

Hidden Pain?

Self-injury and people with learning disabilities

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Copies of this report are available from both addresses above. It is also available in electronic format from both websites above.

Copies of a summary of the report, and an easy-read summary are available from both addresses above. They are also available in electronic format from both websites above.

Copies of the other project resources are available from Bristol Crisis Service for Women for a small charge. These include:

- A DVD of people with learning disabilities talking about their experiences of self-injury
- A workbook for people with learning disabilities who self-injure, to help them think through and address their self-injury
- An information booklet for family members/supporters of people with learning disabilities who self-injure
- A training pack for those working with people with learning disabilities who self-injure.

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Introduction

This report presents the findings from a UK-wide three-year research project about the views of people with learning disabilities who self-injure. The research has been undertaken by Bristol Crisis Service for Women in partnership with the Norah Fry Research Centre at the University of Bristol. It has been funded by a Big Lottery Fund Research Grant.

In the first Chapter of the report, we outline what we already know about self-injury, any comparisons between self-injury in people with learning disabilities and those without learning disabilities, what those who self-injure say about the purpose and meaning of self-injury for them, and what types of approach, support or services best help them. Existing best practice guidance is also considered.

The second Chapter summarises how the current project was undertaken. This includes an explanation of the methodological approaches used, how people with learning disabilities with personal experience of self-injury and other stakeholders have been involved in advising the project, the ethical issues encountered and how they were resolved, how the research visits were structured and undertaken, the support offered to research participants during and after the research visits, and how the data has been analysed.

The third Chapter presents the main findings of the research. It starts by outlining who the research participants were and their circumstances up to the time of the research visits. The findings relating to what people with learning disabilities say about self-injury are then detailed.

Chapter Four of the report presents the findings of the research in relation to what family members and professionals say about self-injury.

The fifth and final Chapter discusses these findings, in the light of existing literature about self-injury in people with learning disabilities, policy and practice. It concludes with recommendations for policy, practice and further research in the field.

N.B. Throughout this report, the names of people and places have been anonymised in order to protect their confidentiality.

Chapter 1:

What we already know about self-injury in people with learning disabilities

There is a wealth of research conducted over the past decade about self-injury in populations with learning disabilities (see for example: Jones et al., 2004; Oliver and Petty, 2002; Emerson et al., 2001a; Murphy, 1999).and without learning disabilities (see for example: Sinclair and Green, 2005; Lovell, 2004; Hawton et al., 2003; Hawton et al., 2002; Harris, 2000). Yet 'self-injury' remains a contested term, and there is a lack of clarity about what is being investigated and how best to tackle it. In this Chapter, we provide an overview of definitions of self-injury and its prevalence; consider evidence pertaining to the causative factors of self-injury; and the evidence we have for best practice in the management of self-injury. Throughout, we consider evidence drawn from both learning disabled, and non-learning disabled populations in order to draw comparisons and contrasts between understandings and approaches for the two groups.

Defining self-injury

A number of different terms and definitions of 'self-injury' are used in research, policy and practice spheres. In the past, self-injury, or 'self-injurious behaviour' (SIB) has been most frequently used within the context of learning disability services, and the term 'self-harm' in relation to mental health (Lovell, 2007). More recently, organisations working in the field have started to view 'self-injury' as a range of behaviours within the broader spectrum of 'self-harm' (Bristol Crisis Service for Women, 2004). We all engage in self-harm to some degree or other – we eat too much, take insufficient exercise, experience high levels of stress, smoke tobacco or drink alcohol excessively knowing that such behaviours can cause considerable harm to our bodies. Indeed, these behaviours are often socially sanctioned in western cultures. Turp (2003) coined the term *cashas* (culturally acceptable self-harming activities) which include a range of behaviours with general social acceptability including body-contact sports, sleep deprivation, tattooing, body-piercing and over-work in addition to those mentioned above. Within the self-harm spectrum, however, there are a range of behaviours that are not socially sanctioned in western culture (although they sometimes are in other cultures) and that inflict direct injury to the body. These are actions that can be described as:

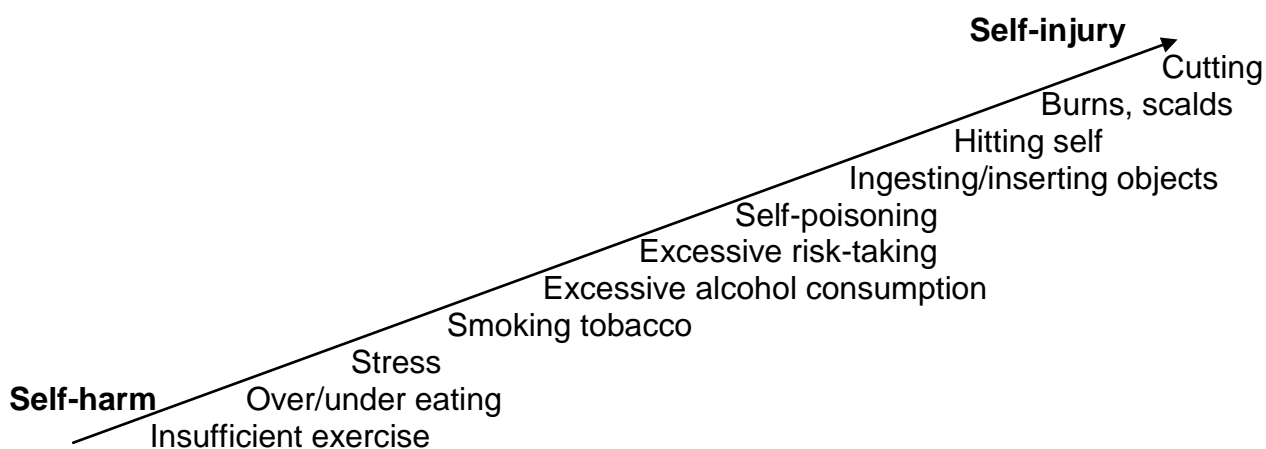
'a wide range of things that people do to themselves in a deliberate and usually hidden way, which are damaging' (Camelot Foundation/Mental Health Foundation, 2004)

These include: cutting, scratching, burning, scalding, hitting one's body with another body part, hitting one's body with or against an object, self-biting, self-pinching, hair-pulling, self-poisoning, ingesting objects, inserting objects into body orifices, and eye poking. Figure 1 illustrates the 'self-harm spectrum' and the position of some different types of behaviours within it.

This study focuses on actions that people take to cause (or intend to cause) direct injury to their bodies. Evidence suggests that these are likely to occur in people with learning disabilities (see for example, Emerson et al., 1997) and without learning disabilities (see for example, Camelot Foundation/Mental Health Foundation, 2004) and that the earlier distinction between self-injury or SIB only being understood in the context of people with learning disabilities, and self-harm as being understood in the context of people with mental health support needs, cannot be upheld. The legacy of such a distinction is that

self-injury in people with and without learning disabilities has been counted differently, attributed to different causes and managed in different ways (Jones et al., 2004).

Figure 1: The self-harm spectrum



Estimates of the number of people who self-injure

Estimates of the number of people who self-injure are generally accepted to be an underestimate as many acts of self-injury are conducted in private and do not come to the attention of health or social services. Further, many estimates in the general population use the term 'self-harm' and may or may not include specific behaviours such as self-poisoning (a predominantly female form of self-injury), excessive risk-taking (a predominantly male form of self-harm) and self-injury where there is suicidal intent. Differences also arise between community and hospital surveys, and even within samples, findings will not necessarily be compatible as the wording of questions and whether or not information is collected anonymously appear to influence responses (De Wilde & Kienhorst, 1994).

People without learning disabilities: Hospital surveys

A multi-centre study in three areas of England (Oxford, Leeds and Manchester) analysed presentations of self-injury (described as self-injury and self-poisoning) at six general hospital Accident and Emergency Departments in 2000-2001 (Hawton et al., 2007). During the 18-month study period, 7,344 individuals presented with 10,498 episodes of self-injury. The proportion of females (57%) was greater than that of males (43%), although this was more markedly so in the younger age groups and almost reached parity in people over the age of 30. There were 'comparatively few' cases (156) in people under the age of 15, most of whom (83%) were female. The highest proportion of overall self-injury was in the 20-24 age group, followed by those aged 15-19. After the age of 24 there was a steady decrease with age. However, gender differences were apparent here: the highest rate in females was in the 15-19 age group, and the highest rate for males was in the 20-24 age group. The annual rate of self-injury across the three cities was 390 per 100,000. The authors extrapolated that based on this data, general hospitals in England would be annually dealing with approximately 220,000 episodes of self-injury involving 150,000 people over the age of 15.

Hawton et al., (2003) estimated that, based on studies in Oxford, approximately 25,000 adolescents would present to hospitals in the UK each year following self-injury. However, these represent only a minority of those who self-injure. It is also suggested that only one in ten children and adolescents who self-injure present to hospital following an episode (Hawton et al., 2002).

Horrocks et al., (2003) studied self-injury attendances at two Accident and Emergency departments in Leeds over an 18-month period from 2000 – 2001. They included in the study people aged 12 years and over. During the study period, 5,066 attendances for self-injury were identified; this included 189 cases where both self-injury and self-poisoning had occurred. The proportion of men and women were the same, although men accounted for 54% of those who had self-injured and 45% of those who had self-poisoned. The age groups 20-29 and 30-34 were over-represented by 6% in those who had self-injured compared with those who had self-poisoned. The 45-49 year old age group had a 4% higher proportion of self-poisoning cases. In this study, 58% of cases were admitted to a general hospital bed and 19% admitted to a psychiatric ward, suggesting that national Hospital Episode Statistics data which reports admissions is of limited value in assessing the number of patients presenting with self-injury.

Copper et al., (2006) reported higher rates of self-injury among young South Asian women than others in a study of people presenting with self-injury to four Accident and Emergency departments in two cities in England over a four year period between 1997-2001. They found that South Asian women were more likely to harm themselves than White women at age 16-24 years, although above that age South Asian women were at lower risk. The risk of South Asian women harming themselves was considerably greater than that for South Asian men across all age groups, and the risk for South Asian men was lower than in White men across all age groups.

Gunnell et al., (2005) conducted an eight-week service audit of a stratified random sample of 31 Accident and Emergency Departments in England found 4,033 episodes of self-harm (described as self-injury and self-poisoning – episodes were excluded however if they involved punching walls or head injuries from head banging) amongst adults age 18 or over. This equates to an average of 2.3 episodes per Trust per day. The proportion of males was 45%, and of females 55%, and the median age of males and females was the same, at 33. Fewer than half of the episodes (46%) were admitted to a general hospital bed and 10% were admitted to a psychiatric ward.

People without learning disabilities: Community surveys

A study of data from the 1999 survey of the mental health of children and adolescents in Great Britain reported that, according to parents, 1 in 50 (2.1%) of 11-15 year-olds had ever tried to harm, hurt or kill themselves (Meltzer, 2001). The highest rate, 3.1 per cent, was found among 13-15 year-old girls. Among 5-10 year-olds, according to parents, approximately 1 in 100 (1.3%) had ever tried to harm, hurt or kill themselves. The lowest rate, 0.4 per cent was among 5-7 year old girls; the highest was 2.1 per cent of 8-10 year-old boys. Unfortunately, due to the way that the data was collected, no differentiation can be made between the number of children who self-injured, and the numbers of children who tried to kill themselves.

In 2000, over 8,000 adults living in private households in Great Britain were interviewed for the National Psychiatric Morbidity Survey (Meltzer et al., 2002). Analysis of this data found that between 4.6% and 6.6% of people had self-injured (Meltzer et al., 2002). Younger

people are much more likely than older people to report self-injury: nearly one in 40 reported that they had deliberately harmed themselves without wanting to die.

A survey of 41 schools in England conducted in 2001 found a higher proportion of adolescents who self-injured (defined as self-injury – behaviour intended to cause harm - or self-poisoning) than expected (Hawton et al., 2002). The study was conducted in partnership with the Samaritans, and as part of the Child and Adolescent Self-harm in Europe (CASE) Study. Self-report, anonymous questionnaires were completed by 6020 pupils aged 15 and 16. A lifetime history of self-injury was reported by 13% of the pupils, and self-injury within the previous year was reported by 7% of pupils. Self-injury within the previous year occurred more frequently in females (11%) than males (3%). In only 13% of cases had self-injury resulted in presentation at hospital.

In 2004 the Camelot Foundation and the Mental Health Foundation launched a National Inquiry into self-harm among young people (Mental Health Foundation, 2006). The Inquiry Panel met for two years and produced a report called 'Truth Hurts: Report of the National Inquiry into Self-harm among Young People. The Inquiry concluded that there is a clear and important need for much better data on the prevalence of self-harm among young people in the UK. They urged caution in drawing firm conclusions from existing data about the prevalence of self-injury, not least because of variations in research methodology. However, they concluded that taking all the available research data into account, it indicates a prevalence rate of between one in 12 and one in 15 children and young people who deliberately self-harm and around 25,000 who are admitted to hospital every year due to the severity of their injuries.

People with learning disabilities

The prevalence of self-injury in people with learning difficulties has ranged from 1.7% - 24%, but in institutional studies rates of up to 41% have been reported (Cooper et al., 2008). The differences are largely due to methodological variations between the studies, although studies conducted in institutional settings do tend to report higher rates. Many of these studies date from the 1970s and 1980s. The most recent studies (during the last decade) from the UK are outlined below.

Emerson et al., (2001a) studied children and adults with learning disabilities in two health authorities in England. All services were asked to identify people with 'challenging behaviour' and key informants completed an interview schedule that included a measure of self-injury. Across all ages, Cooper et al., (2008) calculated the overall rate of self-injury (from data presented in the paper) as being 3% of over 2000 people with learning disabilities in the population.

A higher proportion of people with learning disabilities who self-injured was reported by Deb et al., (2001). They interviewed a random sample of 101 adults with learning disabilities (aged 16-64) known to a social services department in Wales. Interviews were conducted with each person, supported by their carer. Overall, 24% were considered to self-injure, the majority of whom (67%) were female. The rate of self-injury varied with the severity of learning disability: 73% of the 11 people with severe learning disability self-injured, compared with 19% of the 42 people with moderate self-injury, and 17% of the 48 people with mild self-injury.

More recently, Lowe et al., (2007) collected data on 901 adults and children over the age of five using learning disability services in a defined area of Wales. Services were asked to identify people with 'challenging behaviour' and the primary carer of each person was

interviewed. The interview schedule included a measure of self-injury. Overall, 9% were considered to self-injure, 3% seriously.

Evidence pertaining to factors associated with self-injury

People without learning disabilities

A number of factors have been recognised as being associated with self-injury in the general population. Some of these studies, however, are over a decade old. Amongst the factors identified are:

- Previous self-injury: As many as a third of adolescents who self-injure report previous episodes, many of which have not come to medical attention (Hawton & James, 2005; Hawton et al., 2003). Fortune and Hawton (2007) found that a history of past self-injury is one of the 'most powerful and clinically relevant' predictors of eventual suicide and future self-injury.
- There are strong links between suicide and previous self-injury: in adolescents, the risk of suicide after self-injury varies from 0.24% to 4.4%. Between a quarter and a half of young people completing suicide have previously carried out a non-fatal act (Hawton & James, 2005). Cooper et al., (2004) found the rate of suicide in their self-injury cohort studied over four years to be 34 times higher than expected: it was 50 times greater for females and 29 times higher for males. Zahl and Hawton (2004) reported long-term suicide risk increased with multiple repeat episodes of self-injury in females, and Hawton et al., (2003b) found the risk of suicide increased markedly with age at the time of the initial self-injury episode.
- Life events - there is a strong relationship between the likelihood of self-injury and the number and type of adverse events that a person reports having experienced during the course of his/her life. These include having suffered victimisation and, in particular, physical and sexual abuse (Hawton et al., 2002; Meltzer et al., 2002; Babiker and Arnold, 1997; Arnold 1995); violence (Hawton & James, 2003); and domestic violence (Kershaw et al., 2000; Babiker and Arnold, 1997).
- Life problems: most people who self-injure have multiple life problems. Key amongst these are relationship problems with a partner or family member (Haw and Hawton, 2008; Hawton and Harriss, 2007; Milnes, 2002). Other problems reported include: problems with employment (including unemployment) or studies, and financial problems.
- Socio-economic factors – self-injury is more common among people who are disadvantaged in socio-economic terms and among those who are single, live alone, are single parents or have a severe lack of social support (Meltzer et al., 2002). O'Loughlin and Sherwood (2005) reported a high rate of self-injury in separated people. Meltzer (2001) reported self-injury was greater among young children from Social Class V families and among children of all ages from families who were social sector tenants. In adults, Hawton et al., (2001) reported socio-economic deprivation to be associated with self-injury rates in both males and females.
- Physical illness – for many people physical illness is a factor that precipitates self-harm (De Leo et al., 1999).
- Mental illness - in a survey of a sample of the British population, people with current symptoms of a mental disorder were up to 20 times more likely to report having harmed themselves in the past (Meltzer et al., 2002). The association was particularly strong for those diagnosed as having phobic and psychotic disorders. House et al., (1999) identify a psychiatric history, especially as an inpatient, as being associated with self-injury. Aglan et al., (2008) identified chronic major depression as a key risk factor independently associated with self-poisoning.
- Alcohol and drug use. Haw et al., (2001) reported that about one-quarter of those who self-injure have a diagnosis of harmful use of alcohol. Hawton et al., (2007) found that in

over half of all cases of self-injury the person had consumed alcohol either as part of the event or during the six hours beforehand. Hawton and Harriss (2008) however, found this not to be the case for under 5 year olds. People who self-injure have also been found to be more likely to be misusing drugs (Hawton et al., 2003; Taylor et al., 1999).

