DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

Davies, Lauren

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Awarding institution:
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Doctorate in Clinical Psychology

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Main research project abstract

People with intellectual disabilities (PWID) are reported to have low self-esteem and to have experienced high rates of negative life events. The present study compared the frequency of negative relational life events and levels of shame, self-compassion and self-esteem in 50 PWID and 47 people without ID on a number of self-report measures. It was hypothesised that shame and self-compassion would mediate the relationship between negative interpersonal life experiences and self-esteem whilst social support would moderate this relationship. As predicted, shame and self-compassion were found to mediate the relationship between negative interpersonal life events and self-esteem for PWID. There was no evidence for a moderating effect of social support and no difference in shame or self-compassion for PWID in comparison to controls. PWID were found to have higher self-esteem than participants from the general population. The findings suggest shame and self-compassion are important concepts for PWID. Clinical and future research implications are discussed.

Service improvement project abstract

Guided self-help (GSH) has been found to be an effective intervention for mild to moderate depression in the general population. There is limited research into the feasibility and effectiveness of GSH for adults with Autism Spectrum Disorder (ASD) and co-existing depression. Two NHS adult autism clinics have helped to develop and deliver an autism adapted GSH intervention for depression as part of a feasibility study and pilot randomised controlled trial (RCT). The current study aimed to explore the acceptability of this adapted intervention for adults with ASD. Twelve participants who had engaged in the GSH intervention completed a qualitative interview on their experiences of the intervention. A thematic analysis was conducted and the findings revealed a number of suggestions for improvements to the adapted intervention, including changes to the pacing and length of sessions. The findings informed recommendations to the service who had developed the

intervention, with the aim that such recommendations will be implemented and improve the acceptability of GSH for depression for adults with ASD.

Critical review of the literature abstract

The effectiveness of a range of psychological models adapted for use with people with intellectual disabilities has been well documented. A number of studies have used qualitative methods to examine people with intellectual disabilities' experiences of these adapted interventions. Such research is important for identifying service users' views on the helpful and challenging aspects of psychological interventions to ensure they meet the needs of people with intellectual disabilities. To consolidate this research, a systematic review using a meta-ethnographic approach was undertaken. A systematic search identified sixteen relevant studies. These studies were reviewed, critically appraised and key themes were extracted. Five key concepts were identified: adapting to therapy, the therapeutic environment, group dynamics, the therapeutic relationship and the impact of therapy on life. Clinical implications and limitations are discussed. In particular, the review highlights the need for further consideration of power differentials within the therapeutic relationship and further adaptations to ensure accessibility of therapy for people with intellectual disabilities.

Critical Literature Review

People with Intellectual Disabilities' Experiences of Psychological Therapy: A Systematic Review and Meta-ethnography

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Introduction

The prevalence of mental health difficulties amongst people with intellectual disabilities has been estimated at between 10 to 40 percent (Borthwick-Duffy, 1994; Deb, Thomas, & Bright, 2001; Cooper, Smiley, Morrison, Williamson, & Allan, 2007), suggesting higher rates than in the general population (Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2003). Exact rates have been difficult to establish due to limited data and epidemiological studies which use different diagnostic criteria and assessment methods, small sample sizes, and different subpopulations. Negative life events and genetic vulnerability are thought to increase the likelihood of mental health difficulties in this client group (Clarke, 2003; Hulbert-Williams & Hastings, 2008). For instance, people with intellectual disabilities are at significant risk of abuse (Brownridge, 2006) and are exposed to a higher number of traumatic life events compared to the general population (Fenwick, 1994). However, despite a likely higher prevalence, there continues to be a relative dearth of literature looking at the experiences of mental health difficulties for people with intellectual disabilities. This may be due to the historical exclusion of people with intellectual disabilities from research, historical assumptions that people with intellectual disabilities do not experience the same range of emotions as people without intellectual disabilities, diagnostic overshadowing where all difficulties were thought to be due to the intellectual disability, low attendance at primary care services which reduces opportunities for assessment, and a failure to discriminate between challenging behaviour and mental health difficulties (British Psychological Society, 2015). Treatment traditionally focused on pharmacological and behavioural approaches, because of assumptions that the cognitive difficulties associated with an intellectual disability would prevent engagement in psychological therapy (Adams & Boyd, 2010). However, a range of psychological models have now been adapted from the general population and applied to this client group. A recent report by the British Psychological Society reviews the use of such models in clinical practice, including adaptations to consider for this client group such as use of simple language, short sentences, non-verbal techniques, visual material, and role plays (British Psychological Society, 2015).

A number of studies have used quantitative methods to examine the effectiveness of adapted interventions. A recent meta-analysis by Vereenooghe and Langdon (2013) suggests psychological therapy has an overall moderate effect for treating mental health difficulties in people with intellectual disabilities. Effectiveness depended on therapy type and presenting difficulty. For instance, CBT interventions focused on anger were found to have a large effect size whilst group psychotherapy interventions focused on interpersonal functioning were not found to be effective. When CBT was excluded, there was no significant evidence regarding the effectiveness of other psychological therapies. In addition, attrition rates were variable but reasons for attrition were not consistently reported across studies. This review highlighted the need for additional, more robust research examining the effectiveness and experiences of psychological interventions for this client group.

Quantitative research exploring the effects of psychological therapy for people with intellectual disabilities tends to focus on outcomes, examining whether the symptoms of someone's mental health difficulties have reduced following psychological treatment. Qualitative research can complement quantitative measurement by exploring sensitive, complex experiences and attitudes (Pope & Mays, 1995). It is important to understand service users' perspectives on the process of therapy as well as the outcomes to be able to further understand reasons for attrition rates (Vereenooghe & Langdon, 2013) and to offer acceptable treatment options. This is further indicated in a meta-analytic review by Martin, Garske and Davis (2000) who found the therapeutic alliance was moderately related to therapy outcome. In line with this, Bordin's (1979) theory of the working alliance proposes treatment success depends on the working alliance between client and therapist. The working alliance involves a mutual understanding and agreement of therapy goals, completion of tasks aimed at moving towards these goals and an established bond to maintain this work. Such research gives further support to the importance of exploring the process of therapy as well as therapy outcomes.

Qualitative research in the general population has identified a number of themes related to helpful and unhelpful aspects of therapy (Elliott, 2008). The helpful aspects include: the therapist listening, providing reassurance, exploring difficult emotions, and being empathetic and validating. The development of a collaborative relationship is also valued (Llewelyn, 1988, Glass & Arnkoff, 2000). There is limited feedback on the helpful nature of specific therapeutic interventions, although offering specific techniques for dealing with problems has been reported as valuable (e.g. Berg, Raminani, Greer, Harwood & Safren, 2008). Unhelpful aspects of therapy include: the therapist being judgmental or invalidating, making assumptions, showing a lack of respect and a reluctance to explore difficult areas (Glass & Arnkoff, 2000; Llewelyn, 1988). This research highlights the importance of aspects of the process of therapy for people who are engaging in therapy. This is supported by the findings of quantitative research, which has demonstrated an association between outcomes and several aspects of the therapeutic alliance including a collaborative relationship, empathy, positive regard and genuineness from the therapist (Norcross, 2002). Qualitative research can therefore provide insight into service users' overall satisfaction with a type of therapy as well as clients' views of positive and negative aspects of the process (Khan et al., 2007). This is particularly relevant for people with intellectual disabilities who have traditionally not been provided with opportunities to discuss their therapy experiences (Hoole & Morgan, 2010).

Although the themes identified above may well be relevant for people with an intellectual disability, it cannot be assumed they will have the same experience of psychological therapy as people without an intellectual disability. The social exclusion of people with intellectual disabilities has been well documented (Department of Health, 2001). The social model of disability emphasises how barriers, negative attitudes and exclusion by society can contribute to disabling a person (Hasler, 1993). As people with intellectual disabilities may have had such experiences, they may not have had many previous opportunities to talk about themselves and their feelings. Thus, people with intellectual disabilities may find it more difficult to access and engage with therapy; potentially impacting on their experience of psychological interventions. Furthermore, although there is guidance on the adaptations that should be made for engaging people with intellectual disabilities in psychological therapy (British Psychological Society, 2015), it is important to seek people with intellectual disabilities' views on whether such adaptations were accessible for them during therapy.

Preliminary searches suggested a number of studies using qualitative methodology to gain feedback on people with intellectual disabilities' experiences of therapy have recently been conducted. The aims of this review were therefore:

1) To systematically identify and appraise the quality of qualitative studies regarding the experiences of psychological therapy for people with intellectual disabilities.
2) To use meta-ethnography to synthesise the results of the identified studies.

Method

Design

There were three stages to this literature review. Firstly, a systematic search of the literature was conducted. The second stage involved evaluating the quality of the included papers. Finally, following the guidelines of Noblit and Hare (1988) and as modified by Britten et al. (2002) for use in health research, a meta-ethnographic approach was used to synthesise the findings.

Search method

Web of Science, PsychInfo and PubMed were used to conduct a literature search for all peer reviewed, primary research papers in 'all years' relating to experiences of individual or group-based psychological therapy for people with intellectual disabilities. Studies had to meet the following criteria: (i) be published in English in a peer-reviewed journal; (ii) use qualitative methodology; (iii) involve a psychological intervention aimed at the treatment of emotional, behavioural or mental health problems; (iv) involve participants aged 18 years or older with a diagnosed intellectual disability in accordance with the DSM-IV criteria (American Psychiatric

Association, 2000) or ICD-10 (World Health Organization, 1992). Studies involving mixed methods which met the above criteria were included if detailed information was given on the qualitative methodology and findings. Table 1 lists the search terms that were used.

Table 1.

Search terms used in the systematic review of the literature.

Search term	**Variation**
Intellectual disability	"Intellectual* disab*"OR "learning disab*" OR "mental* disab*" OR "mentally disabled" OR "cognitive* disab*" OR "mental* retard*" OR "mental* handicap*" OR "mentally handicapped" OR "mental* deficien*" OR "learning difficult*"
Psychological therapy	"Psycho* therapy" OR "Psycho* treatment" OR "Psycho* intervention" OR "Psychotherap*" OR "psycho-therap*" OR "therap*"
Service user experience	"Service user experience" OR "Service user views" OR "Experiences" OR "Views" OR "Satisfaction" OR "attitudes" OR "Perceptions" OR "Client attitudes" OR "Patient Satisfaction" OR Therapeutic process* OR Psychotherapeutic Process*
Qualitative research	"Qualitative research" OR "Qualitative method*" OR "Thematic analys*" OR "Interpretative Phenomenological Analys*" OR "Grounded Theory*" OR "Discourse Analys*" OR "Content Analys*"

A literature search was conducted on 9th February 2018. The process for identifying eligible articles is illustrated in Figure 1.

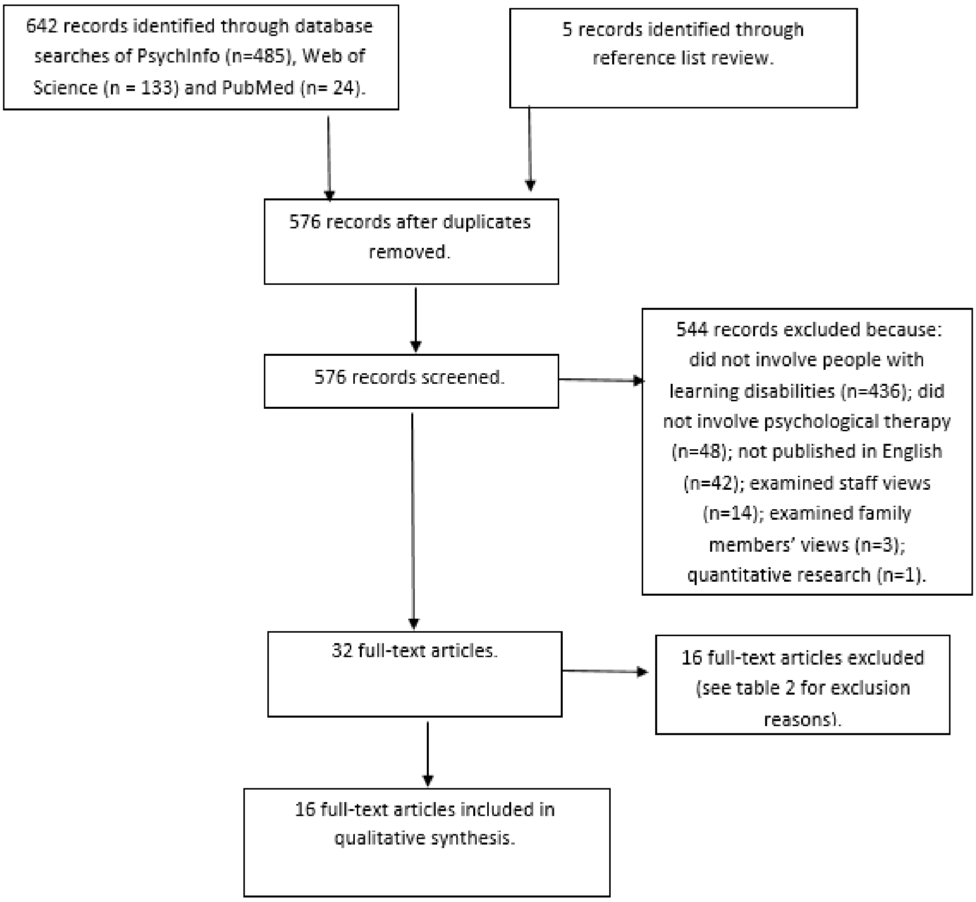


Figure 1. PRISMA flow diagram of search outcomes.

Table 2.

A record of the reasons for excluding full-text articles retrieved from the systematic literature search.

Reason for paper exclusion	Number of papers this applied to
Not focused on people with intellectual disabilities experiences of psychological therapy	13
Involved children or adolescents with an intellectual disability	2
Review paper	1

Study characteristics

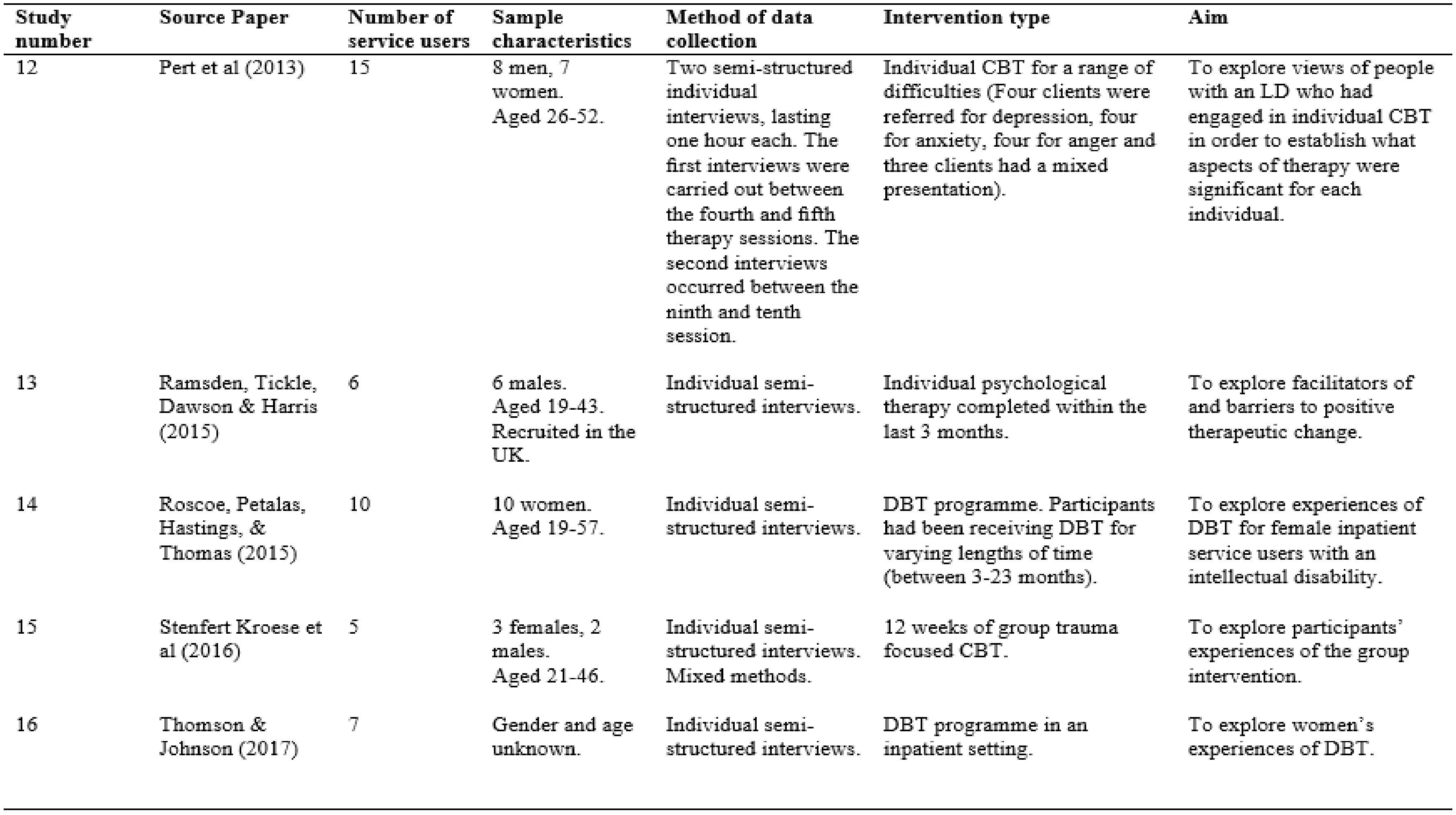
Table 3 outlines the characteristics of the included studies. Ten of the papers included in this literature review used solely qualitative methodology (2, 6, 7, 8, 9, 11, 12, 13, 14, 16). Six papers used mixed methods, incorporating a qualitative component using semi-structured interviews (1, 3, 4, 5, 10, 15). It was decided to include the qualitative results from mixed methods papers as detailed information was given on their qualitative methodology and findings. Sample sizes ranged from 3 to 20 and included 71 males and 48 females, although three of the studies did not state the gender of participants (24 participants in total whose gender was unknown). Included studies had all been conducted in the UK. Six of the studies used cognitive behavioural therapy (CBT) either individually or in a group setting, three studies used a psychodynamic model, three studies used dialectical behaviour therapy (DBT) and one used compassion focused therapy (CFT). Three studies did not state the models used, which limits comparisons that can be made across models. Six studies involved group based therapy, seven involved individual therapy and two used a full DBT programme, which involves both individual and group treatment.

Four of the included studies (4, 8, 11, 13) used full scale IQ to confirm the level of intellectual disability of participants. Full scale IQs indicated that participants within these studies had a mild or moderate level of intellectual disability. Four studies indicated participants had mild intellectual disabilities and two studies reported participants had mild to moderate intellectual disabilities (1, 3, 4, 9, 12, 15). However, these studies did not screen participants to confirm this. The remaining studies did not comment on the level of intellectual disability of participants. Although all participants were recruited from intellectual disability services, the lack of screening of level of intellectual disability is a limitation as this increases the risk of inclusion of people who may not meet criteria for a diagnosis.

Table 3.
Study characteristics.

Study number	Source Paper	Number of service users	Sample characteristics	Method of data collection	Intervention type	Aim
1	Crossland, Hewitt & Walden (2017)	4	3 females, 1 male. Aged 24-48.	Individual semi-structured interviews. Mixed methods.	18 week DBT skills training group.	To evaluate the DBT group.
2	Gifford, Evers & Walden (2013)	8	2 females, 6 males. Aged 27-46.	Individual semi-structured interviews.	Individual psychological therapy.	To investigate what is helpful and what is not helpful to people with intellectual disabilities about working with clinical psychologists.
3	Hardiman, Willmoth & Walsh (2018)	3	2 females, 1 male. Aged 31-48.	Individual semi-structured interviews.	Individual CFT. 12-15 weeks.	To investigate the effects of a CFT intervention.
4	Hassiotis et al (2013)	13	Gender and age unknown.	Individual semi-structured interviews.	Individual CBT for mood disorders. 16 weeks.	To investigate the acceptability of the sessions for service users and clinicians.
5	Hays, Murphy, Langdon, Rose & Reed (2007)	16	16 males. Aged 20-61.	Individual semi-structured interviews.	Group CBT for individuals with an LD who have sexually offended. Ran for 1 year.	To gather the views of people with intellectual disabilities who have sexually offended of a CBT group.
6	Khan and Beail (2013)	20	12 men, 8 women. Aged 17-64.	Individual semi-structured interviews.	15 participants had psychodynamic therapy, 2 participants had integrative counselling and 3 participants had CBT.	To measure service user satisfaction with individual psychological therapy delivered in an out-patient setting.

Study number	Source Paper	Number of service users	Sample characteristics	Method of data collection	Intervention type	Aim
7	Lewis, Lewis & Davies (2015)	6	5 females, 1 male. Aged 20-43.	Individual semi-structured interviews.	Individual psychological therapy with a clinical psychologist or a trainee clinical psychologist which had ended no more than 6 months ago.	To explore the individual experiences of service users with an intellectual disability who have accessed direct psychological therapy.
8	MacDonald, Sinason & Hollinsal (2003)	9	4 men, 5 women. Ages unknown.	Individual semi-structured interviews.	Two groups based on psychodynamic group psychotherapy. One group was a sexual offenders group and one was a woman's group. The four male participants had been attending the group for over a year. The five female participants had been in the group for 2-8 months.	To elicit clients' views on their experience of group analytic therapy.
9	MacMahon et al (2015)	11	8 men, 3 women. Aged 22-44.	Semi-structured individual interviews within 2 weeks of the last group session.	12 sessions of group CBT for anger management.	To provide opportunities for participants to express their opinions and discuss their experiences of the group.
10	Marwood and Hewitt (2012)	4	Gender and age unknown.	Individual semi-structured interviews. Mixed methods.	6 sessions of group CBT for anxiety.	To investigate the effectiveness of group CBT for individuals with an intellectual disability who experience anxiety.
11	Merriman and Beail (2009)	6	6 males. Aged 22-45.	Individual semi-structured interviews.	Individual psychotherapy for two or more years.	Aimed to ascertain service user's views on individual psychotherapy.



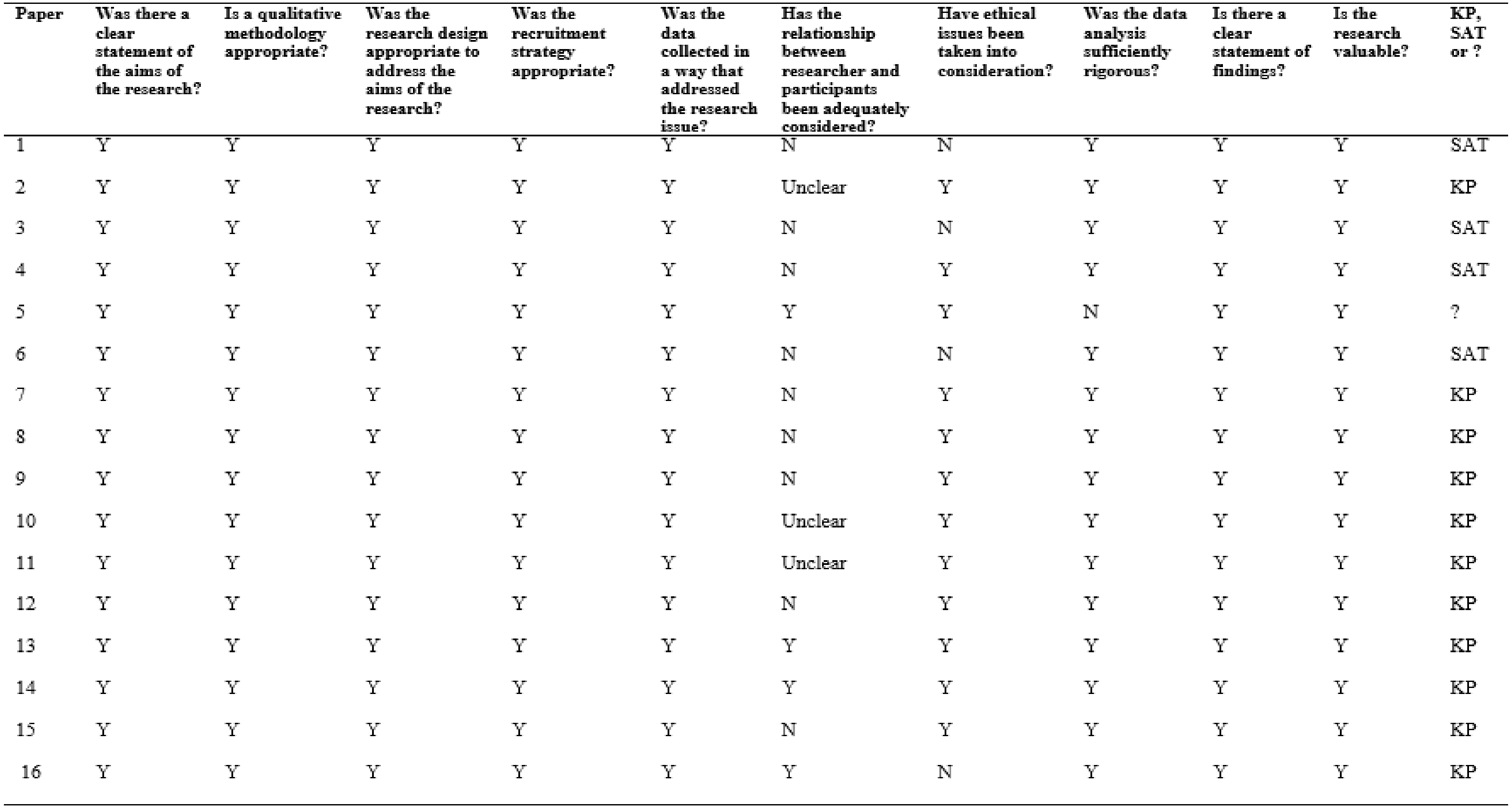
Study number	Source Paper	Number of service users	Sample characteristics	Method of data collection	Intervention type	Aim
12	Pert et al (2013)	15	8 men, 7 women. Aged 26-52.	Two semi-structured individual interviews, lasting one hour each. The first interviews were carried out between the fourth and fifth therapy sessions. The second interviews occurred between the ninth and tenth session.	Individual CBT for a range of difficulties (Four clients were referred for depression, four for anxiety, four for anger and three clients had a mixed presentation).	To explore views of people with an LD who had engaged in individual CBT in order to establish what aspects of therapy were significant for each individual.
13	Ramsden, Tickle, Dawson & Harris (2015)	6	6 males. Aged 19-43. Recruited in the UK.	Individual semi-structured interviews.	Individual psychological therapy completed within the last 3 months.	To explore facilitators of and barriers to positive therapeutic change.
14	Roscoe, Petalas, Hastings, & Thomas (2015)	10	10 women. Aged 19-57.	Individual semi-structured interviews.	DBT programme. Participants had been receiving DBT for varying lengths of time (between 3-23 months).	To explore experiences of DBT for female inpatient service users with an intellectual disability.
15	Stenfert Kroese et al (2016)	5	3 females, 2 males. Aged 21-46.	Individual semi-structured interviews. Mixed methods.	12 weeks of group trauma focused CBT.	To explore participants' experiences of the group intervention.
16	Thomson & Johnson (2017)	7	Gender and age unknown.	Individual semi-structured interviews.	DBT programme in an inpatient setting.	To explore women's experiences of DBT.

