

**Title:** Experiences of shame and intellectual disabilities: two case studies

**Abstract** (150 words)

## **Background**

Shame is a trans-diagnostic phenomenon which underlies a variety of mental health difficulties. People with Intellectual Disabilities (ID) are reported to be one of the most stigmatised and excluded groups in society, and are more likely to experience mental health problems than the general population. Consequently, this group may be at significant risk of shame-related distress. However, a lack of research has been conducted which investigates the experience of shame in people with ID, and there is currently a lack of interventions targeting shame in people with ID.

## **Method**

Two case studies were undertaken to document the experiences of stigma, discrimination and shame in people with ID, and to explore how shame may present in this population.

## **Results**

Shame was found to be a significant barrier to social inclusion and can contribute towards poor psychological health in people with ID.

## **Conclusions**

The development of interventions which specifically target shame in this population are required.

## **Introduction**

### What is Shame?

Shame is a self-conscious experience, characterised by feelings of inferiority, undesirability, defectiveness, and worthlessness (Clapton, Williams & Jones, 2018). It is often manifested in negative emotions such as depression and anxiety, cognitive self-evaluations such as self-criticism and negative social-comparisons, and defensive coping behaviours such as lowering the head, avoiding eye contact, and the desire to conceal oneself from others (Gilbert, 1998;

Gilbert & Procter, 2006; Rüsç et al., 2007). Shame can be examined at a number of different levels: as an emotion, self-evaluative cognitions and beliefs, and observable behaviours (Tangney, 1991; Tomkins, 1963; Yelsma, Brown & Elison, 2002) as well as taking into account motives/motivational tendencies and physiological components/levels (Dickerson et al., 2004, 2009; Dickerson, 2008). This means that definitions of shame in the literature are often inconsistent. However, the majority of the literature distinguishes between two types of shame: external shame and internal shame (Clapton, Williams & Jones, 2018; Gilbert, 1997; Gilbert, 1998; Gilbert & Procter, 2006).

External shame corresponds with the belief that we are judged negatively by others. A key precursor of external shame is stigma: the process of a person being devalued, discriminated and marginalised by society because they possess values or characteristics which differ from the dominant cultural group (Ali, Hassiotis, Strydom & King, 2012). This is supported by the fact that external shame is particularly prevalent in individuals belonging to stigmatised groups (Kaufman, 2004), such as people with intellectual disabilities and mental health conditions (Ali, Hassiotis, Strydom & King, 2012; Shahar, 2001). In the context of stigma, external shame is related to stigma awareness (Clapton, Williams & Jones, 2018), the extent to which one is aware of the stigmatising views of others.

Internal shame, also referred to in the literature as internalised-stigma or self-stigma (Ali, Hassiotis, Strydom & King, 2012; Corrigan & Rao, 2012), is concerned with feelings of becoming an undesired self. Internal shame is typically indicated by negative cognitive evaluations of oneself as inadequate (Tangney & Dearing, 2002). This can include processes such as engaging in self-devaluation, self-criticism and negative social-comparisons (Clapton, Williams & Jones, 2018).

Although external and internal shame are separate constructs that can be experienced in isolation; for example, a person can feel shamed by others whilst not shaming themselves, they are often experienced together (Clapton, Williams & Jones, 2018; Gilbert & Procter, 2006). When external and internal shame occur together, a person experiences both their external and internal worlds as hostile, and can feel overwhelmed and unsafe, in what Lewis (1992) refers to as “the exposed self”. Therefore, according to the above definition, shame relates to the process of perceiving oneself as existing negatively in the minds of others as well as existing negatively in one’s own mind.