- Higher rates of self-injury have been reported in young Asian women (Bhui, 2007; Cooper et al., 2006). Chantler et al., (2003) reported a number of factors contributing to this. These included: sexual and physical abuse, domestic violence, immigration issues, forced marriages, racism and issues of loss. Poverty and homelessness also generated stress. Neeleman et al., (2001) suggested that a more complex picture arises, and that the rate of self-injury in minority ethnic groups relative to the white populations of the area in which they live varies, suggesting protection in some areas and higher risk in others. They hypothesised that rates in minority ethnic groups would be higher in areas where minority groups are smaller.
- There is a suggestion of higher rates of self-injury in gay men, lesbians and bisexuals (King & McKeown, 2003). This is thought likely to be linked to the higher rates of bullying and victimisation experienced by these groups.
- Goth subculture: current Goth identification was associated with a 53% likelihood of self-injury (Young et al., 2006).
- Older people are less likely to self-injure but those who do have high rates of physical ill health, social isolation and depression (Draper, 1996; Merrill & Owens, 1990; Pierce, 1977)
- The rate of self-injury among prisoners is higher than the rate reported in the general population (Ireland, 2000)
- Higher rates of self-injury in young people are often manifestations of distress associated with problems such as substance misuse, poor school attendance, low academic achievement and unprotected sex (King et al., 2001; Kerfoot, 1998). Other issues relevant for young people include bullying, being in trouble with the police, recent self-injury by friends or family members, worries about sexual orientation, and high levels of depression, anxiety, and impulsivity and poor self-esteem (Hawton et al., 2002).

People with learning disabilities

Within the population of people with learning difficulties, a much narrower range of factors associated with self-injury has been identified. These include:

- Genetically-determined syndromes: Self-injury has been regarded as a core feature of Cri du Chat syndrome (Collins and Cornish, 2002); to have a higher prevalence in people with Cornelia de Lange syndrome than other people with severe learning disabilities generally (Hyman et al., (2002); and to be associated with Lesch-Nyhan Syndrome, Rett Syndrome, Smith-Magenis Syndrome and others (Oliver and Petty, 2002; Mikhail and King, 2001; Deb, 1998). It is possible that self-injury is not syndrome-specific but related to underlying brain abnormality or damage (Deb, 1998).
- Disrupted neurotransmitter pathways: it has been suggested that the levels of certain neurotransmitters are associated with self-injury, relating to pain (Wisley et al., 2002; Symons and Thompson, 1997), impulsivity (Zlotnick et al., 1999) and addiction (Sandman and Touchette, 2002).
- Severity of learning disability: an association between self-injury and increasing severity of learning disability has been reported (Cooper et al., 2008; McClintock et al., 2003; Deb et al., 2001; Emerson et al., 1997).
- Developmental delay: it has been suggested that stereotyped behaviour, potentially a precursor of self-injury (Richman, 2008), may appear later in developmentally delayed children. This would allow the behaviours to be perpetuated and social reinforcement to take place (Symons et al., 2005).

- Autism: the degree of autism is a risk marker for self-injury – those with more severe autism and associated difficulties were more likely to show more self-injury. The pattern of higher risk included lower age and higher daily living skills delay (Baghdadli et al., 2003; McClintock et al., 2003). This was not found to be the case by Cooper et al., 2008.
- No speech: the occurrence of self-injury was highest in people with no speech (Baghdadli et al., 2008; McClintock et al., 2003; Deb et al., 2001). This was not found to be the case by Cooper et al., 2008.
- Pain: congenital insensitivity to pain (Zafeiriou et al., 2004) or the presence of physical pain (Moss et al., (2005). Breau et al., (2003) suggest that children with chronic pain may exhibit self-injury differently from children without pain.
- Central nervous system disturbances: people who self-injure are more likely to have central nervous system malfunction (Nottestad and Linaker, 2001)
- The existence of previous self-injury: a seven-year follow-up of people with learning disabilities and severe self-injury reported high persistence rates for self-injury. The presence of head banging at the earlier time period was the strongest predictor of self-injury at the later date (Emerson et al., 2001b).
- Environmental setting: some forms of self-injury were associated with environmental events in individuals with Cornelia de Lange syndrome, but the characteristics of the settings are variable across individuals (Moss et al., 2005). Impoverished environments that lack stimulation and where there are poor relationships are also considered to be associated with self-injury (Emerson and Bromley, 1995).
- Oppression: the higher incidence of the use of self-injury by people with learning disabilities is thought to be reflective of the severity and nature of oppression they experience (Jones et al., 2004; Northway, 1998)
- Coping with a difficult set of life circumstances: self-injury could be regarded as a rational response to difficult, sometimes impossible, circumstances (Lovell, 2007) or abusive, neglecting or traumatic environments or events (Halliday and Mackrell, 1998). Self-injury was also regarded as a coping strategy in a study of women with learning disabilities in a secure unit (James and Warner, 2005).

The functions of self-injury

Linehan (1993) suggests possible functions of self-injury in her work about the development of borderline personality disorder. She argues that when emotional vulnerability and invalidating environments interact self-injury may function to regulate painful emotions that cannot be tolerated.

Other research has also conceptualised self-injury as an emotion-regulation strategy. Gratz (2003) reviewed literature about self-injury and concluded that clinical and empirical data suggest that self-injury may operate as a form of emotional avoidance, functioning to escape, avoid or alter unwanted emotions. Klonsky (2007) reviewed 18 studies that directly addressed the functions (i.e. motivating and reinforcing variables) of self-injury for individuals. He found that affect-regulation was mentioned in all 18 studies. People who self-injured commonly spoke about their self-injury stopping 'bad feelings', relieving feelings of anxiety or terror, and reducing anxiety and despair. Several studies also provided strong evidence for a self-punishment function. Other functions that received moderate support included:

- To end the experience of depersonalisation or dissociation
- To seek help from or manipulate others
- To generate exhilaration or excitement
- To replace, compromise with or avoid the impulse to commit suicide
- To assert one's autonomy or a distinction between self and other.

Tantum and Huband (2009) suggest a number of additional functions of self-injury. These include:

- Subconscious means of resolving conflict over sexuality
- Redirected social aggression
- Control of others
- Communication and expression
- Repair of faulty boundaries.

The authors, however, suggest that self-injury may serve several different functions for some individuals. In others, the meaning of self-injury may be undetermined; it may be extremely important for the person concerned, but it may completely lack any easily-defined purpose or meaning.

The persistence of self-injury

It has already been mentioned that a history of past self-injury is one of the 'most powerful and clinically relevant' predictors of eventual suicide and future self-injury in people without learning disabilities (Fortune and Hawton, 2007).

The persistence of self-injury in people with learning disabilities is unclear and there is considerable discrepancy between studies – ranging from 4% - 96% (Cooper et al., 2008). It has been shown to be associated with younger age, higher stability of self-injury over the previous six-months, and self-injury to the head (Emerson et al., 2001b). Totsika et al., (2008) identified that over an 11-year period people with learning disabilities who persistently self-injured were of a younger age and had lower sociability scores than those who never self-injured. Baghdadli et al., (2008) suggested that persistent or recurrent self-injury over a three-year period was associated with having greater speech impairment and more severe signs of autism in children with pervasive developmental disorders. A number of these factors, however, are likely to overlap and require further investigation (Cooper et al., 2008).

Treatment approaches for self-injury

People without learning disabilities

Respondents in Arnold's (1995) survey were highly dissatisfied with many of their experiences of services. The major reasons for their dissatisfaction were; negative attitudes and misunderstandings displayed by many staff, professionals' failure to recognise and address women's distress and its causes, the inadequate, inappropriate and oppressive nature of services and a failure to provide adequate support, particularly at time of crisis. The most helpful services were considered to be those offering: acceptance, respect, caring and listening; time and willingness to explore the issues underlying a woman's self-injury; help to find alternative ways of coping with distress; and support from professionals and/or peers, particularly at times of crisis. Women highlighted the need for treatment approaches that included self-help literature, counselling and therapy, support groups, crisis support and practical help.

A systematic review of the worldwide literature regarding treatment studies of patients who self-injure was conducted by Hawton et al., 1998. All randomised controlled trials evaluating psychosocial or physical treatments were identified and included in the review if the following criteria were met: existence of self-injury shortly before entering the trial; repetition of self-injury was reported as an outcome measure; and study participants had to have been randomised to treatment and control groups. A meta-analysis was conducted

to identify the most effective interventions, but the authors concluded that there was considerable uncertainty about which forms of psychosocial and physical treatments for people who self-injure were most effective. Promising results were found for problem-solving therapy, and the provision of a card to allow patients to make emergency contact with services. Depot flupenthixol and psychological therapy were both found to be promising for some patients with recurrent self-injury.

The National Institute for Clinical Excellence (NICE) produced guidelines in 2004 for the short-term physical and psychological management of self-harm in primary and secondary care (NICE, 2004). They reviewed the most robust, up-to-date evidence and concluded that the evidence base for the treatments of self-harm is extremely limited. The main recommendations of the NICE guidelines include a number of components of good practice: treating patients with care, respect and privacy; providing appropriate training to frontline staff; and offering a psychosocial assessment to all patients. Other recommendations include assessment by a mental health specialist, and the use of psychological therapy (dialectical behaviour therapy) for some patients with multiple episodes of self-harm.

In 2005 the Royal College of Psychiatrists launched a national quality improvement programme to drive up standards in the assessment and care of people who self-injure. The quality standards produced (Royal College of Psychiatrists' Centre for Quality Improvement, 2006) were intended to help services to audit and improve their performance. The work built on that of NICE (2004) and included recommendations from other sources. It was intended to be a source of reference for those working in emergency settings (such as ambulance, emergency department and mental health professionals) who come into contact with people who self-injure. Some standards are applicable to all staff regardless of their profession, such as *'People who have self-harmed should be offered the same quality of care and range of treatments as any other patient...'* (p. 7) and that *'Staff should not behave in a punitive, threatening, dismissive or judgmental manner towards people who self-harm'* (p.7). Other standards describe best practice along a common care pathway, such as *'Assessment should be conducted in a respectful and supportive manner, with the individual's views taken into account throughout'* (p. 11), and *'A specialist mental health professional should assess the needs of the person who has self-harmed'* by evaluating the *social, psychological and motivational factors specific to the act of self-harm* (p. 13).

Despite the Guidelines, Kapur (2005) concluded that attitudes among those responsible for providing services need to change in order to ensure appropriate management of people who self-injure. He reported work by James (2004) that suggests *'there is still a body of opinion that views those who self-harm as immature individuals who divert resources from those with 'serious' physical or psychiatric illness'* (Kapur, 2005, p.498).

This is borne out by Mackay and Barrowclough (2005). They studied the responses of Accident and Emergency staff to people who had self-injured, and suggested that where self-injury was perceived by staff to be caused by a factor that was controllable by the person concerned, staff were more likely to express higher levels of irritation and less helping behaviour. The same study found that belief that the self-injury was likely to be repeated was associated with less staff optimism and a reduction in helping behaviour. Palmer et al., (2007) also found that staff attitudes were the single most important factor affecting the experience of service users who had self-injured. If treated with respect, support and understanding service users said they generally felt better able to cope on leaving hospital. However if they felt judged, criticised or discriminated against by staff it

was likely to exacerbate the feelings that had led them to self-injure in the first place, and may even result in immediate further self-injury.

Thompson et al., (2008) explored community psychiatric nurses experiences of working with people who self-injure. The nurses reported finding working with people who self-injure stressful, and they described a variety of negative emotional reactions, including frustration, hopelessness, anger, distress, shock and disgust.

Bennewith et al., (2004) investigated the variation in services and delivery of care in hospitals in England for patients who had self-injured. They found 'striking' variability in organisation and provision of services and a wide variation in the implementation of recommended service structures. There was a four-fold variation in the proportion of attendances leading to admission, and a two-fold variation across hospitals in levels of psychosocial assessment. People attending hospital after self-laceration were least likely to have a psychosocial assessment, while those who self-injured in ways other than self-laceration or overdose were the most likely to receive an assessment (Gunnell et al., 2004).

Although the overall evidence base is limited, Jones et al., (2004) identify six main treatment approaches for self-injury, which differ in their emphasis on medical, social or behavioural understandings of self-injury:

- The medical treatment of the resultant injuries
- An immediate response to reduce factors which might aggravate self-injury e.g. isolation of the person, the removal of objects from the person's environment, activation of a crisis strategy
- A behavioural response e.g. mechanical restraint, withdrawal of pleasurable activities, differential reinforcement of other behaviour
- Pharmacological interventions e.g. the use of sedative or antipsychotic medications
- Psychological interventions e.g. counselling, psychotherapeutic approaches. An overall approach that values the individual but not the behaviour e.g. support with the development of alternative coping skills, self-confidence and self-esteem, and developing social networks.

People with learning disabilities

Most of the research about the effectiveness of treatment interventions in people with learning disabilities who self-injure consists of anecdotal reports, case studies, and studies with a small number of participants (Khang et al., 2002). Historically, treatment approaches have tended to be based on behavioural or pharmacological interventions (Oliver and Petty, 2002; Wisely et al., 2002; Ashraf et al., 2001; Mikhail and King, 2001). More recently, newer and more alternative interventions such as 'positive behaviour support' and 'gentle teaching' have been introduced (Gates, 2000).

Behaviour management strategies include the use of contingent and non-contingent reinforcers of behaviour. Reports of behavioural approaches to 'problem' behaviour began to appear in the research literature around 1960 and the use of behaviour modification techniques followed a few years later (Halliday and Mackrell, 1998). The treatment of choice came to involve the application of aversive stimuli or events contingent upon the behaviour – i.e. 'punishment'. Punishment was found to be effective in the short-term, but limitations with the techniques and ethical concerns led to efforts to develop non-aversive approaches. The increased use of functional assessments that investigate the function of the behaviour for the individual promoted interventions that focus on teaching the person

to communicate needs and desires in a more socially acceptable way, so replacing 'challenging behaviour' with communication (Halliday and Mackrell, 1998). Oliver and Petty (2002) identify a number of studies that demonstrate the success of this strategy although Kahng et al., (2002), in their analysis of behavioural treatments over a 36-year period for people with severe or profound learning difficulties who self-injure conclude *'it is discouraging to find that self-injurious behaviour continues to be a disorder that is very difficult to treat'* p. 220.

More recently Positive Behavioural Support (PBS) techniques that are based on person-centered values and systems change have become more commonplace. PBS aims to increase quality of life and decrease problem behaviours. The first step of an individual PBS plan, and the corner-stone of the approach, is Functional Behavioural Assessment. This seeks to describe the behavior, and the environmental factors and setting events that predict it, in order to guide the development of effective support plans. Some of the most commonly used approaches in PBS are:

- modifying the environment, antecedents to behaviour, or routine
- providing positive reinforcement for an appropriate behaviour
- changing expectations and demands placed upon the person
- changing how people around the person react.