Quality appraisal

The CASP checklist (Critical Appraisal Skills Programme, 2017) was used as a tool for appraising the quality of the papers. The aim of this appraisal was to determine whether the quality of the study affected the contribution of the study to the overall synthesis. No study was excluded based on its' quality appraisal but instead the appraisal process was used to test the contributions of the papers at a later stage. Table 4 outlines the scores of each paper for each of the quality appraisal criteria. Following the approach outlined by Dixon-Woods et al. (2007), each paper was appraised as 'KP' ('key paper' that is theoretically rich and could have a significant influence on the synthesis); 'SAT' (a 'satisfactory' paper); or '?' (when the importance of the paper to the review is unclear). 40% (6) of the papers were also critically appraised by a second independent researcher. The findings of the appraisal were discussed between the two researchers and any discrepancies were discussed and resolved. Eleven of the papers were evaluated as 'KP', four papers were evaluated as 'SAT' and one paper was evaluated as '?'. Studies judged as being of a poorer quality did not involve rigorous data analysis, did not provide sufficient details as to the consent procedures, which is of particular importance when involving people with intellectual disabilities in research, and did not explicitly consider the relationship between researcher and participant and how this may have impacted on the findings. Issues of power are particularly pertinent when working with people with intellectual disabilities and so the researcher-participant relationship should be considered when conducting research in this field.

Table 4.

CAPS Checklist



Paper	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	Is the research valuable?	KP, SAT or ?
1	Y	Y	Y	Y	Y	N	N	Y	Y	Y	SAT
2	Y	Y	Y	Y	Y	Unclear	Y	Y	Y	Y	KP
3	Y	Y	Y	Y	Y	N	N	Y	Y	Y	SAT
4	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	SAT
5	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	?
6	Y	Y	Y	Y	Y	N	N	Y	Y	Y	SAT
7	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
8	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
9	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
10	Y	Y	Y	Y	Y	Unclear	Y	Y	Y	Y	KP
11	Y	Y	Y	Y	Y	Unclear	Y	Y	Y	Y	KP
12	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
13	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP
14	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP
15	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	KP
16	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	KP

Synthesis

The synthesis of the literature used a meta-ethnographic approach (Noblit & Hare, 1988). Meta-ethnography is an interpretive method, which aims to develop new interpretations and conceptual insights (Noblit & Hare, 1988). As this review aimed to contribute to the theoretical understanding of people with intellectual disabilities' experiences of psychological therapy, this approach seemed appropriate as it allows for preservation of the interpretive properties of the data. A meta-ethnography aims to develop 'third order constructs' from the 'second order constructs' used by the authors of the papers (Britten et al., 2002). As definitions of first, second and third order constructs can vary, table 5 shows the definitions used in this review, which draws on the work of Noblit and Hare (1988), Britten et al. (2002), and Malpass et al. (2009):

Table 5.

Definition of first, second and third order constructs (definitions drawn from the work of Noblit and Hare (1988), Britten et al. (2002) and Malpass et al. (2009)).

First order constructs	People with intellectual disabilities' perspectives of psychological therapy.
Second order constructs	The authors' perspectives and understanding (indicated by themes and concepts) of people with intellectual disabilities' views of psychological therapy.
Third order constructs	The perspectives and interpretations of the research team (indicated by themes and key concepts).

Determining how studies are related and identifying second-order constructs

The first step of the synthesis was to read the included articles in chronological order and to extract key themes and concepts as expressed originally by the participants (first order constructs) and authors (second order constructs). A table was used to document the second order constructs from each paper and raw data from the papers (first order constructs) which illustrated the second order constructs.

Additional ideas which arose as papers were read were also noted. This aided with the development of third order constructs.

Translating studies into one another

Once the first and second order constructs from each paper had been extracted, the next step involved translating the studies into one another. Translating within meta-ethnography refers to comparisons of themes, concepts and interactions of the studies whilst maintaining the central themes in the original studies (Noblit & Hare, 1988). To do this, a grid was created in Microsoft ‘Excel’. Each paper was entered into a separate cell and the second order constructs from each paper were entered into the rows of the grid. The initial phrases used in the papers or a close paraphrase were used for the row labels. A summary of the second order constructs was also included. The authors then considered each second order construct and looked for key concepts across all papers. Each cell of the grid was considered in turn to ensure the second order construct from each paper was encompassed. Reference was made to the first order constructs whilst doing so to understand the interpretations that the authors of the papers had made of first order constructs. The outcome of this translation process is illustrated in table 6. Those papers in bold were rated as ‘Key Paper’ (‘KP’) during the quality appraisal stage of the review. When papers rated as ‘SAT’ or ‘?’ were not included, this did not change the presence of second order constructs. During this process, a conceptual map was also drawn to visually represent the themes and subthemes (appendix I).

Table 6.

Translation of second order constructs and resulting third order constructs.

Third order construct	Second order construct	Papers that included the second order construct
Adapting to therapy	The emotional impact of preparing for therapy	**2**, **7**, **9**, **11, 15**.
	Accessibility of therapy	1, 3, 4, 6, **7**, **9**, **10**, 13, **14, 16**
	Talking is helpful	**2**, 5, 6, **7**, **8**, **9**, **10**, **11**, **12**
	Talking can be distressing	5, **7**, **8**, **12**
The therapeutic environment	Confidentiality	1, **2, 7, 11, 12,**
	Choice	1, **2, 4,** 5, 6, **7, 10, 11, 13**
Group dynamics	Inclusion	1, 5, **8**, **9**, **10**, **14, 15**
	Group composition	1, **8**, **9**, **10**, **14, 15, 16**
The therapeutic relationship	Positive feelings towards therapist	**2**, 3, 6, **7**, **11, 13**
	Feeling listened to and valued	**2**, 3, 4, **8**, **12, 13, 15**
	Collaborative	**7**, **8**, **11**, **12**
The impact of therapy	Positive impact on life	**2**, 3, 4, 6, **7**, **9**, **11**, **12, 15, 16**
	Use of new skills	1, 3, 5, **7**, **9**, **10**, **14, 16**
	Maintaining change	1, **2**, 4, **9**, **12, 13, 15, 16**

Synthesising translations

Finally, the translations were synthesised to determine how the studies were related to each other. Noblit and Hare (1988) proposed three potential types of synthesis: ‘reciprocal’, where themes across papers are similar; ‘refutational’, where there is disagreement in themes across papers; and ‘line of argument’, where concepts across papers are taken together and interpreted as a ‘line of argument’. In this review a ‘line of argument’ approach was used to compare interpretations, explore similarities and differences and integrate these to produce an overarching framework. A data-driven, inductive approach was used to analyse the data. Themes were coded at a semantic level using a realist approach to reflect the reality of participants' experiences and to identify broader meanings across the data set (Braun & Clarke, 2006).

Reflexivity of the researcher

It is important to recognise the researcher's perspective to consider how this may have impacted on the research procedure and data interpretation. The lead author is a 27 year old female White British trainee clinical psychologist with a background of working with people with intellectual disabilities. This has impacted on her research interest within this area through wanting to promote the inclusion and empowerment of people with intellectual disabilities and to gain a deeper understanding of their experiences of psychological interventions. Given the researcher's previous experiences of working therapeutically with people with intellectual disabilities, the researcher was aware that she may have had a bias towards wanting therapy to be useful. The researcher was aware of this throughout the synthesis and looked at the findings with an open mind as much as possible to try to avoid potential bias in the synthesis.

Findings

From the synthesis, five key concepts were identified: adapting to therapy, the therapeutic environment, group dynamics, the therapeutic relationship and the impact of therapy on life.

Adapting to therapy

The emotional impact of preparing for therapy

Therapy was initially highly anxiety-provoking, with participants talking of the nerves they felt prior to attending both group and individual session (2, 7, 9, 11, 15). This seemed to relate to anxiety about meeting new people and also anxiety due to not knowing what to expect from therapy.

Accessibility of therapy

Adaptations were made to therapy which seemed to increase accessibility. For example, one participant talked about how they had 'done like a big project, we done like a big sea, like a back to the future timeline thing, but it was a sea thing. It had fishes like, from the start to the end of my past…' (7). Such adaptations made therapy fun and enjoyable for participants (7, 9), which in turn is likely to have increased participants' engagement in therapy.

The use of hand-outs and homework tasks also increased accessibility as it helped participants to remember and explain their feelings and difficulties (1, 4, 6,10). However, for some participants the materials did not seem to be fully adapted to their needs, illustrating the importance of tailoring materials for the individual (1, 10, 16) whilst for others the concept of having homework checked was unpleasant (4). The role of support staff in increasing accessibility of therapy was highlighted. Some participants described how the support of staff both during sessions and with homework aided their understanding (1, 13) whilst others would have liked their staff to have more of an understanding of the treatment model (16).

Although adaptations seemed to increase accessibility of therapy and a number of participants demonstrated a good understanding of the treatment model, making links between the content of therapy and its application outside of therapy was very difficult for some participants (10) as was understanding and remembering aspects of the treatment programme (1, 3, 13, 14). For instance one participant commented they “didn’t like the mindfulness bit…I didn’t understand that very well” (13). One participant also highlighted how the therapist ‘talked to me in drabs and talked too fast. I could only understand half the time’ (6), illustrating the importance of the therapist adapting their approach to increase accessibility for people with intellectual disabilities.

Talking is helpful

Having space in therapy for the person to talk about their difficulties was seen as helpful. One participant stated it was ‘helpful that you can go somewhere and talk to someone about problems…’ (8) whilst another said ‘it felt great when I started talking to him and getting things off my chest which I’d done in the past to stop me doing it again. It was a great relief’ (11).

Participants also illustrated the beneficial effects of talking on their wellbeing. One participant stated ‘It’s like going in a great mood...talking to somebody’ (9) whilst another said ‘I feel a lot better, relaxed. I feel this great big weight come off my shoulders and I felt thingy, and that weight can stay away altogether and I feel a lot better’ (12). For some participants talking also had beneficial effects in terms of helping them to resist the urge to reoffend (8).

Talking can be distressing

Although participants indicated that talking about their problems could be helpful, for some participants talking about difficult times in their past was very distressing, indicating that they previously would have avoided thinking about these experiences (5, 7, 8, 12). For instance, one participant indicated “[What do you think was the worst thing about meeting a psychologist?] Talking about the past….What I found hard was the time I had to think about the past, that is all” whilst another said

“[What was the worst thing about meeting with the psychologist?] Having to open up, when you see them you have to open up a lot.” (6).

The therapeutic environment

Confidentiality

Participants highlighted the private, confidential nature of therapy and how this enabled them to feel more able to share their experiences. One participant said ‘I felt a bit more comfortable one to one, because you can talk about things that are private and confidential. Any, like…eh problems that you’ve got that you don’t want anybody else to know because it’s private, you know’ (12). Although participants seemed to value the confidential nature of therapy, some struggled when the psychologist met with their staff, expressing anxiety that they would be told off by their staff for what they had shared in therapy (7).

Choice

Participants indicated that they did not feel they had choice or control over many aspects of therapy including decisions about therapy ending (6, 13); the number of sessions (1, 2, 5); and who attended therapy (4, 6, 10). Some participants did not feel included in the setting up of therapy in terms of session days/times (7), were unhappy with waiting times for therapy (6) and found it difficult if sessions had to be cancelled (2). Participants often did not initially choose to access psychological therapy and were referred by someone other than themselves (13). Although most participants engaged relatively quickly following this referral, for one participant they did not engage as they did not think they needed to change; highlighting the importance of choice in accessing therapy.

Group dynamics

Inclusion

For studies involving group interventions, the relationships which developed amongst group members were important for participants (1, 5, 8, 9, 10) and appeared more helpful than the therapeutic relationship within group interventions. Attending a group with individuals with similar experiences helped participants to feel able to share their experiences as they felt other group members understood their situation and provided support (5, 8, 14, 15). This inclusive nature of the group contrasted experiences elsewhere, where participants did not feel able to talk as openly for fear of judgement (8).

Group composition

Although the inclusive nature of a group could be helpful, some participants found being in a group environment difficult and described high anxiety about talking or doing practice exercises, such as mindfulness, in a group setting (10, 14, 15, 16). Participants also talked of difficult interpersonal relationships within the group (9, 15) and seemed to struggle if others in the group were dissimilar to them (1, 8, 10). Observing other participants' distress within the group and hearing about their life experiences could also be upsetting for participants (8). For some participants, the presence of their support worker helped them to manage difficult group dynamics (15).

The therapeutic relationship

Positive feelings towards therapist

A number of participants indicated that they had general positive feelings towards the therapist, describing the therapist as 'nice' and talking of their like of the therapist (2, 3, 6, 7, 11, 13).

Feeling listened to and valued

As well as general positive feelings towards the therapist, participants indicated that they felt understood and listened to within therapy (2, 3, 4, 8, 12, 13, 15). This is illustrated by one participant who said 'but you can actually see by (therapist) that she's listening, because she's looking straight at you when, when you're talking to her and she just listens as well' (12).

Collaborative

The findings highlighted how, through the collaborative process of therapy, participants felt treated as an equal, working together with the therapist rather than the therapist being viewed as the expert (12). Some participants highlighted how they had to put work in themselves to therapy (7), further demonstrating the collaborative nature of their therapy sessions. However, other participants seemed to struggle with the therapist asking questions of them in a collaborative nature (8). Moreover, other participants indicated a dependent alliance with the therapist rather than a collaborative one, ‘X sorts my problems out. I’ve had problems the last three weeks and he wrote them down and sorted it out. I leave it to him to sort things out’ (11).

The impact of therapy

Positive impact on life

Participants saw positive changes in social aspects of their lives and in their emotional wellbeing and behaviour following therapy (2, 3, 4, 6, 7, 9, 11, 12, 15, 16). For instance, one participant illustrated the social gains ‘I go out a lot and do things. I do yoga, church and to groups’ (6) whilst another highlighted the positive changes to their emotional wellbeing and behaviours, ‘and I seem to find I’m feeling a hell of a lot, lot better and happier and I mean I’m not hitting anybody. I’m not falling out with anyone’ (12). The positive influence of therapy on relationships was also apparent, with participants noting interpersonal difficulties had reduced following the psychological intervention (6, 9, 16).

Use of new skills

Participants talked of how they have used some of the skills they learnt through therapy effectively in their daily life (1, 3, 5, 7, 9, 10, 14, 16). One participant illustrated this, ‘…and I went and walked off to count to ten. I counted to ten in my head (. . .) you got to count to ten in your head and that’s what I done (. . .) that’s what I done good with that’ (9).

Maintaining change

Although participants reported on how they had effectively used their new skills and strategies outside of therapy, sometimes participants found it hard to use these skills during difficult situations (1, 4, 9, 13, 15, 16). Furthermore, participants seemed to struggle with their difficulties still persisting after therapy and the time it took to see change (4, 12). For example, one participant reported ‘what was hard like problems in your life, like you’re obsessed with it…won’t fade away easily’ (4). The role of the person with an intellectual disability in maintaining change over time was highlighted, ‘I mean she can give me all the advice in the world cause virtually that’s what she was doing but it was up to me to take on board what she was saying and do something about it myself, so it was all about me’ (2). The importance of a supportive social network for maintaining change outside of therapy sessions was also key for some participants as was the role of the psychologist in facilitating wider changes related to health and social care needs (13, 15).

Comparisons across interventions

There were some differences in themes for individual vs. group interventions. Interestingly, the theme of ‘the therapeutic relationship’ did not arise within any of the included group studies. Participants of group interventions instead highlighted the helpful and unhelpful aspects of the group relationships, rather than the therapeutic relationship. Furthermore, ‘use of new skills’ was mainly identified from group intervention studies.

Although the majority of themes were relevant across therapeutic models, there were some differences. ‘Use of new skills’ arose in studies which involved CBT, DBT and CFT but not in studies using psychodynamic models. The theme of ‘maintaining change’ occurred in studies involving CBT and DBT but did not occur in studies using psychodynamic models. This is not surprising given the emphasis of CBT and DBT in using and practicing new skills outside of therapy.

Discussion and recommendations

This synthesis of 16 papers using a meta-ethnographic approach has identified a number of themes related to experiences of therapy from the perspectives of people with an intellectual disability. Helpful aspects of therapy included: talking about difficulties, confidentiality, adaptations to increase accessibility, feeling listened to and valued by the therapist, collaboration, inclusive nature of a group environment, the positive impact of therapy on participants' lives, and use of new skills outside of therapy. Challenges of therapy included: anxiety elicited when preparing for therapy, the distressing nature of talking about difficulties, inaccessible session content and homework, and difficulties in maintaining change after therapy has ended.

Although there are some similarities when comparing these findings to the general population, this review highlights a number of challenges and therapeutic dilemmas specific to people with intellectual disabilities and indicates there are significant changes that still need to be made in order to offer people with intellectual disabilities a psychological service that is fully adapted to their needs. Firstly, the theme of 'adapting to therapy' highlights that talking openly within a therapeutic context can be very powerful for people with intellectual disabilities but can also be very difficult and distressing. Difficulties in talking about experiences have also been found in other minority groups. For instance, refugees rarely access mental health services, which is in part likely to be due to stigma of mental health within refugee communities and experiences of abuse of power by those in authority, where sharing personal information with strangers could place people at risk of violence (Ellis, Miller, Baldwin, & Abdi, 2011). There is extensive research illustrating the social exclusion of people with intellectual disabilities (e.g. Hall, 2005). Given these experiences, people with intellectual disabilities may not have had many previous opportunities to talk about themselves and their feelings. This limited experience of self-disclosure may make talking more distressing for people with intellectual disabilities and could also explain the anxiety experienced by participants prior to commencing therapy. These findings suggest that currently there is not enough support given to setting up therapy for people with intellectual disabilities and preparing them for what therapy may involve. Consideration should be given to this by clinicians in the future when they begin to work therapeutically with a person with an intellectual disability. This also has potential implications for services, such as Improving Access to Psychological Therapies (IAPT) and adult mental health services, who should where possible be making ‘reasonable adjustments’ so that people with intellectual disabilities can access these services (Dagnan, Burke, & Davies, 2015). It is therefore extremely important that these services are aware of these challenges and recommendations in terms of setting up therapy for people with intellectual disabilities.

Furthermore, the theme of ‘group dynamics’ showed that a group environment could be experienced as inclusive and beneficial, as contact with those with similar difficulties can provide some comfort. The usefulness of this inclusive group environment was focused on more than the relationship with the therapist in group intervention studies. This highlights the importance of validating and normalising peer experiences for people with intellectual disabilities but exposure to such experiences is often very limited for this client group. This is further supported by qualitative research showing the importance of talking to others and being accepted for people with intellectual disabilities (Abbott & Mcconkey, 2006). Exposure to those with more significant needs can also be an unwanted, distressing mirror to people’s own difficulties. Given people with intellectual disabilities’ limited experiences of self-disclosure, they may not be prepared for the level of distress and disclosure that they may hear within a group environment. This again shows the importance of spending time preparing participants for the nature of a group environment and the potential distressing events others may discuss within the group so people with an intellectual disability are more informed and can make an informed choice before participating in a group intervention.

Although adaptations increased engagement in therapy, participants struggled to apply the content of sessions to everyday life and to maintain change outside of therapy. This raises the question as to how truly accessible therapy is for people with intellectual disabilities. Guidelines suggest that written summaries and regular feedback on sessions to family members or support workers may be helpful to support the implementation of strategies outside of therapy (BPS, 2015). However, given that confidentiality enabled participants to share more openly with their therapist, this highlights a dilemma in terms of how much the wider system should be involved in therapy and how this is managed if the client does not want members of their system to be included. The findings suggest that current adaptations to therapy are not of an acceptable level and further, individually-tailored work is needed to support people with intellectual disabilities to fully understand session content and to maintain long-term changes following therapy whilst still being sensitive to the dilemma of how much to involve a person's wider system. Moreover, participants shared concerns about what was being shared with their wider network and did not feel included in decisions about the therapeutic environment, indicating that they may have felt powerless and as if they had no control in terms of the knowledge shared with their wider system or over the therapeutic process. These findings illustrate that there are still improvements needed in order for people with intellectual disabilities to feel empowered, fully included and equal within the therapeutic environment.

It is interesting that within this review there was less focus on unhelpful aspects of the therapeutic relationship in comparison to the general population. Power could provide one possible explanation as to why participants with an intellectual disability may feel less able to express any difficulties within the therapeutic relationship. Further research is needed to ensure evidence-based pathways are developed through which people with intellectual disabilities feel able to share difficulties within the therapeutic relationship. Research using single case experimental designs to gather feedback on a session by session basis may provide more opportunities for people with intellectual disabilities to express what was particularly helpful or unhelpful within the therapeutic relationship during a particular session, an approach which has been used in the general population (Martin et al., 2000). However, it is important to consider whether people with intellectual disabilities would feel able to give honest feedback if asked to do so at the end of a session by their therapist. Interviews with someone other than the therapist at regular time points during therapy could overcome this and allow for more detailed feedback on therapy sessions. The review also raises recommendations for researchers within this field. In particular, researchers should ensure they clearly document consent procedures and how they considered the researcher-participant relationship.

There are some limitations to the current review. Firstly, although the majority of included studies used interviewers who were not known to the participant, these interviewers may still have been perceived as working within the service (e.g. trainee clinical psychologists). This may have influenced participants' responses, especially in relation to challenging aspects of therapy, and the majority of papers did not explicitly state how this researcher-participant relationship was considered. Moreover, studies included in this review tended to involve people who had participated in therapy for a set number of sessions (e.g. minimum of 6 sessions). This excluded participants who had dropped out of therapy at an early stage, who may have had less helpful experiences of therapy, and so this may have biased the findings of this review. Gathering qualitative feedback on a session by session basis would enable the views of participants who have dropped out of therapy to be captured and may provide valuable information as to why people with intellectual disabilities leave psychological therapy. Furthermore, the number of sources contributing to each theme was small in comparison to the overall sample size of sixteen included studies, although each of the presented themes were derived from a minimum of four sources.

In summary, this review has identified a number of helpful and unhelpful aspects of psychological therapy specifically for people with intellectual disabilities. The findings indicate that there are significant changes that still need to be made in order to offer people with intellectual disabilities a psychological service that is fully accessible and adapted to their needs. In particular, more consideration is needed of power differentials within the therapeutic relationship and further thought given as to how people with intellectual disabilities can feel empowered, fully included and equal within the therapeutic environment.

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Service Improvement Project

An Evaluation of the Acceptability of Guided Self-Help for Depression in Adults with Autism Spectrum Disorder.

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Introduction

Depression in adults with Autism Spectrum Disorder

There are limited studies examining the epidemiology of depression in adults with Autism Spectrum Disorder (ASD) but research suggests depression is common (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). The National Institute for Health and Care Excellence (NICE) recommends offering psychosocial interventions based on existing NICE guidelines for the specific disorder (NICE CG142, 2012) for adults with autism and co-existing mental health problems. The NICE recommended psychological treatment for mild to moderate depression is low intensity cognitive behavioural therapy (CBT) in the form of guided self-help (GSH) or computerised CBT (NICE CG96, 2009).

There is currently a paucity of research examining the effectiveness of CBT-based interventions for depression in adults with ASD. NICE guidelines (NICE CG142, 2012) recommend a number of adaptations to CBT for adults with ASD including: a more concrete approach with frequent use of written and visual information, an emphasis on changing behaviours rather than cognitions, helping to sustain attention by offering breaks, using an individual’s special interests, and involvement of a family member or professional where possible. An adapted GSH intervention for depression in adults with ASD has recently been developed and investigated in a feasibility study; the ADEPT Randomised Controlled Trial (RCT) (Russell et al., 2017). The GSH treatment was based on behavioural activation for depression and followed the adaptation principles outlined by NICE guidelines for adults with autism (NICE CG142, 2012). Adults from two NHS clinics with a diagnosis of ASD, experiencing depression (as measured by a PHQ-9 score of 10 or more), and consenting to help with the research study were randomly allocated to receive the adapted GSH intervention or treatment as usual (e.g. provided with information about local talking therapies services).