### Shame and People with an Intellectual Disability (ID)

People with ID have been described as one of the most stigmatised and excluded groups in society (Scior, Kan, McLoughlin & Sheridan, 2010). It is reported that this group can experience stigma and discrimination daily, such as being denied the right to make choices, being treated like children, as well as being institutionally labelled and stigmatised by the educational and welfare systems (Chen & Shu, 2012; Jahoda, Wilson, Stalker & Cairney, 2010). People with ID are also at a much higher risk of having or developing health problems, including mental illness, compared with the general population (Cooper, Smiley, Morrison, Williamson & Allan, 2007; Emerson & Baines, 2011; Emerson, Robertson, Baines & Hatton, 2014). It is unlikely that these adverse effects and experiences of stigma and discrimination are unrelated; there is increasing evidence that stigma and shame play a significant role in the maintenance of poor health outcomes in this population (Ali, King, Strydom & Hassiotis, 2015; Garaigordobil & Pérez, 2007; Paterson, McKenzie & Lindsay, 2012; Szviov-Bach, 1993).

There is very limited research available directly examining the role of internal and external shame in the lives of people with ID, although some information emerges from the research conducted that investigates stigma. Research has consistently shown that individuals with mild to moderate ID are aware of the stigmatising treatment that they experience, which may result in symptoms of psychological distress. For example, awareness of stigma has been shown to be associated with low levels of self-esteem and self-efficacy, feelings of inferiority and symptoms of anxiety and depression in people with ID (Ali, King, Strydom & Hassiotis, 2015; Garaigordobil & Pérez, 2007; Paterson, McKenzie & Lindsay, 2012; Szviov-Bach; 1993). Furthermore, these symptoms may be exacerbated in people with moderate ID who are older and have health and/or sensory problems, as these demographic factors have been identified as significant predictors of self-reported stigma in individuals with ID (Ali, King, Strydom & Hassiotis, 2016).

There is also evidence to suggest that stigma awareness may be related to the extent to which people accept and internalise the label of ID. In a meta-analysis, Ali, Hassiotis, Strydom and King (2012) referenced two studies which documented an association between being categorized as disabled and being aware of stigma surrounding the label (Todd, 2000; Cunningham & Glen, 2004). The authors of these papers concluded that participants who did not associate themselves with having an ID were less sensitive to the stigma surrounding their diagnosis and therefore had not internalised stigmatising views. It is suggested that some people may try to cope with stigma by attempting to distance themselves from others with an ID because they do not want to be associated with the label assigned to them (Jahoda, Wilson, Stalker & Cairney, 2010; Chen & Shu, 2012) or because they fear being viewed as different (Chen & Shu, 2012).

Chen and Shu (2012) investigated the experiences of stigmatisation among students with IDs in Taiwan. Some students in the sample reported sentiments which suggested that they had internalised stigmatising views about themselves. For example, upon a teacher reminding one student to attend a special educational class, the student reported that they “suddenly realised that [they were] an idiot” and that they “felt like crying”. Students also reported feeling ashamed about having to attend special classes and felt embarrassed about possessing a ‘handicapped card’ which the government assign to people with IDs in Taiwan. Moreover, the ways in which the students coped with these experiences were also indicative of shame. Avoidance and isolation were common themes. For example, one student would ask another person to buy her bus ticket so that she could avoid revealing her card, and thus conceal her identify as a disabled person. Participants also avoided entering relationships with classmates without IDs, fearing that interaction with a “normal person” would expose their differences. These examples clearly indicate that experiences of stigmatisation have contributed to self-stigmatising beliefs and feelings and behaviours of shame associated with having an ID.

Another article describes feelings of internal shame in people with ID (Jahoda, Wilson, Stalker and Cairney, 2010). This paper examined the self-perceptions of two individuals as they attempt to establish their own identities as young adults in the face of stigma. One dominant theme that emerged from the case studies was the participants’ desire to not be seen as “disabled”, possibly because they were ashamed of the label. It was also identified that both individuals put pressure on themselves to be independent members of mainstream society. Although feelings of shame were certainly hinted at in this study, these feelings were interrupted by the researcher, rather than being articulated as such by the participants. Therefore, it is suggested that research is needed which involves closer collaboration with people with ID to examine their first-person perspectives of shameful experiences. The present study seeks to take a first step towards this.

## **Method**

### *Ethical Issues*

In consultation with the R&D Management at the research site and following NHS guidance, the study was determined to be service evaluation as no patient allocation occurred and an intervention was already in use (NHS HRA, 2013). Informed consent was gained by both individuals for their information to be used for research purposes (participants were given information sheets presented in easy-read format) and pseudonyms have been used to protect their identities. Personal data was stored on password protected computers in a secure building and the audio recordings were deleted from the device they were recorded once they had been transcribed.