A multiplicity of pharmacological treatments are employed in the treatment of self-injury in people with learning disabilities. Zarcone et al., (2001) described a positive effect half of their research participants from using risperidone. Risperidone was also considered optimistically for use in treating behavioural disturbances in Prader-Willi syndrome (Durst et al., 2000). Other atypical antipsychotics have been considered to be ineffective in reducing self-injury (Ruedrich et al., 2007), although there is some optimism with clozapine (Hammock et al., 2001). Older type antipsychotics have been used with some success, but their use is controversial (Janowsky et al., 2005). The antidepressant medication sertraline has been shown to decrease self-injury (Luiselli et al., 2002), as has olanzapine (McDonough et al., 2000). The opioid antagonist naltrexone hydrochloride has also been shown to play a part in reducing self-injury (Symons et al., 2001).

Psychological interventions have developed over the past 30 years or so. A psychological understanding of self-injury frames it in terms of the individual trying to manage cognitively and emotionally their anger and distress arising from disability and trauma (Halliday and Mackrell, 1998). Self-injury is the person's best attempt to deal with their distress arising from an environment that is 'regarded as frightening, meaningless or traumatic' (Jones et al., 1995). Psychological interventions therefore need to address environmental, interpersonal and intrapersonal factors, and an individual's ability to respond to individual therapy, whatever their level of cognitive functioning, should not be under-estimated (Halliday and Mackrell, 1998). Nevertheless, people with learning disabilities experience a comparative lack of access to psychological therapies (Hollins and Sinason, 2000).

Physical interventions or restraint procedures are sometimes used in order to prevent people from harming themselves and a number of versions have been developed, including Control and Restraint, and Non-Aversive Psychological and Physical Interventions (NAPPI). Concerns about the lack of a national framework for such physical interventions resulted in the British Institute of Learning Disabilities and the National Autistic Society drawing up a policy framework for the use of physical interventions in people with learning disabilities (Harris, 1996). Murphy et al., (2001), in a review of this policy framework, contend that there is a long way to go in improving practice in the use of

physical interventions, which should only be used as part of a planned programme of positive behaviour support.

A number of other strategies are also used in the management of self-injury in people with learning disabilities. Richman (2008) suggests that children can benefit from intensive early intervention and prevention strategies which involve encouraging appropriate use of play materials, reducing distracting external stimulation, and promoting and reinforcing appropriate forms of communication.

Phillips (2004) reviewed the effectiveness of risk management systems in an acute forensic admissions ward for people with learning disabilities. She found that existing measures such as restricting the access of potential self-injuring objects and the use of special nursing observations were not effective in either the prevention or general management of self-injury. Phillips suggests that an alternative approach to managing persistent self-injury might be to allow the patient to self-injure in the presence of a nurse, who can ensure that implements are clean, and which would result in self-injury being safer and more controlled, reduced levels of aggression from the patient and more therapeutic interactions with the staff. Failing this, a fine balance may need to be struck where staff do not advocate the use of self-injury, or become indifferent to it, but neither do they apply significant pressure on the individual not to engage in such behaviour (Gough, 2005).

The views of people themselves about their self-injury

People without learning disabilities

There is an increasing literature about the personal perspectives of people without learning disabilities who self-injure, and their own views of their motives for self-injuring.

Arnold's (1995) study found that women had considerable insight into their reasons for hurting themselves and such insight was rarely tapped by those seeking to understand or help people who self-injured. Respondents considered that neglect, emotional abuse, physical abuse, loss or separation and parental illness were all important factors underlying their self-injury. Her findings indicated that successful approaches to helping someone overcome self-injury need to fully examine the purposes served for an individual, and the alternatives that may need to be in place, before they can leave their self-injury behind.

Harris (2000) undertook a correspondence study with six women who regularly self-injured. Many of the women stated that they self-injured in order to exercise control. They also claimed that medical and nursing professionals viewed their self-injury as irrational and illogical, but Harris suggests that the women's self-injury possessed an internal logic to the women that the professionals failed to understand. Harris concluded that there are real connections between the oppressive nature of modern society, the oppression of women, and their self-oppression. To a woman oppressed by society, self-injury is something a person can control – perhaps the only thing she can control. The behaviour is therefore understandable, given the circumstances it produced.

The issue of control was also picked up by Sinclair and Green (2005) who interviewed 20 men and women with a history of self-injury but who no longer hurt themselves. The men and women spoke about their experiences of self-injury in terms of lack of control over their lives, including through alcohol dependence, untreated depression or, in adolescents, uncertainty within their family relationships. Key to the recalled needs of the participants

was someone outside the family who had space and time 'just to talk' and listen to their story.

In many studies the views of women predominate, but Taylor (2003) obtained the personal perspectives of five men who self-injured. He found that their self-injury was linked to low self-esteem and that it functioned firstly as a coping mechanism in order to manage their own feelings, experiences and life, and secondly in order to communicate what could not be verbalised. Taylor concluded that there was a need for staff to listen to men who self-injure and to increase their understanding by learning from individual service users about the issue.

Rodham et al., (2004) analysed the self-report questionnaires of 398 pupils aged 15 and 16 who had self-injured in the past year. The most frequently given reason for their self-injury was that they wanted to get relief from a 'terrible state of mind'. This was reported by 73% of the adolescents. Two thirds (67%) of those who had self-poisoned reported that they wanted to die, compared with 40% of those who had self-injured in other ways. Other motives, reported by over a third of all respondents were that they wanted to punish themselves, and they wanted to show how desperate they were feeling.

Other, slightly older personal accounts of people without learning disabilities describe self-injury as a way of coping with overwhelming distress, a means of taking control, a way of communicating distress to oneself or others, an expression of anger, a release of tension, a distraction from emotional pain onto something which feels more manageable, or a means of survival (Babiker and Arnold, 1997; Pembroke, 1994).

People with learning disabilities

The literature about the personal perspectives of people with learning disabilities is extremely small.

The subjective experiences of self-injury from the perspective of a woman with mild learning disabilities were explored by Harker-Longton and Fish (2002). For the woman concerned 'Catherine', self-injury appeared to be an important coping strategy. She obtained relief from self-injury which she used when she was upset, spoke about the need to punish herself, and described the need for people to see that she had injured herself as a form of communicating her distress. Her feelings of failure and that she was not being trusted within the medium secure service in which she lived increased her negative thoughts, as did the use of negative labels and terminology. Catherine repeatedly commented that she would not be stopped from self-injuring. Catherine had strong views on the service delivery that she received, perceiving some interventions as a form of punishment; she was clear that the improvements that she would like included respect, understanding and acceptance.

James and Warner (2005) obtained the perspectives of a small number of women with learning disabilities who self-injured and were living in a medium secure unit. Their accounts emphasised that self-injury was meaningful to the women concerned and that it formed one strategy for coping with the complex needs they had. The women were variously coping with past traumatic experiences, current relationships and issues around privation and security, as well as internalised anxiety, hurt and guilt. The study also suggested that some aspects of interventions, such as exerting control, may actually increase the likelihood of self-injury.

The perspectives of nine men and women with learning disabilities also living in a medium secure unit were reported by Duperouzel and Fish (2008). The participants described the need to talk about their self-injury, but said that the staff were reluctant to do so and avoided having such discussions with them. They saw self-injuring as their choice and as a right, and it was futile of the staff trying to prevent them from self-injuring. The participants felt punished, judged and misunderstood, and perceived there to be a lack of trust and understanding towards them.

The research question

Knowledge about what people with learning difficulties say about their self-injury and the functions it has for them is vital. Without it, responses to self-injury will continue to be based on past patterns of provision or on assumptions about what might be best for this group of people. How people with learning difficulties and their supporters make sense of the person's self-injury may offer alternative perspectives for service providers to consider, and suggest more appropriately tailored interventions to support those involved. This research study therefore attempted to address the following aims:

- To find out more about the experiences of people with learning disabilities who self-injure, and their carers/supporters
- To explore in what ways they have been supported by the services and professionals with whom they are involved
- To identify ideas, and then produce resources, for training and policy development.

Chapter 2

How the research was undertaken

Background

The research project arose from a number of concerns. First, the researchers' work at the Norah Fry Research Centre, and as individuals involved in supporting people with learning disabilities, indicated to us that services and supports for people with learning disabilities who self-injured were inconsistent at best, and punitive at worst. Secondly, Bristol Crisis Service for Women had been experiencing a demand for training, particularly for front-line workers who were supporting people with learning disabilities who self-injured. Third, our awareness had been heightened in an article by Victoria Jones, who explored the differences in approach towards people with and without learning disabilities in response to self-injury. Traditionally, Jones argued, self-injury in people with learning disabilities was understood within a biological framework and primarily linked to genetically-determined syndromes. It was regarded as 'maladaptive' or 'challenging behaviour', and often managed by behavioural responses including aversive techniques, and medication. In contrast, research considering the views of people without learning disabilities suggested that for them self-injury had a clear function and was largely used as a coping strategy for dealing with intense emotional distress. For them, the use of counselling or therapies was advocated, to enhance self-esteem and develop a broad repertoire of coping skills. Finally, we were unable to locate any published work carried out with people with learning disabilities that explored their feelings about, and experiences of, self-injury, whereas there was some research evidence of this for people without learning disabilities.

A series of meetings was held between Bristol Crisis Service for Women, a voluntary sector organisation experienced in supporting women in emotional crisis, including those using self-injury, and the Norah Fry Research Centre at the University of Bristol, a research centre with particular expertise in undertaking applied research about services and supports for people with learning disabilities. At these meetings, and with additional input from people with learning disabilities and other stakeholders, ideas were formed into a research proposal investigating the perspectives of people with learning disabilities about their own self-injury. A successful application for funding was lodged with the Big Lottery Research Fund, and the research commenced at the beginning of October 2007.

The aims of the research were:

- To find out more about the experiences of people with learning disabilities who self-injure, and their carers/supporters
- To explore in what ways they have been supported by the services and professionals with whom they are involved
- To identify ideas, and then produce resources, for training and policy development

Setting up the project

Considerable thought was given to setting up the project so that it was conducted in as safe and supportive a manner as possible for all concerned. This included obtaining NHS national research ethics approval and the approval of the (then) Directors of Social Services. Policies and procedures were drawn up regarding: the role of the research advisory group and the advisors with learning disabilities and personal experience of self-injury, arrangements for local site Research and Development (R&D) approval, accessing potential participants, assessing capacity to consent to take part in the research, particular

issues for the consent of 14-16 year olds and the consent process for these young people, the conduct and content of research interviews, the provision of information and post-interview support to research participants, fieldwork safety for researchers, supervision for researchers, and a robust complaints policy. Topic guides were piloted with people with learning disabilities who self-injured, family carers and professionals, adjustments made and then approved by the research ethics committee.

Identifying potential research participants

To avoid potentially irresolvable problems concerning definitions of 'learning difficulties' we included in the research people who used, or who were eligible to use learning disability services. This included people diagnosed as being on the autistic spectrum, as long as they also met the criteria for using learning disability services. There was considerable debate about the terminology that was used: the advisors with learning disabilities and personal experience of self-injury were anxious that we adopted the terminology 'learning difficulties', preferring this to what they considered to be the more stigmatising term 'learning disability'. However, the population we were covering was those people with a lifelong impairment, who found it significantly more difficult to learn, understand and communicate with others which, as a result, had a significant effect on many areas of their day-to-day lives. In the UK, these people would more usually be considered to have a learning disability, which is the terminology that we have adopted in this report.

The age of the participants was 14 years and over. Evidence from studies of people without learning disabilities suggested that the majority of self-injury occurred in adolescence and young adulthood (National Institute of Clinical Excellence, 2004), and the current research needed to be able to take this into account. No assumptions were made about an upper age limit for self-injury.

The definition of self-injury used was that given in the National Inquiry into Self-harm Amongst Young People (Camelot Foundation/Mental Health Foundation, 2004):

'a wide range of things that people do to themselves in a deliberate and usually hidden way, which are damaging. Within this, the particular focus is...cutting behaviours; other forms of self-harm e.g. burning, banging, hair-pulling; self-poisoning'.

We also recognised the specific typographies of self-injuring behaviour commonly presenting in people with learning difficulties (Emerson et al., 1997). These included: hitting one's body with another body part, hitting one's body with or against an object, biting self, self-scratching, self-pinching, ingesting objects, inserting objects into body orifices, and eye poking. Again, there was considerable debate about terminology, and whether the term self-injury or self-harm should be used. For the most part, these terms were used interchangeably, although some learning disability services did use the terms self-injurious behaviour (SIB) or 'challenging behaviour' and differentiated it from the term 'self-harm' which they used when referring to people without learning disabilities. Some also referred to the term 'self-harm' when referring to behaviour such as taking an overdose, eating disorders or risky behaviour that may not cause direct injury to one's body. To resolve this difficulty, we provided a clear description (as above) of the behaviour that we sought to include in the research, irrespective of whether it was called 'self-injury', 'self-harm' or indeed, any other name. In the event, as will be discussed later, participants engaged in a range of behaviours, often straddling those of the perceived self-harm/self-injury divide.

The recruitment of research participants

People with learning disabilities

People with learning disabilities who self-injured were recruited to the research project via multiple means. First, the project was advertised through both the Norah Fry Research Centre and Bristol Crisis Service for Women's extensive networks: the former of people with learning disabilities and their organisations, and the latter of organisations and groups focusing on supporting people who self-injure. Secondly, the research project was widely advertised via learning disability and mental health media, and carers and professionals' newsletters and journals, and people invited to take part through this route. Third, services likely to support people with learning disabilities who self-injure were contacted directly to inform them about the research and ask them to support any service users interested in taking part in the research to contact the researchers directly.

The recruitment material specified the criteria for inclusion in the study as being that the person:

- Used, had used, or was eligible to use learning disability services
- Was aged 14 years or over
- Self-injured (and a clear definition as above was given).
- That the person was able to relate their experiences directly to the researcher using their usual means of communication. The key issue here was the understanding of the person concerned, rather than their communication per se. As long as the person understood what the research study was about and consented to take part in it, the researchers adopted a suitable means of communication particular to the individual concerned. This involved, for some participants, using non-verbal communication including Makaton or other signing systems, pictures, symbols, gestures and eye pointing. The minimum requirement was that the person was able to indicate 'yes' and 'no' and to show the researcher if they wanted to stop the interview. Providing the person was able to do this, nobody was excluded from the research on the basis of communication alone. They were excluded from the research, however, if it was believed that they were unable to understand the purpose of the research.
- A note was also given that although the research was being conducted, in part, by Bristol Crisis Service for Women, the research was about the views and experiences of both men and women.

Once an expression of interest had been received by the research team, the researchers arranged a preliminary visit to the person concerned at a time and place of their choosing. This was either arranged directly with the potential research participant, or with a third party on their behalf, such as a key worker or family member. The purpose of the preliminary visit was:

- to explain in full about the research project to the potential participant, including providing a summary of the research questions to be asked, answering any questions the potential participant had and ensuring their understanding;
- to get to know the person concerned, including their usual means of communication and general background information about the person;
- to find out what their preferences were regarding the time, place and conduct of the interviews, including if they wanted anyone else present to support them, and a demonstration of the digital recorder so that they could provide informed consent as to its use;

- to find out likely stress triggers for the person concerned and their current ways of managing stress and distress, so that some of these strategies could be adopted at the end of each interview if necessary
- if appropriate, to check that the persons Healthcare Trust or PCT had given the correct permissions for the research to take place in that area
- if appropriate, to obtain written consent from the person concerned to take part in the research. If this was the case, the research team also obtained the contact details of the persons GP to inform them about the study, and found out from the person concerned whether they consented for the research team to contact a family member and/or professional involved in supporting them to determine whether they would also be interested in being interviewed as part of the research project. Confidentiality between any linked research participants was assured, and it was stressed that no information about what was said in the research interviews would be shared with anyone else. The consent process also involved obtaining the name and contact details of a responsible adult that the person with learning disabilities felt that they trusted. This was the person who would be contacted if the interviewee disclosed during the interview that they had experienced undisclosed previous abuse, or were currently experiencing abuse, suicidal thoughts, or had an intention to harm anyone else.