Qualitative research on GSH for depression

As a newly developed intervention based on GSH, the team wanted to know if the intervention was acceptable to adults with ASD and how it could be improved. This is in line with current policies which emphasise services should be patient-centred (NICE, 2009). Qualitative research focused on service users' experiences can increase understanding of the way in which interventions are used and experienced (Khan, Bower, & Rogers, 2007), indicating their acceptability. Khan et al (2007) conducted a meta-synthesis of service users' experiences of GSH for depression in primary care and highlighted a number of key issues which may influence its' effectiveness. Self-help was described as `hard work' and participants reported lapses in their abilities to use the techniques at times. Participants struggled to view themselves as the mechanism for change. It took time to fully understand the active nature of treatment, which proved difficult given the time limitations of GSH. Further specific difficulties of using GSH for depression were highlighted by Macdonald, Mead, Bower, Richards and Lovell (2007). Participants reported symptoms of depression, such as lack of motivation and poor concentration, led to difficulties with engagement. Although some participants reported a good therapeutic relationship, others did not feel able to fully self-disclose due to the structured nature of GSH and felt they did not have a clear understanding of their difficulties following the intervention. These findings highlight the important feedback which can be gained on GSH through qualitative research, which can lead to improvements in the accessibility of GSH for service users.

Although the above limitations of GSH may also be relevant for adults with ASD, research is needed to establish whether there are similar and/or additional barriers to the use of GSH for this client group. To the author's knowledge, it has not previously been tried or evaluated. Individuals with ASD can have difficulties with emotional literacy, where they struggle to identify and understand their own and others emotions (e.g. Baron-Cohen, Leslie, & Frith, 1985). This may serve as an additional barrier to the use of CBT, which requires identification of thoughts and feelings. Secondly, it is thought the nature of the therapeutic relationship may contribute to the outcomes of CBT (Gilbert & Leahy, 2007). Individuals with ASD can find it difficult to develop and maintain new relationships and thus these difficulties may impact on the development of an effective therapeutic relationship. Adults with ASD may experience fewer barriers in accessing GSH because of the reduced interpersonal demands involved in comparison to other forms of individual therapy. Difficulties with verbal and non-verbal communication, in understanding complex and abstract ideas, and in the ability to self-reflect may be potential barriers for the use of CBT in this population, particularly with a short, time-limited intervention such as GSH. This highlights the importance in gaining the views of adults with ASD on the adapted GSH intervention to investigate whether these barriers are relevant. In previous research, adults with ASD have provided qualitative feedback on modified group CBT resources (Langdon et al., 2016). This feedback was used to further develop the treatment, indicating psychological interventions for adults with ASD can be further adapted and improved following qualitative feedback.

The current study

As part of the ADEPT initiative, this qualitative service improvement project aimed to investigate the acceptability of the newly developed GSH intervention for people with ASD. Individual interviews were conducted with participants who had received GSH.

Study aims:

1) To investigate whether people with ASD found the GSH intervention acceptable and useful.
2) To investigate whether the structure of GSH, such as amount of session content and pacing, was acceptable for people with ASD.
3) To identify whether the level of support and understanding received from the therapist was adequate for people with ASD.
4) Based on service user experiences and perspectives, to formulate key recommendations for those who developed the GSH intervention with a view to improving the acceptability of the intervention for people with ASD.

Method

Ethics and consent

Ethical approval for this qualitative study was granted by the Wales Research Ethics Committee (16/WA/0077) and by the University of Bath's Department of Psychology Ethics Committee. For face-to-face interviews, participants completed a written consent form. For telephone interviews, verbal consent was audio recorded prior to the interviews. Participants were assured their comments would be anonymised in the write up of the results and it was reinforced that participants could decline to answer any of the questions or stop the interview at any time.

Recruitment and participants

All participants in this qualitative study had attended GSH as part of their involvement in the ADEPT study. Thus, they were all adults (aged 18 years or over) recruited from Adult Autism Clinics, with a clinical diagnosis of ASD and current depression (as measured by a PHQ-9 score of 10 or more). Greater detail about the recruitment procedures are described in the study protocol (Russell et al., 2017).

All participants consenting to participate in the ADEPT study were asked if they would take part in qualitative interviews about their experience of the treatment they had received. Twelve people who had received GSH agreed to a follow-up interview at the end of treatment, ten were male and two were female. The mean age of participants was 39. All participants were White British. Six of the interviews were conducted within the Bristol area by the author and six were conducted within the Newcastle area by a trainee clinical psychologist from Newcastle University. The data from the interviews was combined. The author (LE) analysed the data in terms of the research questions posed by this paper whilst the trainee from Newcastle University analysed the data in terms of the acceptability of involvement in a research trial. Table 1 shows participants' demographic details and the pseudonyms given to protect their identities.

Table 1.

Participants' demographic details.

Pseudonym	**Location**	**Age**	**Gender**	**Ethnicity**	**PHQ-9 Score**	**IMD Score**
Mr B	Newcastle	46	Male	White British	17	6
Mr C	Bristol	41	Male	White British	22	6
Mr E	Bristol	35	Male	White British	13	3
Mrs F	Newcastle	39	Female	White British	16	4
Mrs G	Newcastle	29	Female	White British	14	5
Mr H	Bristol	22	Male	White British	11	8
Mr K	Bristol	47	Male	White British	20	9
Mr M	Newcastle	32	Male	White British	15	6
Mr N	Newcastle	41	Male	White British	17	9
Mr O	Bristol	52	Male	White British	14	10
Mr P	Newcastle	28	Male	White British	10	6
Mr Q	Bristol	56	Male	White British	12	9

IMD = Index of Multiple Deprivation (1=most deprived, 10 = most affluent).

Interviews

Individual interviews were conducted with participants, either in person or by telephone depending on the participant's preference. The interviewers were not known to participants. Each interview lasted between 33 and 61 minutes. A semi-structured interview format was used, with a flexible topic guide to ensure primary issues were covered during all interviews but still allowing participants to introduce unanticipated issues. Interview topic guides explored participants' experiences of the GSH intervention (appendix V). The topic guide was modified to reflect emerging findings as the interviews were conducted. It is generally recommended that qualitative interviews involve open-ended questions. The communication style characteristic of adults with ASD, for instance limited elaboration in response to questions, means people with ASD can find open-ended questions difficult. To facilitate responses, participants were asked specific questions, more closed directive questions were used, and questions sometimes needed to be repeated using different wording. Sampling continued until data saturation was achieved, meaning no new themes were emerging from the data. All interviews were audio recorded and transcribed verbatim. All participants were offered a debrief at the end of the interview and guidance on how to access appropriate support if needed.

Data analysis

Following transcription, interview transcripts were checked for accuracy and anonymised before being imported into NVIVO 10 qualitative data analysis software. Analysis began shortly after data collection and was ongoing and iterative, informing further data collection. Preliminary findings from early interviews were explored in later interviews. Thematic analysis, as described by Braun and Clarke (2006), with a data-driven inductive approach was used to analyse the transcripts as this is a flexible approach which is not tied to a particular theoretical approach. The use of thematic analysis allows for the identification and analysis of patterns and themes across the dataset. A 'realist approach' was adopted to 'examine the meaning of participants' experiences'. Themes were coded at a 'semantic level' to 'reflect the reality of participants' experiences and to identify broader meanings across the data set' (Braun & Clarke, 2006).

Following Braun and Clarke's (2006) guidance, each transcript was read several times, noting down any initial ideas. Codes were then assigned to segments of transcripts. Following this, codes were grouped into themes and summary descriptions of each theme were produced. Data was then reconsidered against the description of the theme to determine whether the description sufficiently captured the data. A consensus about the final list of themes was reached through discussion with the qualitative research team (JH and HH). Any discrepancies were discussed and resolved to achieve a coding consensus. Due to the large scope of the interviews, the themes related to the research questions posed by this paper will be reported.

Researcher position

The researcher (LD) has previously worked in learning disabilities services, during which she worked with a number of individuals who also had a diagnosis of a developmental disability. This has impacted the researcher's work in this area, with an interest in further understanding the experiences of psychological therapy for people who have a learning or developmental disability, an area with limited research. The researcher's previous experiences were helpful when conducting the interviews to aid accessibility. LD did not have previous experience of using GSH with people with ASD. Prior to data analysis, LD had anticipated that participants would find aspects of GSH helpful. As much as possible, LD held an open mind during data analysis. HH conducted the interviews for Newcastle participants. HH also had previous experiences of working with adults with ASD and adopted a 'realist approach'.

Results

Analysis led to the development of three key emergent themes and 10 sub-themes. Each theme will be discussed in turn. Table 2 summarises the themes and sub-themes identified from the analysis.

Table 2.

Themes and sub-themes identified in the transcripts.

Theme	Sub-theme
Format of GSH	Sessions
	Pacing
	Active nature of GSH
Views of coach	Style of coach
	Explanation of concepts
	Presence of coach
	Additional support
Outcomes	Positive outcomes
	Change in perspective
	No change

Format of GSH

Sessions

In relation to the content of sessions, four participants suggested it would be helpful to have more sessions to cover the material in more depth, particularly for the material covered in the mid to late sessions. One participant thought it would have been useful to have more follow up sessions, for example three and six months after treatment, as they felt this would motivate them to continue applying the GSH principles.

'*I like it is in depth and there was a significant amount of material was covered but maybe if it was one or two sessions longer that may help' (Mr E).*

‘I think maybe double amount of sessions…gives you more chance to make it stick’ (Mr O).

‘Given that you’re trying to reset somebody’s life for a different direction actually a session three months out or a session six months out would be the useful thing… I wanna try and make myself do some of the stuff we agreed but who will ever know if I don’t and the fact that oh I’ve gotta tell her what I’ve done actually it does have an effect’ (Mr Q).

Several participants said they found the 30-minute sessions too short, and would have found sessions around an hour in length more acceptable to facilitate more in-depth discussions around core therapeutic concepts or to allow for more conversations about their individual situations.

‘It seemed, it was really quick, because it was only like half an hour sessions and stuff and you went in and that and it seemed to be over really quickly. It seemed to be like it should be like an hour…Longer sessions, so you could talk more about you know individual, personal individual things…’ (Mr N).

The majority of participants found weekly sessions acceptable, although two participants felt the sessions should have been further apart to give them more time to complete tasks in between sessions. For one participant, sessions did not always occur on a weekly basis, sometimes occurring every two weeks or two in one week. This meant they did not always have enough time to complete tasks in between sessions and they would have preferred regular weekly sessions. One participant commented on difficulties with the timing of sessions and highlighted the importance of having a set time each week.

‘I think it's important that I did it weekly because again if there were any gaps I would've disengaged so the fact that I was coming weekly then made it part of my routine’ (Mrs G).

'Because ((sessions every two weeks)) would mean, if I couldn't have gone to the pub with my friends, cancelled or whatever, then I could reschedule it because I had a bit of a window of opportunity to play with because I think there were times where obviously I've got to do this and when am I going to do it?' (Mr M).

'Probably having them every week as they were intended because having two weeks and then we'd have like two days between the things and a week's tasks so struggling to carry out the tasks…' (Mr P).

'…it took them a while to realise, you know, which one I wanted… what time I wanted to come in or whatever' (Mr K).

Pacing

Comments in relation to the pacing of sessions were mixed. Two participants thought sessions included the right amount of content. However, several participants felt the pacing of the initial sessions, which focussed on introducing the concept of CBT and the GSH materials, was too slow. These participants thought initial sessions could have included more content, or they could have been given the materials to read at home.

'It didn't feel like it was too much or anything. We obviously discussed it, you know, in enough, what I felt was enough depth' (Mr C).

'I just felt that we spent the first three weeks, for most of the time, going through explaining what CBT is and how it worked, and I felt it could have all been compressed into one or two sessions. If felt it was very, like it was dragged out and extended and very slow, which made it quite difficult to keep motivated throughout' (Mr H).

Active nature of GSH

Some participants said they found the active nature of GSH helpful as they felt they had a role in contributing to their progress. On the other hand, two participants found this difficult as they would have liked more guidance or their low mood impacted on their motivation to engage in tasks.

'*You feel like you're doing something useful while you're in-between sessions and you've got to get used to practicing these things on you own' (Mrs F).*

'I mean I suppose for me it seemed to be left up to, left to the person's devices kind of thing, but I mean it would have been nice to be able to, for someone to tell me what to do you know, to not leave it up to you' (Mr N).

'I don't really know. A couple of times I did put them off but that wasn't so much to do with the task it was more to do with the mood I was in…' (Mr K).

Views of coach

Style of coach

All participants expressed positive views about the coach. They described positive aspects of the coach's style, highlighting how the coach appeared relaxed, containing and interested in participants.

'Puts you at ease, makes you feel comfortable, laughs at my jokes' (Mr O).

Explanation of concepts

When asked about the coach's understanding of their autism, some participants described how the coach explained concepts in detail so it was understandable for them, which was helpful. However, three participants commented that they would have benefited from more explanations on the purpose of tasks.

'If there was anything that I had particular difficulty with or I might have a problem, which she may have to explain more or use a different way of explaining it. She just seemed to be already aware of that' (Mr B).

'Well just some information about why we need to make a map of where you've been that week and what you've been doing that week. Because actually it

was really only that third week when you put it together with feelings that it makes sense. And obviously when things don't make sense it does affect your motivation to do it so…' (Mrs F).

One participant thought it took a few weeks for the coach to adapt their style to accommodate their level of autism.

'I think maybe the other people she worked with were at the non-Asperger's end of the spectrum rather than the Asperger's end because she kept being surprised that I wanted to read it myself and how quickly I was doing it…I think ((therapist)) expected me to go slower and I expected her to go faster but I think after a few weeks we got used to each other and it was fine' (Mrs F).

Presence of coach

All participants, apart from one, said they felt it was useful to have a coach present during the GSH to keep them focused, to check their understanding of key concepts, and so they could ask questions if needed to aid their understanding. One participant highlighted how important it was for the support from the coach to be in person rather than over the telephone, as they struggled to speak on the phone.

'Certainly having a weekly appointment did help a lot. It certainly made it more focused and being able to have an active dialogue helped' (Mr E).

'It's better to have someone to talk some of the deeper elements out rather than 'cause otherwise it would kind of like perhaps skin deep rather than the further elements of it…' (Mr P).

'I don't think it would work by telephone possibly because I'm not a telephone person in the first place. And you would find that with autistic people. I think we're above averagely not telephone people' (Mr Q).

One participant felt the coach did not add anything extra to the GSH intervention:

‘...I think that she didn’t add much by being there. Maybe if I had had questions, it would be helpful, but as I didn’t, I didn’t think it was needed…’ (Mr H).

Additional support

Several participants suggested ways in which they could have been provided with additional support throughout treatment, proposing more time during sessions for a general update on mood and well-being, computerised CBT alongside guided sessions, and further reading around key treatment components (e.g. Maslow’s hierarchy). Two participants said it would have been helpful to have signposting to other services following treatment.

‘It would maybe be nice just to have 5, 10 minutes talking about what's going on and how we're feeling’ (Mrs G).

‘An interactive element like computerised CBT in conjunction with the course with an actual therapist…It might help to re-engage with the ideas and to help maintain a focus…’ (Mr E).

‘...so I don't know if it's just because I'm a high achiever that I was like, 'Well I wanna learn more about Maslow,' or something like that you know’ (Mrs G).

‘...once the course had finished there was no… the next steps sort of thing’ (Mr H).

Outcomes

Positive outcome

All participants, apart from one, commented on improvements in their mood over the course of treatment.

‘Well I feel a lot better and I think I could probably say I wasn’t depressed anymore’ (Mr B).

Participants also noted other outcomes associated with the treatment programme. The majority shared they felt they were engaged in more activity after treatment and they were trying to prioritise time to engage in activities they enjoyed.

'It's made me spot the activities that I do that pick my mood up but also the activities that make my mood go down as well…So one of my objectives was cook a meal once a week and I'd maybe do it twice a week so I was then over achieving and you feel a lot better about yourself for that' (Mrs G).

Other benefits reported included: an increase in self-awareness, a more positive outlook and learning more strategies to manage and improve mood.

'Just being more self-aware and just looking at things that are more positive but being aware of the negatives as well' (Mr B).

'I'm a lot happier at the moment. I'm much more upbeat, but I was really low in the beginning, really low, but I try to see positives and try and find a purpose in everything I do' (Mr M).

'It definitely appeared to have been that I'd taken away strategies to help myself to raise my mood. I was obviously not in a low mood as I had been prior to the study' (Mr C).

Understanding of concepts

Most participants described how GSH had helped them to understand the relationship between low mood, thoughts and behaviours and commented on how making changes to their activities can impact on their mood.

'… instead of me thinking, oh I feel terrible because of this, this and this, it's like to analyse it in the three areas. The thought, the behaviour and the situation. To find out whether a different situation would make me feel different, feel better or whatever.' (Mr K).

'...if my mood is low, then I keep repeating the same behaviour, then my mood will be expected to stay low so therefore changes to those patterns and routines would need to take place' (Mr E).

No change

One participant said they did not notice any improvement in their mood or level of meaningful activity. They felt CBT was not an appropriate treatment for them because they found it difficult to motivate themselves to implement the strategies within the treatment.

'For me, I didn't find it worked very well because I found it very difficult to motivate myself to implement any of the things that I was required to do…' (Mr H).

There was some overlap of the theme 'outcomes' with the theme 'sessions' as those who had more positive outcomes seemed to find the format of sessions more acceptable.

Discussion

The results of this study provide important insights into people with ASD's experiences of the adapted GSH intervention and it is important to acknowledge qualitative research methods were feasible and helpful. Participants made a number of suggestions for improvements to the format of the new intervention including: sessions of an hour duration, having more sessions, spending less time in the initial sessions explaining GSH concepts and spending more time on concepts covered in mid to late sessions, such as new behaviours and new situations. In terms of participants' experiences of the coach, meeting weekly with a coach who was containing and interested was key as was the coach providing detailed explanations of important concepts and a rationale for tasks. Providing space for a general update on well-being during sessions and signposting to other services following treatment would have been helpful additions for participants. The majority of participants reported improvements in their mood and some participants commented on improvements to their activity levels, self-awareness, and/or their understanding of the link between mood, thoughts and behaviour; indicating most participants found aspects of the GSH intervention useful and helpful.

There are some similarities when these findings are compared to those within the general population. Some participants highlighted difficulties with the highly active nature of GSH due to their motivation, which has also been found in the general population (Khan et al, 2007). Some participants also commented on a lack of time to discuss general well-being due to the structure of GSH, which was found to be a barrier to self-disclosure in the general population (Macdonald et al, 2007). However, this research has highlighted more suggestions for changes to the format of GSH, indicating more adaptations are needed to the session length and pacing of GSH for adults with ASD in comparison to the general population.

Individuals with ASD can have difficulties with emotional literacy, where they struggle to identify their own and others emotions (Baron-Cohen et al., 1985; Gilbert & Leahy, 2007). However, a number of participants commented on an increased understanding of the relationship between their thoughts, feelings and behaviours. This could suggest difficulties with emotional awareness did not act as a significant barrier to the intervention, which may be due to the adaptations made to the intervention to increase accessibility for individuals with ASD. All participants gave positive feedback about the coach, highlighting how the coach's relaxed and containing manner helped them to share their difficulties. Weekly sessions with a coach were emphasised as very important for participants. This highlights the importance of the interactive guided nature of the intervention and could suggest adaptations to GSH, such as the coach providing more detailed explanations of concepts, may have helped to overcome potential difficulties with reciprocal social interactions, which can be common in people with ASD. The coaches had received training in working with people with ASD and therefore incorporation of such training may need to be taken into account by other services.

Service recommendations

The findings of this study have important implications for those working on developing the intervention for further use in adult autism clinics in the NHS. The recommendations about adjustments to the treatment have been fed back to the team so the findings can be included in the development and next iteration of the GSH materials and planned delivery. Thus, the intervention can be patient-centred. Table 3 outlines the recommendations. By including these recommendations, the delivery of this adapted GSH intervention would look very different to current service delivery in IAPT settings where, for example, GSH lasts up to 30 minutes and can occur via telephone.

Table 3.

Recommendations for changes to the GSH intervention.

Structure of GSH

- The initial two sessions could be condensed so less time is spent explaining the nature of CBT and the GSH materials and instead more time could be spent covering the content of mid-to-late sessions (for example, sessions on new behaviours and situations).
- Consider making sessions an hour in duration, rather than 30 minutes.
- Ensure sessions are offered on a weekly basis.
- Offer participants the opportunity to have sessions at a set time and day each week.
- Consider offering participants a follow up session three months after treatment to review progress.

Support level

- It is important for GSH to involve weekly sessions with a coach, and for this to be face-to-face rather than via telephone.
- Allow for a check in on general wellbeing at the start of sessions.
- Ensure the rationale for tasks is fully explained, with use of examples to aid understanding.
- Consider offering additional reading on key concepts.
- Give information for signposting to other relevant services at the end of treatment.

Limitations

A limitation of this study was the mixed data collection methods as participants had the choice of completing the interview face-to-face or via telephone. Although the option of a telephone interview may have increased participation, some of the depth and richness of the data may have been lost due to the absence of non-verbal communication (Chapple, 1999).

Furthermore, there were difficulties with recruitment as a number of participants did not respond to initial emails or phone calls inviting them to take part. As participants opted into the interviews, those who had overall positive experiences of the GSH intervention may have been more likely to take part, which means the data may have missed experiences of those who dropped out of treatment or had a more negative experience. The people interviewed were broadly representative of those within the trial and included a range of ages and socioeconomic statuses. However, all participants were white British and the majority were male. This is representative of ethnicity and gender within the trial but can only be a partial description of the full range of experiences of people with ASD.

It is also important to recognise the current study involved one interview and looked at global experiences of the whole GSH treatment. Descriptions of experiences may have been influenced by outcomes and views of the intervention may change over time during treatment, which may not be captured by this study.

Reflections

As a researcher, I enjoyed conducting the interviews and hearing participants' experiences of GSH. Participants were more forthcoming with their responses than I had expected, although I am aware this may partly be due to an adapted interview style. Prior to conducting the interviews, I had wondered whether participants' difficulties in reciprocal social interactions may have impacted on their relationship with the coach and so, when analysing the data, I was struck by the importance of a containing and interested coach for participants.

Conclusions

This study provides an insight into the experiences of people with ASD of a newly developed GSH intervention. Drawing on these experiences, this study has made a number of recommendations aimed at improving the acceptability of GSH for individuals with ASD experiencing depression.

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Main Research Project

The relationship between adverse interpersonal life experiences and self-esteem in people with intellectual disabilities: the role of shame, self-compassion and social support.

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Introduction

Intellectual Disability (ID) is defined by significant impairments in intellectual and adaptive functioning, including deficits in conceptual, social and practical domains, with the onset occurring during the developmental period (American Psychiatric Association, 2013). Four levels of ID are distinguished: mild, moderate, severe and profound. The world-wide prevalence of ID has been estimated at 1% (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Low self-esteem is common in people with ID (PWID) (Dagnan & Sandhu, 1999) and lower self-esteem has been found in PWID compared to people without ID (Garaigordobil & Pérez, 2007). Negative and critical self-concepts are also common (Shessel & Reiff, 1999). PWID are often subject to negative interpersonal life experiences such as abuse, bullying, neglect, discrimination and social exclusion by society (e.g. Brownridge, 2006; Beadle-Brown et al., 2014). They are exposed to a higher number of traumatic life events compared to the general population (Hughes et al., 2012) and negative interpersonal experiences have been found to cause greater stress than other negative experiences (Hartley, MacLean, & Floyd, 2005). Research has demonstrated the significant negative impact of adverse interpersonal life events on psychological distress and self-esteem for PWID. For instance, using a longitudinal design Hulbert-Williams et al (2014) found life events were a predictor for later psychological difficulties. No research has yet examined the potential mechanisms by which life events may contribute to psychological problems in PWID.

In the general population, research has documented the role of shame in the development and maintenance of psychological distress and mental health difficulties (E.g. Kim, Thibodeau, & Jorgensen, 2011; Scheel et al., 2014). Shame is an emotion characterised by feelings of worthlessness, powerlessness, inferiority, humiliation, a sense that one is bad, and a desire to hide away from others (Gilbert, 1998). Shame has also been found to act as a mediator and moderator in the relationship between stressful interpersonal life events and psychological difficulties in the general literature (Beck et al., 2011; Harper & Arias, 2004; Shorey et al., 2011).

Gilbert (2009) places the emotional experience of high shame as central to the notion of self-compassion. Compassion focused therapy (CFT) suggests there are three emotion regulation systems: the threat system, the drive system, and the contentment system (Gilbert, 2009). This model provides an explanation for the association between early adverse interpersonal life experiences and feelings of shame documented in the general population by proposing negative interpersonal life experiences contribute to increased sensitivity of the threat and/or drive systems and an insufficiently activated contentment system, leading to high levels of shame and self-criticism and low levels of self-compassion. This proposes early interpersonal experiences are important in terms of how people view themselves and their ability to be self-compassionate (Gilbert, 2005). CFT suggests self-compassion can be an important coping strategy for reducing distress and helping individuals to deal with negative life events. Thus, CFT aims to develop an individual’s ability to be self-compassionate and, in turn, facilitate the development of the soothing system. Supporting this, self-compassion has been found to be related to reduced shame and self-criticism (Gilbert & Procter, 2006), a more stable sense of self-worth and is a predictor of emotional well-being (Gilbert & Procter, 2006; Neff & Vonk, 2009).

