain social scenarios, it appears that those with ID may also experience differences in the quality of their interactions with others. This has been examined in the literature in the context of *stigma*, that is, the 'culturally judged negative evaluation of a difference or impairment' which can be associated with ID status (Goffman, 1963). People with ID are often subject to high levels of stigmatising behaviour by others (Jahoda & Markova, 2004), and studies by Dagnan&Sandhu (1999), Dagnan&Waring (2004) and Paterson, Mackenzie & Lindsay (2011) have suggested a possible process whereby awareness of stigmatised status leads to internalisation of stigma, impacting negatively on self-concept via comparing the self with others. Further, this internalisation of stigma may lead to self-monitoring of an individual's social presentation in an attempt to manage the

stigmatised aspects, which arguably puts individuals with ID at risk for becoming socially anxious (Dagnan&Jahoda, 2006). Indeed, a recent study by Forte, Jahoda&Dagnan, 2011 has looked specifically at worries in adolescents with ID, and found that indeed, young people with ID reported more social worries (such as making and keeping friends) and were more distressed by these worries than those young adults without ID.

In addition to differences in social experience, developmental aspects associated with the ID itself may also influence social coping. Unsurprisingly, it appears that patterns of coping become more sophisticated during development to adulthood (Losoya, Eisenberg & Fabes, 1998). It seems probable that the wide range of cognitive developmental deficits observed in the ID population would in some cases encompass those higher-order skills required for complex or difficult social interaction. Indeed, one study found that those with ID show less well-developed social skills in response to social stress (Carison, 1987). Developmental factors may also influence emotional response to social stress - a study by Kindt *et al* (1997) on childhood anxiety found that older children appear to control anxiety through inhibition of the anxious processing style, and that younger children are less able to do this. It may be therefore that developmental deficits in emotion regulation occurring in the context of ID could influence ability to cope with social stress.

It seems unlikely that social experience and developmental factors would exert their effects on social coping independently. It seems rather that the valence of past social experiences may interact with existing socio-cognitive skills, to create a buffering effect against social anxiety, or in some cases to heighten sense of social threat and perpetuate unhelpful coping strategies (such as avoidance).

Few studies have actually examined social coping in the ID population. One study looking at choice-making in ID found differences in coping strategies between ID and non-ID groups, with ID participants appearing to make more unconsidered, 'knee-jerk' responses to unfamiliar decisions (Jenkinson&Nelms, 1994). This could conceivably reflect a higher degree of worry in relation to novel situations, however these findings were not explicitly linked to anxiety, or to social concerns specifically. Another study examined social coping within the ID population and found that

individuals with ID were more likely to use 'problem-focussed' than 'emotion-focussed' active coping strategies (Hartley & Maclean, 2005). This study did not use a control group and therefore did not allow for comparison between ID and non-ID populations, but the emerging evidence nevertheless appears to suggest differences not only in nature and extent of social anxieties, but also in coping strategies for social stress.

Transition to adulthood is a key stage for developing social contacts beyond the family context, and it is a stage when these broader social relationships take on greater importance (Elias, Gara&Ubriaco, 1985). Adolescence has been shown to be a stressful time for many young people (Eccles *et al*, 1995), and there is no reason to imagine why this would differ for individuals with ID, who may struggle with achieving life goals ordinarily expected of young people when they leave school, and may have to negotiate new and unfamiliar social situations. Gaining insight into these young people's style of social coping at this transitional stage of their lives might have important implications for tailoring support to their particular needs.

The current study will therefore comprise a task to examine whether individuals with ID do express more social worries than their non-ID peers, before going on to investigate whether they predict responding to social threat in a different way.

Research Aims:

To compare content and salience of social worries and to examine subsequent behavioural responses to social threat for those with and without ID transitioning to adulthood.

Hypotheses:

- 1. Young people with ID will report more social worries than those without ID**
- 2. Young people with ID will report more anxiety in relation to salient worries, compared to the non-ID group**

3. Young people with ID will report different patterns of responses to social threat situations, with a greater propensity towards avoidant responses, compared with those without ID.
4. Across groups, there will be an association between level of reported anxiety and a tendency to respond to social threat with avoidance.