### *Participants*

Participants were two individuals, Sylvia and Anthony (pseudonyms), who were at the time of writing, receiving support from Clinical Psychology within a Community Team for People with Learning Disabilities (CTPLD). The participants were approached by the Clinical Psychologist and asked if they would like to participate in the study. They were chosen because they were able to recognise and articulate their feelings of shame. After they had consented to be included in the study, case studies were constructed by the Clinical Psychologist which focussed on their feelings of shame. The case studies were written based on information of their presentation and histories collected during sessions, and by reading historical case notes.

### *Procedure*

After the case studies had been written, Sylvia and Anthony were invited to attend appointments with the study researchers (Clinical Psychologist and research assistant) in a familiar location. A friend accompanied Sylvia to her appointment whilst Anthony attended by himself. During the appointment, the case studies were fed back to participants who made comments about them in order to ensure their accuracy and suitability. Both participants expressed that they agreed with their case studies and that their feelings had been written about faithfully, however, a few minor changes were made to Anthony's case study in accordance with his comments. Following the presentation of the case study to each participant, participants were interviewed in a semi-structured fashion, using probing questions devised by the researchers from the case studies, aimed to gain deeper insight into the participants' affective, cognitive and behavioural responses to shame. Questions focused on their coping strategies in response to shame, the responses of others, potential triggers, the effects of other individuals' and their own expectations of themselves, the thoughts and feelings of others, and their opinions about identifying with the label of ID. With the participants' consent, audio recordings were taken of the interviews and they were subsequently transcribed.

## **Results**

### Case Study 1: Sylvia

#### *Reason for Referral*

Sylvia, a woman in her 60's, was referred to the CTPLD by her GP. The referral was for input to help her to express her emotions and cope with feelings of anxiety.

### *Background Information*

Sylvia lives with her husband Mark, who she has been in a relationship with for over 30yrs. She volunteers at a day centre, doing washing up and giving out lunches. She also attends groups organised by the charity MIND and goes line dancing. She spends a lot of time with her friend, who she often goes shopping with or to cafés. In the past she has worked in factories and a large supermarket.

### *Presenting problems and presentation*

For some time, Sylvia has experienced a great deal of anxiety. This is particularly apparent when she is faced with novel situations, or out in the community in shops, shopping centres and standing in queues. In these situations Sylvia struggles to think what to do or say. She also struggles to go through busy doorways, push trolleys, cope with others asking her to move so that they can see items, or tolerate others queuing behind her. Instead, Sylvia typically removes herself from the situation (e.g. repeatedly moving out of a queue whenever anyone comes behind her), becomes highly agitated, or shouts at people.

Sylvia also experiences difficulties in relation to her family. She reports that they are often negative towards her, apart from one sister who has a son with a chromosomal disability. She worries that she takes things to heart too much. Recently she described her mum telling her off for attempting to hug her and other people, due to her mother believing it may spread germs and contribute to her mother's physical health problems.

### *Psychological formulation*

Sylvia has had a large number of negative life experiences. These include emotional abuse, physical chastisement, bullying and sexual assault. Many of these experiences feel to Sylvia as if they are directly or indirectly linked to her ID. She often reports feeling as if she is slow to think of things, that there is something wrong with her, that she will be punished, that bad things will happen to her and that unlike others, she does not know how to do things the right way. Whilst many people experience the same difficulties without having an ID (e.g. not knowing what to say in a difficult situation), Sylvia's history means that she feels very alone with this experience, as well as very self-critical and ashamed. She also feels scared that others cannot be trusted and are going to hurt her.

In order to cope with these feelings and beliefs, Sylvia likes to know the rules for how to do things or for what to say. This is to prevent her from being able to get things wrong. Whilst this is helpful in some situations, when out in the community it often increases her anxiety because other people do not follow these rules (e.g. they do not allow people through

doorways when it's their turn or wait their turn when looking for items in a shop). This can make Sylvia very agitated. Sylvia also tries to seek reassurance from others, or avoid difficult situations, which increases her sense of incompetence. Interactions with her family also reinforce these feelings.