Recent research has investigated the potential impact of shame on psychological wellbeing for PWID. A review by Clapton, Williams and Jones (2017) found higher levels of perceived shame were associated with higher levels of self-reported psychological distress and lower levels of self-esteem. This research suggests it is important to consider experiences of shame when working with this client group in terms of reducing psychological distress and improving emotional wellbeing. However, the studies included in this review do not directly measure shame. Instead, shame is measured indirectly via concepts such as stigma and social comparison through use of self-report measures or experiences of shame were inferred from qualitative interviews. As shame is not measured directly, this limits the conclusions which can be drawn. The studies included in this review used a range of different measures of stigma, social comparison and psychological difficulties. These measures have varying levels of validity and reliability and some of the measures had not been validated with PWID, which makes it difficult to generalise findings. The use of well validated and reliable measures is particularly important when conducting research with PWID given their potential difficulties with emotion recognition.

In the general literature, there is also a range of evidence demonstrating both direct and moderating effects of social support on psychological well-being (Cohen & Wills, 1985). The social support networks of PWID are thought to be significantly limited in comparison to the general population (Lunsky & Benson, 2001). Research has demonstrated the direct effect of social support on wellbeing for PWID. For instance, LaBarbera (2008) found social support from parents accounted for 35% of variance in students with IDs’ levels of self-esteem whilst Scott & Havercamp (2014) found PWID who lacked social support were twice as likely to have mental health difficulties. A review by McGillivray and McCabe (2007) found infrequent and poor social support was associated with higher levels of depression. However, to date there is limited research examining the potential moderating effects of social support on the relationship between negative life events and psychological wellbeing. One study by Hulbert-Williams, Hastings, Crowe and Pemberton (2011) found no evidence for a moderating effect of social support on this relationship when measuring psychological difficulties using the Brief Symptom Inventory, which examined depression, anxiety, anger and hostility. This is in contrast to the findings in the general population.

As outlined above, research has demonstrated a relationship between perceived shame and psychological wellbeing for PWID (Clapton, Williams & Jones, 2017), indicating shame could be an important concept for this client group. However, this research has not yet directly measured shame or the relationship between early adverse interpersonal experiences and shame in PWID; an association which has been documented in the general population and is explained within the CFT model. As previous research has demonstrated the impact of both adverse interpersonal life events and levels of perceived shame on psychological distress and self-esteem for PWID (Hulbert-Williams & Hastings, 2008), shame may provide a mechanism for explaining the impact of negative interpersonal life events on psychological distress and self-esteem for PWID; a relationship which has been found in the general population but is yet to be investigated within PWID. The role of self-compassion within the association between negative relational life events and psychological distress, as outlined by CFT, has also yet to be addressed within this population. Furthermore, given findings that social support is an important factor for psychological wellbeing for PWID, social support may act as a protective factor for the effects of adverse interpersonal life experiences on self-esteem, which has not yet been investigated.

This study aimed to investigate whether shame and self-compassion act as mediators in the relationship between negative interpersonal experiences and self-esteem for PWID and whether perceived social support acts as moderator in this relationship. Given previous research has found PWID are exposed to a higher number of traumatic life events than the general population (Hughes et al., 2012), this study also aimed to examine whether PWID experience a higher number of negative relational life events than people without ID and whether there are differences in levels of shame and self-compassion in PWID compared to the general population. This study proposes the following hypotheses:

1. PWID will have experienced more adverse interpersonal life events than people without ID and they will have experienced more adverse interpersonal life events which are perceived as having a negative impact on their lives.
2. PWID will have higher levels of shame and lower levels of self-esteem and self-compassion than people without ID.
3. For PWID, there will be a relationship between experience of negative relational life events and self-esteem, which will be mediated by levels of shame and self-compassion.
4. Social support will act as a moderator of the relationship between negative relational life events and self-esteem.

Method

Design

This study employed a cross-sectional design, involving between-group comparisons.

Ethical approval

Full ethical approval for this study was granted by Wales NHS Ethics Committee (17/WA/0032) and the University of Bath Ethics Committee (17-079) (see appendix VI).

Participants

Adults with and without ID were recruited for this study. Adults with ID were recruited from Community Learning Disability Teams (CLDTs) in the 2gether NHS Foundation Trust, higher education colleges which offered courses to PWID, and voluntary organisations for PWID. Participants without ID were recruited from advertisement on social media. Included participants all met the inclusion and exclusion criteria outlined in table 1.

Table 1.

Study inclusion and exclusion criteria.

	Inclusion criteria	**Exclusion criteria**
Participants with ID	A) Diagnosis of ID with a mild level of impairment. B) Aged 18 or over. C) Sufficient receptive and expressive verbal ability to describe everyday events. D) English as first language. E) Able to provide informed consent.	A) Judged to lack capacity to consent to the study B) Severe visual or hearing impairment which would make it difficult to engage with study materials. C) Diagnosis of Autism Spectrum Disorder, which may confound the findings.
Participants without ID	A) Aged 18 or over. B) English as first language. C) Able to provide informed consent.	A) Diagnosis of ID. B) Diagnosis of Autism Spectrum Disorder.

Measures

Understanding of relationships

As a control measure to check participants' understanding of relationships, section 7 of the knowledge section of the Assessment of Sexual Knowledge (ASK) was used. This measure is designed to examine sexual knowledge and attitudes of PWID (Butler, Leighton, & Galea, 2003). The ASK has shown reliability across respondents and elicits responses which are stable over time (Galea, Butler, Iacono, & Leighton, 2004). The majority of participants performed highly on this measure (mean = 19.28; median = 21; SD=3.56), suggesting participants had a good understanding of relationships.

Perceived social support

Current level of perceived social support was measured using a simplified version of the Social Network Map (SNM; Tracy & Abell, 1994; Tracy & Whittaker, 1990), which gathers data on the extent and nature of a person’s social network (appendix IX). Participants were presented with a large circle divided into four segments. Each segment has a label: family, friends, people I work with and professionals/carers. Each segment is split into three parts: 'people who are very close and I trust them', 'people I like to meet and spend time with' and 'people I know and may be important'. Participants were asked to list any people known from each segment and to place them in the circle according to their perceived closeness. A simplified version of the SNM, using only the first step to gain information on network size, has been used successfully with PWID (Raitasuo, Taiminen, & Salokangas, 1998). Hulbert-Williams et al (2011) found PWID could name participants in their social network and rate their closeness without difficulties. Total network size is calculated by giving each person a score of 1. To calculate the mean closeness score, each person listed within the ‘people who are very close and I trust them’ segment is given a score of 3; each person within the ‘people I like to meet and spend time with’ segment is given a score of 2; and each person within the ‘people I know and may be important’ is given a score of 1. A mean closeness score is then calculated for each participant, with scores ranging from 1 to 3. For data analysis, the mean closeness score was used as a measure of current perceived social support.

Self-esteem

The adapted version of the Rosenberg Self-Esteem Scale for PWID (Dagnan & Sandhu, 1999) was used to measure self-esteem. This is a six-item self-report scale, where the participant rates how true each item is using a five-point visual analogue scale (with options ranging from never true to always true). Responses for each item are assigned a score from 1 to 5 and overall a higher score represents a greater level of self-esteem. This scale has been shown to have adequate internal consistency (Cronbach’s alpha coefficient of 0.62) when used with PWID (Dagnan & Sandhu, 1999).

Self-compassion

Self-compassion was measured using an adapted version of the Self-Compassion Scale Short-Form (Raes, Pommier, Neff, & Van Gucht, 2011) . This is a twelve-item self-report measure, which has demonstrated good internal consistency (Cronbach's alpha coefficient of 0.86) in the general population (Raes et al., 2011). This measure was adapted with the original authors' permission so it was accessible for PWID (see appendix IX). The wording of each item was simplified whilst retaining the original meaning of each item. For example, the item "When I'm feeling down, I tend to feel like most other people are probably happier than I am" was adapted to "When I feel sad, I think other people are happier than me". Participants rate how often they feel this way on a five-point scale, with options ranging from almost never to always.

Shame

Shame was measured using the shame subscale of the State Shame and Guilt Scale (Marschall, Sanftner, & Tangney, 1994). The shame subscale is a five-item self-report measure, which has demonstrated good internal consistency (Cronbach's alpha coefficient of 0.8) (Tangney & Dearing, 2002). This measure was adapted so it was accessible for PWID (see appendix IX). The wording of each item was simplified whilst retaining the original meaning of each item. For example, the item "I feel humiliated, disgraced" was adapted to "I feel embarrassed of myself". Participants rate how often they have felt this way this week on a five-point scale, with options ranging from almost never to always.

Negative interpersonal life events

Adverse interpersonal experiences was measured using the 'Relationships' section of the Bangor Life Events Scale for Intellectual Disabilities (Hulbert-Williams et al., 2011). This is a semi-structured interview schedule where life events are rated for frequency and impact both on a 3 point scale. Studies have demonstrated good internal reliability (Cronbach's alpha coefficient of 0.73)

(Wigham, Taylor, & Hatton, 2014). For the purpose of this study, five additional questions were included to examine experiences of bullying, verbal abuse, physical abuse, sexual abuse and emotional abuse (see appendix IX). Participants were asked whether the events had occurred before the age of 18 to measure experiences of early interpersonal life events. The scoring system produces three types of score: a total unique life events score, in which repeated events are not counted; a negative life event score, in which only events perceived as having a negative impact are scored; and a weighted life event score, in which repeated events count twice as much towards the total score. For this study, the weighted life event and negative life event scores were used. The weighted life event score was generated by calculating a sum of frequency scores for each participant, with 'more than once' taking the value of two and thus contributing more to the total score than a single occurrence of a life event. The negative life event score was calculated by multiplying the frequency and impact of each life event rated as having a negative effect, and totaling these.

Procedure

Feedback on the adapted measures, information sheet and consent form was gained from a group of PWID who assist with creating easy read materials for the 2gether NHS trust. Amendments were made to the materials based on this feedback. A pilot interview was carried out with a PWID. Feedback on the interview format and measures was given following this and minor amendments were made.

For recruitment of PWID, managers of the Gloucestershire CLDTs, college course directors, and managers of voluntary organisations were initially contacted via email. They were provided with a brief rationale for the study, a brief description of the methodology and the study information sheet. Four CLDTs, four colleges and three voluntary organisations agreed to take part. Potential participants, who met the inclusion and exclusion criteria, were approached by a staff member from the relevant organisation, offered the opportunity to take part in the research and given an information sheet on the study. An individual appointment was arranged with those who met the above inclusion and exclusion criteria, were interested in participating and were judged to have capacity to make a decision regarding participation by staff working in the service from which they were recruited.

At the beginning of the appointment, the researcher went through the information sheet and gained consent. Capacity to consent to participation was assessed by asking participants questions regarding this information to assess their understanding. If it was felt the participant had capacity to consent to participation, a written consent form was completed. Participants were given the opportunity to ask any questions and were reminded they were able to withdraw at any time should they wish to do so. It was made explicit to participants that there were no right or wrong answers. Two potential participants were deemed to lack capacity to provide informed consent and so were not included in the study. It was important PWID completed the study in person, rather than online, to ensure participants gave informed consent and understood the measures.

The above measures were completed in the following order: Social Network Map task, adapted Self-Compassion Scale Short-Form, adapted Bangor Life Events Scale for Intellectual Disabilities, Assessment of Sexual Knowledge subtest, adapted shame scale of the State Shame and Guilt Scale and adapted Rosenberg self-esteem scale. Following completion of the questionnaires, a debrief was offered. Interviews lasted approximately 45 minutes. Participants were paid £5 voucher as a thank you for their participation.

Participants without ID were recruited on social media and participated online using Qualtrics online survey programme. Firstly, they read an online information sheet explaining the nature of the study and completed an online consent form. They then completed the questionnaires in the following order: adapted Self-Compassion Scale Short-Form, adapted Bangor Life Events Scale for Intellectual Disabilities, adapted Rosenberg self-esteem scale and adapted shame scale of the State Shame and Guilt Scale. At the end, an online debrief sheet was provided including signposting to relevant agencies. Participants had the opportunity to be entered into a random prize draw for the chance to win a £25 voucher as a thank you for their participation. Completion took approximately 15 minutes.

Data analysis

A priori power calculations were completed using G*Power. To achieve power of 0.8 with alpha of .05 and a medium-large effect size of 0.6, a total sample size of 72 (36 participants per group) is required when comparing PWID to controls. When completing the mediation and moderation analysis with four predictor variables, to achieve power of 0.8 with alpha of .05 and a medium-large effect size of 0.3 (F statistic), a sample size of 45 is required. As there was no available study for direct comparison of effect size, the aim of medium-large effect sizes was theoretically driven.

Data was analysed using the Statistical Package for Social Sciences (SPSS) version 24 for Windows. Cronbach's alpha was calculated to investigate the internal consistency of the main self-report measures. Between-group comparisons were conducted using non-parametric statistics as the main variables were not normally distributed (see appendix X). Spearman's correlation coefficient was used to explore associations between the measured variables. Mediation and moderator effects were examined using the PROCESS tool in SPSS to calculate total, direct and indirect effects (Preacher & Hayes, 2008). Linear regression modelling (to test direct effects) and bootstrapping procedure with bias-corrected estimates (to test indirect effects) were used to investigate mediation and moderation hypotheses. Bootstrapping does not assume a normal distribution or require a large sample size. 5000 bootstrap re-samples were used to calculate the bias-corrected 95% confidence intervals of the indirect effects (Preacher & Hayes, 2008). Indirect effects were considered significant if zero was not within the 95% confidence interval.

Results

Demographic characteristics

A total of 47 adults with ID and 50 adults without ID took part in this study. Of the ID participants, 3 were recruited from CLDTs, 22 were recruited from higher education colleges, and 22 were recruited from voluntary organisations for PWID.

Participants were aged between 18 and 64. Table 2 shows the demographic characteristics. Statistical analysis was conducted, using t-tests and chi-squared tests, and indicated there were no between-group statistical differences in age, gender or ethnicity.

Table 2.

Demographic information for the study participants.

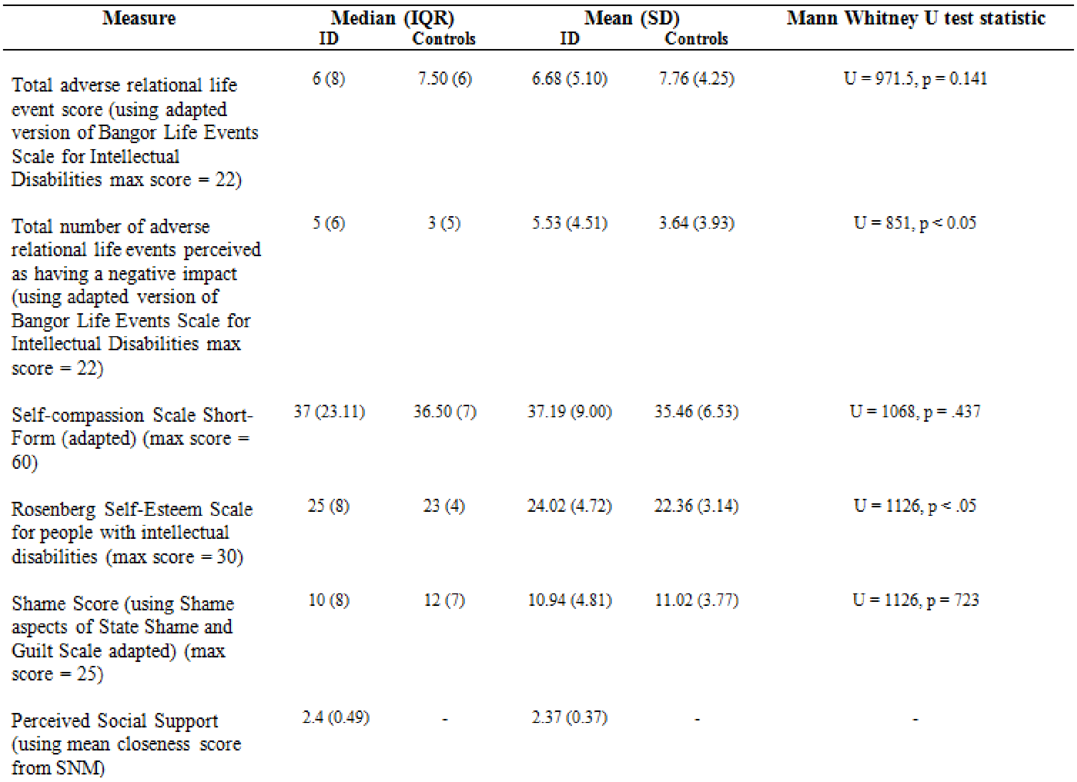
	ID (n = 47)	**Control (n =50)**	**Test statistic**
Age: M (SD)	32.9 (15.8)	32.8 (11.8)	t(95) = -0.48, p = .962
Gender: N (%)			
Female	29 (62%)	36 (72%)	χ^2(1) = 1.162, p = .281
Male	18 (38%)	14 (28%)	
Ethnicity: N (%)			
White British	47 (100%)	44 (88%)	χ^2(1) = 6.012, p = .111
Asian or Asian British-Indian	0	1 (2%)	
Chinese	0	1 (2%)	
Other	0	4 (8%)	

Reliability of adapted scales

As the Self-Compassion Scale Short-Form (Raes et al., 2011) and the shame subscale of the State Shame and Guilt Scale (Marschall et al., 1994) were adapted for this study, the psychometric properties of the adapted scales were assessed. The adapted shame scale was found to have good internal consistency; Cronbach's α = .79 for PWID and Cronbach's α = .83 for people without ID. The Self-Compassion Scale Short-Form also demonstrated good internal consistency; Cronbach's α = .81 for PWID and Cronbach's α = .86 for people without ID. For PWID, on examining correlations between items of the Self-Compassion Scale it was noted question ten 'if I think badly about myself, I try to remember everyone feels like this sometimes' did not correlate well with the overall scale (r = -.16) and removal of this item increased the reliability of the overall scale to Cronbach's α = .84. Therefore, question ten was removed from the analysis for ID data. This question was removed from the analysis for control data for between-group comparisons.

Table 3.

Descriptive statistics for ID and control participants on measured variables.



Measure	Median (IQR)		Mean (SD)		Mann Whitney U test statistic
	ID	Controls	ID	Controls	
Total adverse relational life event score (using adapted version of Bangor Life Events Scale for Intellectual Disabilities max score = 22)	6 (8)	7.50 (6)	6.68 (5.10)	7.76 (4.25)	U = 971.5, p = 0.141
Total number of adverse relational life events perceived as having a negative impact (using adapted version of Bangor Life Events Scale for Intellectual Disabilities max score = 22)	5 (6)	3 (5)	5.53 (4.51)	3.64 (3.93)	U = 851, p < 0.05
Self-compassion Scale Short-Form (adapted) (max score = 60)	37 (23.11)	36.50 (7)	37.19 (9.00)	35.46 (6.53)	U = 1068, p = .437
Rosenberg Self-Esteem Scale for people with intellectual disabilities (max score = 30)	25 (8)	23 (4)	24.02 (4.72)	22.36 (3.14)	U = 1126, p < .05
Shame Score (using Shame aspects of State Shame and Guilt Scale adapted) (max score = 25)	10 (8)	12 (7)	10.94 (4.81)	11.02 (3.77)	U = 1126, p = 723
Perceived Social Support (using mean closeness score from SNM)	2.4 (0.49)	-	2.37 (0.37)	-	-

Table 4.

Descriptive statistics for the Social Network Map.

Mean total network size (SD)	Mean total network size per segment (SD)				Mean Closeness score (SD)
	Family	**Friends**	**Work colleagues**	**Professionals**	
15.29 (6.91)	7.43 (6.10)	3.77 (2.61)	2.11 (2.73)	2.28 (2.53)	2.37 (0.37)

Hypothesis 1: PWID will have experienced more adverse interpersonal life events than people without ID.

Total number of adverse relational life events experienced by PWID did not differ significantly from control participants. However, PWID had experienced significantly more adverse relational life events which they perceived to have had a negative impact on their lives (Table 3).

Hypothesis 2: PWID will have higher levels of shame and lower levels of self-esteem and self-compassion than people without ID.

There were no significant differences between groups for reported levels of shame and self-compassion. Levels of self-esteem were significantly higher in PWID in comparison to people without ID (Table 3).

Relationship between variables

Spearman’s correlations were used to examine the association between the main variables. Age was significantly correlated with self-esteem for PWID and shame for control participants. For PWID, all of the studied variables were significantly correlated, apart from perceived social support. There were no significant correlations between number of adverse relational life events perceived as having a negative impact and self-compassion, shame or self-esteem for control participants.

Table 5.

Spearman's correlation coefficients for the measured variables for PWID.

ID participants	Age	Total number of negative relational life events	Number of adverse relational life events with a negative impact	Self-compassion Scale Score	Shame Score	Self-esteem Score	Perceived social support
Age	1	-.283	-.269	.009	-.174	.368*	-.164
Total number of negative relational life events	-.283	1	.935**	-.383**	.640**	-.484**	-.027
Number of adverse relational life events with a negative impact	-.269	.935**	1	-.355*	.605**	-.476**	-.009
Self-compassion Scale Score	.009	-.383**	-.355*	1	-.532*	.586**	.086
Shame Score	-.174	.640**	.605**	-.532**	1	-.592**	-.147
Self-esteem Score	.368*	-.484**	-.476**	.586**	-.592**	1	-.076
Perceived social support	-.164	-.027	-.009	.086	-.147	-.076	1

**p<.01; *p<.05.

Table 6.

Spearman’s correlation coefficients for the measured variables for control participants.

Control participants	Age	Total number of negative relational life events	Number of adverse relational life events with a negative impact	Self-compassion Scale Score	Shame Score	Self-esteem Score
Age	1	.023	-.062	.265	-.336*	.054
Total number of negative relational life events	.023	1	.701**	-.282*	.381**	-.184
Number of adverse relational life events with a negative impact	-.062	.701**	1	-.178	.275	.023
Self-compassion Scale Score	.265	-.282*	-.178	1	-.706**	.709**
Shame Score	-.336*	.381**	.275	-.706**	1	-.532**
Self-esteem Score	.054	-.184	.023	.709**	-.532**	1

**p<.01; *p<.05.

Hypothesis 3: Shame and self-compassion will mediate the relationship between adverse interpersonal life events perceived as negative and self-esteem.

Table 7 shows the results of the bias-corrected bootstrapping mediation analysis. Given the significant correlation between age and self-esteem for PWID, age was controlled for in the analysis. As table 7 shows, for PWID there was a significant indirect negative relationship between adverse relational life events perceived as negative and self-esteem through shame, *b* = -0.21, 95% BCa CI [-0.45, -0.02]. There was also a significant indirect negative relationship between adverse relational life events perceived as negative and self-esteem through self-compassion, *b* = -0.14, 95% BCa CI [-0.29, -0.01] (see Figure 1).

As there were no significant correlations between adverse relational life events perceived as negative and shame, self-compassion or self-esteem for control participants, a mediation analysis was not conducted.

Table 7.

Results of bootstrapping mediation analysis for ID participants.

	b coefficient	*t* value	*p* value	Lower CI, upper CI Bootstrap 95% CI for indirect effects
Adverse relational life events perceived as negative – shame	0.64	4.84	0.00	0.37, 0.90
Adverse relational life events perceived as negative – self compassion	-0.73	-2.54	0.02	-1.31, -0.15
Shame – self-esteem	-0.34	-2.27	0.03	-0.63, -0.04
Self-compassion - self-esteem	0.19	2.77	0.01	0.05, 0.32
Direct effect: adverse relational life events perceived as negative – self-esteem	-0.08	-0.52	0.61	-0.37, 0.22
Total effect: adverse relational life events perceived as negative – self-esteem	-0.43	-3.02	0.00	-0.71, -0.14
Indirect effect: adverse relational life events perceived as negative – self-esteem via shame	-0.21			-0.45, -0.02
Indirect effect: adverse relational life events perceived as negative-self-esteem via self-compassion	-0.14			-0.29, -0.01

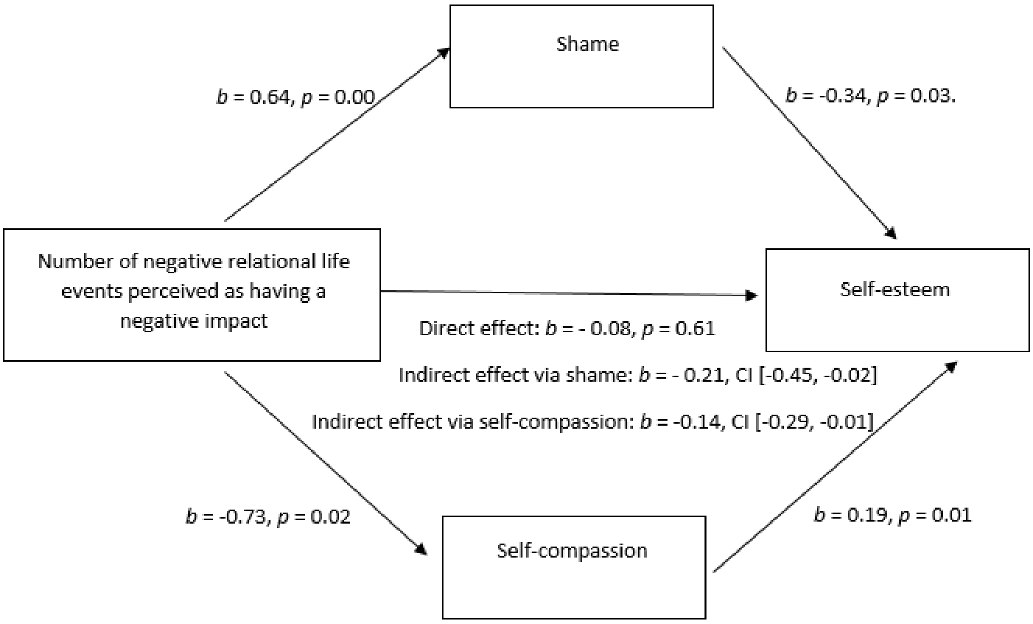


Figure 1. Model of number of negative relational life events perceived as having a negative impact as a predictor of self-esteem, mediated by levels of shame and self-compassion.