DESIGN

This study will adopt a between-groups design, since the primary focus is on the differences in i) worry content/salience and ii) coping responses, between ID/non-ID groups. The study will use content analysis to categorise verbatim worry data and will then compare content and salience of worries between groups. Salience of worries will be established using summing of self-reported rankings by participants of their 4 'top' worries.

Verbatim coping response data will be categorised via content analysis, and will primarily be explored descriptively. If appropriate, coping data will also be compared between groups statistically. Data on distress and rumination caused by social worries will also be compared between groups using independent-samples testing.

PLAN OF INVESTIGATION

Participants/recruitment

Participants will be recruited from further education colleges in the Glasgow area. This approach to recruitment has been used successfully in previous studies and contacts within the colleges have been established. The ID and non-ID groups will be matched for stage of transition, age, gender and as closely as possible for socio-demographic status. College staff will be consulted to ascertain which classes of students with ID would have sufficient ability to engage in the research tasks. Suitability for inclusion will be confirmed by use of items from the Adaptive Behaviour Scale (ABS-RC:2, Nihira, 1993) pertaining to verbal expression and comprehension, and inclusion/exclusion criteria are listed below.

Inclusion Criteria

- Ability to talk to others about sports, family, group activities, etc.
- Ability to sometimes use complex sentences containing 'because' 'but' etc., and
- Ability to answer simple questions such as 'what is your name?' or 'what are you doing?'
- Age between 16-22 years old (as in previous research on transition).
- All participants will either have had recent experience of transition within the previous year or will be transitioning from college within the current year.

Exclusion Criteria

- Those who do not have sufficient receptive or expressive language, due to difficulties understanding and completing the experimental tasks.
- Those students whose first language is not English
- Any students with a diagnosis of Autistic Spectrum Disorder (ASD), due to potential difficulties in socio-emotional understanding within this group. Previous studies in this area have not included those with ASD for this reason.

Interviews and measures to be used in this study (in the order it is intended to present them):

ID worry interview (IDWI)

This is an interview framework previously developed by Forte, Jahoda & Dagnan (2011). The measure was developed specifically for eliciting salient worries across young ID and non-ID individuals. It was shown to be a sensitive and effective method of eliciting information about worries across the ID and non-ID populations. For this measure, participants are presented with visual stimuli and verbal descriptions representing different areas of worry (areas covered: decision-making; work; family; relationships; money; home – from Forte *et al*, 2011). Participants are asked to identify their four main sources of worry and to rate them in order of salience. If

participants identify a topic as a salient worry, they are then asked to rate this worry for 1) degree of rumination and 2) degree of distress, using a 3-point visual analogue scale. These analogues are in the form of blocks of increasing size, representing 'sometimes a worry', 'often a worry' and 'always a worry'. This interview was developed to be engaging and of interest for the participants, and has been shown to elicit a good response in previous research of this nature.

Glasgow Anxiety Scale – Intellectual Disability (GAS-ID)

The GAS-ID is a 27-item scale, developed by Mindham and Espie (2003) as a way of measuring anxiety specifically in those with ID. The scale was based on focus group discussion and has been shown to have good test-retest reliability ($r = 0.95$), good internal consistency (0.96) and an acceptable correlation with the Beck Anxiety Inventory ($p = 0.75$).

Socially Anxious Situations Task (SAST)

This measure will be developed specifically for this study by adapting existing vignettes from the ID literature on aggression (e.g. Pert, Jahoda & Squire, 1999; Jahoda, Pert & Trower, 2006; Larkin, in press). Vignettes have been shown to be an effective way of examining individuals' response to social provocation. Vignettes will consist of 'stories' in the first person involving situations of 'social threat'. Each vignette will be accompanied by photographs depicting the situation, to aid in engagement and understanding. Six 'socially threatening' stories will be interspersed with three positive stories in order to prevent participants from becoming caught in a negative response set (Jahoda *et al.*, 2006). The pictures and stories will be presented one by one and participants will be asked to imagine they are in the situation. They will be asked 'what would you do?' and their verbal response will be recorded by the experimenter. Verbatim responses will be content analysed and the categories of responses will be compared between the two groups, in a method previously carried out by Forte, Jahoda & Dagnan (2011). The vignettes will be piloted before the measure is finalised for use in the main study. Sample items for the proposed vignettes are included in Appendix A.