## Case Study 2: Anthony

### *Reason for Referral*

Anthony (24 years old) was referred to the CTPLD by carers at his supported accommodation. The referral was for anger management due to him punching walls or swearing at carers to the extent that his tenancy was at risk.

### *Background Information*

Anthony lives in supported living accommodation. He shares his house with another young man who requires one to one support at all times. During the day he attends a sheltered work place, volunteers at a charity shop and attends swimming and martial arts classes. In addition, he enjoys cooking and making decorations (e.g. for Halloween and Christmas) to decorate the outside of his house. He receives one-to-one support focusing on helping him with his personal care and independent living skills, as well as accessing additional community activities. However, there remains large periods of time when Anthony has nothing to do.

### *Presenting problems and presentation*

Anthony has presented with anger management difficulties for some time. These result in destruction to property and verbal aggression. Typically, Anthony is reported to become angry when he struggles to complete a task or when someone asks him to do something. When this happens he usually shouts or swears, destroys property (e.g. punching walls) and occasionally pushes past people.

### *Psychological formulation*

Discussions with Anthony revealed that he feels very negatively towards himself. Reasons for this include: him comparing himself to siblings who attended private school while he attended a special school; his needs not being fully understood and attributed incorrectly to the side-effects of medication rather than ADHD and ID; expectations placed on him by others, and difficulties making friends with peers. As a result Anthony would appear to struggle with situations where he believes he is being belittled, for example when asked to carry out chores by carers. He also tends to take on projects that he then becomes overwhelmed by, such as

too many voluntary jobs and creating large holiday displays outside of his house, in order to try to prove that he is clever and able.

Anthony finds it extremely difficult to open up and talk about his difficulties. As a result he does not talk to carers about his emotions and reports that he will do anything so that he doesn't feel sad. This and societal expectations about people with ID being passive, maintains Anthony's difficulties by preventing him from being able to vent his emotions in a gradual calm way, and instead results in him "exploding". His regret at having "exploded" and become verbally aggressive to people (often to carers he really likes), reinforces the idea to Anthony that he is bad or not good enough, maintaining a negative cycle.

#### Case Study Discussion:

After discussing the case studies, Sylvia and Anthony were asked a number of semi structured questions to elicit further information about their experiences of shame as a result of having ID.

First, Sylvia and Anthony were asked if they talk to other people about their feelings of shame. Both Sylvia and Anthony initially said they tended not to talk about this to others. Anthony said that he tends to hide his feelings from those around him, voicing that he locks up his feelings in a box "with a triple lock and bolt" so that no one can get to them. Sylvia stated that she had talked to one or two of her friends about her feelings of being scapegoated by her family and her difficulties in relation to processing information, but feels "a bit silly" when people are unable to understand her difficulties and voiced that "some people don't understand".

When asked if other people do things or say things that make them feel worse, Sylvia identified that she tends to feel worse when she is talking to people and they are unable to understand her: "Times when you get to talk to someone and they don't understand you, you feel a bit down". After prompting, Sylvia also revealed that she finds it especially difficult when she is around new people. Anthony was vocal about the discrimination he faces: "People do say things... It's not right if people take the mickey out of you, but that's not right. I remember last year I got bullied, and the police didn't do anything, because he was too young and they don't care. So that annoys me, and it annoys me how people treat other people with a disability and how the police and everybody just push us away to one side".

In response to being asked what she does when experiencing feelings of shame and if anything has helped her to feel better, Sylvia said that she attempted to cope by engaging in breathing exercises she learnt in her psychology sessions: "I try to think what [psychologist's name] taught me to do and take me deep breaths". Sylvia expressed that she finds engaging in this coping behaviour helpful and that her friend, who accompanied her to the interview,

also encourages her to engage in deep breathing exercises. On the other hand, Anthony expressed that he copes with feelings of shame by comfort eating and that this makes him feel better: "The chocolate always makes it better. Or jam. Always cures, cures it".