Hypothesis 4: Social support moderates the relationship between adverse relational life events perceived as negative and self-esteem.

Social support was not significantly correlated with any of the measured variables (table 5), indicating social support does not moderate the relationship between adverse relational life events and self-esteem.

Discussion

The present study sought to investigate the contribution of early negative relational life events, self-compassion and shame to emotional wellbeing in PWID. The findings indicated PWID experience a greater impact from negative relational life events, but that these do not occur at a higher frequency. There were no between-group differences on some of the main constructs; shame and self-compassion. However, PWID were found to have higher self-esteem than people without ID. Mediation analysis found the relationship between negative relational life events and self-esteem was mediated by shame and self-compassion in PWID. Social support was not found to be a significant moderator. These findings will be discussed in turn.

Firstly, it was possible to use self-report methods to measure shame and self-compassion in PWID. The measures were adapted and found to be reliable in respect of internal consistency, with the exception of a single item on the self-compassion scale. This may be accounted for by the grammatical structure of the item. PWID did not report significantly greater numbers of negative relational life-events than the group without ID but did report greater impact of these life events. The measure of adverse relational life events utilised in this study only included options to indicate if the event had happened once or more than once. If the event had happened to participants more than once, there is no measure of the total frequency of this occurrence. It is therefore not possible to investigate the impact of higher frequency of events, meaning it is not clear whether PWID are more affected by the experience of adverse relational life events or whether PWID experience these events more frequently. The study also did not measure the occurrence of adverse life events post aged 18. This may be a confounding factor as the experience of such negative events may have impacted on participants’ emotional wellbeing.

There were no between-group differences in shame or self-compassion. Furthermore, PWID reported significantly higher levels of self-esteem than those without ID, which is contrary to previous findings (Garaigordobil & Pérez, 2007).

Within this previous research, all participants completed the original, non-adapted Rosenberg self-esteem scale (Rosenberg, 1965) which could provide one explanation for this difference in findings. PWID may have found it more difficult to understand the concepts in the non-adapted measure. Furthermore, the majority of PWID were recruited from colleges or volutary organisations. It could be argued participants engaged in further education and active community participation are likely to be functioning well and may feel positively about themselves and their place in the world. Also, the sample may be biased towards more motivated individuals with higher self-esteem as staff may have been more likely to invite people who they thought were functioning well and likely to take part. The limits the generalisability of the findings.

The mediating effects of shame and self-compassion on the relationship between adverse relational life events and self-esteem provides a potential explanation for the impact of negative life experiences on psychological well-being for PWID. This is, to the author’s knowledge, the first study to directly measure shame and to demonstrate the mediating effects of shame and self-compassion for PWID. This is consistent with findings in the general literature of the mediating effects of shame (Beck et al., 2011; Harper & Arias, 2004; Shorey et al., 2011). However, as self-esteem in the PWID was not low, these findings are subject to careful consideration. No evidence was found for the mediating effects of shame in control participants, which is well documented in previous research. There were differences in the types of life events reported by control and LD participants. LD participants reported a higher frequency of sexual abuse, physical abuse and bullying in comparison to controls whilst control participants reported a higher frequency of friendship and relationship break-ups, serious illnesses of family members or close friends, and a decrease in amount they saw their family. It may be that the type of interpersonal life event is important in order for shame to have a mediating effect. This would fit with previous findings in the general population, which has demonstrated the mediating effects of shame for people who had experienced child maltreatment or intimate partner violence (Harper & Arias, 2004; Beck et al., 2011).

It would be interesting for future research to investigate whether the mediating effects of shame and self-compassion are found for other measures of psychological distress as well as self-esteem for PWID. Self-esteem was chosen as a global, stable construct which can be representative of emotional wellbeing. However it is possible that the experience of negative emotions such as anxiety and depression are more salient in considering the impact of negative life events. These dimensions of psychological function have been shown to be distinct in causal pathways for emotional wellbeing (Kinderman et al., 2015).

The findings are in line with the assumptions of CFT which suggests negative interpersonal life experiences contribute to increased sensitivity of the threat and/or drive systems and an insufficiently activated contentment system, leading to high levels of shame and low levels of self-compassion, which impact on an individual's level of distress. These findings therefore highlight the importance of considering the concepts of shame and self-compassion for reducing psychological distress when working therapeutically with PWID and may provide support for the application of the CFT model for PWID. Currently research into CFT for PWID is still very limited and the findings are mixed. Clapton, Williams, Griffith and Jones (2017) found significant reductions in self-criticism and unfavourable social comparisons following a CFT group for adults with ID whilst Cooper and Frearson (2017) found no significant changes on measures of psychological well-being or self-compassion following the use of CFT with a man with ID.

The lack of evidence for a moderating effect of social support on the relationship between adverse interpersonal life events perceived as negative and self-esteem is similar to the findings of Hulbert-Williams et al (2011) and contrary to research documenting indirect effects of social support in the general population (Cohen & Wills, 1985). The standard deviation indicated there was little variability in perceived social support scores, which may have influenced these findings. The mean closeness score from the SNM may not be an accurate measure for assessing the quality of social support. Additionally, information about current social support was collected whilst information about negative life events prior to age 18 was measured. Hence it is possible that the social support available to the individual at the time of the difficult relational life events is most important, particularly as self-esteem is considered a stable and global construct and therefore unlikely to change in response to current support if impacted by early life events or at least only over a considerably longer time period. Future research which measures experiences of helpful and unhelpful aspects of social support is needed.

A further limitation of this study is staff from the relevant organisation confirmed whether participants had a diagnosis of a mild ID. Including a formal measure of ID would have reduced the risk of people with borderline ID participating. Moreover, control participants were recruited online meaning there was a difference in the procedure across groups, which is a limitation of the study design. Completing the measures in person may have meant PWID felt more at ease sharing difficult experiences if they had built a good rapport with the researcher. Alternatively, the anonymity of online participation may have meant that control participants found it easier to disclose experiences of difficult life events and difficult feelings about themselves. Completion of the measures in person also reduces the likelihood of participants losing concentration, which could be an issue with online recruitment. Furthermore, the use of self-report measures are open to responder bias and so the findings should be considered with caution.

Although there are some similarities in the concepts of shame, self-esteem and self-compassion, for example self-compassion and self-esteem both involve positive instead of negative feelings towards the self, research has highlighted a number of differences in these concepts. Self-compassion involves being kind to oneself even when considering personal weaknesses and does not involve evaluations of self-worth whilst self-esteem refers to self-evaluations of worth across multiple life domains (Neff & Vonk, 2003). Shame, on the other hand, refers to feelings of worthlessness and a sense that one is bad (Gilbert, 1998). There was some overlap in the items used to measure these concepts and these similarities could impact on the conclusions drawn from this study. The data used in this study is cross-sectional and so this cannot confirm causation for the documented mediation effects. Causal mechanisms need to be investigated in future research using longitudinal research methodologies. Given that you cannot infer causality, it is also possible that self-esteem could have acted as a mediator variable. This was not tested with this study and could be examined further in future research.

Overall this study demonstrated that shame and self-compassion may mediate the relationship between negative early experiences of adverse interpersonal life events and self-esteem for PWID; providing a mechanism for explaining the association between relational life events and psychological wellbeing for this client group. Contrary to predictions, social support did not moderate this relationship and there were no differences in shame and self-compassion in PWID in comparison to people without ID. The findings of this study have clinical implications, highlighting the importance of considering shame and self-compassion when working therapeutically with PWID.

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Executive summary

People with intellectual disabilities (PWID) are reported to have low self-esteem and are often subject to negative interpersonal life experiences such as abuse, bullying, neglect, and discrimination. Research has demonstrated the significant negative impact of these experiences on well-being and self-esteem for PWID. However, no research has yet examined the potential mechanisms by which interpersonal life events may contribute to psychological difficulties in PWID.

Shame is an emotion characterised by feelings of worthlessness, inferiority and a sense that one is bad. In the general population, research has shown that shame may contribute to both the development and maintenance of psychological distress and mental health difficulties. It has also been found that feelings of shame may provide an explanation for the association between stressful interpersonal life events and psychological difficulties in the general population (i.e. experiences of stressful interpersonal life events lead to high levels of shame which impacts on emotional wellbeing). Compassion focused therapy (CFT) provides an explanation for the role of shame in this association. CFT suggests there are three emotion systems: the threat system, the drive system and the contentment system. This model proposes negative interpersonal life experiences contribute to increased sensitivity of the threat and/or drive systems and an insufficiently activated contentment system, leading to high levels of shame and self-criticism and low levels of self-compassion. CFT suggests self-compassion can be an important coping strategy for reducing distress and helping individuals to deal with negative life events.

Recent research has begun to investigate the role of shame in the wellbeing of PWID. This research found that higher levels of perceived shame were associated with higher levels of self-reported psychological distress and lower levels of self-esteem for PWID. This suggests feelings of shame are also relevant for PWID. However, research has not examined the relationship between early negative interpersonal experiences and shame or self-compassion in PWID; an association which has been documented in the general population and is explained within the CFT model.

Furthermore, in the general population there is a range of evidence demonstrating both direct and indirect effects of social support on psychological well-being. The social support networks of PWID are thought to be limited in comparison to the general population. Research has demonstrated the direct effects of social support on psychological wellbeing for PWID. However, to date there is limited research examining the potential moderating effects of social support on the relationship between negative life events and psychological wellbeing for PWID (i.e. if you have high levels of social support, there is less impact of negative interpersonal events on self-esteem).

This research investigated whether shame and self-compassion may provide an explanation for the relationship between experiences of early negative interpersonal life events and self-esteem for PWID (i.e. experiences of early negative interpersonal life events may lead to high levels of shame and low levels of self-compassion which may then affect self-esteem) and whether social support acted as a protective factor in this relationship (i.e. if you have high levels of social support, there is less impact of negative interpersonal events on self-esteem). This study also examined whether PWID experience a higher number of negative interpersonal life events and have higher levels of shame and lower levels of self-compassion and self-esteem compared to the general population.

In order to assess this, 47 PWID and 50 people without ID completed questionnaires. PWID were recruited from Community Learning Disability Teams, voluntary organisations for PWID and colleges offering courses to PWID. People without ID were recruited through advertisement on social media. PWID completed the questionnaires in person with a researcher whilst people without ID completed the questionnaires online. The questionnaires measured: number of negative interpersonal life events experienced before the age of 18, shame, self-compassion, and self-esteem. PWID also completed a measure of perceived social support. Participants were aged between 18 and 64.

The findings indicated PWID experience a greater impact from negative relational life events, but that these do not occur at a higher frequency in comparison to people without ID. There were no between-group differences for levels of shame and self-compassion. However, PWID were found to have higher self-esteem than people without ID. As predicted, this study found that shame and self-compassion explained the relationship between early negative interpersonal life events and self-esteem for PWID. This suggests experiences of early negative interpersonal life events may lead to high levels of shame and low levels of self-compassion which may then affect self-esteem. This is, to the author’s knowledge, the first study to demonstrate this relationship. There was no evidence that social support acted as a protective factor in the relationship between negative interpersonal life events and self-esteem. The findings suggest shame and self-compassion are important concepts for PWID and should be considered when working therapeutically with PWID. The results could provide support for the use of CFT with PWID.

Connecting narrative

Overview

During clinical training I have completed three research projects and five clinical case studies. One aspect that drew me to clinical psychology training at Bath University was the strong focus on producing a portfolio of publishable research studies. Prior to training, most of my experiences were clinically focussed and I was keen to develop my research skills. I was also interested in how to further integrate research into my clinical practice. Through this narrative, I will reflect on the process of completing each piece of research and the case studies over the course of clinical training.

Main research project

Prior to commencing clinical training, I had worked in intellectual disabilities (ID) services. I was keen to carry out research within this field as it is an area I am very passionate about and I was aware of the dearth of literature within this area in comparison to the general population. When considering the options for my main research project, I was drawn towards the approach of compassion focussed therapy (CFT). From researching the literature I realised, although there has been a large amount of research into the use of this model in the general population, research into the application of this model for people with ID is still in its infancy. I felt there was an opportunity to explore whether the theory behind the CFT model also fitted with people with IDs' experiences and thus whether this model could be helpfully utilised in clinical practice with people with ID. I spoke with Dr Cathy Randle-Phillips, whose research interests are within the area of ID. Cathy was very supportive of and enthusiastic about my initial ideas.

I was excited by the prospect of conducting research within this area as the limited research meant there were many avenues which could be explored but I also found it difficult to define specific research questions which fitted with the requirements of the course because there was such little research to draw on within this clinical area. Cathy’s support in defining the research questions was very helpful at this time. A number of the questionnaires had not previously been used with people with ID and so they needed to be adapted to simplify the language and make them more accessible. I sometimes found it difficult to know how best to rephrase certain aspects of the wording to ensure the language was simpler whilst still maintaining the original meaning of the question. I gained feedback on the adapted measures from a group of people with ID and I also piloted the questionnaires with a person with an ID. I am very grateful for the feedback I received as I was able to further amend the questionnaires to make them more accessible based on this feedback. This highlighted the importance of involving people with personal experience in research as they were able to give valuable feedback and recommendations for changes.

My main research project involved seeking ethical approval from a variety of different ethical review teams including NHS-IRAS, a local NHS trust, and the University’s ethics board. I found the NHS-IRAS process very long and time consuming. Attending the REC panel meeting was anxiety provoking as I had not experienced this process before and thus did not know what to expect. On reflection it was useful to experience the IRAS process and to attend a REC panel meeting, particularly as I am keen to continue to conduct research within the NHS in the future which is likely to involve the NHS ethics process.

I had underestimated the difficulties I would face with recruitment. As I was recruiting from four different CLDTs within the Gloucestershire area, I thought I would be able to recruit most of my participants from these four teams with few difficulties. However, I only managed to recruit three participants from across these four CLDTs. I was very surprised by the lack of uptake, which may reflect the current climate of stretched NHS services. Clinicians may have been so overstretched with their daily clinical work that they were not able to consider anything additional, such as identifying relevant participants for the research and giving out information leaflets. Although understandable, I found this frustrating as I feel it is very important that people with ID are given opportunities to participate in research. As I was not based in the CLDTs at the time of recruitment, this made it more difficult to continue to encourage clinicians to hold the project in mind and identify relevant potential participants. When I attended team meetings to talk about the project, clinicians were very enthusiastic about the research but they also shared they were struggling to identify service users who had a mild ID, did not have a diagnosis of ASD, and were stable enough to participate and answer potentially distressing questions about their past experiences. These barriers to recruitment highlighted the difficulties of prioritising and conducting research within an NHS context and could also possibly highlight one of the reasons for limited research within the field of ID. Based on these experiences, if I were to work in a CLDT in the future, I would be keen to become involved in a research network and to encourage discussions around how CLDTs can be more actively involved in engaging their service users in research and how they can overcome some of the barriers I encountered during the recruitment phase.

Due to the recruitment difficulties from the CLDTs, I decided to apply for an ethical amendment to include recruitment from colleges as well as non-statutory organisations. Once this was approved I began to email colleges who offered educational courses for people with ID and voluntary organisations for people with ID asking for interest in taking part in this research study. I received far more interest from my initial emails than I had anticipated. Several colleges and voluntary organisations were very keen to help with the research and I was much more successful in recruiting from these areas in comparison to the CLDTs. In contrast to recruitment of participants with ID, recruitment of control participants online through advertisement on social media worked very well and I was able to recruit the required number of control participants very quickly. Again, this highlights differences and inequalities in the lives of people with ID, who often do not have access to a computer or potentially do not have the skills to be able to complete questionnaires online.

I met individually with each of the participants with an ID to complete the questionnaires and this was one of the most enjoyable parts of the research project. I was amazed at how open participants were about their life experiences and I felt privileged to hear their stories. Although this was one of the most enjoyable parts of the project, it was very time consuming as each individual meeting took around 45 minutes. This was difficult to manage alongside my other research and placement demands. Following the PAS at the end of my first year of training, it was suggested I could use an honorary research assistant to help with the data collection as it was recognised there was a significant time commitment involved in the data collection phase of this project. Through discussion with my supervisors, I recruited a research assistant who had experience of working with people with ID to collect data from participants from Gloucester and Cheltenham localities. However, as recruitment from the CLDTs was very limited, the research assistant did not meet with any participants and I therefore met with each participant myself. If I had known about these difficulties with recruitment and the time commitment of individual interviews, I would have considered this more carefully when initially designing the project. However, it is difficult to overcome the need for individual face to face interviews when involving people with ID in research; an area which I am passionate about conducting research within.

During the recruitment phase of the project, Cathy began maternity leave and I was supervised by Dr Ailsa Russell. I had not carried out in depth statistical analysis since my undergraduate degree and I was initially daunted by the data analysis phase. I found the data analysis stage to be one of the most difficult parts of the project. I was guided during this time by Ailsa and I am very grateful for her support in talking through different dilemmas as they occurred during the analysis. Due to the large scope of the project, I struggled initially to write the different components into a coherent narrative for the introduction. I have been very grateful for the support of both Ailsa and Cathy, who has stayed involved with the project during her maternity leave, in helping me to keep focused on what I was investigating.

Critical review of literature

When deciding on a topic for my critical review of the literature, I was keen for this to involve qualitative research with people with ID as I am passionate about enabling the voices of people with ID to be heard through qualitative research; an experience which people with ID have historically not be given. By spending time looking at the literature, I found a number of recent papers had begun to explore people with IDs' experiences of psychological therapy and it seemed timely to conduct a literature review within this area. Through discussions with Cathy Randle-Phillips, we agreed this could fit with using a meta-ethnography approach. I did not have previous experience of conducting literature reviews or have prior knowledge of meta-ethnography. We did not have any teaching on meta-ethnography approaches and so the literature review process was a steep learning curve. I was well supported throughout the process by Cathy and her knowledge of qualitative methodologies. The process of the literature review took much longer than I had anticipated, particularly when analysing the themes which required a lot of thought. Although there was a lot to learn throughout this process, I enjoyed conducting a qualitative synthesis and it is an area of research I would look to use again.

I was surprised by the themes which emerged from the literature review. In particular, the amount of work which is still needed to make therapy truly accessible for people with ID. I felt frustrated by this and the significant gap which still exists in accessible services for people with ID in comparison to people from the general population. This has further highlighted the importance of conducting qualitative research with people with ID to fully understand from their perspective whether adaptations made are truly accessible and acceptable; something which I hope to continue if I were to work in ID services in the future.

As Cathy was beginning maternity leave in July of my second year, we decided to aim to finish the literature review before this rather than involving a second supervisor at such a late stage of the project. Although this was challenging on times because of the reduced time scale, this was very beneficial during my third year as I was then able to focus my attention on my other research projects. This also meant I was able to submit the review for publication in the Journal of Intellectual Disabilities. I had not previously submitted a paper for publication and so this was again a new process which I initially found daunting. From experiencing the submission and peer review process, I now feel much more confident in submitting papers for publication in future. I am very grateful for the support Cathy gave with the publication process, even when she was on maternity leave.

Service improvement project

Prior to commencing clinical training, I had worked with a number of individuals who had a diagnosis of Autism Spectrum Disorder (ASD). These experiences developed my interest in working with people with ASD and in further understanding their experiences of psychological therapy. I had noticed the significant gaps in the evidence base for effective psychological interventions for adults with ASD and I was curious about adults with ASD’s experiences of adapted interventions. I was therefore very enthusiastic when I heard Dr Ailsa Russell talk about a potential Service Improvement Project (SIP), which involved a qualitative evaluation of a newly developed guided self-help intervention for depression in adults with ASD as part of a larger Randomised Control Trial (RCT) evaluating the effectiveness of this intervention across two research sites: Bristol and Newcastle. I spoke with Ailsa to find out more information about the proposed SIP and I was keen to become involved as I am interested in exploring the experiences of adults with ASD of adapted interventions. I was also interested in being involved in a larger research trial as I had limited research experience prior to training and so I felt involvement in the qualitative arm of the trial would be a helpful experience for improving my research knowledge and skills.

Recruitment into the RCT took much longer than anticipated and thus this slowed recruitment for my SIP as participants were invited to take part in the qualitative interviews ten weeks after they had been recruited into the RCT. It therefore took longer to begin the interviews than I had anticipated and planned for in my research timeline, which I found frustrating as I felt I had little control over this. Once I could begin contacting potential participants, recruitment for the interviews was very slow, which I found anxiety provoking as I worried about whether I would be able to recruit enough participants within the time scale. Many participants did not respond to initial attempts to contact them about taking part in the study and I had to follow up participants with phone calls if they had consented to this to try and increase recruitment. Once recruitment began, I really enjoyed conducting the interviews with participants and hearing their stories about their experiences of the adapted guided self-help. I found my previous experiences of working with people with ASD were helpful for aiding accessibility when conducting the interviews.

I previously had little experience of qualitative research methods and I had not previously used thematic analysis or NVIVO software. I found I quickly learnt about qualitative research methods through my involvement in this project. My external supervisor for this project was Dr Jeremy Horwood. I initially received training from Jeremy on conducting qualitative interviews, thematic analysis and NVIVO software; which was a very useful learning experience for improving my qualitative research skills. Throughout the data collection and data analysis stages, I consulted regularly with Jeremy and his knowledge of qualitative methodology was invaluable and a huge support. It was also very helpful to discuss the data analysis process with Hannah Harvey, a trainee clinical psychologist from Newcastle University, who was conducting interviews in Newcastle.

The scope of this project was large for a SIP and it was difficult to manage the time commitments of this alongside other course research requirements. Ailsa Russell provided feedback on the write up of the project and this feedback was very helpful in shaping the final report. The findings from the SIP were fed back to the service and the recommendations will be included in the development and next iteration of the GSH materials. I feel proud to have been involved in a piece of research which will influence the further development of an adapted psychological intervention for adults with ASD.

Case studies

Throughout training I have completed five case studies, each summarising a piece of clinical work. A common theme across the case studies is the application of cognitive behavioural therapy (CBT) for various presenting difficulties. I have developed different skills across different areas, for example making adaptations depending on the cognitive abilities and developmental age of the individual within older adult, ID and CAMHS settings. Through writing the case studies, this has provided opportunities to reflect on how my formulation and intervention skills have developed over the three years of training. I found the literature review section of the case study write ups particularly helpful for illustrating effective interventions for the presenting difficulties of the case and to make links between the clinical setting and the wider theory and evidence base. This highlighted the value of continuing to refer to research literature to inform knowledge for interventions, which I think can be hard for clinicians to prioritise when working in extremely stretched NHS services. The case study written on my learning disabilities placement has been published in the journal Advances in Mental Health and Intellectual Disabilities, which has again increased my confidence in submitting papers for publications.

Overall reflections and ongoing interests

There is an overarching theme across the three research projects of maximising the effectiveness of psychological interventions for service users with a learning or developmental disability. In the future I would like to continue to conduct research within these areas. I am particularly interested in further developing my skills as a qualitative researcher and to use these skills when qualified to help to evaluate new service initiatives and interventions, with the aim of ensuring services are acceptable for service users as well as in line with the evidence base.

My confidence in designing research projects and taking this further forward through ethics, data collection, data analysis and write up has grown significantly through training. I have gained experience of publishing in journal articles and this process now seems much less daunting. I found it difficult to juggle the different demands of completing three research projects concurrently whilst also managing placement and teaching. This has meant at times I have had to complete things in as not as much depth as I would have liked. I am aware these difficulties with juggling different demands and prioritising research will also be present when working as a qualified psychologist in stretched NHS services, as I encountered during recruitment for my main research project. As a qualified psychologist I will need to continue to emphasise the value of research to other professionals and the helpful role which psychologists can take within this.