The Wechsler Abbreviated Scale of Intelligence (WASI-III) (Wechsler, 1999)

The WASI-III is an abbreviated version of the Wechsler Adult intelligence Scale (WAIS-III) and will be used in this study as a formal measure of cognitive ability. Correlations between the WASI and WAIS -III are reasonable, at 0.88 for Vocabulary, 0.66 for Matrix Reasoning and 0.87 overall. As in previous studies (e.g. Forte, Jahoda & Dagnan, 2011) the Vocabulary and Matrix Reasoning subscales will be used.

Procedure

Pilot phase: This will be for the purpose of confirming that the vignettes adapted from previous aggression literature (Jahoda, Pert & Trower, 2006) represent social threat. A small group of young adults with mild ID will be presented with the series of vignettes and accompanying photographs, to check comprehension of the vignettes and the overall 'threat vignette' task.

Main study: Prior to participation, participants will be given information on the study and asked to provide consent in the presence of a member of staff, in order to check comprehension. All participants will be seen within the college environment. Data collection sessions with each participant should last around 1 hour. There is a possibility that the tasks can be split into 2 sessions if the participant appears tired or is unable to maintain concentration. Participants' responses will be recorded onto response sheets by the researcher during the tasks. Consent will be sought to audio-record the participants' responses to the interview, which will be checked against the recorded response sheets for accuracy.

Participants will be engaged in conversation before beginning the task, to ensure they are relaxed and engaged. Explanation will be given of the purpose of the study and participants will be advised that there are no 'right' or 'wrong' responses before proceeding. Measures will then be administered in the order stated above. Participants will be engaged in conversation at the end to ensure no residual distress carries over from the experimental tasks.

Settings and equipment

Data collection will be conducted within the college environment. Access to the WASI will be required.

Justification of sample size

The primary aims of this study are **i) to examine the content and extent of social concerns in young people with and without ID, and ii) to explore the differences in social coping between groups**. It is proposed that the analysis of coping responses will be primarily descriptive, based on a content analysis of the responses provided by the participants in both groups. A sample size of 50 participants, 25 with mild intellectual disabilities and 25 without disabilities, was successfully used in a previous study comparing the participants' open ended views about their worries (Forte, Jahoda & Dagnan, 2011). Consequently, the current study will also aim to recruit 50 participants, in order to compare the groups' open-ended answers about their response to social threat.

Data analysis

Data on salient worries will be recorded verbatim, content analysed and categorised, and will be compared descriptively between groups, as in Forte *et al* (2011), as qualitative differences are expected between groups. Differences between groups on measures of worry-related distress/rumination will be examined using independent-samples t-tests or non-parametric equivalent such as Mann-Whitney U. Data on responses to the social threat scenarios will be similarly recorded verbatim (e.g. "I would go and tell a member of staff") will be coded into categories using content analysis and inter-rater agreement. Differences between groups for coping response will be described in detail, and may be analysed using χ -square if appropriate. All data will be analysed using Statistical Package for Social Sciences software (SPSS) version 17.

Health and Safety Issues

All data will be collected within standard working hours, and researchers will comply with standard safety procedures within the colleges. College staff will be present in an adjacent room whilst participants are being interviewed. No home visits will be conducted for data collection. Confidentiality will be explained clearly to each participant before taking part, with opportunity for the participant and carer to ask any questions. If disclosure is made during the interviews which implies risk of harm to the participant or to others, researchers will act in accordance with professional guidelines and will respect limitations to confidentiality. If it is deemed appropriate to refer any participant for physical or psychological intervention, this will be discussed with the participant/carers and appropriate contacts will be recommended i.e. GP services.