Asked if their own and other people's expectations have an effect on their feelings, Sylvia talked about her experiences at work: "sometimes, the bosses... they expect too much of you". Sylvia also spoke about how she tends to put incredible amounts of pressure on herself to be able to do things: "That's one of my downsides is I put pressure on me". Sylvia voiced that she always wants to have a go at things and does not like it when she is denied opportunities to learn: "I like to try, I'm not a person that doesn't try things, I like to try things and if it's too much then I can't do it then I'll... leave it". For example, Sylvia spoke about a time when she was denied the opportunity to work on the till in the supermarket because her colleagues assumed that she would not be capable of operating the till. Anthony spoke about his frustration when people underestimate his intelligence and abilities and subsequently deny him opportunities: "I think it's when people look at you and kind of push you away and think, oh you've got a disability, you can't do this, and you can't do that, when actually, we can. We are much more capable than you think". Despite this, Anthony acknowledged that he does, at times, require support, however, the support must be suited to his needs and abilities. He spoke about how at the swimming club he attends he receives excellent support without being belittled or underestimated.

Sylvia responded to the question: "Is there anything you would like to say to other people about what they could do to make things better?" by focussing on the understanding others have about ID. Anthony was very vocal about the mistreatment that disabled people face: "I do think that people treat us terribly... people taking the mickey out of us, nobody cares, if you tell the police, they don't care and I think it's really disgusting... We have feelings... we are human beings like everybody else and I think that we should be treated like anybody else... We're stuck in a little bubble... a bubble that can't be burst. It's wrong, and I think everybody should know that we should be treated like anybody else". Anthony's use of the term "us" indicated that Anthony identifies with other disabled people, a theme that resurfaces later on in the interview.

When asked the question: "Are you proud to be a person with a Learning Disability", Sylvia responded with a very strong and clear: "oh no". When asked to clarify why she felt this way, Sylvia expressed her frustration at being unable to do things even if she spent all day trying and voiced "I'm not proud of that but I wish I was sometimes, I was, you know... better". Conversely, Anthony expressed that he felt very proud to be someone with an ID. At the same time, Anthony expressed his dislike of the stereotypes that come with having a disability: "Yeah, and I think you should be proud of yourself, and people think that you're weird... deep down you can do stuff, and I think it's just horrible that people don't actually understand that

we can, we can do things that they can do and we're smarter than that... we're actually more intelligent than you think". Throughout the interview, Anthony also focused on the good he can do to help other disabled people, which may be a factor contributing towards his positive view of identification with the label of ID: "I'm working on a blog at the moment, and it's helping people with advice, so if they get bullied there's advice on there and everything. So that's a work in progress, to help them".

When asked if they liked spending time with people with this diagnosis, both Sylvia and Anthony expressed positive attitudes towards others with ID. When asked why she enjoyed spending time with people with ID, Sylvia responded: "I enjoy it because we're in the situation the same", signifying that she feels a sense of belonging. Anthony expressed that he likes spending time with his flatmate who also has disabilities: "I mean, with my other client, that I live with, I spend a lot of time with him. So getting to know this client, to try and learn his disability, do yeah, I do [enjoy spending time with him]". Anthony said that he enjoys drinking "cups of tea...watching movies, [and] eating popcorn" with his flatmate, but acknowledged that: "sometimes I like it sometimes I don't. I need my own space". Therefore, both participants generally seemed to think spending time with others with ID is enjoyable.

The final question asked took a form of the 'miracle question': "Based on everything we have talked about today, if you could wave a magic wand, what would you wish for?" Responses to this question differed between the participants. Sylvia expressed that if given the chance she would want to change herself, voicing "I wish... wish it didn't happen and I were a better person sometimes". Conversely, Anthony's response focused on the treatment that people with disabilities face from other people and ultimately wished that other people would treat him and others with disabilities better: "I just kind of wish for that everybody would get on with each other, treat us as the same as we can, because we have feelings...".