Acknowledgements

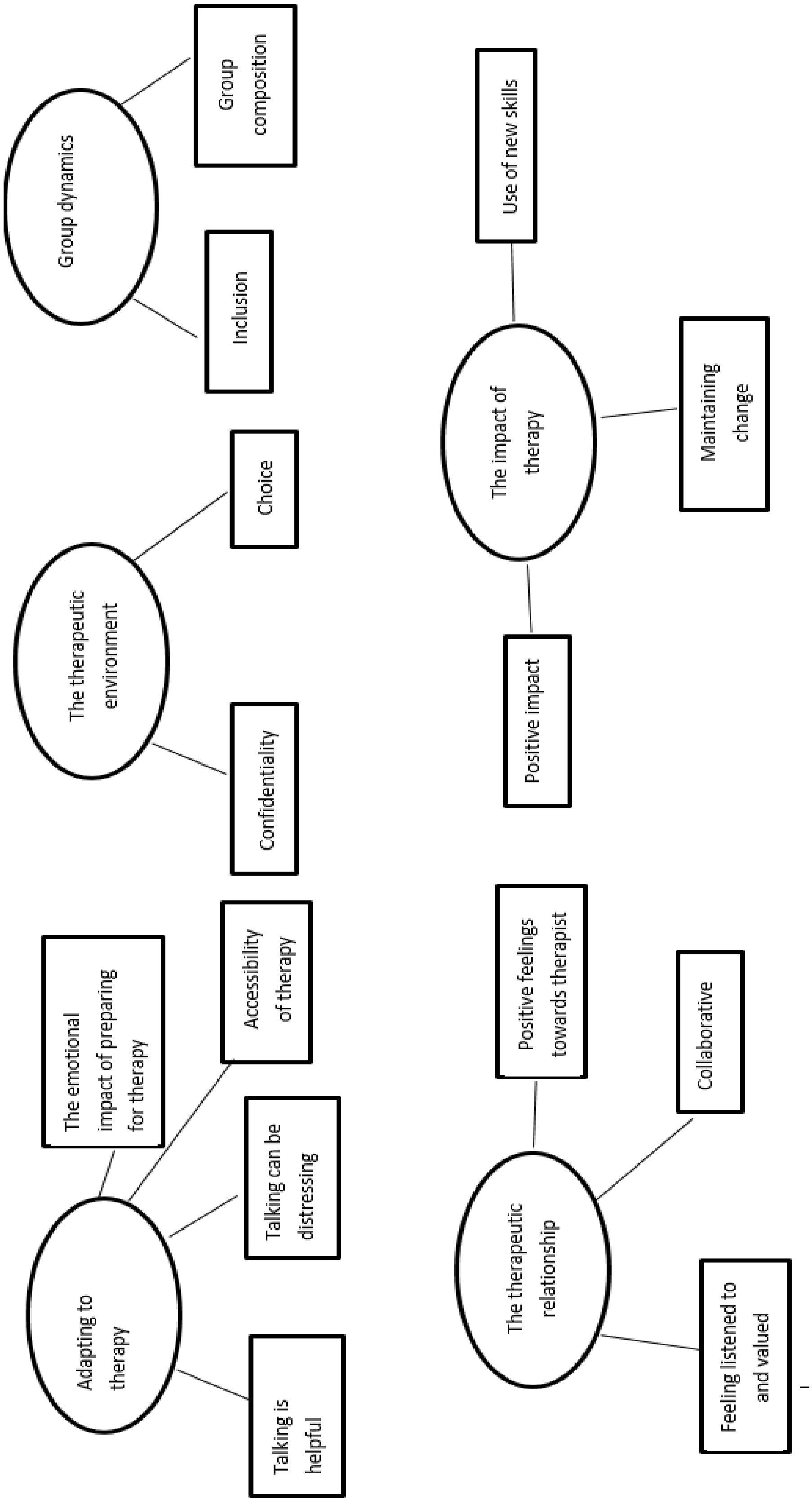
Thank you to Dr Cathy Randle-Phillips for supervising both my main research project and my literature review and for acting as my clinical tutor during the first two years of training. Cathy has provided a constant source of support, advice and encouragement throughout training, even when she has been on maternity leave. Thank you to Dr Ailsa Russell for supervising my service improvement project and also taking on supervision of my main research project during my final year. Ailsa has provided invaluable feedback, huge enthusiasm for my research ideas, and a calm and containing presence. Thank you to Dr Anna Strudwick, clinical tutor for my final year of training, for understanding and for helpful feedback on drafts. I would also like to thank Dr Jeremy Horwood for providing invaluable supervision during the qualitative data analysis process of my service improvement project.

I am very grateful for the excellent supervision I have received from placement supervisors throughout training: Dr Kian Vakili, Dr Nick Benians, Dr Kate Allez, Dr Jennifer Davis, Dr Samantha Phillips, Dr Anna Fussell and Dr Polly Nugent.

To Cohort 2015, thank you all for the friendship and laughter throughout the ups and downs of training and for making trainee life more manageable. It has been lovely to get to know you all. To my wonderful friends, thanks for always putting things into perspective and helping me to maintain a life outside of training!

Thank you to my mum and dad for always believing in me and for providing never-ending encouragement, love and support with whatever I choose to do in life. Finally, thank you to my husband Ryan for your unwavering support and understanding every step of the way during the highs and lows of the last three years. I know you never really signed up for what the last three years have entailed but you have taken it in your stride, kept me calm, helped me to believe I can do this at frequent times of doubt, and even still wanted to marry me at the end!! Thank you for everything, I really couldn’t have done it without you.

Appendix I: Thematic map for critical review of literature



Appendix II: Service improvement project lay summary

Research has shown depression is common in adults with Autism Spectrum Disorder (ASD). In the general population, guided self-help (GSH) has been found to be effective in reducing mild to moderate depression. GSH involves self-help resources with support from a trained practitioner to guide individuals through the self-help materials. Recently, GSH has been adapted for use with people with ASD and is being evaluated to see whether it is an effective treatment for depression. As part of this, interviews were conducted with people who had taken part in the adapted GSH to evaluate whether GSH is an acceptable treatment for people with ASD. From these interviews, a number of recommendations for improving the GSH intervention were identified. This included: increasing the length of sessions to one hour, changing the structure of sessions so more time is spent on the content of later sessions, offering a follow up session 3 months after treatment, and including a check-in on general wellbeing at the start of sessions. The recommendations will be used to guide further changes to the GSH treatment.

Appendix III: Service Improvement project participant consent form

Bristol Randomised Trials Collaboration
University of BRISTOL
Newcastle University
UNIVERSITY OF BATH

Avon and Wiltshire NHS
Mental Health Partnership NHS Trust

Northumberland, Tyne and Wear NHS
NHS Foundation Trust

ADEPT Study Consent Form

Please read the ADEPT Study – '**ADEPT Study Project Information Sheet v. 1.2'** carefully. If you agree to participate in the study, please put your initials in the boxes by the items to which you agree to give your consent.

Please initial the boxes e.g. AB

1. I confirm that I have read and understand the *ADEPT Study Project Information Sheet dated 19/10/2016 (version 1.2)* ☐ ☐

2. I agree to the researcher recording the interview ☐ ☐

3. I understand that the information given will be strictly confidential and used only for the purposes of the study. My consent depends on the Universities of Bath and Bristol complying with their duties and obligations under the Data Protection Act ☐ ☐

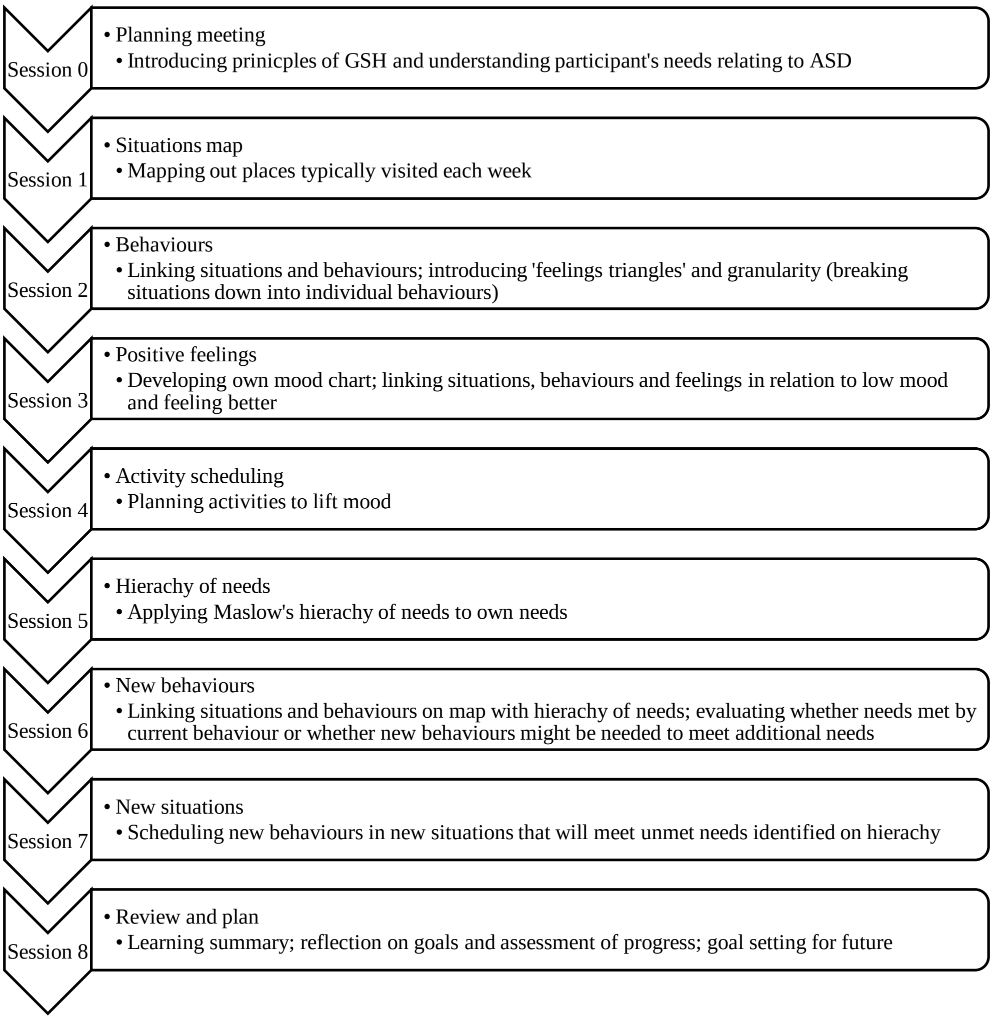
4. I agree to the study publishing anonymous quotations from the interviews and understand that it will not be possible to identify me in any way ☐ ☐

5. I understand that regulatory authorities may require access to the study information where it is relevant to my taking part in this research. All information accessed will remain strictly confidential. I give permission for these individuals to access this information ☐ ☐

6. I agree to take part in the above study. ☐ ☐

--	----/----/----	------------------------------------
Name of Participant	Date	Signature
--	-----/----/----	--------------------------------------
Researcher taking consent	Date	Signature
--	-----/----/----	--------------------------------------

Appendix IV: Service improvement project summary of GSH session content



Session 0
- Planning meeting
  - Introducing prinicples of GSH and understanding participant's needs relating to ASD

Session 1
- Situations map
  - Mapping out places typically visited each week

Session 2
- Behaviours
  - Linking situations and behaviours; introducing 'feelings triangles' and granularity (breaking situations down into individual behaviours)

Session 3
- Positive feelings
  - Developing own mood chart; linking situations, behaviours and feelings in relation to low mood and feeling better

Session 4
- Activity scheduling
  - Planning activities to lift mood

Session 5
- Hierachy of needs
  - Applying Maslow's hierachy of needs to own needs

Session 6
- New behaviours
  - Linking situations and behaviours on map with hierachy of needs; evaluating whether needs met by current behaviour or whether new behaviours might be needed to meet additional needs

Session 7
- New situations
  - Scheduling new behaviours in new situations that will meet unmet needs identified on hierachy

Session 8
- Review and plan
  - Learning summary; reflection on goals and assessment of progress; goal setting for future

Appendix V: Service improvement project topic guide

Introduction, consent and background

Thanks, introduce self, re-state purpose of the interview

- Discussion of how interview will be recorded, right to withdrawal, issues of confidentiality, anonymisation and informed consent. (*face-to-face written consent, telephone verbal consent).* Verbal consent: *switch audio recorder on* - For the audio recording, can I check that:
    - You read and understood the study information sheet?
    - You know that taking part in the interview is voluntary and you are free to stop the interview at any point and you may skip questions you would prefer not to answer?
    - You agree to our conversation being audio recorded?
    - You understand that quotes from the interview may be used to illustrate our findings but it will not be possible to trace who said them?

- Background information on participant (e.g. age, ethnicity, location, general health)
- Previous experience of therapy

Experience of trial participation

Intervention arm

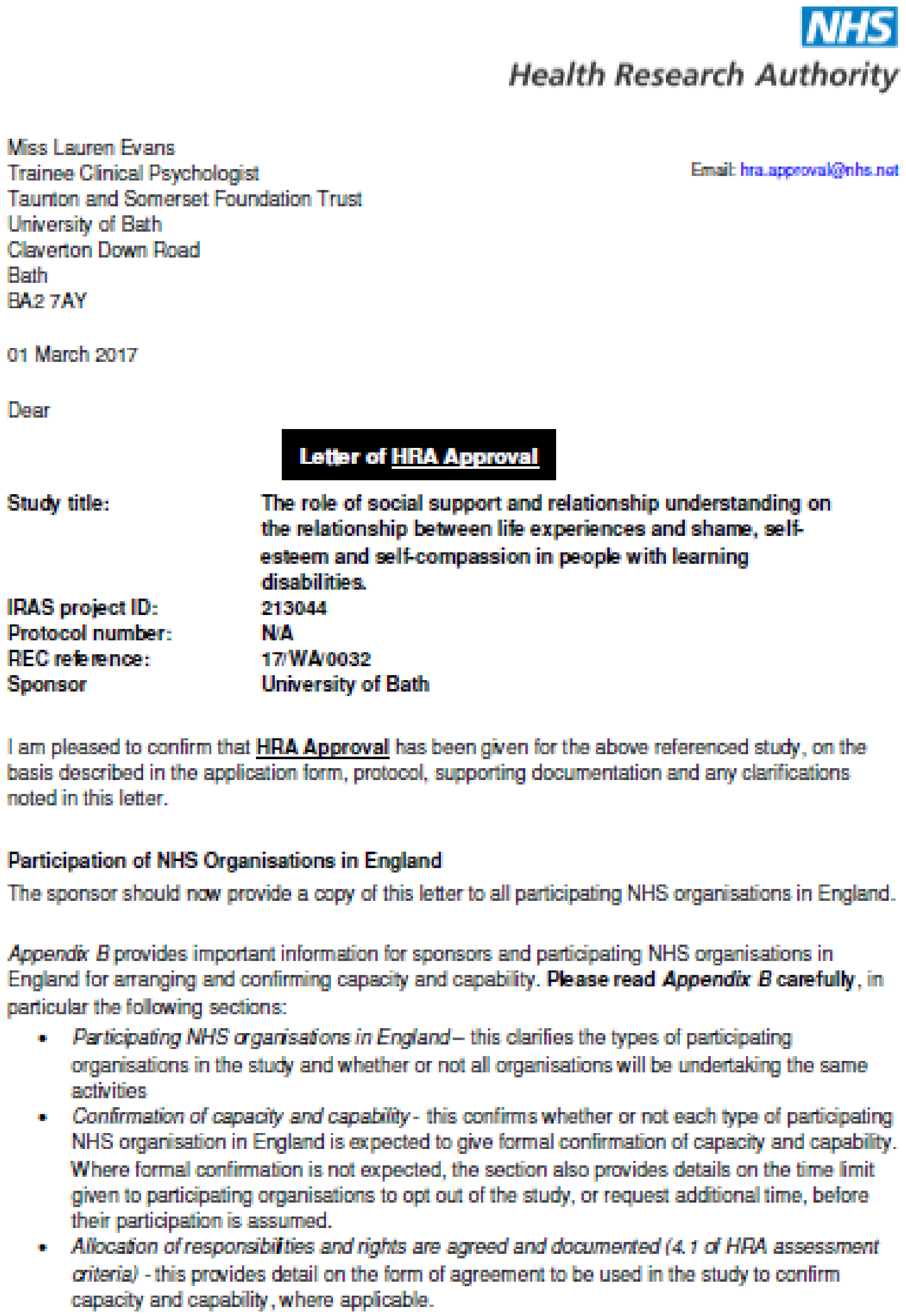
- Views on self help, understanding of aims of self help ? expectations? acceptability ?
- Personal goals – what they wanted to get out of it / were goals met
- Self-efficacy – did they want to and feel able to help themselves with their low mood?
- Self help material: understandable/level, format (paper/online), pace, read the materials between sessions/ever return to the materials?
- The map – was it necessary? how was it used (i.e. as given, with own photos)?
- Feelings chart – did they need and use a visual chart?
- Sessions - best/worst, why ?
- Was the amount of content each session about right, too much, too little?
- Sessions: views on number, length of time, frequency of sessions suitable ?
- Between session activities/homework: which most helpful, why, changes made, facilitators/barriers, how overcome barriers, improvements
- Therapist/guide: understanding of your autism, autism knowledge helpful, what did to help, engagement, support level (understand the nature of a coach), needed for self help?
- Did they feel connected with and supported by others?

- What worked well, what was useful about the treatment?
- What 2 things have you learnt as a result of the treatment?
    - Did the participant understand the principles of the treatment?
    - Suggested improvements: name 2 things that could be better/improved?

Final thoughts

- Would it be helpful to have someone else (friend/family) present in therapy
- Personal changes: mood/depression/activities/relationships - facilitators/barriers
- Questionnaire: how did you find filling out the questionnaires? usefulness/if filling out? Explore which measure of depression best captured experience/could best relate to

Appendix VI. Confirmation of ethical approval for main research project.



NHS
Health Research Authority

Miss Lauren Evans
Trainee Clinical Psychologist
Taunton and Somerset Foundation Trust
University of Bath
Claverton Down Road
Bath
BA2 7AY

Email: hra.approval@nhs.net

01 March 2017

Dear

Letter of HRA Approval

Study title: **The role of social support and relationship understanding on the relationship between life experiences and shame, self-esteem and self-compassion in people with learning disabilities.**
IRAS project ID: **213044**
Protocol number: **N/A**
REC reference: **17/WA/0032**
Sponsor **University of Bath**

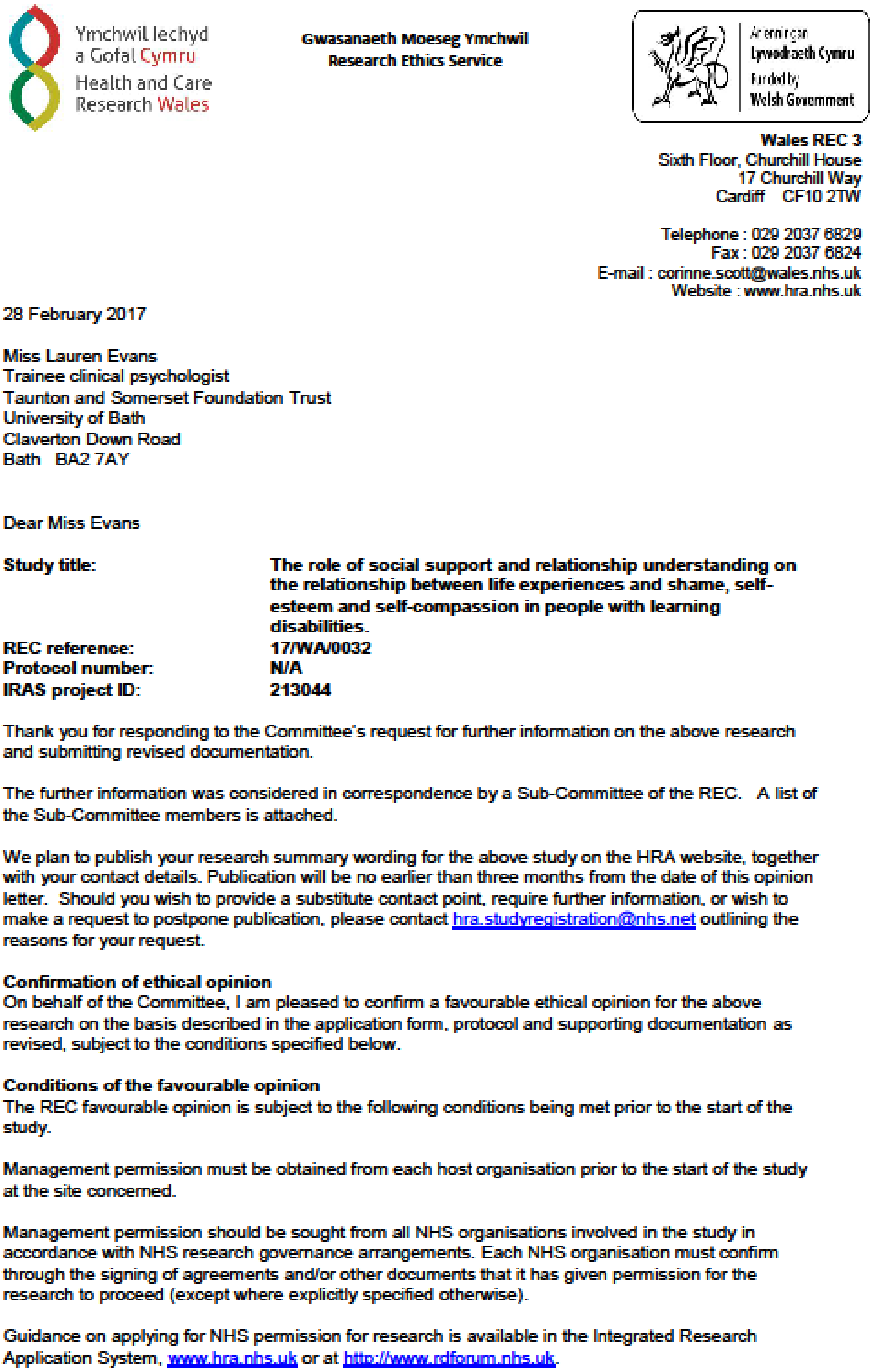
I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan
Llywodraeth Cymru
Funded by
Welsh Government

Wales REC 3
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6829
Fax : 029 2037 6824
E-mail : corinne.scott@wales.nhs.uk
Website : www.hra.nhs.uk

28 February 2017

Miss Lauren Evans
Trainee clinical psychologist
Taunton and Somerset Foundation Trust
University of Bath
Claverton Down Road
Bath BA2 7AY

Dear Miss Evans

Study title:	**The role of social support and relationship understanding on the relationship between life experiences and shame, self-esteem and self-compassion in people with learning disabilities.**
REC reference:	**17/WA/0032**
Protocol number:	**N/A**
IRAS project ID:	**213044**

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

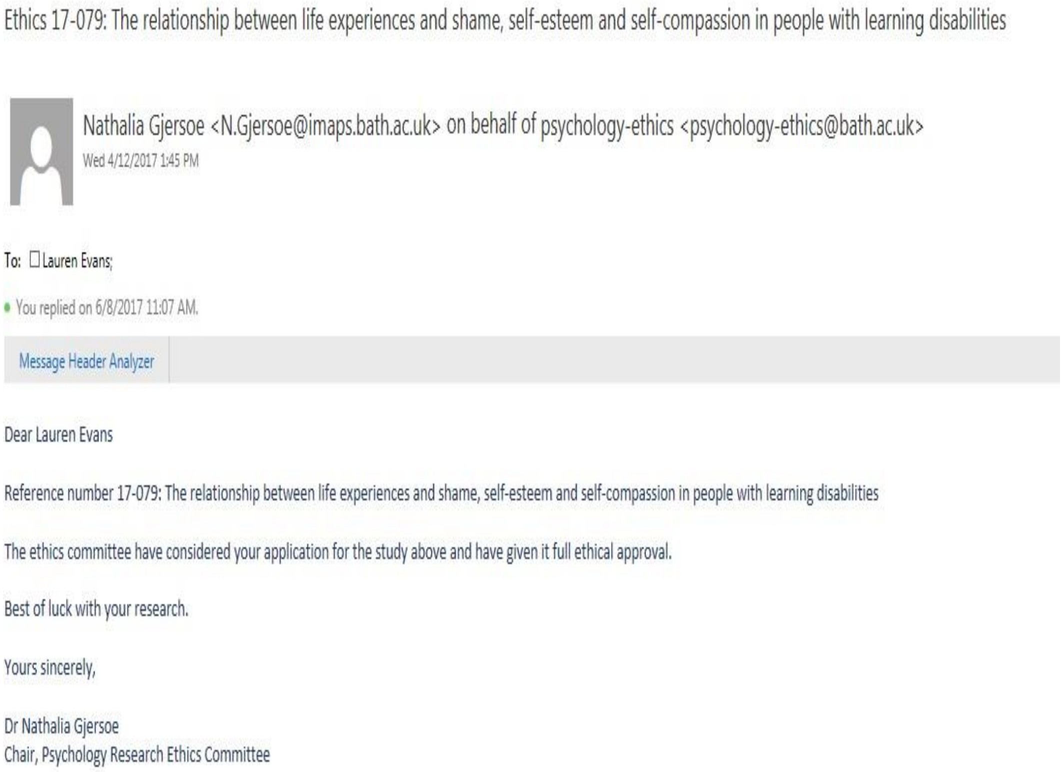
Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion
The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.



Ethics 17-079: The relationship between life experiences and shame, self-esteem and self-compassion in people with learning disabilities

Nathalia Gjersoe <N.Gjersoe@imaps.bath.ac.uk> on behalf of psychology-ethics <psychology-ethics@bath.ac.uk>
Wed 4/12/2017 1:45 PM

To: ☐ Lauren Evans;

● You replied on 6/8/2017 11:07 AM.