For most research participants, one preliminary visit was sufficient. For some participants, more than one visit was made to ensure full understanding and informed consent by the person concerned. Further, if there was a time delay between the preliminary visit and the start of the interviews (e.g. because local R&D approval needed to be obtained before starting the interviews, or the person wanted to delay the start of the interviews for any reason) the preliminary visit was repeated to ensure that the potential participant remembered what the research project was about and what it would involve, and still consented to take part. The maximum number of preliminary visits was three visits made to one participant.

Family members and professionals

Most family members and professionals who took part in the research were linked to a person with learning disabilities who was the key respondent. With consent from the person with learning disabilities, most of these family members and professionals were approached by letter, with information about the research study and a reply slip for them to return to the research team informing them if they were interested in being interviewed. Once a reply slip had been obtained, the research team contacted the family member or professional to arrange a single interview at a time and place of the interviewee's convenience. At the start of the interview, the research project was explained in full, and written consent to take part in the research study was obtained.

In addition to the linked interviews outlined above, a number of additional unlinked interviews were conducted with key informants. These included family members and/or carers of people with severe learning disabilities who were unable to consent to take part in the research themselves, professionals supporting groups of people with learning disabilities who self-injured rather than individuals (such as college tutors, support group facilitators), and family members and professionals who were particularly interested in the research project and felt that they had particular views to contribute. The process for obtaining consent and conducting a single interview was the same as for linked family members and professionals.

The research interviews

Semi-structured qualitative interviews (following a topic guide) were carried out with all research participants. Throughout, the approach was flexible with people with learning disabilities, and adapted to take account of their individual differences. Questions from the topic guide were therefore open-ended and designed to provide space for the respondents in which they could share their views and experiences. More focused questions were only asked with sensitivity, and if appropriate to encourage elaboration of a subject already raised by the participant. Most of the interviews were recorded using a digital recorder. Where consent was not given for this, or it was not possible due to environmental restrictions, notes were written during and after each interview.

The focus of the interviews was:

- to obtain narrative accounts of people's experiences of self-injury, including the circumstances and feelings leading up to, and after, self-injury, and the meaning and function of self-injury for that person
- to explore any difficulties that people with learning disabilities, and/or their supporters had experienced in obtaining appropriate support for their self-injury
- to explore how services and those who supported people with learning disabilities addressed their self-injury
- to find out what had helped, or would have helped, people with learning disabilities and their supporters obtain optimal support in addressing issues of self-injury.

In those circumstances where the main respondent with learning disabilities did not communicate fluently verbally, alternative means of communication were used. For some participants, this involved the use of a series of picture cards developed specifically for the research project. The picture cards were of a wide range of responses that other people had given when questioned about self-injury, drawn from existing literature about self-injury, and responses given by other research participants in the current study. Additional cards indicating 'yes' and 'no' were used with the picture cards, enabling the respondents to indicate which were relevant to them. The picture cards were presented in black and white and colour, and duplicate and repeat meaning cards were included to verify responses.

The researchers were all aware of the particular challenges of interviewing people with learning disabilities about sensitive subjects. They needed to be able to develop rapport with the research participants, to change the subject and/or pace of the discussion in response to non-verbal cues, to be flexible in the ways they elicited responses from participants, not to show emotion when shocking or distressing issues were raised, and to be aware of potential and actual power imbalances in the relationship.

The process of consent was seen as an on-going feature of the research. Because each person with learning disabilities received a series of research interviews, the information sheet and consent form were revisited at the start of each interview to remind the person about the purpose of the research, to ensure that they were still freely consenting to take part in the research project, and to remind them that they could withdraw their consent at any time without giving the interviewer a reason for doing so. Participants were also informed that they could withdraw their consent by proxy, by asking someone to contact the researchers on their behalf and let them know.

Post-interview support

Research participants with learning disabilities were told in advance when the last research interview would take place, and wherever possible a final visit was arranged to say goodbye. This was so that there was a clear break between meeting for the interviews and saying goodbye. At the final visit, the research team thanked the research respondents with learning disabilities by giving them:

- A £10 gift voucher as a small token of thanks
- A copy of a booklet adapted for people with learning disabilities who self-injure called 'Helping yourself if you hurt yourself'
- A copy of a national contact list, developed by the research team, detailing sources of support for people who self-injure
- A copy of a local contact list, developed by the research team and tailored for each research participant, detailing local services and supports that they might find helpful.

Each research participant with learning disabilities was also offered up to three free counselling sessions, if needed, to focus specifically on any effects the interview had had on them. The research team provided details of accredited counsellors experienced in working with people with learning disabilities who were familiar with the research being undertaken. Alternatively, research respondents already receiving counselling were able to choose to receive additional sessions, if available, from their current counsellor, and arrangements were made for this by the research team where appropriate.

At the end of the interviews with family members and professionals, they were offered:

- A copy of the BCSW booklet: 'For friends and family'
- A copy of the BCSW booklet: 'Women from black and minority ethnic groups and self-injury' if that was appropriate
- A copy of the national contact list
- A copy of the local contact list

All family members and those professionals who took part in an interview in an unpaid capacity were also offered a £10 gift voucher as a small token of thanks.

Data analysis

All interview recordings were transcribed and anonymised and, together with any anonymised interview notes, were entered into the computer software package MAXqda. MAXqda is a powerful, qualitative data analysis package that supports a Grounded Theory approach to analysis. Using MAXqda the researchers coded and categorised the data according to its meaning and description, then retrieved sorted and categorised data to draw out emerging themes, explanations and connections, generate theory that was grounded in the data and identify areas which required further data collection. These themes and explanations were then tested in later interviews, using if necessary, new picture cards to introduce them to participants not fluent verbally. Throughout the research process, there was a dynamic interplay of data collection and analysis, with constant comparison being made between new and developing themes and current data being collected.

In addition to the search for themes and theory, the data was used to identify implications for training, resource development and policy development related to self-injury in people with learning disabilities. As an applied research project, one of the aims of the study was to develop specific outputs that would be beneficial for people with learning disabilities who self-injure, and those supporting them. Data was therefore analysed to identify ideas on which to base the production of resources for information, training and policy development.

Chapter 3:

Research Findings: The research participants with learning disabilities

Twenty-five people with learning disabilities and personal experience of self-injury took part in one or more research interviews. Three of the participants withdrew after one interview, but consented to their information being used in the analysis. All three withdrew from the study because they found talking about their experiences difficult. In the findings that follow, all names of people and places have been disguised in order to preserve the confidentiality of those contributing to the research.

Demographic details

Table 1 shows the demographic details of the research participants.

Table 1: The research participants with learning disabilities

	Age	Sex	Comments
England	14	M	Used gestures and pictures
England	19	F	
England	23	F	
England	24	F	
England	24	F	
England	30	F	Withdrew after one interview
England	33	M	
England	35	F	Withdrew after one interview
England	35	F	Withdrew after one interview
England	39	F	Used symbols, pictures and word boards
England	37	F	
England	40	F	Used symbols, signs, pictures and word boards
England	40	M	
England	65	F	
Scotland	37	F	
Scotland	40	F	
Scotland	47	F	
Scotland	48	F	
Wales	24	M	
Wales	32	F	
N.Ireland	20	M	
N.Ireland	24	F	
N.Ireland	31	F	
N.Ireland	34	M	
N.Ireland	42	F	

As Table 1 shows, 14 participants lived in England, four lived in Scotland, two in Wales and five in N. Ireland. Their ages ranged from 14 to 65; the mean (average) age was 33. Six of the 25 participants were male; 19 were female.

Medical and other health-related conditions

The participants said they experienced a range of medical conditions. Two reported having seizures, two had mobility impairments, one had a hearing impairment and one each said they had diagnoses of cerebral palsy, depression, Personality Disorder and Aspergers Syndrome. Other conditions mentioned by the participants with learning disabilities included: being paranoid, having panic attacks, having migraines, hearing voices in their head, and having 'behaviour problems'.

Diagnoses that had been given to the participants with learning disabilities reported by family members and professionals included: autism for two people, and for one person each: depression, diabetes, breast cancer, epilepsy, affective disorder, Cornelia de Lange syndrome and Borderline Personality Disorder. Other conditions mentioned by family members and professionals included the person having: allergies, leg pain, gynaecological problems and brain damage.

Three of the participants had particularly limited verbal communication and relied on augmentative and alternative communication (AAC) to relate their thoughts and experiences. For these participants, this involved the use of gesture, signing, symbols and word boards. None used speech output devices.

Behaviours that might be considered to 'challenge' those supporting them

Just over half of all participants (n=14; 56%) engaged in other behaviours that might be considered to 'challenge' those supporting them. These behaviours were either mentioned by the participants themselves, or by the family members or professionals linked with them. Table 2 below shows the types of behaviours that were mentioned.

Table 2: Types, and frequency of the reporting of other behaviours that might be considered to 'challenge' those supporting them

Type of behaviour	Number of participants (of 25) reporting that they engaged in this	Overall % of participants engaging in this type of self-injury
Hitting out at, hurting or being aggressive towards another person	10	40
Being destructive and smashing, breaking objects	5	20
Throwing objects	4	16
Verbal abuse, shouting	2	8
Running away	2	8

Total does not add up to 100% as some participants did not engage in any of these behaviours, and some engaged in more than one type.

As Table 2 shows, the most frequently mentioned behaviour was that of hitting out at, hurting or being aggressive towards another person. Almost three-quarters (n=10; 71%) of

the participants who engaged in other behaviours that might be considered to ‘challenge’ those supporting them were said to do this, but they represented fewer than a half (40%) of all participants.

Five participants (20%) engaged in more than one type of behaviour. The maximum number of different types of behaviour was four; the mean (average) number was two.

Living arrangements

Twelve of the 25 (48%) participants with learning disabilities lived in supported living arrangements with other residents. Five (20%) lived alone with support. Four (16%) lived in residential homes, three (12%) lived with their parents in the family home, and one person (4%) lived in hospital.

Of the 25 participants, six (24%) lived in conditions of security, ranging from a high secure setting (one person) to low secure settings or environments where their freedom was severely curtailed. To our knowledge, three participants were held under a section of the Mental Health Act.

Daily activities

Most of the participants had programmes of activities throughout the week, involving day services, work and/or college. Fourteen attended day services for all or part of their week, eight had work placements usually for one to three days a week on a voluntary basis, and one had a permanent, paid job. Five attended school or college on a full or part-time basis.

The participants experiences of self-injury

Type of self-injury

Table 3 below shows the types of self-injury and number of participants reporting that they engaged in this type of injury

Table 3: Types, and frequency of reporting of type of self-injury

Type of self-injury	Number of participants (of 25) reporting that they engaged in this	Overall % of participants engaging in this type of self-injury
Scratching	13	52
Cutting	13	52
Hitting self	12	48
Biting self	6	24
Taking an overdose	6	24
Hitting out at something else	5	20
Head banging	4	16
Burning self – scalds/chemical burns	4	16
Self-strangulation	3	12
Gouging/picking skin/pinching self	3	12
Swallowing objects	3	12
Dangerous activities	2	8
Inserting objects into body	2	8
Eye-poking	1	4

Total does not add up to 100% as most participants engaged in more than one type of self-injury

As Table 3 shows, the three most common types of self-injury amongst the 25 participants were scratching, cutting their skin and hitting themselves. Half of all participants reported engaging in these behaviours. The next most frequently reported types of self-injury were self-biting, taking an overdose and hitting out at something else such as a wall or hard object. A quarter of all participants reported engaging in these behaviours.

All but five participants (80%) engaged in more than one type of self-injury. The maximum number of different types of self-injury was seven; the mean (average) number was three.

When considered purely as behaviours, there was no clear pattern as to the types of self-injury that participants engaged in. No-one 'only' engaged in what might be perceived as 'self-harming' behaviour. All of those who did take overdoses or engage in behaviour that left no obvious injury on their body also cut, scratched, burned or hit themselves causing external injuries.

A number of participants, family members and professionals commented on how the type of self-injury had changed over time. Sometimes this was for no apparent reason, but in other cases it was because the person's usual means of self-injury had been removed:

'This is a new thing now, this self-harm, burning herself with the kettle. This is different now'.

'She started off with ... cutlery, knives, things like that, nothing was major,....and then we took the sharp knives, then she started with the cutlery and anything that she could get hold of that was sharp, anything that scratched or whatever. Then when all that was taken.... she started drinking, I think the first one was tea tree oil...and then...the slapping'.

The age at which the person's self-injury started

Most of the participants, or the family members or professionals linked with them knew the approximate age at which the person's self-injury had started. For some of the participants, the start of their self-injury was associated with a particular place or event in their lives:

'Bridge House was the first time it happened, when I did it'.

'I was about 15 at the time, just because there was so much shouting going on from the member in charge (of children's home), it's all because she threatened me if I didn't go to Roseton with her again, I'd get put in the assessment centre....and that's when I self-harmed'.

For others, the approximate age was deduced from careful questioning of particular phases of a person's life, and subsequently linking up the phases with the age of the participant. In the excerpt below, checks are also made to assess the consistency of responses:

I - ...last time, we were trying to think about when you started hurting yourself that way. Can you remember now?

P - No. I can't.

I - Did you do it when you lived with your mum?

P - Yes.

I - And you said you did it when you lived with your sister?

P – No I don't think I did when I lived with Isabel, no. Any case, she tries to help me quite a lot, Isabel does.

I – Right. So let me get this right. Let's go back a little bit more. When you were at school did you do that?

P – No.

I – Then you were living with your mum.

P – Yes.

I – And did you do it then?

P – Yes.

I – You did it then. And then you moved to live with Isabel

P – Yes.

I - ...and did you still do it then?

P – I stopped for a while.

I – You stopped for a while.

P – Yes.

I – OK. And then when you moved the first time, you moved to a residential home.

P – Yeah.

I – Did you hurt yourself there?

P – Yes, I think so.

I – OK. And then when you moved to Kerridge you hurt yourself there?

P – Yes.

Table 4 below shows the approximate age when participants started self-injuring, drawn from the accounts of the participants and the family members or professionals linked with them. Almost two-thirds of the participants had started self-injuring before the age of 20. Apart from one participant, these were fairly equally distributed between those who had started self-injuring between six and 12 years of age (28%), and those who had started self-injuring between 13-19 years of age (32%)

Table 4: Approximate age when self-injury started, according to participants and the family members or professionals linked with them

Approximate age when self-injury started	Number of participants	% of participants
Young childhood (before 6 years of age)	1	4
Childhood (6-12 years of age)	7	28
Teenage (13-19 years of age)	8	32
Young adulthood (20-25 years of age)	5	20
Adulthood (26 years of age or older)	2	8
Not known	2	8
Total	25	100%

The trajectory of self-injury

As the quote above illustrates, for some of the participants, self-injury was a behaviour that they picked up and put aside again at various periods of their lives. This was by far the commonest trajectory for participants.

'It's just started again'.

'I did stop...but I went back on again'.

'Sometimes, only on special occasion I do. Yes only on special occasions I do'.

For others, their self-injury had become a behaviour that had persisted. However, even here, few of the participants thought their self-injury had remained exactly the same frequency or intensity:

'I used to be a lot worse than this'

I: *Have you had any of those feelings at all?*

P: *Not this week, no.*

I: *What about last week?*

P: *Aye ... oh last week.*

We found little evidence from the participants, nor the family members or professionals they were linked with, to suggest that self-injury was a static behaviour that was entirely predictable or inevitable over long periods of time. Rather, the common feature of all participants' self-injury was that it was a very individual affair, with periods of exacerbation and abeyance that were generally understood within the context of the person's life.

The frequency of self-injury at the time of the study

In the light of the changing trajectories of participant's self-injury, participants were asked about when they last self-injured. For two participants, this information was obtained from the professionals supporting them. Table 5 shows the frequency of self-injury by the participants at the time of the study. A quarter self-injured on a daily basis, with a further 20% injuring themselves more frequently than fortnightly. Five could be no more precise than reporting the frequency of their self-injury to be 'sometimes' or 'occasionally'. Two participants had not injured themselves for over a year; one saying that she had now stopped self-injuring.