Overall, although there were many common themes in the responses of Sylvia and Anthony relating to their experiences of shame, such as the lack of understanding from others about their difficulties, key differences emerged. The greatest difference between the response of Sylvia and Anthony emerged when asked if they were proud to have a Learning Disability. Sylvia was clear that she did not feel proud of having an ID whilst Anthony felt that it was something to be proud of. The fact that Anthony manages to experience feelings of pride and solidarity associated with the label of ID suggests that it is also possible for others. However the fact that for some, overcoming feelings of shame is difficult highlights the need for interventions which can help to ameliorate these feelings.

## **Discussion**

The case studies presented here, along with previous research and the clinical experience of the authors highlight that shame is a prevalent issue experienced by people with IDs. Sylvia and Anthony were both subjected to stigma that they responded differently to, with Sylvia blaming herself and Anthony displaying anger.

As in Sylvia's case, stigma may have exacerbated her anxiety. People with IDs who experience mental health conditions may be subject to double stigma, including being stereotyped as being dangerous, incompetent and to blame for their difficulties (Mirnezami, Jacobsson & Edin-Liljergren, 2016; Reavley, Mackinnon, Morgan & Jorm, 2014; Watson, Corrigan, Larson & Sells, 2007). Studies have shown that perceived stigma can have detrimental effects on the wellbeing of people with mental illness, leading to decrements in self-esteem and self-efficacy (Corrigan, Watson & Barr, 2006; Link, Struening, Neese-Todd, Asmussen & Phelan, 2001; Watson, Corrigan, Larson & Sells, 2007).

As a result of such stigma and the shame it can engender, people may be more likely to conceal their difficulties (Isaksson et al., 2017) and be less likely to seek treatment or support due to embarrassment and fear of being judged (Barney, Griffiths, Jorm & Christensen, 2006; Corrigan, Druss & Perlick, 2014; Schnyder, Panczak, Groth & Schultze-Lutter, 2017; Schomerus & Angermeyer, 2008). Esdale et al. (2015) suggests people with ID are more distressed by and self-blaming in response to social criticism than equivalent individuals without an ID, as Sylvia's case study suggests. Failure to seek appropriate treatment can prolong difficulties, as it is well documented that the longer mental health problems are left untreated, the worse the outcomes are for prognosis (Boonstra et al., 2012; Dell'Osso, Glick, Baldwin & Altamura, 2013). Furthermore, even when people do seek treatment, perceived service provider stigma has been found to be a predictor of feelings of disempowerment and internalised stigma (Wang, Link, Corrigan, Davidson & Flanagan, 2018), which are significant barriers to recovery.

Anthony was able to recognise that the stigma was not his fault. There is evidence to suggest that some people are able to reject stigmatising views through group identification due to increased social support, stereotype rejection, and stigma resistance (Chen & Shu, 2012; Crabtree et al, 2016; Jahoda & Markova, 2004). However, Paterson, McKenzie and Lindsay (2012) suggests that this only protects against adverse experiences and elevates self-esteem if one views oneself as more capable than peers who also have an ID. This is consistent with evidence that favourable in-group comparisons are associated with lower levels of psychological distress and higher levels of self-esteem (Finlay & Lyons, 2000; Jahoda & Markova, 2004; Jahoda, Markova & Cattermole, 1988). This highlights the importance of social comparison in defining self-worth in this population and suggests that the label of ID is not

inherently damaging when comparisons appear favourable. However, when it is not, researchers have found that people experience a desire to be seen as non-disabled (Jahoda, Wilson, Stalker & Cairney, 2010).

### **Interventions to target shame in people with ID**

There are currently limited interventions to target shame in people with IDs. Of those interventions which do exist, the focus has tended to be on developing initiatives to reduce stigmatising attitudes towards this population through targeting the media, people who influence policy, employers, schools, families and health and social care providers (Scior & Werner, 2015). Although this is a positive move, stigmatising attitudes towards people with ID still remain prevalent within the general population (Scior, Kan, McLoughlin & Sheridan, 2010; Scior & Werner, 2015; Wilson & Scior, 2015). Therefore, it is proposed that interventions could be developed with the hope of providing a 'buffer-effect' (increasing resilience) which may reduce the impact that the experience of shame has upon individuals with ID. Factors such as recounting memories and feelings of warmth, feeling loved and cared for, and social safeness can buffer the impact of shame and could be a part of developed interventions (Matos et al. 2015). Seeking to enhance openness and responsiveness to care and support from others may also be a useful part of an intervention to increase resilience (Hermanto et al. 2016).