Dear Lauren Evans

Reference number 17-079: The relationship between life experiences and shame, self-esteem and self-compassion in people with learning disabilities

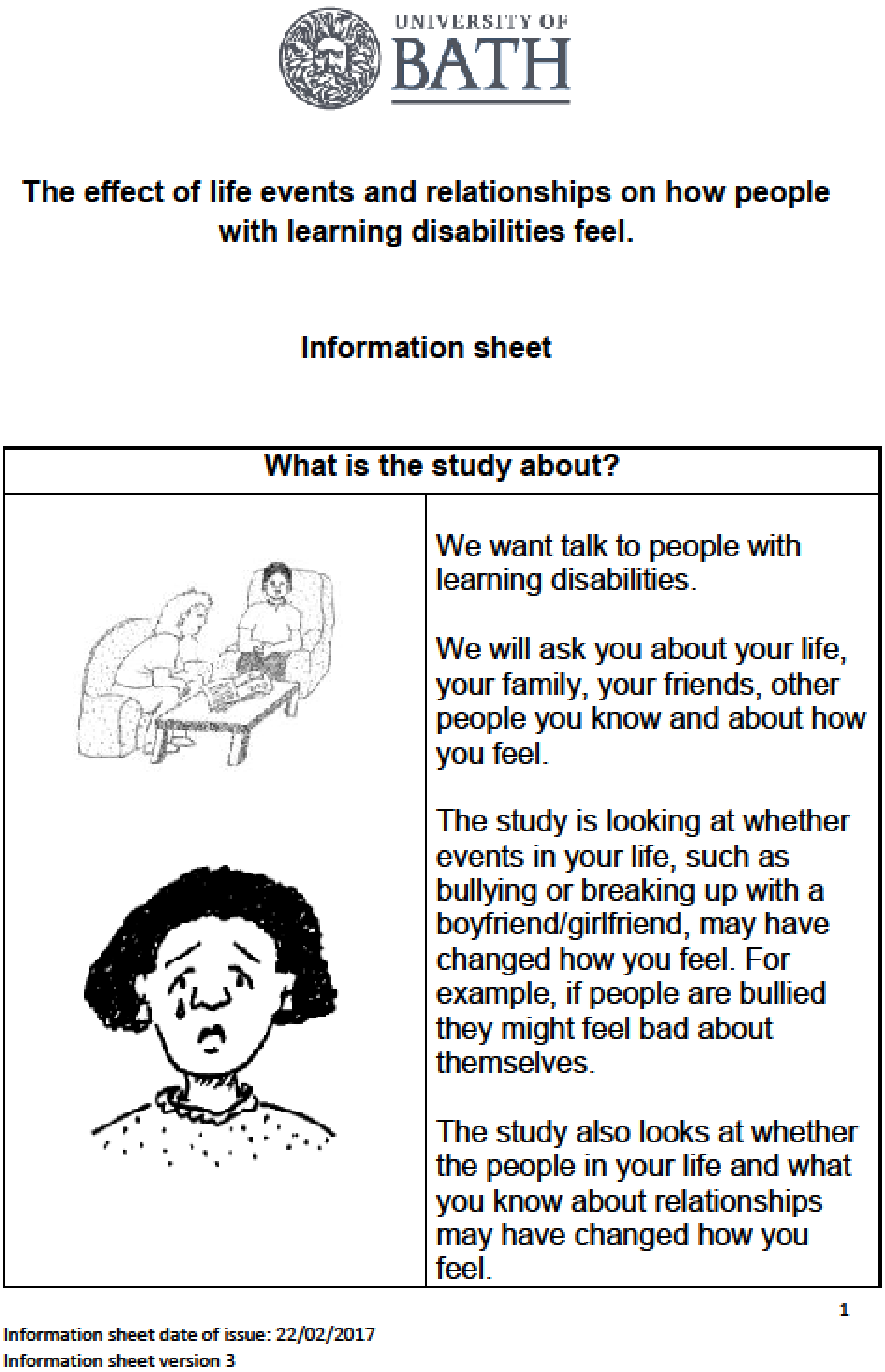
The ethics committee have considered your application for the study above and have given it full ethical approval.

Best of luck with your research.

Yours sincerely,

Dr Nathalia Gjersoe
Chair, Psychology Research Ethics Committee

Appendix VII. Information sheets for main research project



UNIVERSITY OF BATH

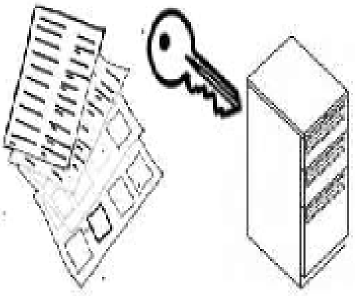
The effect of life events and relationships on how people with learning disabilities feel.

Information sheet

What is the study about?	
	We want talk to people with learning disabilities. We will ask you about your life, your family, your friends, other people you know and about how you feel. The study is looking at whether events in your life, such as bullying or breaking up with a boyfriend/girlfriend, may have changed how you feel. For example, if people are bullied they might feel bad about themselves. The study also looks at whether the people in your life and what you know about relationships may have changed how you feel.

1

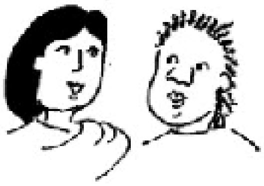
Information sheet date of issue: 22/02/2017
Information sheet version 3

<table>
<tr><th colspan="2">Who will know my answers to the questions?</th></tr>
<tr><td></td><td>We will keep your answers private. Only people working on the study will see your answers.

You do not have to say anything you do not want to.

Your answers will not include your name or address.

We hope to report the results in a journal. You will not be named in the study.

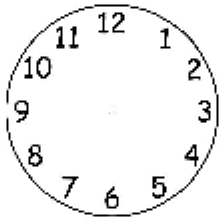
Your answers will be kept in a locked cupboard and on a computer. The computer will have a password. Only people working on the study know the password.</td></tr>
<tr><td></td><td>If you or someone else is in danger we will have to tell someone who can help.

If you tell us about something bad that happened to you in the past and you haven't told anyone else about it before, (for example someone touching you when you didn't want them to), we will have to tell someone who can help.</td></tr>
</table>

How might this study help other people?

	The study may help to change the way talking therapy is offered to people with learning disabilities.

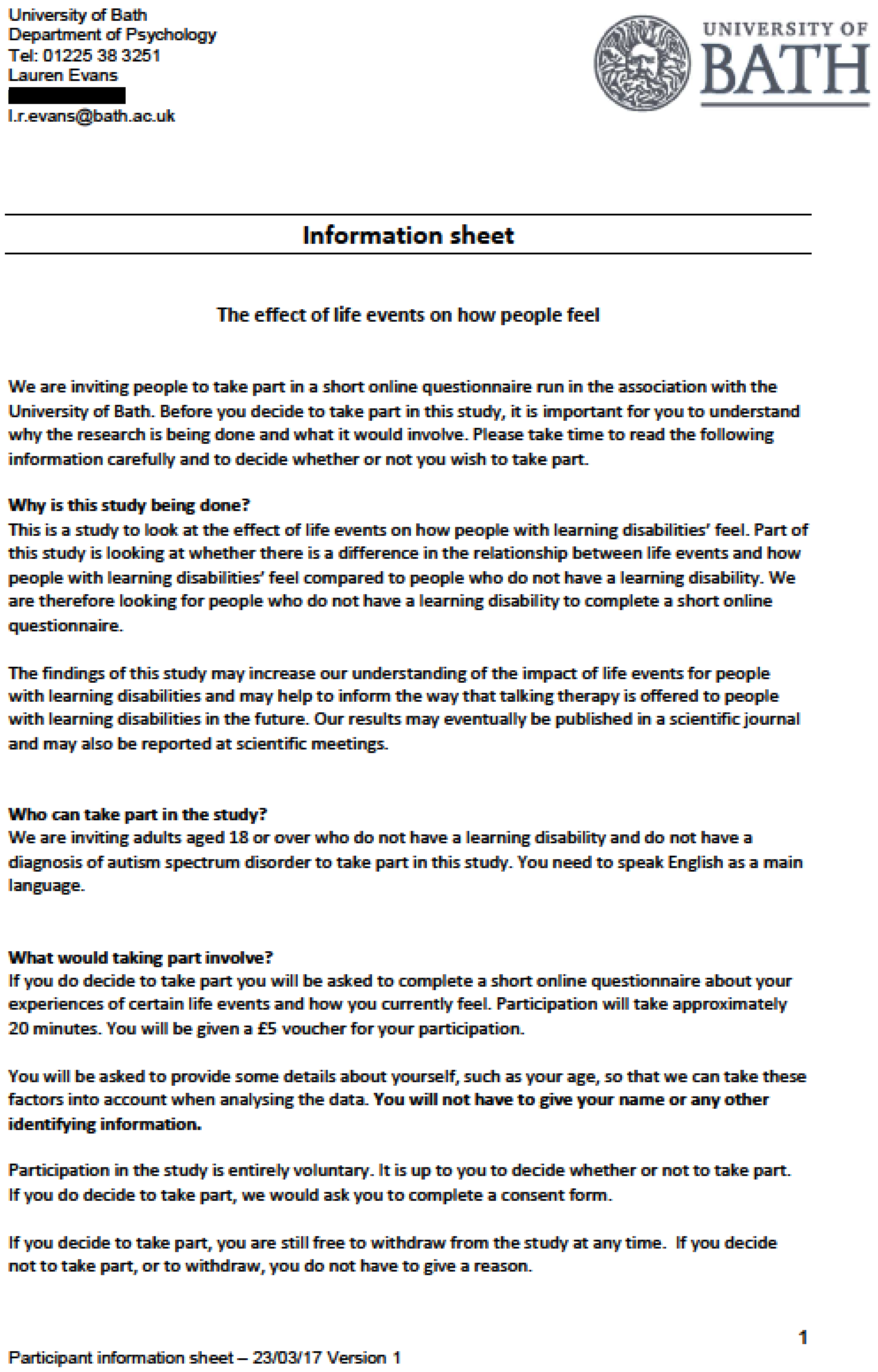
Are there any reasons to not take part?

	The meeting will take around 45 minutes of your time.
	If you feel sad at any time during the study, you can tell the person you meet. You could ask them to talk about something else or to stop the interview. If you are sad at the end of the meeting, we will stay with you until you feel better or make sure you are not left alone. We can tell someone who supports you if you are feeling sad. If you are still feeling sad when the meeting has ended, you could talk to a family member, one of your carers, the person who gave you this leaflet or your GP.

What do I do next if I want to take part?

If you would like to take part you can tell the person who gave you this leaflet or you can contact:

Lauren Evans	**Cathy Randle-Phillips**
[redacted]	
l.r.evans@bath.ac.uk	C.M.Randle-Phillips@bath.ac.uk



University of Bath
Department of Psychology
Tel: 01225 38 3251
Lauren Evans
[redacted]
l.r.evans@bath.ac.uk

Information sheet

The effect of life events on how people feel

We are inviting people to take part in a short online questionnaire run in the association with the University of Bath. Before you decide to take part in this study, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and to decide whether or not you wish to take part.

Why is this study being done?
This is a study to look at the effect of life events on how people with learning disabilities' feel. Part of this study is looking at whether there is a difference in the relationship between life events and how people with learning disabilities' feel compared to people who do not have a learning disability. We are therefore looking for people who do not have a learning disability to complete a short online questionnaire.

The findings of this study may increase our understanding of the impact of life events for people with learning disabilities and may help to inform the way that talking therapy is offered to people with learning disabilities in the future. Our results may eventually be published in a scientific journal and may also be reported at scientific meetings.

Who can take part in the study?
We are inviting adults aged 18 or over who do not have a learning disability and do not have a diagnosis of autism spectrum disorder to take part in this study. You need to speak English as a main language.

What would taking part involve?
If you do decide to take part you will be asked to complete a short online questionnaire about your experiences of certain life events and how you currently feel. Participation will take approximately 20 minutes. You will be given a £5 voucher for your participation.

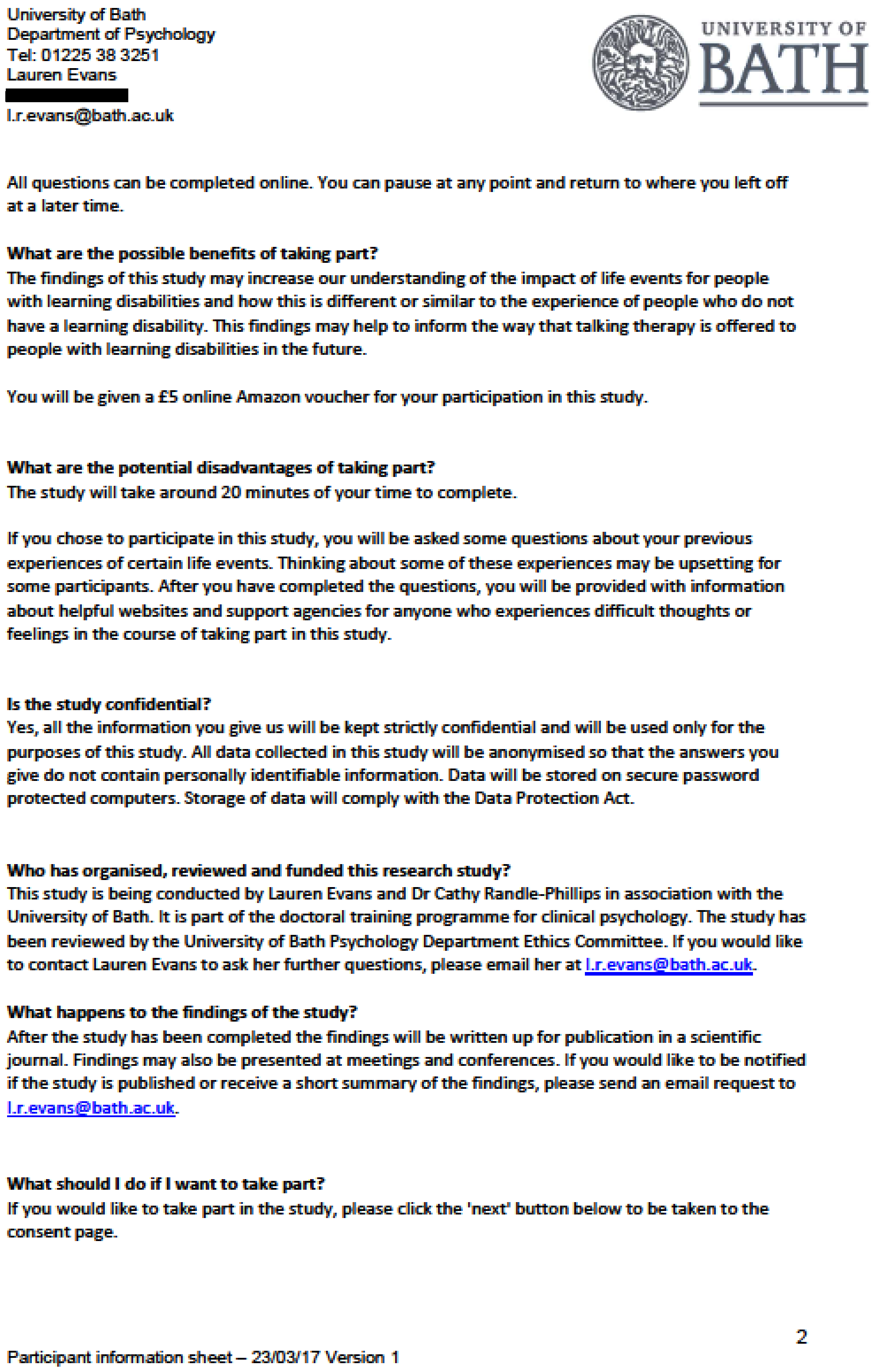
You will be asked to provide some details about yourself, such as your age, so that we can take these factors into account when analysing the data. **You will not have to give your name or any other identifying information.**

Participation in the study is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, we would ask you to complete a consent form.

If you decide to take part, you are still free to withdraw from the study at any time. If you decide not to take part, or to withdraw, you do not have to give a reason.

1

Participant information sheet – 23/03/17 Version 1



University of Bath
Department of Psychology
Tel: 01225 38 3251
Lauren Evans
[redacted]
l.r.evans@bath.ac.uk

All questions can be completed online. You can pause at any point and return to where you left off at a later time.

What are the possible benefits of taking part?
The findings of this study may increase our understanding of the impact of life events for people with learning disabilities and how this is different or similar to the experience of people who do not have a learning disability. This findings may help to inform the way that talking therapy is offered to people with learning disabilities in the future.

You will be given a £5 online Amazon voucher for your participation in this study.

What are the potential disadvantages of taking part?
The study will take around 20 minutes of your time to complete.

If you chose to participate in this study, you will be asked some questions about your previous experiences of certain life events. Thinking about some of these experiences may be upsetting for some participants. After you have completed the questions, you will be provided with information about helpful websites and support agencies for anyone who experiences difficult thoughts or feelings in the course of taking part in this study.

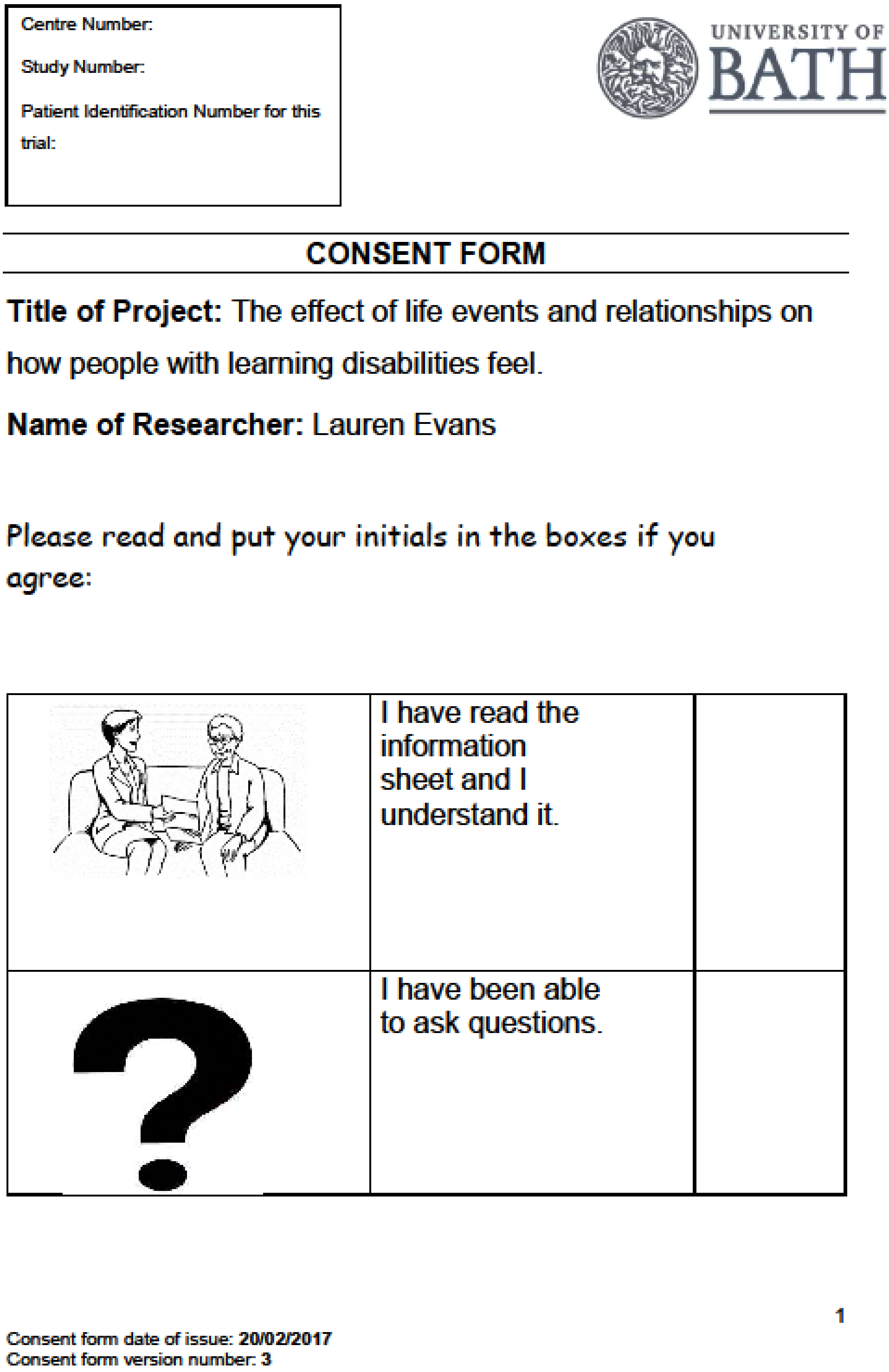
Is the study confidential?
Yes, all the information you give us will be kept strictly confidential and will be used only for the purposes of this study. All data collected in this study will be anonymised so that the answers you give do not contain personally identifiable information. Data will be stored on secure password protected computers. Storage of data will comply with the Data Protection Act.

Who has organised, reviewed and funded this research study?
This study is being conducted by Lauren Evans and Dr Cathy Randle-Phillips in association with the University of Bath. It is part of the doctoral training programme for clinical psychology. The study has been reviewed by the University of Bath Psychology Department Ethics Committee. If you would like to contact Lauren Evans to ask her further questions, please email her at l.r.evans@bath.ac.uk.

What happens to the findings of the study?
After the study has been completed the findings will be written up for publication in a scientific journal. Findings may also be presented at meetings and conferences. If you would like to be notified if the study is published or receive a short summary of the findings, please send an email request to l.r.evans@bath.ac.uk.

What should I do if I want to take part?
If you would like to take part in the study, please click the 'next' button below to be taken to the consent page.

Appendix VIII. Consent forms for main research project



Centre Number:

Study Number:

Patient Identification Number for this trial:

UNIVERSITY OF BATH

CONSENT FORM

Title of Project: The effect of life events and relationships on how people with learning disabilities feel.

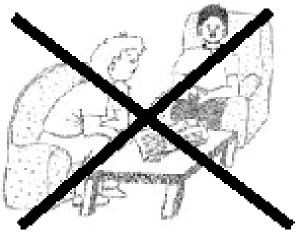
Name of Researcher: Lauren Evans

Please read and put your initials in the boxes if you agree:

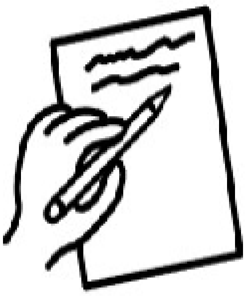
	I have read the information sheet and I understand it.	
?	I have been able to ask questions.	

1

Consent form date of issue: **20/02/2017**
Consent form version number: **3**

	I know that I do not have to take part if I do not want to.	
	I can stop taking part in the study at any time.	
	I agree for Lauren Evans and her supervisors to look at my answers.	
	I know people who support me may be told I am taking part.	

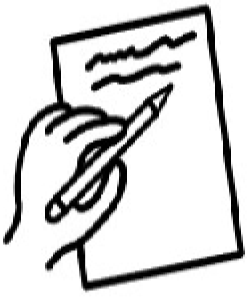
	I want to take part in the study.	



Name:

Signature:

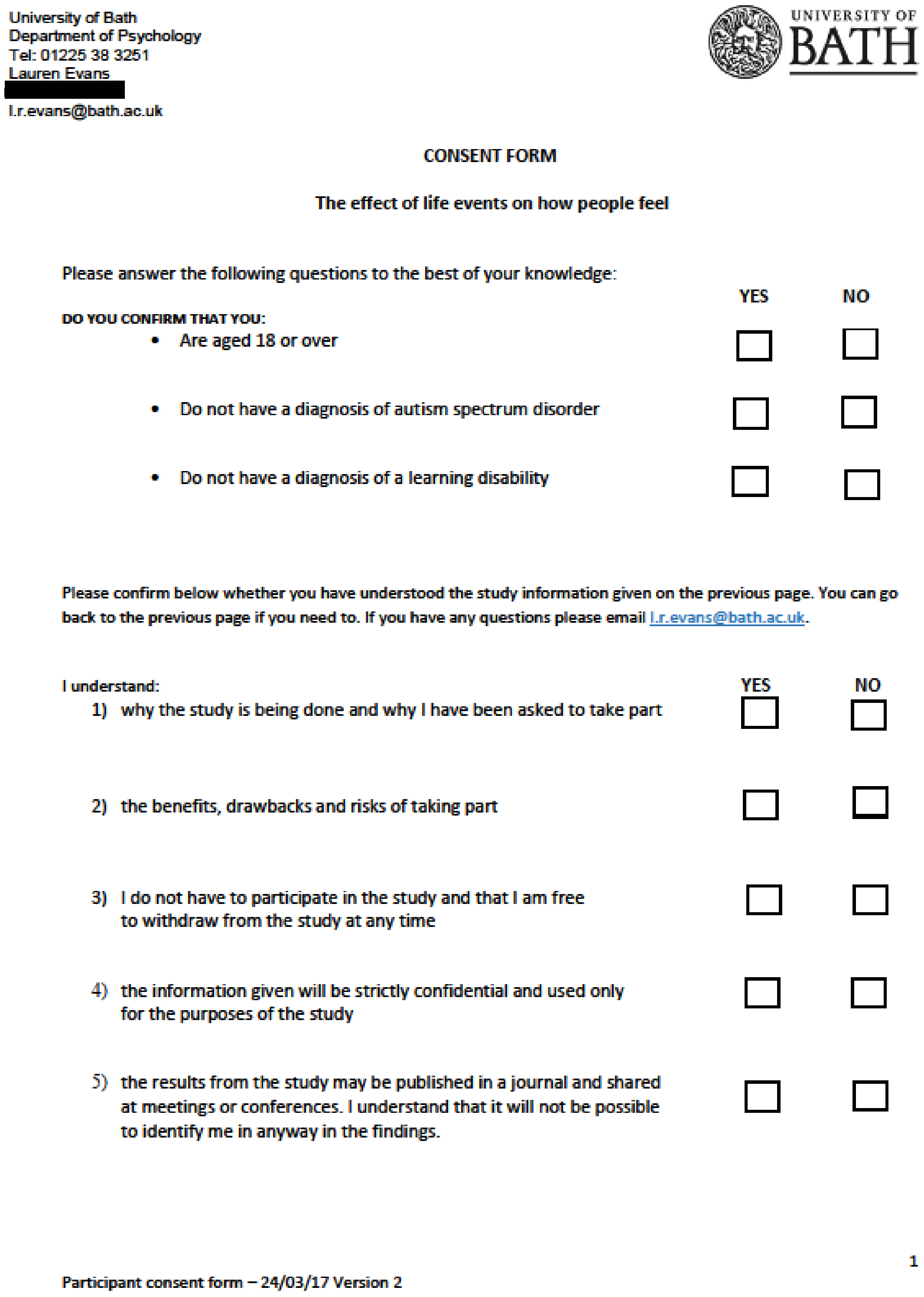
Date:



Name of person taking consent:

Signature:

Date:



University of Bath
Department of Psychology
Tel: 01225 38 3251
Lauren Evans
[redacted]
l.r.evans@bath.ac.uk

CONSENT FORM

The effect of life events on how people feel

Please answer the following questions to the best of your knowledge:

DO YOU CONFIRM THAT YOU:	YES	NO
• Are aged 18 or over	☐	☐
• Do not have a diagnosis of autism spectrum disorder	☐	☐
• Do not have a diagnosis of a learning disability	☐	☐

Please confirm below whether you have understood the study information given on the previous page. You can go back to the previous page if you need to. If you have any questions please email l.r.evans@bath.ac.uk.