Ethical issues

Approval will be sought from college management before proceeding with recruitment. Since the novel section of the study involves inducing anxiety through use of vignettes, participants will be fully informed before consenting and debriefed after participation. Participants will have a chance to reflect positively on the experience with the guidance of the researcher, following the task. Evidence from previous similar studies (e.g. Forte *et al*, 2011) suggests no residual distress will be caused as a result of the proposed procedure. If any participant becomes distressed during testing, the researcher, a Trainee Clinical Psychologist, will discuss this with them in the first instance. This information will be shared with the appropriate person providing pastoral support in the school or college. In the case of significant distress or worry the researcher will recommend that the appropriate figure at the school/college contacts the person's GP.

Financial issues

Financial cost: 50 x WASI forms = £100 (approx)

Timescale

April 2012:	Submit proposal to University
June 2012:	Proposal assessed

Aug/Sept 2012:	Apply for ethical approval
October 2012:	Begin recruitment
March 2013:	Analysis
April-June 2013:	Write up research
July 2013:	Submit research to University
September 2013:	Viva

Practical Applications

There is very little research looking at the nature of worry and coping in relation to social threat for those with ID. Information about coping strategies in response to interpersonal stress can inform the development of tailored cognitive-behavioural interventions for those with ID. This information on coping will be useful for teachers and college staff in supporting this group to deal with transition in an adaptive way. This information will also contribute to understanding about the impact of stigma on those with ID. This will enable support strategies to be refined.

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Appendix A: Proposed Vignettes for the Socially Anxious Situation Task (SAST)

Examples of previously used vignettes (From Larkin, in press):

1. "You are sitting talking with a good friend at lunch time and you notice that another guy/girl you know well is eating at another table. You tell your friend that you're going over to say hi. But before you can leave the table, the friend you are with stops you. He/she says that the other guy/girl said really nasty things about you to your other classmates yesterday. Since she is a good friend, you know that she's telling the truth."

2. "You are waiting for the bus home and notice that a student you've seen at school/college but have never spoken to is walking towards the bus stop. When they see you they start pointing and laughing at you and tell you to go stand somewhere else."

3. "You've arranged to meet your friend at the cinema and you're really excited about seeing the movie. You are waiting outside the cinema but your friend's about a half hour late and hasn't been answering their phone. Then, your friend calls you and says that they can't be bothered meeting you today because they're staying in to watch a dvd with a different friend."

The following are adapted from Bögels&Zigterman (2000; from literature on social anxiety and threat in children):

4. You have decided to start going to a new club. Today you are at the club for the first time. In the corridor you see about 8 other people who are members of the club. You don't know any of them yet. They all look at you when you walk towards them.
5. On the first day of a new job, some people are talking and when you approach them you hear them say something rude about you.
6. It is your first day at a new job. Your boss asks you a question about the job. You answer and he says 'that's wrong' and asks somebody else.
7. One of your close friends tells you that another of your friends is having a party next Saturday. He received an invitation in the mail but you have not yet received an invitation.
8. You are at a dance. You noticed some people looking at you while you were dancing. Then you heard one person say 'Look at him/her, he/she can't even move'

Addendum to MRP Proposal:

- It was initially proposed that neutral vignettes would be used in between experimental 'social threat' vignettes. However it was decided that this was not necessary for the present study since the vignettes were designed be diverse and to examine emotional and behavioural reactions to mild social threat, rather than to elicit a particular emotion or behavioural response (e.g. anger/aggression, as in the previous studies cited here). It was therefore decided that only the 6 experimental vignettes would be used, as this would also reduce overall task time for the participants. Piloting confirmed that the vignette task was not perceived as distressing, and different responses were elicited throughout.
- Initially the study was designed with specific hypotheses, however due to the exploratory nature of this study it was felt that specific hypotheses were not appropriate and would not have allowed for full exploration of the data on worries and coping. Hypotheses were therefore removed and the study explored trends in the data descriptively.
- The original proposal states that scores on rumination and distress would be taken during the IDWI, and compared between groups using quantitative methods. These measures were taken during the study, but it was felt that a descriptive and qualitative exploration of the content of responses would better reflect the commonalities and differences between groups within the present paper, so the distress and rumination data was not included in the final write-up.