Table 5: The frequency of self-injury at the time of the study

Current frequency of self-injury	Number of participants	% of participants
Daily	6	24
Weekly	4	16
Fortnightly	1	4
One to two monthly	4	16
More than two months but less than a year	3	12
More than a year ago	2	8
Occasional/sometimes	5	20
Total	25	100%

The secrecy or otherwise of self-injury

All but three of the participants self-injured in private. A further two tried to self-injure in private, but it was not always possible for them to do so. Information was not obtained about one participant. This means that three-quarters of the participants injured themselves privately, usually waiting until they were in a place where they knew they wouldn't be disturbed:

'I used to lock myself in the bathroom and I used to take knives up to the bathroom and cut myself. I would go down to the kitchen and I would take big sharp knives up'.

'I do it in me room where there's nobody around so people won't be able to see what I'm doing'.

'I never did it when there were staff there, apart from the time when I was not in control, that was the only time'.

The privacy of the act of self-injury was corroborated by most family members and professionals. However, once someone had self-injured, the degree to which the self-injury was able to remain hidden varied considerably, according to the environment in which the person was in, the availability of support staff, the attitudes of those present, and the skill of the person in caring for an injury (in all cases without access to any dressings) and concealing it. Table 6 shows whether participants told anyone after they had self-injured.

Table 6: Whether participants told anyone after self-injuring

Participants' response	Number of participants	% of participants
Did not usually tell anyone	6	24
Did not tell anyone, but injuries usually obvious and noticed	8	32
Usually told someone voluntarily after self-injuring	6	24
Would tell someone only if asked	2	8
Response varies	1	4
Would prefer to tell someone, but no-one interested	1	4
Response missing	1	4
Total	25	100%

As Table 6 shows, a third (32%) of participants did not tell anyone verbally, but their injuries were usually unable to be concealed. For some, the lack of concealment of their injuries may well have been a welcome way of communicating that they had self-injured, without having to do so verbally. For others, their preference would have been to conceal their injuries, but they were unable to do so:

'I didn't have anywhere private because mum and dad were everywhere'.

'They knew 'cause the blood was coming through everything',

A participant who did not use verbal communication indicated that she preferred to keep her self-injury hidden, but that the staff usually saw it.

A quarter of the participants said that they didn't usually tell anyone, for a number of reasons, including feeling ashamed, being worried about the consequences, or not feeling comfortable enough with the staff to disclose what they had done:

'Most of the time I'm ashamed of the fact it's got to that so I get to the point I clean myself up'.

'I was too scared to mention it to anybody'.

A further quarter said that they usually did tell someone voluntarily after they had self-injured, although this may not have been until the next day:

'I had to tell [care coordinator]because she's supposed to be helping me'.

'It goes on me records the next day, like I tell them the next day that I've done it'.

Disclosing one's self-injury

Seven participants talked about their experiences of disclosing their self-injury to someone. Mostly, these were difficult, but positive experiences:

'...it was very hard to tell her though. It was very hard, but I'm glad I did'.

'I just spat it out... there was a big ton weight coming off my body to make me feel better that somebody knew....Aye, I was glad, I was very happy with myself that I told somebody'.

Some suggested that they would only tell someone about their self-injury when they knew the person well, and felt comfortable with them. They needed some sort of knowledge about the person so that they could anticipate their reaction, and to have a good enough relationship with them upon which trust could be built. The personal qualities and attributes that participants looked for in a good support worker are outlined on p.66; their evidence was clearly of great importance to people when it came to talking about their self-injury. The implication was that support workers had to 'prove themselves' to be non-judgemental and trustworthy before people with learning disabilities could feel comfortable talking to them about their self-injury. In addition, one participant emphasised that she was able to tell only one person – she relied on teamwork and partnership working to pass on the information to other professionals who needed to know.

One participant said that although it was a '*nerve racking*' experience, it had been made easier by having the research project information leaflet about self-injury with her that she could show to her support worker. Another participant said that she had found it easier to tell someone when they were busy doing something, such as being out for a walk. A third said that she had felt more relaxed going to a quiet café to talk about self-injury, rather than being in an office environment. Clearly, these were individual preferences that might not suit everyone, but do offer suggestions by people with learning disabilities about what might work best for them, and indicate the importance of 'preparing the ground' for disclosure. Two participants added that they did not want to be asked many questions

when first disclosing their self-injury: they wanted to set the agenda themselves and for the discussion to go at their own pace, rather than them being forced into discussing things that they were not yet ready to talk about.

Leading up to self-injury

Participants were asked about the lead up to their self-injury, and most talked about both circumstances and feelings at this time. These were the precipitating factors to a person's self-injury: the actual reasons why people said they self-injured are given later.

Participants described three main categories of circumstances leading up to their self-injury: external factors, interpersonal factors, and internal factors.

External factors

More than half of the participants described two main external factors leading up to their self-injury. By external factors we mean those in which the participant is not central; they involve what is going on around the participant, but the participant generally has little or no control over them. They are what is external to the individuals. The two main external factors identified were:

- Being in disempowering circumstances
- Having a lack of control within their living environment

Being in disempowering circumstances

Participants described a number of disempowering circumstances leading up to their self-injury. These included not feeling listened to, being told off, being told what to do (or what not to do), having too many demands placed on them without enough support, being treated like a child, or other people talking about them. Clearly many of these circumstances were linked to being in a situation where poor support was being provided – support that was either in short supply, or was controlling, uninterested or belittling.

'This place puts you in bad form half the time. You try and tell the staff things, they don't listen to you half of them, they tell you to go away. They don't listen to you half the time'.

Interview notes: Annie says that she 'gets a temper' (gets in a temper) then she might get angry and spit or bite her hand. Annie said that 'when Jo (support worker) says no' (i.e. don't do that) is an example of when she gets in a temper and gets angry. When she is told off she feels like biting her hand.

'I would be sitting in the class trying to do the work and I couldn't do it because I couldn't read it....I would ask the tutor would she help me...and then she would go round the whole class and help them first and I was still sitting there and waiting for help...I couldn't do the work myself, I needed a wee bit of help and they wouldn't help me'.

'They treat us like kids...and its very horrible'.

Having a lack of control within one's own living environment

Whilst having a lack of control within one's own living environment could be considered to be a disempowering circumstance, and so might fit into the section above, there were a number of circumstances described that deserve separate consideration. Many of the participants had had little or no choice about where they lived, who they lived with, and who supported them. In addition, some also had little choice over what went on in their

home or what they did during the day. Having so little control within ones own living environment was a key issue for many of the participants. They spoke or indicated that circumstances leading up to their self-injury included being irritated by other residents, not having enough personal space, there being too much noise, having a lack of autonomy, not being able to go out when or where they wanted, and that coming up against some of the 'systems' in their living environment led up to their self-injury.

'This other boy there he looks in the paper and talks about football...and I don't really like to hear him talk about football...I don't like football...I just don't like football'

'Sometimes I would just want to be on my on, and I can't get on my own'

'I don't like being with Emma (support worker)...I slap myself. I don't like her louder voice. Louder voice'

'I have to have my lunch when they have their lunch, and I couldn't have anything else if I was hungry....I was starving hungry. I wanted a biscuit and I ended up getting...I found an iron.....'

'I used to do that [self-injure] when I couldn't get out'

'I wanted to get out basically; I was craving to get out...and because there was only one person on, there was supposed to be two on that night...they couldn't take me out....I just felt (sound of frustration and swears). And that's when I just went like I was gonna cut myself'

Having the opportunity to do so

A further external factor described as leading up to a person's self-injury was that they had the opportunity to do so. A third of participants mentioned this, and it was the third most frequently mentioned external factor leading up to a person's self-injury. Having the opportunity to self-injure occurred either by chance or through pre-planning. Some participants said that they would find something that they could harm themselves with, either actively by seeking something out, or accidentally if something was lying around. Others reported that they would deliberately break items so that they could hurt themselves with it, or store items for later use if needed. Common to all of these participants' descriptions was the importance of being on their own at the time.

'When I was in my room, if there was anything broken, say a cassette, then I would be squeezing that trying to make myself bleed'

'I mean when they're in my room, I don't like go to them and look at them all the time. They're there if I'm going to self-harm, and if I'm going to self-harm I know that they're there for me to do that, instead of me going back to the shop and buying some more.'

One person had written down some of her feelings and was discussing what she had written with the researcher:

I: *'So here you've written that you were in the kitchen'*

P: *'Yeah'*

I: *'You were emptying the dishwasher and you picked up a sharp knife'*

P: *'I was by myself'*

Another participant indicated that she used to break a glass then hide pieces of broken glass to use later when she felt the need to.

Interpersonal factors

A second theme in understanding the circumstances leading up to a participant's self-injury was that of interpersonal factors. By interpersonal factors we mean those involving relationships between two or more people. A third of participants mentioned either of two key interpersonal factors leading up to their self-injury. These were:

- Being bullied
- Arguments – either having an argument with someone else, or overhearing an argument

Being bullied

Participants described a range of ways in which their experience of being bullied led up to their self-injury. They talked about being bullied physically, by being hit or punched. They also talked about being picked on, called names, made fun of or laughed at. Whilst many of the participants mentioned being bullied as something that they had experienced in the past, a number specifically said that being bullied was a factor that had led up to their self-injury.

'People it's the people make me do it...cause I hear things saying they hate me and all, they don't like me, you know? And I got bullied all my life'.

'People say I smell'.

'When people are horrible to me' – indicated by a participant with limited verbal communication

For some of the participants talking about being bullied was particularly painful. A number mentioned that their own experience of being bullied had led them to 'lash out' and bully others. One, when describing to a researcher that she self-injured when she was 'worked up', coped with her feelings by changing the subject:

I: Are there any particular times you get worked up?

P: Sometimes yeah when people ... I get picked on by a lad called Mark.

I: Is that here or somewhere else?

P: Yeah it's here. Yeah it's here. Do you like my bracelet?

Arguments

The second key interpersonal factor leading up to self-injury was issues to do with arguments. Being involved in, or overhearing, an argument was something that distressed a number of the participants, and several said or indicated that arguments could directly lead up to them self-injuring. The fieldwork notes of one participant reported:

'She usually self-harms when she wakes up in the morning, if she has been feeling 'worked up'. The most usual thing to work her up is having arguments with others. She will think of the arguments of the day before, and this will make her want to self-harm in the morning'.

Some participants indicated the importance of arguments leading up to their self-injury when selecting pictures. Comments made by other participants included:

'I know when I'm feeling so low that I think I start fights or something – not that I'd start fights, but I would argue with somebody and then I would get down and end up hurting myself'.

'I don't like arguments at all, I hate it. So that's when self-harm comes into it again too, arguments'.

I: *'So tell me....you were arguing, you had an argument.....'*

P: *'Yeah, and I had, that was on Tuesday....and, yeah. I didn't even think what was going to happen, I just went and done it (self-injured)'.*

Internal factors

The third main category of circumstances leading up to a person self-injury was that of internal factors. Internal factors were those to do with the person themselves, irrespective of what was going on in their current environment, or the people with whom they were interacting. Two main internal factors were identified when considering the circumstances leading up to self-injury for the participants. Each of these was of importance for a quarter of the participants. The factors were:

- Physical health issues
- Having particular thoughts or memories

Physical health issues

Participants mentioned a number of different aspects to do with their physical health as being circumstances leading up to self-injury. Most frequently identified was physical illness – when a participant was physically unwell they were more likely to self-injure. One participant described how the first time she self-injured was in response to physical illness that left her in considerable pain and feeling very weak. Another reported that an indication she may be leading up to a seizure was that she would harm herself increasingly in a particular way. Although this person with learning disabilities was aware of this, none of her carers were.

Another aspect of physical health that was mentioned as being a factor in leading up to self-injury was of mobility impairment. For one person this was directly related to the fact that she couldn't get out and about as much as she wanted to; for another it was because she tended to fall or bump into things and this made her anxious and frustrated; another couldn't walk fast.

Two other physical health issues that were mentioned, albeit by only a small number of people, deserve mention because of their applicability in a broader sense. Tiredness or exhaustion was considered to be a factor that could lead up to self-injury: when people were tired their own coping resources were lowered and self-injury seemed to be more likely. The other factor was the over-consumption of alcohol. Again, few participants mentioned this, but it seemed to be a particularly important factor for them in the lead up to their self-injury.

Some of the comments made by participants to illustrate how physical health issues would be involved in the lead up to their self-injury are given below.

'I just saw myself as a person covered in sores and I just hated myself'.

'Sometimes, when I start building up to a seizure I start bashing myself there, there, on my neck, on my body, on my arms, I get my teeth and bite myself'.

'I hadn't slept for three days'

'I was just so tired I didn't know what I was doing. I couldn't even get off the floor'

I: 'If you were better and you were able to go out to places...would you still hurt yourself?'

P: 'No'

P: 'If you've got alcohol in you <prff> that's the worst thing'.

I: 'Do you think that makes you more likely to hurt yourself if you've been drinking?'

P: 'Yeah, oh yeah it does, yeah 'cause you're full of like anger really and it's just not the answer at all, because in a way you're ruining yourself really. That's what I'm saying because if you've been drinking and it all comes out and that's the worst thing you could ever do'.

Having particular thoughts or memories

Half of the participants were preoccupied by particular thoughts or memories that were at the fore of their minds in the lead up to their self-injury. Some of these were thoughts or memories relating to past traumatic events in their lives. Others were persistent thoughts of wanting or needing to self-injure. A third group of thoughts were characterised by a more general internal dialogue relating to anxiety or worry, lack of self-confidence or self-esteem and being under pressure.

There was a huge amount of past trauma in the lives of those we interviewed, although this was unknown at the time when they were selected to take part in the research project. Most of the participants reported this to the researchers themselves over the course of the interviews. Only one participant, the youngest, did not express some traumatic event from her past. In this Chapter, however, we are only considering the views of those participants who said that directly before they self-injured, they had thoughts or memories of those difficult times. The memories or thoughts were largely centred on two types of difficult past experiences: abuse and bereavement.

Participants who considered their thoughts of previous abuse to be a circumstance in leading up to their self-injury often mentioned that these were memories that they could not put aside. One participant said:

'You know the way that I was abused...it would be like thoughts of him doing it and hurting me and stuff, those kinds of thoughts and they'd be constantly in my head'.

For another participant, however, the memories came in the form of flashbacks:

'Sometimes...my eyes are all over, if I see somebody in the corridor I automatically think about that tutor.'

Memories of the death of someone close tended to be triggered by certain events, rather than being present all the time or appearing 'out of the blue'. It was when one of these triggers had been encountered that was most likely to lead up to self-injury. One participant recalled a close relative's death and the effect that it had on her:

'If I sat in the house I would just be upset all the time. I mean, I'm getting alright now but its just sometimes...like I can't get on a bus, and I can't look at his house....and that's why I tend to go out...(that's why) certain things happen'.

The second group of thoughts mentioned by participants was of thoughts in their minds about wanting or needing to self-injure. For most of the participants these thoughts came and went. All but two perceived them to be internal thought processes: one participant was sure that she heard a man's voice at these times; another wasn't sure whether she was hearing a voice external to her, or if it was her own thought processes telling her to harm herself. Some of the comments made by the participants were as follows:

'The thoughts would be in my head night or day.'

'Weird thoughts...in your head, in my head just ... it just comes up in my head that self-harm, self-harm, self-harm, you know, instead of going to tell somebody, but see I didn't think of that at the time, I was so wound up and so cross and then ... I just started bleeding, I'd done something to me arm'.

'The thoughts are that strong that I wanna get rid of them, so the only way to get rid of the thoughts is to do it.'

A third group of thoughts was characterised by a more general internal dialogue relating to anxiety or worry, lack of self-confidence or self-esteem and being under pressure. These thoughts were troubling to participants, and considered to lead directly to self-injury. One thing that a number of these participants had in common was that they found it very difficult to talk about these feelings, and they tended to build up their feelings and 'explode'.

'I didn't like myself, I didn't wanna know and I hated my body, the way it was and that's why I sort of did it, then I thought I hate myself and just <prff>'...I just couldn't cope anymore and I'd just had enough really'.