I understand:	YES	NO
1) why the study is being done and why I have been asked to take part	☐	☐
2) the benefits, drawbacks and risks of taking part	☐	☐
3) I do not have to participate in the study and that I am free to withdraw from the study at any time	☐	☐
4) the information given will be strictly confidential and used only for the purposes of the study	☐	☐
5) the results from the study may be published in a journal and shared at meetings or conferences. I understand that it will not be possible to identify me in anyway in the findings.	☐	☐

1

Participant consent form – 24/03/17 Version 2

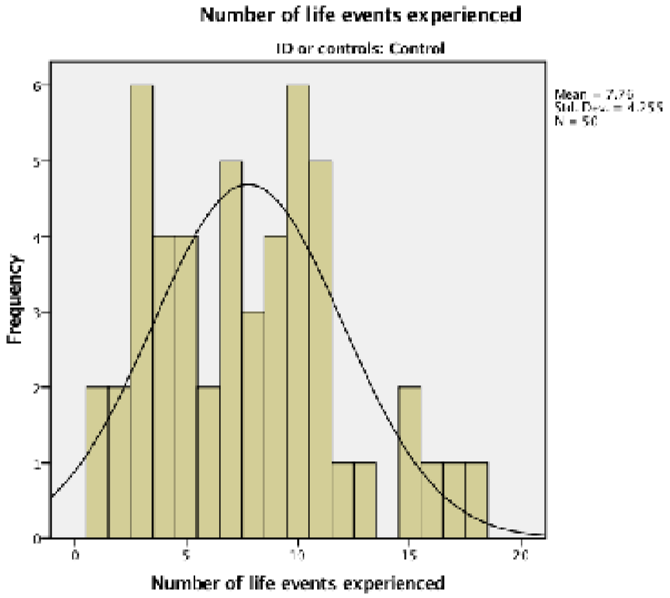
University of Bath
Department of Psychology
Tel: 01225 38 3251
Lauren Evans
[redacted]
l.r.evans@bath.ac.uk

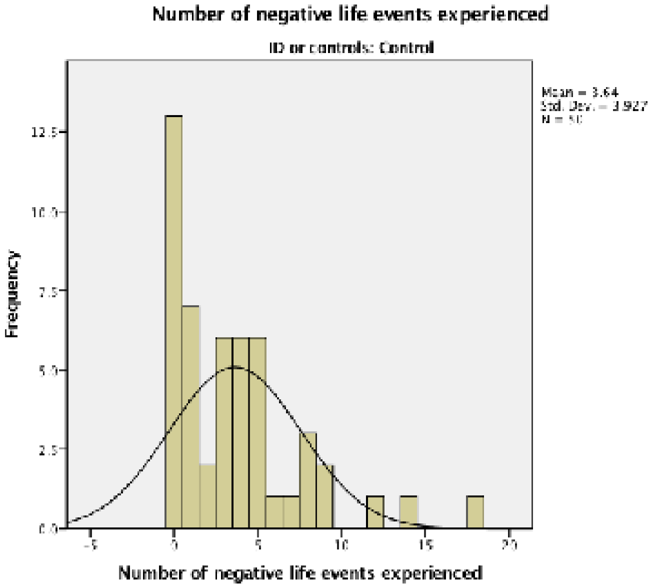
UNIVERSITY OF BATH

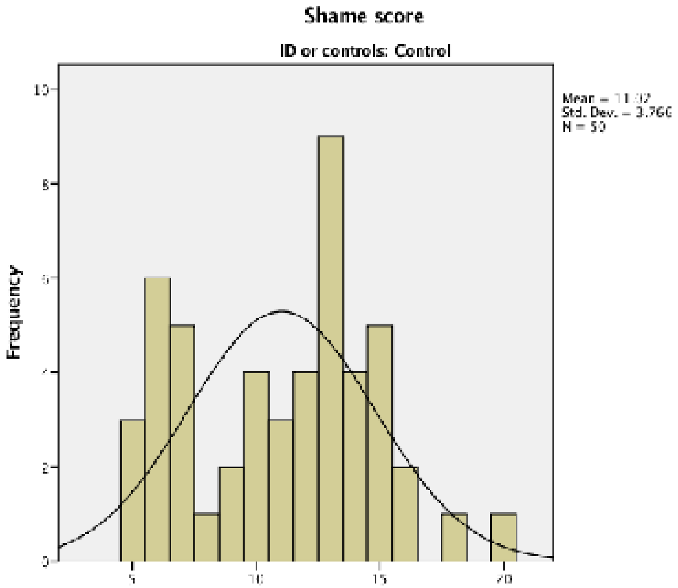
I have answered 'yes' to the above 5 points and agree to participate in the research

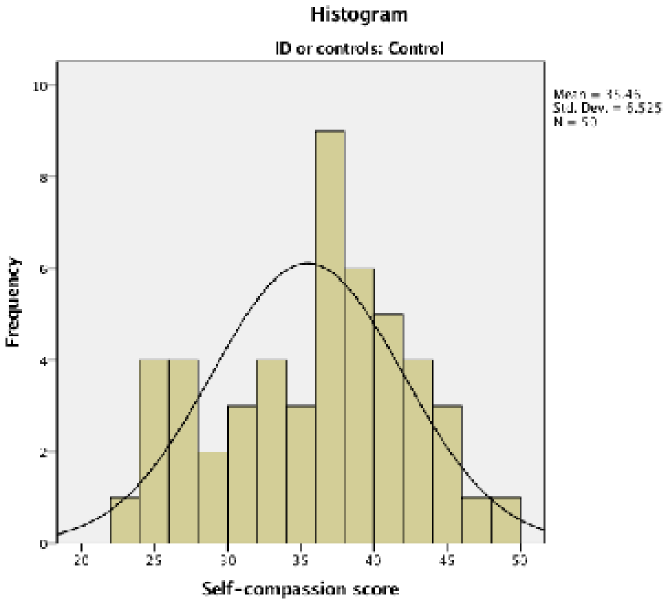
Yes ☐ No ☐

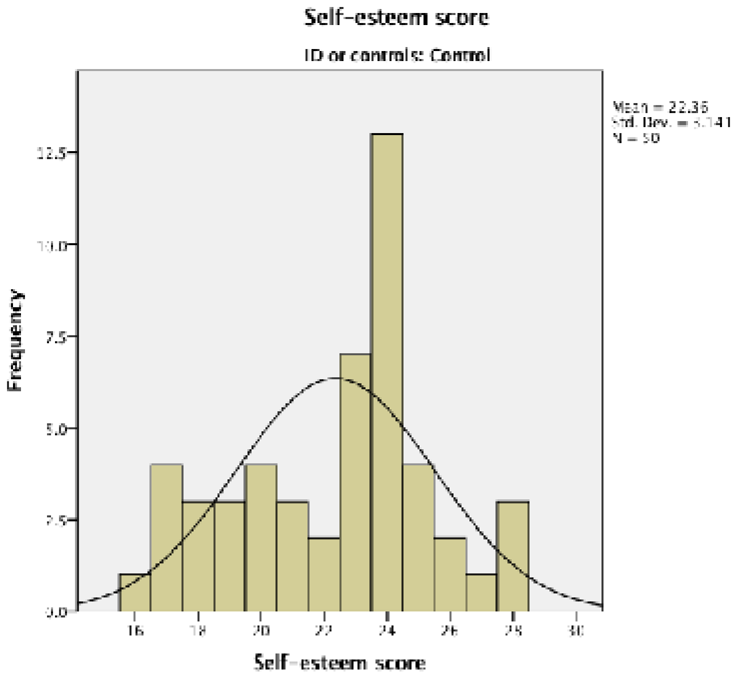
Appendix IX: Histograms for main research project

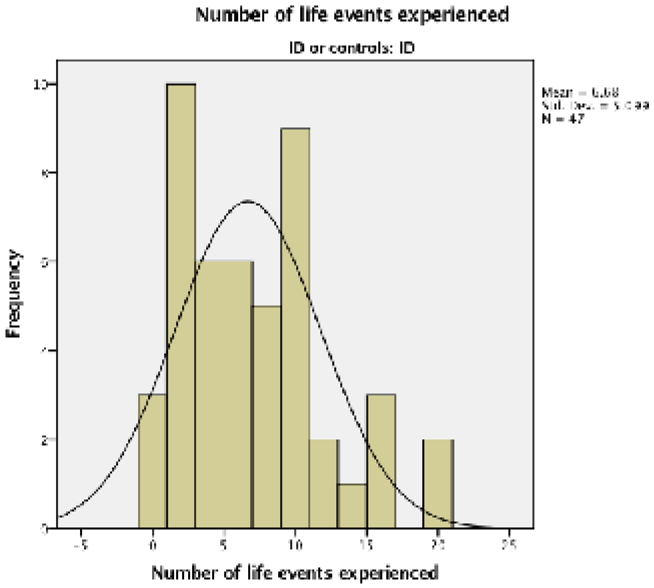


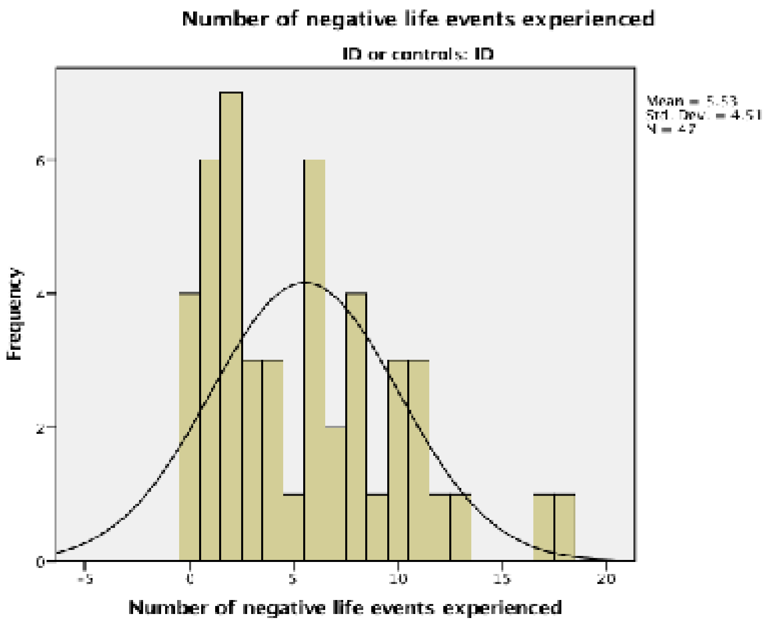


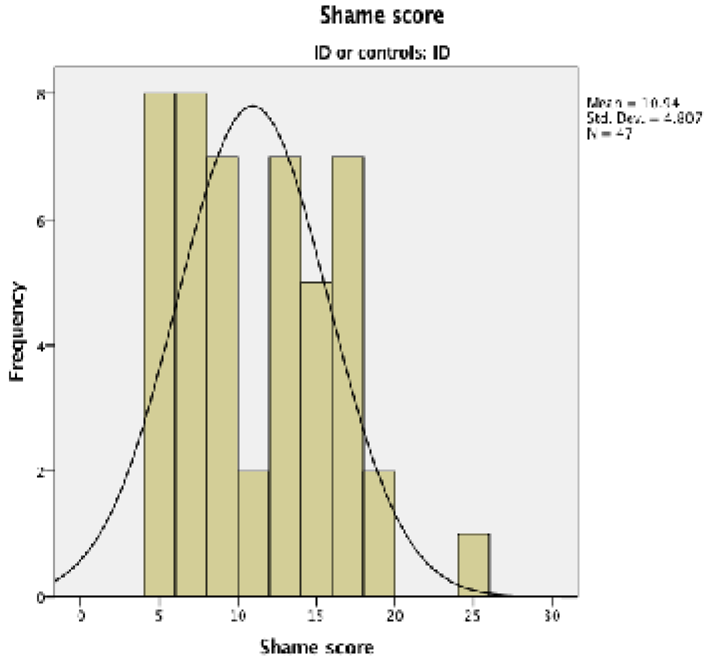

Shame score
ID or controls: Control
Mean = 11.02
Std. Dev. = 3.760
N = 50
Frequency
0
2
4
6
8
10
5
10
15
20

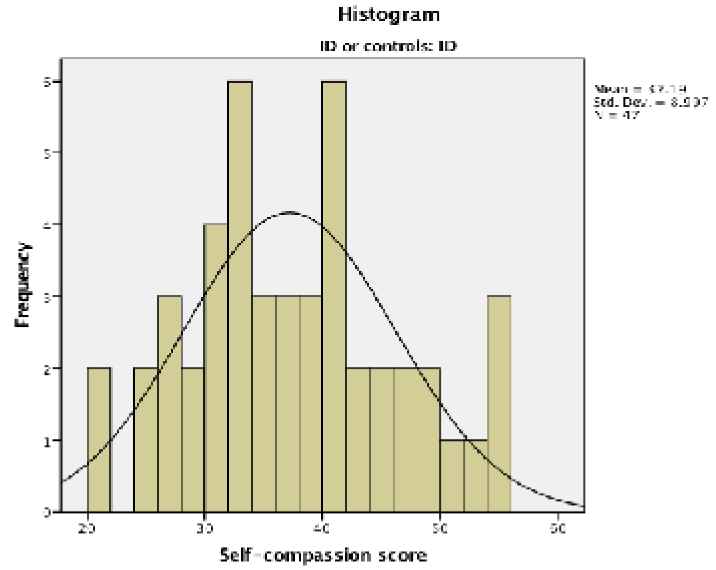

Histogram
ID or controls: Control
Mean = 35.46
Std. Dev. = 6.525
N = 50
Frequency
0
2
4
6
8
10
20
25
30
35
40
45
50
Self-compassion score


Self-esteem score
ID or controls: Control
Mean = 22.36
Std. Dev. = 3.141
N = 50
Frequency
12.5
10.0
7.5
5.0
2.5
0.0
16
18
20
22
24
26
28
30
Self-esteem score


Number of life events experienced
ID or controls: ID
Mean = 6.68
Std. Dev. = 5.099
N = 47
Frequency
10
8
6
4
2
0
-5
0
5
10
15
20
25
Number of life events experienced


Number of negative life events experienced
ID or controls: ID
Mean = 5.53
Std. Dev. = 4.51
N = 47
Frequency
0
2
4
6
-5
0
5
10
15
20
Number of negative life events experienced


Shame score
ID or controls: ID
Mean = 10.94
Std. Dev. = 4.807
N = 47
Frequency
0
2
4
6
8
0
5
10
15
20
25
30
Shame score


Histogram
ID or controls: ID
Mean = 37.74
Std. Dev. = 8.937
N = 47
Frequency
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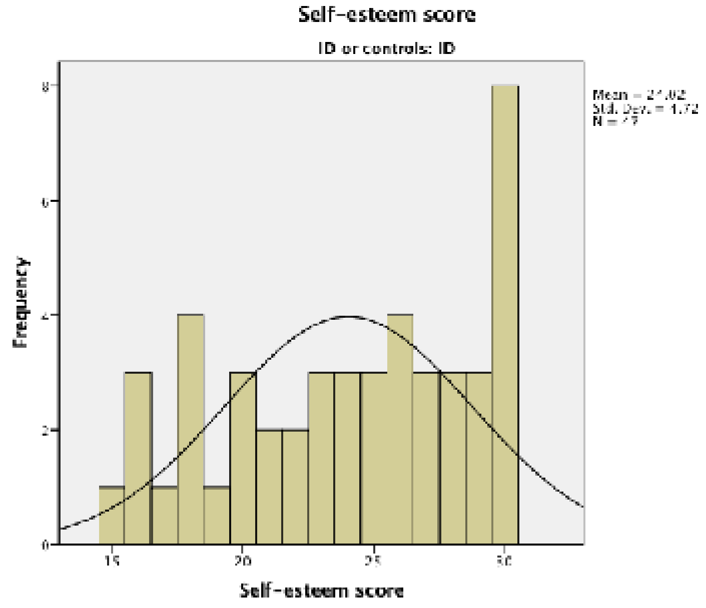
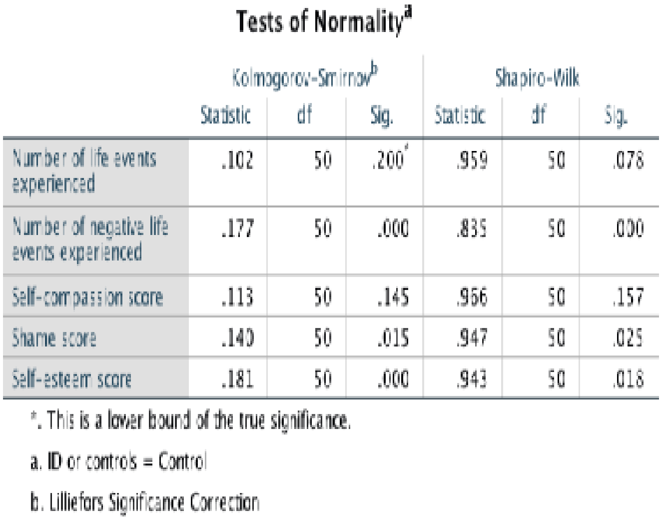
1
2
3
4
5
6
20
30
40
50
60
Self-compassion score


Self-esteem score
ID or controls: ID
Mean = 24.02
Std. Dev. = 4.72
N = 47
Frequency
0
2
4
6
8
15
20
25
30
Self-esteem score

Appendix X: SPSS output for tests of normality and homogeneity of variance



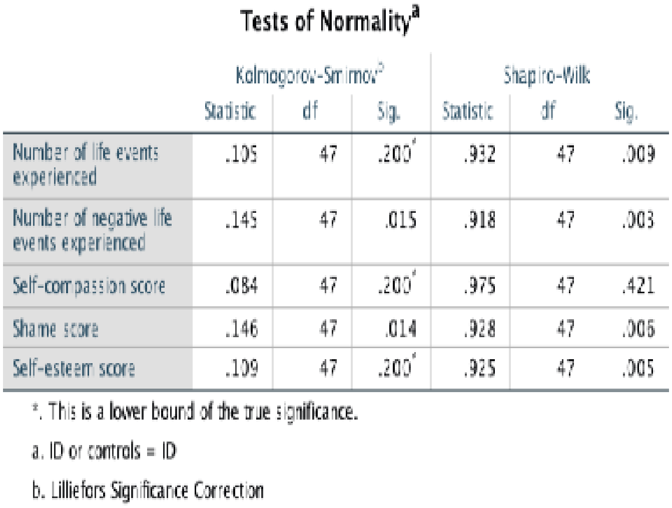
Tests of Normality[a]

	Kolmogorov-Smirnov[b]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Number of life events experienced	.102	50	.200*	.959	50	.078
Number of negative life events experienced	.177	50	.000	.835	50	.000
Self-compassion score	.113	50	.145	.956	50	.157
Shame score	.140	50	.015	.947	50	.025
Self-esteem score	.181	50	.000	.943	50	.018

*. This is a lower bound of the true significance.

a. ID or controls = Control

b. Lilliefors Significance Correction



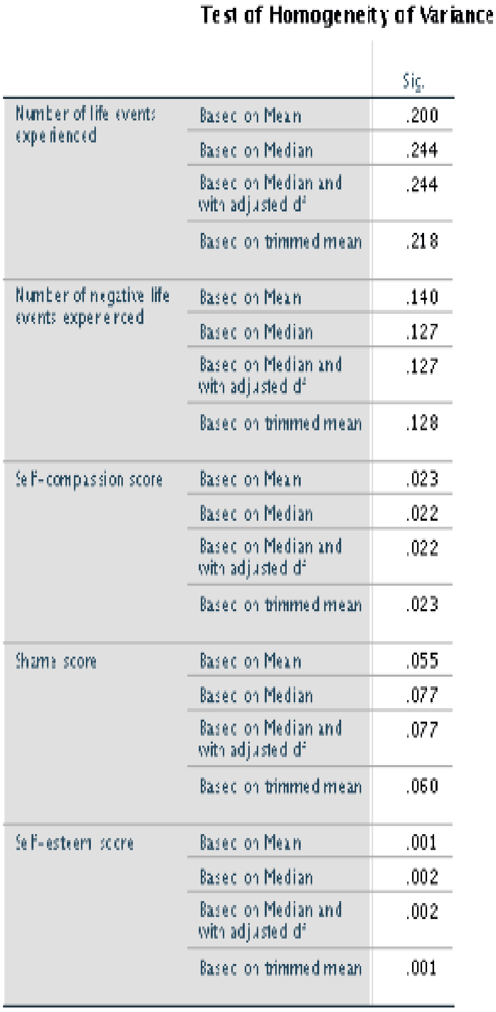
Tests of Normality[a]

	Kolmogorov-Smirnov[b]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Number of life events experienced	.105	47	.200*	.932	47	.009
Number of negative life events experienced	.145	47	.015	.918	47	.003
Self-compassion score	.084	47	.200*	.975	47	.421
Shame score	.146	47	.014	.928	47	.006
Self-esteem score	.109	47	.200*	.925	47	.005

*. This is a lower bound of the true significance.

a. ID or controls = ID

b. Lilliefors Significance Correction



Test of Homogeneity of Variance

		Sig.
Number of life events experienced	Based on Mean	.200
	Based on Median	.244
	Based on Median and with adjusted df	.244
	Based on trimmed mean	.218
Number of negative life events experienced	Based on Mean	.140
	Based on Median	.127
	Based on Median and with adjusted df	.127
	Based on trimmed mean	.128
Self-compassion score	Based on Mean	.023
	Based on Median	.022
	Based on Median and with adjusted df	.022
	Based on trimmed mean	.023
Shame score	Based on Mean	.055
	Based on Median	.077
	Based on Median and with adjusted df	.077
	Based on trimmed mean	.060
Self-esteem score	Based on Mean	.001
	Based on Median	.002
	Based on Median and with adjusted df	.002
	Based on trimmed mean	.001

Appendix XI: Author guidelines for Journal of Intellectual Disabilities

The Journal of Intellectual Disabilities is a peer reviewed journal that provides a medium for the exchange of best practice, knowledge and research between academic and professional disciplines from education, social and health settings to bring about advancement of services for people with intellectual and learning disabilities. The idea of a practice-led journal is both exciting and timely.

Your manuscript should ideally be between 6000 and 8000 words long, and double spaced. Please also supply an abstract of 100-150 words, and up to five keywords, arranged in alphabetical order.

Preparing your manuscript for submission

Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guideline page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

Reference style

Journal of Intellectual Disabilities adheres to the SAGE Harvard reference style. View the SAGE Harvard guidelines to ensure your manuscript conforms to this reference style.

If you use EndNote to manage references, you can download the SAGE Harvard EndNote output file.

Appendix XII: Author guidelines for Journal of Autism and Developmental Disorders

The *Journal of Autism and Developmental Disorders* is the leading peer-reviewed, scholarly periodical focusing on all aspects of autism spectrum disorders and related developmental disabilities. Published monthly, *JADD* is committed to advancing the understanding of autism, including potential causes and prevalence (e.g., genetic, immunological, environmental); diagnosis advancements; and effective clinical care, education, and treatment for all individuals. Studies of diagnostic reliability and validity, psychotherapeutic and psychopharmacological treatment efficacy, and mental health services effectiveness are encouraged. *JADD* also seeks to promote the well-being of children and families by publishing scholarly papers on such subjects as health policy, legislation, advocacy, culture and society, and service provision as they pertain to the mental health of children and families. Review articles are solicited in targeted areas of special interest; book and media reviews provide targeted updates on important new materials; and the Ask the Editor column serves as a forum for addressing timely questions of relevance to *JADD*'s broad readership.

Manuscript format

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins. Text must be double-spaced; APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.

- The blinded manuscript containing no author information (no name, no affiliation, and so forth).

Articles, Commentaries Brief Reports, Letters to the Editor

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.)

Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.
- Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Appendix XIII: Author guidelines for British Journal of Clinical Psychology

Aims and Scope

The *British Journal of Clinical Psychology* publishes original research, both empirical and theoretical, on all aspects of clinical psychology:

- clinical and abnormal psychology featuring descriptive or experimental studies
- aetiology, assessment and treatment of the whole range of psychological disorders irrespective of age group and setting
- biological influences on individual behaviour
- studies of psychological interventions and treatment on individuals, dyads, families and groups

For specific submission requirements, please view the Author Guidelines.

The Journal is catholic with respect to the range of theories and methods used to answer substantive scientific problems. Studies of samples with no current psychological disorder will only be considered if they have a direct bearing on clinical theory or practice.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers, provided that these are sufficiently related to empirical data;
- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications;
- Brief Reports and Comments.

Author Guidelines

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

All papers published in The British Journal of Clinical Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

The following types of paper are invited:

• Papers reporting original empirical investigations

• Theoretical papers, provided that these are sufficiently related to the empirical data

• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications

• Brief reports and comments

Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

Length

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript.

- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.

- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

- All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

- All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading ‘Practitioner Points’.

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

- In normal circumstances, effect size should be incorporated.

- Authors are requested to avoid the use of sexist language.

- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.