There are a number of interventions which may be used to reduce feelings of shame, including Cognitive Behavioural Therapy (CBT), Narrative Enhancement and Cognitive Therapy (NECT) and Acceptance and Commitment Therapy (ACT). However, many of these interventions were not specifically developed with shame in mind and require considerable adaption when used with people with an ID. Furthermore, reducing shame and self-criticism have been noted as difficult to achieve with standard CBT-informed approaches as people with high shame and self-criticism find it hard to engage with the cognitive tasks (Lee, 2005). Specific interventions aimed at reducing self-stigmatising beliefs do exist (e.g. Ending Self Stigma), and preliminary findings indicate that they could be helpful (Lucksted et al., 2011); however, evidence for such conclusions are not yet robust and the target population was people with mental illness.

One intervention has received significant attention in its treatment of shame and self-criticism is Compassion Focused Therapy (CFT). Developed by Paul Gilbert and colleagues (Gilbert, 2009, 2010; Gilbert & Irons, 2005), CFT was specifically designed to target shame and self-criticism in people who have chronic difficulties as a result of a lack of self-warmth and self-acceptance (Gilbert, Baldwin, Irons, Baccus & Clark, 2006). CFT is based on the premise that human beings have three emotional regulation systems: the drive system, the safeness system (including the affiliative/soothing system), and the threat system. The threat

system is dominant and is responsible for negativity bias (Cooper & Frearson, 2017). Throughout the therapeutic process, which includes psychoeducation, formulation and exercises such as imagery and behavioural practices, CFT aims to cultivate self-compassion and the flow of compassion in order to strengthen the affiliative/soothing system, increase feelings of social safeness, and create balance between the three systems (Gilbert, 2014).

CFT has been shown to lead to successful outcomes in people with personality disorders (Lucre & Corten, 2013), eating disorders (Webb & Forman, 2013) and psychosis (Mayhew & Gilbert, 2008), and there are arguments for utilising CFT within the ID population. For example, a large proportion of people with IDs have experienced disrupted relationships with caregivers throughout their lives (Pert et al., 2013) which may compromise the ability to be compassionate towards the self. There are also claims that CFT is less cognitively demanding than other forms of therapy such as CBT, and therefore may be more suitable for those with IDs (Ashworth, Gracey & Gilbert, 2011). To date there has only been three studies investigating the suitability and efficacy of adapted CFT within an ID population (Clapton, Williams, Griffith & Jones, 2018; Cooper & Frearson, 2017, Hardiman et al, 2018). Limited conclusions can be drawn from these studies as the evidence for suitability and efficacy was mixed, therefore more research is needed to be able to come to any conclusions regarding the efficacy of CFT in reducing shame in people with IDs. Interventions need to be developed which can appropriately equip people with IDs with tools that they can use to cope with the stigma and shame that they experience during everyday life.

## **Conclusions**

This literature review and the case studies presented provide further evidence that shame is a significant barrier to inclusion and contributes towards poor psychological health in people with ID. This suggests that shame could be a risk factor for the development of mental health problems. Although interventions for shame have been developed within the mental health population, shame processes in people with ID have often been overlooked. Research is beginning in this area, but the evidence base is currently limited to CFT. It is suggested that more research should be conducted, into both CFT and other therapeutic modalities, in order to target shame in this population.

## **Limitations**

It should be noted that case studies are in-depth analyses of a very small, purposive sample and therefore cannot be considered as generalisable. Furthermore, Sylvia and Anthony lived within the same region and accessed similar services. It is hoped that this study provides an insight into the everyday experiences of two people with ID and how feelings of shame can

shape these experiences. It is important to point out that these experiences were elicited and disclosed within a safe and non-judgmental environment, and the authors would like to emphasise the importance of these compassionate, affiliative relationships in being able to work with and heal shame.

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#### CONFLICT OF INTEREST

The authors report no competing interests.

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