P: *'If I'm really, really stressed and I'm really, really bogged down and I don't ... I don't even tell no one for months, and months, and months, I just bottle it up... in the end I go quiet, I go really, really quiet. Then it all come out, like a rocket, and I start whacking myself and self-harming myself big time basically'.*

Participants' feelings before self-injuring

Circumstances that were difficult to deal with led to the development of quite intense feelings that were often an antecedent to self-injury. All of the participants in the study were able to identify some of the feelings that they experienced before self-injuring. However, many had difficulties recognising a wide range of feelings or of discerning between them. One participant summed this up succinctly by saying: *'I didn't know whether I was angry, happy, or sad'*. For this reason it was important for the researchers to explore participants' own understanding of emotions before exploring with them their feelings in relation to self-injury. The fieldwork notes below illustrate the complexity of this with one participant who had limited verbal communication.

Moira put the cards 'happy' and 'sad' together. She indicated that they 'go together'. It seemed that Moira didn't view them as separate emotions – rather they seemed to her

to be part of the same feeling. When 'happy' and 'sad' were put together it made 'laughing' for Moira. She made it clear to me that when she is laughing, she sometimes feels sad.

Moira gave a number of examples of feeling 'scared'. She said that it was like being frightened of a wasp. She also identified 'scared' as being when people are laughing at her, or when she is laughing at others. She indicated that when people are screaming she feels scared, and then bites her hand and screams herself.

Moira recognised the card picture card of someone being 'angry'. She indicated that when she is angry she spits or bites her hand. An example of when she might get angry is when she is 'told off', which would result in her biting her hand. However, Moira used the cards to show that when she is told off she feels sad as well as angry. For Moira there seemed to be two issues relating to her anger: she would bite her hand when she was angry, but biting her hand could also make her angry.

We also talked about the feeling of 'frustrated'. Moira was familiar with the usual meaning of this word, and gave the example of feeling frustrated particularly when someone told her not to bite her hand.

I asked Moira about clapping her hands, which she sometimes does for prolonged periods of time, often making them sore. She indicated that she claps her hands when she is laughing, happy, excited, and sad. Feeling excited could also lead to Moira biting her hands, but she would then feel sad afterwards.

The extract above illustrates how someone was clearly able to recognise some emotions and link them with her self-injury, but that the emotions in themselves were not always clearly defined. The further steps of understanding and managing one's emotions were only explored in the context of self-injury where appropriate, but one participant summed up her confusion at understanding her emotions by saying *'I don't know a lot of things that go on in my head sometimes'*.

Despite this, all of the participants identified some of the feelings that they experienced before self-injuring. There were three feelings leading to a person self-injuring that were mentioned more than any others. These were:

- feeling angry
- feeling sad, depressed or low
- feeling frustrated or wound up.

Three-quarters of all participants reported having one or another, and sometimes a combination of these feelings, immediately before self-injuring. Participants' comments describing their anger before they self-injured included:

'[It] was 'cause I was really, really angry and I needed to do something 'cause somebody had really, really, really, really, really, really annoyed me so'.

'It's like I can get angry at times, and when I do it, it releases that anger a little bit. I'd rather do it to myself than hurting somebody else if you know what I mean?'

'Sometimes I get angry with myself because of this, sometimes I get angry about it...[then] I hit myself'.

The second of the feelings, that of feeling sad, depressed or low, was also mentioned quite commonly. Comments made about this included:

'Sad, sad and cross, then I go into my room and cut myself.'

'Say if I was feeling low, I would feel like I wanted to have to cut myself.'

A conversation between a researcher and a participant using picture cards was as follows:

- I: *'So that one's sad'* (researcher pointing to a picture card of a sad face).
P: *'Yeah'* (the participant then picked up the card, moved it and paired it up with a card that showed a picture of a crying face)
I: *'What do you mean, is that going there or....?'*
P: *'Yeah. That's the same thing as well, isn't it?'* (the participant showed the researcher the pictures of the sad face and the crying face that she was holding together)
I: *'The same thing as...?'*
P: *'Sad and crying'*.
I: *'Yeah'*
P: *'That goes there'* (the participant determinedly placed both cards together on the 'my feelings before hurting myself' pile).
I: *'So you feel sad and you feel like crying at the same time?'*
P: *'I do yeah'*.

For half of the participants, feeling sad, depressed or low had become extreme and they talked about feeling as though they wanted to end their life. Thirteen of the twenty-five participants spoke about times in their life when they had wanted to die. For some, this was a feeling they had that they would not act on. One participant explained:

'You see sometimes I want to kill myself but I don't, if you know what I mean?'

Eight of the participants described incidents of self-injury from which they intended to take their own lives. Six of the eight described serious attempts on their lives that had required active intervention; three had required resuscitation. One participant described her feelings before taking a large overdose:

Participant: To kill myself.

Researcher: You were trying to do that?

Participant: Aye...then no more.

Another participant said: *'I wanna die so I'm sort of hoping that I will really'*.

A third, who was clearly struggling said: *'I just used to do it to have suicide'*. Later in the interview the participant described a recent attempt on her life that she had made but described feeling *'too tired'* and *'it wouldn't let me die'*. She also asked the researcher: *'People are suicidal and some dies and some doesn't. Why is that?'* Crying, she said *'it won't work'*. This was one of the participants that the researcher intervened with, and supported in letting her named contact know about her feelings.

Clearly, the feelings that these participants had were those that should have elicited professional support, but not all did. One said:

'I always used to tell [role of person] I was going to kill myself, and they'd all be like, 'Yeah, yeah, yeah, whatever.'"

The third of the feelings described by participants as being experienced before they self-injured was that of feeling frustrated or wound. Comments about this included:

'I just get frustrated....Yeah, and I get all worked up.'

'When you feel like that, when you want to hurt yourself, you're that angry or frustrated...mainly frustrated more than anything'.

'At the time I just don't think about my actions, I'm just so angry and frustrated with it, so I'll see red.'

As already indicated, some participants reported a combination of feelings before they self-injured. Most included one or other of the three feelings above that were identified by the majority of participants. Other feelings reported included feeling upset (mentioned by a third of participants); and feeling stressed; cross or annoyed; and scared (each of which was mentioned by a quarter of the participants).

Trying to delay or stop self-injuring – immediate measures

Eighteen of the 24 participants (75%) talked about strategies they used to try and delay or stop themselves from self-injuring in a crisis. The participants who did not talk about this were the three who withdrew early from the project, the three with the least verbal communication skills, and one who needed interventions made on her behalf due to her state of mind at the time of the interviews.

Talking to someone

Two-thirds of those who had tried to stop or delay themselves from self-injuring in a crisis said that they found it helpful being able to talk to someone when they felt like hurting themselves. For some, they appreciated having someone to talk to about their feelings. Others wanted someone to talk to more generally: to chat with someone as a way of distracting themselves from their own feelings. One person wanted advice from staff at this time, and to be reminded about how to stop harming themselves.

'Talking to the staff, them listening to us normally calms me down, normally it might take about an hour, two hours maybe tops, then I'm alright again'.

'And it really does help by doing something that you enjoy doing....chatting to people – that really helps'.

All of the participants stressed the importance of the ready availability of someone to talk to at this time of crisis. It was also apparent, that most did not seek out someone to talk to lightly – they had to get to a certain pitch, or pass an invisible and very individual threshold before they could approach someone with a view to talking to them. Two participants explained:

'Sometimes I can try and control how I'm feeling sometimes with talking about the situation when it gets to that....only...when I find I'm pretty low and I really am going to do some harm to myself'.

'I'd like to be able to just pick up the phone and just make a call before I got to that, ...I'm trying my best to make that phone-call now before it gets to that'.

Most participants did not mind who they spoke to in a crisis; circumstances meant that they needed to talk to anyone, rather than someone in particular. Once in contact with someone, however, a number of participants said they found it difficult to say what they wanted to, and needed encouragement, time and space to speak. It was not easy, when distressed, to start talking about how they were feeling, and some appreciated direct questioning at this time. One participant, when asked what she needed to stop self-injuring when she was very distressed said:

'Sit down with me and talk it through before it goes <bcch>. That is the best way- just to sit me down and go, 'What's the matter Mel, what's the matter? Tell me.' Yeah....I don't mind because as long, what I want is as long, if someone can talk to me or listen to me that will work'.

Another participant acknowledged that it was not always easy for staff at this time, as she tended to push people away when feeling most distressed. She admitted the purpose of this was:

'To see if they really mean it, to see if they really want to help you; it's like a little test for them ... to try and get them to prove that they really want to help you'.

Note that these were all circumstances when participants were feeling like self-injuring. Longer-term talking therapies to support someone with reducing or stopping their self-injury are discussed later in this chapter.

Distraction

Just over a half of those who had tried to stop or delay themselves from self-injuring in a crisis said that they found it helpful to try and distract them at that time. Distraction served as a way of breaking the pattern of thinking that the person had got into. Participants mentioned a wide variety of ways in which they tried to distract themselves. The most frequently mentioned effective distraction method was to go for a walk or to do some exercise. One participant thought:

'best of all is if you exercise yourself, 'cause you're concentrating on what you're doing'.

Going out for a walk when feeling distressed wasn't, however, an option for everyone. Some of the participants said that they had to have someone with them if they were to go out, and that staff were not always available to accompany them at those times when they felt it would be most helpful to go out to prevent them from self-injuring. Others said that there was nowhere much to go if they were to go out for a walk – it seemed that having a change of scenery and being in a nice place was as important to them as getting some exercise.

The next most frequently mentioned distractions employed by people in an attempt to delay or stop their self-injury were watching television/DVDs and listening to, or playing music. For some people, watching anything on TV or watching any film available was helpful in distracting them from feelings of wanting to self-injure. One participant commented:

'Well see if I get these voices saying 'burn yourself' I come in my room, watch TV to take it off my mind'.

Other people preferred particular programmes or films, such as comedy or natural history programmes, or favourite films that they knew well and were comfortable watching. A few participants commented that violent programmes or films were not helpful to watch as they could wind the person up more, instead of relaxing them: *'It could escalate me again'* was what one participant said.

The effectiveness of watching TV or a DVD was explained by one participant:

'Anything [would do] but ones that I don't put on, 'cause you know you see a bit of violence and I don't want that. No, like a bit of comedy or a film even that's fine, and that's the best way to keep your mind off it, and then it doesn't make you want to do anything 'cause you're concentrating on watching what's going on in your film or comedy or a programme you like watching. But that'll actually stop me'.

A similar proportion of people found listening or playing music as effective as watching TV or a DVD when feeling like self-harming. One participant felt that she had to do this early:

'If I do get a bit distressed then I can start helping myself out of it, just by putting music on'.

As with TV programmes or DVDs, some participants had favourite music that they knew could help them most:

'When I put my favourite CD on it is the music helps, or when I put my Steps CD on that helps me'.

For other participants it was the volume of the music that was more important:

'I just go in my room and just listen to some ... but if I'm really peed-off, right, I will play loud music but I've gotta think of other people, but if it's during the day I just get on a CD and whack the volume up.'

'When I get angry and angrier the music goes up a lot louder, yeah a lot louder than everything'.

A number of other strategies were mentioned that were helpful for distracting participants when they felt like self-injuring. Some of these strategies were also found to be helpful on a day-to-day basis for preventing a person from getting so distressed that they felt the need to self-injure. These included:

- keeping busy: *'It blocks things out yeah...if I'm busy I can't think'*
- listening to the radio
- painting and drawing, and other craft activities such as cutting out and sticking pictures etc): *'when I draw I focus and concentrate on that so everything else is ... I'm sort of being given a break from all of it'.*
- Writing down one's feelings (even if writing was difficult) *'If you don't feel like talking it's best to write'*
- An activities box: a box of favoured activities that the person could open and use when particularly distressed, such as particular familiar objects, a favourite film or music, a magazine, a puzzle, a stress ball etc – all individually chosen by the

person as being items that could help them distract themselves. The advantage of having a box of activities was that the person didn't have to hunt around for something to distract them - it was all kept in one place; and having a variety of items together meant that there was usually something there that would be suitable for the person at that particular time of that particular day

- Playing computer games.

A number of other creative ways to distract them in order to help them delay or stop themselves from self-injuring when feeling distressed were described by participants:

'I've got some words that me and my carer wrote and they really help me....and I always keep them in my handbag and that....they really, really help me...They are from, there was a pop group called All Star and it's a song, and it's really, really good. It really helps me'.

'I keep a picture (of a previous carer) and that seems to help me. When I feel bad I get both of them out and that helps me'.

'Getting cold ice in your hands and squeezing it, it's like a sort of pain right across the hand, it worked for me. Especially the one with the tea towel, you put ice in a tea towel and you bang it against the table - that gets quite a lot of the anger out of you. Time you've done that you are totally shattered really. You can't be bothered to even think about self-harming'.

'I had a punch bag, which was good. You could get a lot of your anger out on that, with boxing gloves'.

Internal thoughts/dialogue

A half of those who had tried to stop or delay themselves from self-injuring in a crisis said that they tried talking to themselves – aloud or in their head – as a strategy. The dialogue that they conducted with themselves included:

- Trying to put the thought of self-injury out of their mind: *'You are trying not to think about it and do it'.*
- Telling themselves that they shouldn't self-injure: *'I sometimes say to myself, I'm not to do that'.*
- Thinking of the consequences of self-injuring *'I talk myself out of it by saying, 'It's not the answer, you're just ruining your body really and you're just scarring yourself.'"*
- Thinking of the future: *'If I'm looking forward to things nothing (i.e. no self-injury) happens. And sometimes when I am looking forward to things and you're trying so hard to be good, so you can get them places'.*
- Changing their way of thinking to more positive things: *'Then I think, there's Ahmed who's the manager said, 'Well you've been through it before so life is just gonna be ditches and everything else, and then a smooth end.' And I was like, 'Yeah.'*
- Physically trying to shake the thoughts out of their mind by shaking their body and head: *'Like sometimes, I'm not saying the thoughts have ever been away, but sometimes I just feel in my head it's like a thought will come in and I'll go to try and shake it out'.*

Participants seemed to have varying degrees of success with these strategies, and there was a danger that it could make them feel worse about themselves if they did go on and self-injure: it seemed that for it to be effective considerable practice and a degree of self-confidence was required. One participant said that she told herself:

'Look Anika, you don't need to do this no more, it's not doing me no good at all.' Stuff like that. And at the moment I'm not able to do that, I'm going to be honest, and I'm not ready for it'.

Trying to calm oneself down

Several participants mentioned that they tried their best to calm themselves down when they felt like self-injuring. Most acknowledged that this was usually difficult, but some had specific strategies that they used, or had been taught. Once they were familiar with these strategies, they were better able to calm themselves down.

The strategy most frequently mentioned in trying to calm themselves down when they felt like self-injuring, was to go to bed. For some participants this was where they felt safe and comfortable: it acted as a refuge from the world, '*out of the way*' from what was going on around them. For others it was so that they could go to sleep, in the hope that they would feel better when they woke up. For one person it was because they knew they would not physically injure themselves when in bed. Going to bed, whether to sleep or not, was considered to be an effective way to calm oneself down by about a quarter of the participants who had tried to stop or delay themselves from self-injuring in a crisis. It was, however, not always seen as a positive strategy by those supporting them, as two participants mentioned. One participant summed up:

'It's like I've gotta try and....calm down a little bit, and then normally when I've calmed down I'm normally OK; it might take me an hour, it might take me two hours. Sometimes I might even go to sleep to calm myself down; I know it's the wrong method but...'

Additional strategies used to try and calm oneself down when feeling like self-injuring included:

- Removing oneself from a stressful situation
- Finding a quiet, comfortable place
- Doing breathing exercises
- Listening to relaxation tapes
- Consciously slowing down, by sipping some water
- Carrying cards that read: 'Stop', 'Look', 'Listen' and 'Think' and reading the cards when feeling distressed as a way of putting the person in touch with their surroundings – a type of 'mindfulness' approach
- Holding or cuddling a comforting object, such as a favourite teddy bear
- Counting to ten, slowly, until calmer
- Squeezing a stress ball
- Thinking of something to look forward to.

One participant summarised: '*Chilling out, that would definitely do me that would*'.

Being in company, or being alone?

It has already been mentioned that the majority of those who had tried to stop or delay themselves from self-injuring in a crisis said that they found it helpful being able to talk to someone when they felt like hurting themselves. About a quarter of the participants thought that going off to bed on their own was also, at times, an effective way to calm themselves down if they felt like self-injuring. Apart from these circumstances, there was some difference of opinion as to whether being alone and calming oneself down, or being in company, was best when feeling like self-injuring but trying not to. In general, it was a very individual preference, which depended upon the circumstances, the people who might

be available to support them, and the environment that they were in. This lack of a clear preference was repeatedly stressed by the participants:

'It's all according to how wound up I am....so I don't really know what to do about that one'

One participant selected all four picture cards 'being with friends', 'being with other people' 'going to my bedroom on my own' and 'being on my own' when asked about how she delayed or stopped herself self-injuring. Pointing to the card 'being with other people' she said *'yeah I'd definitely do that'*. In response to the cards 'being on my own' and 'going to my bedroom on my own' she commented:

*'Being on my own, yeah...it could work or couldn't...
Going to my bedroom on my ownyeah. occasionally that could go the opposite way....'*

Another participant commented that she preferred to go off into her room and try her breathing and relaxation exercises, and if that didn't work she would hurt herself. However, she also said that having someone available to sit and watch TV with her could also help stop her harming herself *'sit and watch TV with me. Yep'*.

As with the participant above, many who indicated a choice, wither verbally or using pictures, appreciated having someone to stay with them when they felt like harming themselves:

'If you're with somebody it's even better because then you can chat to them, and that really helps 'cause then you're not thinking of how you feel, your mind's off it'

'Yes it would stop me if I had somebody there; it would stop me from doing it, definitely....but they can't be there with us all the time, they've got other service users in the building'

For some people, it was not so much the people that they were with that was important, but the space that they were in:

'But sometimes if I could just like hold it just long enough,but it's just that time to hold it if I could, obviously if I was in a room of people ... see that's the thing, if I'm with people, with everything else, I don't really get angry, I wouldn't get angry, if you know what I mean? It's really difficult to describe'

'There was a couple of times in the week I wanted to hurt myself, but I actually distracted myself from it because I didn't have the chance because I was in a grown up place'

Some participants did want space to be alone, but all but two of these mentioned that being with other people helped too. For one participant, space to be alone and hurt herself was preferential to having to cope with the unhelpful response she received when she tried to ask someone for help:

'And it was like if I was to go into the office in, Hilary would say, 'Get out, get out.' And I would get annoyed and I would go up to my room and I would stay there nearly the whole day and I would just sit there, and it was really tough. It was just so much harm I did there'

Participants' feelings after self-injury

Almost all of the participants were able to explain how they felt after self-injuring, and all of these involved a number of different feelings. The largest group, including almost a half (48%) of the participants, described mixed feelings – in some ways they felt 'better' after self-injuring, and in some ways they felt 'worse'. The next largest group, including almost as many participants, described predominantly 'bad' feelings or feeling worse than usual after their self-injury. Just two participants described feeling entirely better or ambivalent after self-injuring.

Of all the individual feelings mentioned, the most frequently reported feeling by participants after self-injuring was that it made them feel better in some way. As already mentioned, however, feeling better was usually tempered by other less positive feelings, as two participants discussed with the interviewers:

P: *'I feel good and bad, it depends what I did, but it made me feel better, it made me feel more alive...it made me feel better basically'*.

I: *'So that's the good bit, it makes you feel more alive, it makes you feel better; what's the bad bit?'*

P: *'In some ways I wish I didn't do it'*.

P: *All I can remember is the relief of the pain inside, so again, that's all I can say.*

I: *So the pain that you were feeling inside...*

P: *Yeah*

I: *It made it go away?*

P: *Better, yeah.*

I: *It made it better.*

P: *For a while.*

Another participant commented:

'It depends why I wanted to do it at that time... It depends what I wanted from that, if I just wanted relief, yeah, I feel better, but if I don't want to be here anymore, no, I feel worse'.

The second most frequently reported individual feeling was of feeling upset after self-injuring. For some participants this was, at least in part, a continuation of feelings that they already had when they self-injured:

'I get upset.....after I get upsets sometimes....I just do, 'cause ... I get upset 'cause things are going through my mind sometimes of what's going on....what's gonna happen and ... 'cause I don't want that to happen, but it's going through me head what's happening and what I keep doing at home and what I've done'.

For others, it was the act of self-injury that had made them upset:

'Upset and ashamed with myself'

The same number of participants reported the next most frequently reported individual feelings - those of feeling sad, and feeling calmer. For some of those saying they felt sad, it was again a continuation of previous feelings:

'I feel angry and sad and frustrated....The same things' [after self-injuring]

For others, it was the act of self-injuring that could lead them to feel sad. For example, one participant's fieldwork notes report that after she felt sad because she bit her hand. In contrast, all of those who reported feeling calmer after injuring themselves experienced this as a new feeling, different from how they had felt before they self-injured:

'It was just like diverting it to pain so then I chilled out a bit.'

'Sometimes it makes me feel calm and ... even though I'm hurting myself it sometimes makes me feel ... good about myself.'

Approximately a quarter of the participants mentioned each of the next two most frequently reported individual feelings: those of feeling annoyed and ashamed after self-injuring. For all of these participants, it was the act of self-injury that was at the root of these feelings:

'When I did it I used to be annoyed because I did it to myself, so then I got ... I was too scared to mention it to anybody. But I would say to myself, if I tell anybody, they're going to be ashamed of me'.

'Most of the time I'm ashamed of the fact it's got to that'.

Along with a range of other emotional feelings mentioned by participants, one participant only mentioned physical feelings when asked how she felt after injuring herself. These she described as feeling '*horrible inside*'

'I get a funny feeling in my stomach...Sometimes I get the bad feelings in my stomach'.

When considering participants' feelings after self-injury, therefore, there are a number of interesting points that arise. The first point is that most participants expressed a range of feelings, some good, some bad, or only mentioned predominantly 'bad' feelings or feeling worse after self-injuring. Secondly, when each feeling was considered individually, the most frequently reported feeling was that self-injury made participants feel 'better' in some way, even though this was usually combined with less positive feelings. The final point is that the positive feelings that were felt after self-injury were those that originated from the act of self-injury itself. Self-injury sometimes gave participants additional 'good' feelings that they were not experiencing before they self-injured. This was in contrast to the more negative feelings that participants were either already experiencing when they self-injured and subsequently continued to feel, or arose as new feelings as a result of the self-injury itself.

The circumstances for participants after self-injuring

Seventeen of the twenty-five participants described events that usually happened after they had self-injured. Almost all focused on the issue of how they managed their injuries in the immediate aftermath of their actions, and the responses that they were met with as a result. A wide range of circumstances were encountered by participants, and sometimes even the same participant described a number of different circumstances they had faced. Thematic analysis of the circumstances for participants after self-injuring resulted in four categories:

- The first category was comprised of a small number of participants who reported that they received no help, either physical or emotional, after self-injuring. This included one

participant who said of the staff *'They're not interested at all...They just don't want to know...They just said I shouldn't do it. That's all'*. Another participant said that after she self-injured her family never said very much about it, nor checked to see how much she had hurt herself.

- The second category was of participants who said that they received physical help after injuring themselves, but no emotional support. This was by far the largest group. Participants described attention being paid to their injuries, either by those supporting them, or by being taken to a doctor or nurse, but feeling that they were not able to talk about what had happened or what their feelings were. Comments included in this category included:

'I said to Joe 'I've just cut up.' And I used to show him it, and he'll say to me, 'What do you want me to do about that for? I can't do nothing to make it better for you'... and now I don't show him no more'.

'They did bandage me but they couldn't talk about it. She said they couldn't talk about it to me'.

'I would phone them and say, 'Can I come back, or am I allowed to come back or is somebody going to pick me up from the hospital?' But nobody ... I was stuck there....Nobody came. They wouldn't come for me, so I'd have to get a travel warrant thing. Cause I had no money I'd have to get a traveller's thing and then I'd have to get [2 buses] all by myself and it was very hard'.

No participants said that they received emotional support, but no physical help.

- The third category was comprised of a very small number of participants who reported that they received both physical and emotional help after self-injuring.

'sometimes I'll just do it automatically and then when I tell them they'll say, 'Well what have you done that for...but no I think they're pretty caring, they just say, 'Well just try and not do it.' But yeah they're very understanding'.

'They deal with it here, you self-harm they'll put you on obs [regular observations] or whatever and they'll dress your arm or they'll come and talk to you'.

- The fourth and final category was of participants who felt punished or in some way to blame for their self-injury. This was the second largest category of the circumstances for participants after self-injuring. Participants talked about feeling punished when they were sent away from home for care or treatment, when they were shouted at, restrained, or had sanctions imposed on them.

'They don't really understand why I was at that, why I was hurting myself, but see they can't cope with me so they sent me away in the hospital'.

The field notes of one participant read: *'She has felt punished after self-harming. She said: 'They take all our stuff out of our room and lock them away for a few days'. She is left with a bed, mattress and 'strong blankets' in her room, and a TV which is screwed to the wall. Her own belongings are removed.*

Those who felt to blame talked about how they were made to feel as though they were upsetting the staff,

'They were always just like, 'Oh what are you doing to us? You're upsetting us.' So it was always turned back around on them, or if something happened it was because I'd made them stressed and it's my fault, so it was always my fault for everything. It seemed to be anyway'.

'The Crisis Team were like, 'Oh come on you've got to get on with it, it's not fair on your parents'

'I think a few of the hospitals and stuff were like, told me to cover up my arm 'cause otherwise I'd be scaring the rest of the patients and stuff like that'.

Participants were asked to gauge how helpful or otherwise the responses that they had received were, or how helpful the responses they would like to receive, would be. They were also asked to gauge the helpfulness of any experiences they might have. The next Chapter considers what participants considered to be unhelpful forms of support or experiences when they have self-injured.

What people with learning disabilities considered to be unhelpful forms of support after they had self-injured

Nineteen of the 25 participants commented on unhelpful forms of support or experiences when they had self-injured. None of these were hypothetical situations: rather, they were based on the forms of support that the participants had experienced and weighed up in their own minds as being unhelpful. In what ways these responses had been unhelpful were usually, but not always clear, and sometimes differed for different people. Whereas one person might consider a response unhelpful because it made them feel dismissed or humiliated, another might consider the same response unhelpful because it did not lead to them getting the support they wanted at that time. In general, however, there were three things in particular that participants frequently mentioned as being unhelpful to them.

Being told off

First, about a half of the participants found it unhelpful to be told off about their self-injury. This was particularly interesting because it was also something that some participants had found helpful (see next Chapter). Whilst participants said that they could understand why someone would want to tell them off - one participant for example thought that the staff supporting her *'would have had the right for telling me off'* - the actual exchange of being told off usually made the participants who found it unhelpful feel worse about themselves. One summed up her feelings by responding *'bad'* when discussing if being told off would be a helpful form of support or not. Rarely would being told off stop people self-injuring, more usually for this group of participants, it would lead them to *'do it more'*, or to keep their self-injury hidden so that being told off would not occur.

Being ignored

The second most frequently reported unhelpful form of support or experience mentioned by participants was when they were ignored after self-injuring. Just under a half of the participants mentioned this. One participant said that *'No one would speak to me at all when I done that'* which made her feel *'very cross'*. Another participant said:

'I feel its quite hard to understand... they're ignoring the situation instead of talking about it'.

Being told to stop self-injuring

The third most frequently reported unhelpful form of support or experience mentioned by participants was when they were told to stop self-injuring. Participants felt that this was unhelpful in the absence of any other strategies as *'that's not helping the way I'm feeling at the moment'*, and that *'It's gone on for too long'* for them to be able to stop their self-injury at will.

Other support perceived to be unhelpful

Other unhelpful forms of support or experiences mentioned by over a quarter of participants were being watched, and having the perception that staff did not care. Being watched closely in case the person self-injured again made some participants feel as though *'I need to do it more'*. It also echoed difficult childhood experiences for one participant, and made her feel as though she had done something *'wrong'*. Having the perception that staff did not care was very real for some participants. One participant said that she had been told by a support worker:

'He said, 'You can hit yourself as much as you like, I don't care.' That's what he said. Yes he did say that....I was upset when he said it'.

Another said she had been told: *'Well it's your arm, go and do what you wanna do'*.

A third mentioned that what was particularly unhelpful to her was that *'they [the staff] don't give a damn'*.

What people with learning disabilities consider to be helpful forms of support

Almost all of the participants (23 out of 25) explained what they considered to be helpful forms of support. Although participants were specifically asked about helpful support after they had self-injured, most were clear that what happened after they had self-injured depended to a large extent on how they had been responded to beforehand. Many therefore indicated helpful forms of support regarding their self-injury in general, irrespective of whether this was before or after they had injured themselves. These responses have been included here. Again, their responses were based on the forms of support that the participants had themselves experienced and weighed up in their own minds as being helpful for one reason or another. Overall, the findings about what people with learning disabilities considered to be helpful forms of support are presented in the main ways in which the participants spoke about helpful support. The first was about general support that they found helpful, whether or not they had self-injured at that time. The second grouping of responses was specifically in relation to supporting a person who self-injures – whether that be before or after they injure themselves. The third was about the qualities or the attitudes that people with learning disabilities who self-injure say they find helpful from those supporting them.

General support

Someone to talk to and someone to listen

Over three-quarters of the participants said that having someone to talk with, and/or someone to listen to them was particularly helpful. There were a number of different aspects of this that participants commented on, including the accessibility of someone to talk to, how they could best be encouraged to talk, the topic of the conversation, and the qualities and approaches of those that they spoke with.

A separate mention is made here about the three participants who had particularly limited verbal communication, and relied on augmentative and alternative communication (AAC) to relate their thoughts and experiences. Like the other participants, they were clear about what helped (and didn't help) them most. And, as with the other participants, they too expressed that what helped them most was communication-related. All three of these three participants valued physical, rather than verbal communication, and having a hug was mentioned as being helpful. Two wanted someone to spend time with them, and specifically mentioned being helped to communicate how they were feeling. One stressed the importance of someone listening to her, underlining the fact that listening can take place at many levels and does not merely involve only paying attention to the spoken word.

Having access to someone to talk to

A number of participants commented on when it was particularly helpful to talk. For most, talking with someone was not something that could always be timetabled in – what was most supportive was when, additionally, the person themselves had available to them someone that they could talk with when they wanted to, and felt best able to talk about things. For one participant this was the key for her reduction in self-injury:

'If you want to talk, [they] sit and they listen to you...they always talk to you the staff here.'

Having open access to someone to talk to was, as with the participant above, considered the most helpful. Participants stressed that they needed to be able to talk with someone when they had problems that were stressing them, when they felt like harming themselves and after they had done so. Some participants had been living in circumstances where this had not been possible, or the policy of the organisation had been such that this was not the approach taken; all of these participants were clear, however, that being able to speak with someone at a time when they needed to would have been helpful to them. One participant mentioned the difference that being able to speak to someone had made to her self-injury, and described hurting herself much less frequently when living in an environment where she was able to speak to someone when she felt she needed to. Another reflected on her experience of two different styles of support, and said that she felt better supported when able to speak to someone at any time, rather than only feeling able to speak to someone about her problems and feelings during an allotted hour each week.

The importance of having access to someone to speak with at different times was emphasised again and again. For most participants, having access to someone to talk with when they felt like self-injuring was the most helpful; they felt that this could help them stop hurting themselves. One participant summed up:

'Normally if I'm talking it normally stops me from doing it; they pull me around enough for me not to do it.'

Another described that if she was unable to speak with someone when she felt like her emotions were becoming unmanageable *'it could send me over the edge'*. It was more helpful for her to speak with someone when she was thinking about hurting herself because she felt that it was *'all over'* if she was only able to speak with someone after self-injuring: *'by the time I see Eddie I've got over what I needed to see Eddie about'*.

Being able to talk with someone after self-injuring was, however, valued by some participants. For most of these, this was in addition to being able to speak with someone

when feeling like self-injuring. One stressed that *'talking to me after the incident'* was particularly helpful because it could help her think about what had happened and why. Another, however, said that what helped her most was having a chance to talk with someone after she had calmed down a little after self-injuring: *'I would like calm down, then I'd talk about it'* was what was most supportive to her.

Having open access to someone to talk to was recognised to be important at other times too. One participant described how, when distressed, she found it particularly difficult to talk to anyone and would withdraw into herself at those times. She found it most helpful to be able to talk with someone when self-injury was not an immediate issue. When asked about the best time for her to be able to talk to someone she responded:

'when everything's quite calm...when I feel quite good with myself'.

In contrast, another participant explained that she could only talk to someone when she was extremely distressed. She said:

'I have to be crying first... I have to be crying and very upset before my feelings come out... I find them hard to talk about'.

When talking is difficult

A number of participants said that although they found talking with someone helpful, it was not always easy; some admitted *'I'm not very good at that'*. A number felt they needed permission to be able to talk to someone; others needed active encouragement to be able to do so. Where this was not on offer, participants often reported finding it too difficult to approach someone and their feelings escalating as a result. One participant, reflecting on her own self-injury said:

'It would have been better if the staff says, 'Oh if you feel that feeling come and talk to us.' But they didn't'.

Another participant who found approaching staff to be particularly difficult because *'they're always busy'* wished that staff sought her out and gave her the opportunity to talk if she wanted it. She reflected:

'Sometimes I hope, when I'm in the middle of doing it, I hope that somebody will come up and talk to me before I do it, but it doesn't happen'.

When talking was difficult for participants, some gave examples of when staff had been proactive in encouraging them to talk and they had found this helpful. One participant needed staff to be quite assertive with her:

'And sometimes I'll be quite quiet...and if people ask me if I'm alright then I'm like, 'Yeah,' but then I wouldn't be, but I wouldn't ever actually say that I'm not alright. Then sometimes, like at Hillside, a few members of staff would drag me in the office and say, 'What's wrong?!' And I'd be like, 'OK ra, ra, ra.' Sometimes I need to be prompted....I needed them to tell me to do that'.

Another felt she needed permission *'to know that it's OK to talk about certain subjects if you want to'*. A number of participants had experience of living in environments where they were not allowed to talk about self-injury, or could only do so with particular members of staff at particular times. It seemed particularly important for some

participants, especially those who had moved between support placements, that they were explicitly invited to talk about self-injury with staff in ways that were helpful to them.

For another participant, however, being reminded to talk to someone was helpful enough in itself. She had found helpful being told:

'Will you please when you're feeling, even that you're wanting to, will you come and....just talk through it and see if that will help you.'

Who to talk with

There was clearly a lot of individual preference regarding participants' preferences as to who to talk to. For some, being able to talk with someone...indeed anyone...was of crucial importance. This was particularly the case when participants were in crisis. For many, however, what was most helpful was to have someone that they knew and trusted available to talk with them. Participants generally appreciated talking with people that they trusted, and that they had known a long time, as these participants emphasised:

'I find it really hard.....really awkward....it is harder asking carers who I don't know.'

'I just trust her because I know her a long, long time.'

'I only talked to certain people.... Just Ava...I know Ava 22 years.... She's my friend, she listens to me.'

Participants were generally quite discerning about who they spoke with, and many named specific members of staff or supporters who they found it most helpful to talk with. For some, the person was named because of their particular role in the participant's life, such as their key-worker or their psychologist. For others, however, what was important was not the role of the particular person, but their qualities and approach. One participant clarified:

'I don't go to all the staff. I only go to some of the staff.'

A fuller explanation of the qualities and approaches that participants said they found helpful is given on page 67. Suffice to say here, participants exercised a considerable degree of sophistication in deciding who to speak with in a professional capacity.

A minority of participants named family members or friends as being helpful people to speak with. However, even when participants were in close contact with their families, some chose not to speak with them about their self-injury because they didn't want to 'stress' them or worry them. One person said that she would prefer to go to:

'somebody that's getting paid.... 'cause at least I don't have to worry about them, 'cause otherwise I have a tendency to worry about the other person, and then obviously that's not helpful for me and it's not helpful for them.'

What participants want to talk about

Participants identified a number of things that they wanted to talk about, but many were clear that it wasn't just the content of what they were talking about that was important; it was more the quality of the listening. Participants may have been encouraged and enabled to talk with a member of staff when wanted, but if that member of staff wasn't really listening to what they were trying to say, participants suggested that they tended to limit what they said. One participant explained that in such circumstances:

'I mean I could go and talk to them and stuff, but not properly talk to them.'

The topics that participants did want to talk about varied, but predominantly included talking about the problems they faced, day-to-day issues and their feelings. However, without exception, participants reported that what was particularly helpful was the fact that someone was prepared to talk with, and listen to them, rather than what exactly it was that was said. Being able to talk things through and have quality listening helped one participant because:

'It doesn't feel like the problem is so bad, if you know what I mean.'

Participants said how talking things through *'eases a bit of the pain what I'm under'*; *'make[s] me better if I tell it'* and *'makes a relief in me'*. Another participant explained:

'I suppose in order to tell somebody else you've gotta put it in some sort of sense for them to understand it, so then I suppose you're working it out for yourself.'

There were a number of participants, however, who did have clear ideas about what it was, or was not, helpful to talk about. For some, talking about a specific subject was important. This might be debriefing after an incident of self-injury, to talk about their feelings, and to feel reassured:

'I talked over what happened and all that, and they talked me over it and reassured me that everything would be OK....and just talked to me and said, 'Don't worry about a thing, worry about yourself for a change, stop worrying about everybody else.'

It might also be about a specific problem that the person was facing and needed support with:

'We just went for a coffee really and had a talk about the funeral and everything 'cause I've never been to one, it would've been me first time, she just explained what it was all about. She was really good.'

For others, talking about more general issues and helping to distract them was particularly helpful. One participant said that what was most helpful to her was when her support worker responded in the following way:

'And she'll say, 'Just calm, you'll be alright.' And she'll just talk to us....she just sits with us as long as I want. Well she takes me mind off about it, just talking to someone else and making sure that I'm feeling alright.'

What was apparent from many of the participants was that as long as the subject of the conversation was being led, and paced, by them, the experience of talking to a supporter of theirs was positive. It was when a conversation was being forced or directed by someone other than the person with learning disabilities that it was in danger of becoming unhelpful. However, as has already been mentioned, some participants did need prompts, encouragement and/or permission to feel able to lead and pace a conversation themselves. Some liked staff to ask them direct questions about how they were if they appeared distressed. Yet in all of these cases, the impression was that this was more due to their own insecurities and their lack of confidence in directly asking for help. The underlying message from the participants was clear: with respects to what was being said

in a conversation, what helped them most was being reminded of the easy availability of a trusted person who would really listen to the person concerned, and with whom they could communicate whatever they wished to, at their own pace – providing that this was possible.

Supporting a person specifically in relation to their self-injury

The second grouping of responses about what participants considered to be helpful forms of support was specifically in relation to supporting a person who self-injures – whether that be before or after they injured themselves. In addition to general support, and particularly that regarding communication outlined above, participants expressed three key features of helpful support regarding their self-injury. The most frequently reported helpful response was the provision of sensitive support in looking after their injuries. The second most frequently reported helpful response was something that has already been mentioned in the context of unhelpful support: participants being told or encouraged not to self-injure. This will be explored further below, and the differences between what is helpful about this, and what can be unhelpful, are drawn out. The third most frequently reported helpful response specifically in relation to their self-injury was participants knowing that they were not alone, and having contact with someone else who self-injured.

Help with looking after one's injuries

Participants generally hid their injuries as much as possible, as has already been mentioned on page 36. However, the degree to which they were able to keep their injuries hidden varied considerably, and was, in part, due to the skill of the individual in caring for their own injury and concealing it. That said, as with anyone who has sustained an injury, irrespective of how it has been caused, it is hardly surprising that some of the participants felt in need of support in dealing with their injuries. For the majority, this was in the form of practical help with cleaning their wounds and accessing dressing materials such as plasters or bandages.

'I went to the office and I told somebody what had happened, because I thought it was worse than it turned out to be, but it wasn't but I had to, it was bleeding....covered in blood'.

'It was a man doctor.... He said it [the scratch on the participant's body] was horrible....[He] looks at it, and he puts a dressing on it, yeah'.

'They took me up to the bathroom and run water over it to clean it and then I had to go to the hospital'.

The importance of receiving sensitive support and help to look after their injuries was especially crucial to some of the participants because of their own ambivalence about doing so themselves. One participant described wanting to ignore her injuries so they became infected, but also preferring her injuries to be cared for and dressed appropriately. Another said that the most helpful thing for her was to have a bandage on her arm, but that she felt she shouldn't have this because it would help her injuries to heal. A third asked staff to call a doctor for her because she *'can't take pain'* even though she preferred to be alone when she had self-injured. Clearly, the thoughts and feelings that the participants had, and the actions that they took, or that others took on their behalf, were incongruous at times. This is a point that will be returned to later when exploring the views of supporters. For now, it is suffice to say that some of the participants had multiple and complex reasons

for finding it helpful to have a dressing over one's injury when others might not think it necessary. What was apparent was that in most cases, these reasons had not been fully explored or considered by those supporting them.

A key theme emerging from the participants' accounts of their self-injury was their perceived or actual difficulty in accessing support. This was an issue that was again raised when discussing the provision of sensitive support in looking after their injuries. Some participants valued strategies that enabled them to better help themselves or obtain help in a clear and unambiguous manner. For one participant, what had been helpful was attending a First Aid Course with one of her support workers. She described how getting her injuries dressed by a nurse used to make her feel worse, so learning basic first aid herself, and knowing what she could (and couldn't) deal with herself had been empowering:

'I used to go up to the nurse and I used to be annoyed, get fed up...I think they've got enough to cope with.'

Another participant had written a Wellness Recovery Action Plan (WRAP) (Copeland, 2002). A WRAP plan is a tool for self-understanding, and for communicating to oneself and others what helps and what doesn't help, and how others can work in a supportive way with that individual when they are less able to take care of themselves. As the participant explained:

'I wrote a WRAP plan...which was describing me when I was well, triggers, stuff other people could do to help, warning signs of when I was getting poorly and stuff. Then after I wrote that was quite a big change, because then a member of staff said to me, 'Well Nic you're getting all hyper'. And I'd be like, 'No I'm not.' And they were like, 'Well you told us to tell you if you are'. And I'm like, 'Oh yeah, maybe I am.' Because it's my instruction and I told them I couldn't really say, 'well you don't know what you're talking about'. So that was quite a big change around...It's like an easy reference for people. Like I wear quite blacky clothes, and if I came down in a pink flowery skirt or a pair of wacky trousers they'd probably pick me up for the wacky trousers, whereas the pink flowery skirt would be the real alarm bell ringer, 'cause I wouldn't wear it, but then they'd know if they looked ... and it'd save me telling everybody and explaining things'.

A strategy used by another participant was to attend a self-advocacy group where she learnt how to speak up for herself in order to better cope with stress, build her confidence and get her needs met. She spoke highly of the group saying that before attending her confidence was down on the ground, but that it had since been *'growing, and growing, and growing'*.

Being told or encouraged to stop self-injuring

The second most frequently reported helpful response, specifically in relation to a person's self-injury, was participants being told or encouraged not to self-injure. As has already been mentioned, this was also considered to be a particularly unhelpful form of support reported by participants. That being told or encouraged to stop self-injuring was considered to be particularly helpful or particularly unhelpful by participants is interesting, and illustrates the individual, and informed approach to support that is needed.

The key to understanding the polarity of views lies partly in the comment made on page 56 that participants felt that it was unhelpful to be told or encouraged not to self-injure *in the absence of any other strategies*. In part, however, it seems that what mattered was the

degree of genuineness and respect between the participant and the person who was telling or encouraging them not to self-injure. In those cases where participants found it helpful to be told or encouraged not to self-injure, participants seem to have appreciated this when it was said by someone for whom they felt their well-being genuinely mattered, someone who knew them well, and someone with whom there was mutual respect. This was not spelled out by any one participant in such a way; more it is the impression of the researchers based on an analysis of what and how the participants spoke about being told or encouraged not to self-injure.

Helpful support in relation to being told or encouraged not to self-injure was illustrated by one participant talking about her friend. She said that they: *'hate seeing me doing it'*, and when asked what her friend said to her, replied that the friend had told her:

'If you do it again I'll fallout with you.' She added: *'But even though that wasn't true, they will say that and so I wouldn't self-harm again...I didn't really mind...no. No 'cause I knew they cared about me and if they didn't they wouldn't have said that...It made me feel good'*.

Another participant reflected that it was *'maybe helpful'* being told or encouraged not to self-injure. The only person that she found it helpful to hear this from was a professional she had known for a long time. The participant said that what was key was that:

'She would talk to me and tell me to stop it and all...she talks to me a lot better than other people. I trust her more'.

For a third participant it was a close and trusted family member who she knew was upset by her self-injury. There appeared to have been great respect between the two and the participant was able to take the family member's views into account for two reasons: firstly because there were no conditions attached, and secondly because she valued and felt cared for by the person. She reflected:

'If I hurt myself they hate to see me do it, they don't like seeing me doing it, they hate it'.

The issue of conditions being put on a person when they are encouraged or told to stop self-injuring appears interesting. On the whole, no participants who were subject to conditions, sanctions or rewards found them entirely helpful. Almost all spoke of trying to *'outwit'* conditions or restrictions imposed on them, of having heightened difficult emotions because of perceived unfairness and a lack of transparency with sanctions and rewards, and of resorting to dishonesty when they had not met the conditions placed on them. One participant did however find the *'no self-injury'* policy of the unit at which she was temporarily staying helpful in part. She clearly wanted to stay at the unit, believing that it was helping her to *'pick yourself up'*, but also struggled with wanting to self-injure saying that the feelings were *'constant'* and causing stress for herself. She explained :

'I think, I mean still the thoughts are still there, but I'm really not allowed to really do it in here. And I personally think that it does help people, it really does to have that policy there, because they don't say that you can't do it, they just advise you not to do it, but they might advise they might not. And it's a matter of do I really want to stay in here? And yes I do really. And do I want to self-harm when I'm in here? It's like a bit of me wants to self-harm in here, and a bit of me wants to stay here, so I think it's half and half really'.

This participant also talked about drinking more alcohol and having more headaches than usual since staying at the unit, although whether this was related to her perceived stress of not self-injuring is unclear.

Overall, it appeared that what was most helpful to participants in relation to telling or encouraging them not to self-injure was helping them change their ways of thinking, rather than change their ways of behaving. Helping someone to change their ways of thinking was for many, a long, slow process, requiring continuity of support and ample opportunities to talk and be listened to, to frame and reframe beliefs about themselves and their place in the world. It was not impossible for this to happen a great deal quicker, however. One participant, driven by determination and motivation that had helped her survive immense difficulties through her life said that what had been helpful to her was when someone who knew her well and with whom she had a good relationship had commented: *'Oh you're self-harming over stupid things'*. The participant explained:

'I had the thought in my head, the voice would be going, 'You self-harm over nothing.' And I was like, Right. Screw you, I'm not doing it again, I'm gonna prove you wrong. So that's what I did... I was like, Well if you think it's stupid I'm not going to do it again'.

In this case, as has been illustrated by others, what was helpful about being told or encouraged not to self-injure was the relationship between the two people. In summary, it appears that for telling or encouraging someone to stop self-injuring to be helpful, what is needed is:

- for it to be said by someone for whom participants felt their well-being genuinely mattered
- for it to be said by someone who knew them well and with whom there was mutual respect
- for the words to be accompanied by other strategies such as having ample opportunities to talk and be listened to, and
- when it was intended to change a person's way of thinking rather than have an immediate impact on their behaviour.

Knowing someone else who self-injures

The third most frequently reported helpful response, specifically in relation to a person's self-injury, was participants knowing that they were not alone, and having contact with someone else who self-injured. Almost half of the participants said that they thought this was, or would be helpful.

The main reasons why this was thought to be helpful were firstly because it could help participants identify with others and not feel so isolated, secondly because it could help them get their own problems in perspective, and thirdly because it held the possibility of obtaining general support from their peers.

The greatest impact of knowing someone else who self-injured seemed to have been experienced by two participants who had been in contact with workers with personal histories of self-injury. One participant had attended a training day delivered by someone with personal experience and found this interesting and helpful. She recounted:

'the person that actually ran it had seriously stuff wrong with her...but she got through it the other side, so she was like a major inspiration'.

The second participant had attended a support group facilitated by someone with a personal history of self-injury. She said that she had been *'sort of took back'* at finding out about the facilitator's own experiences but that:

'It was sort of a relief because I realised it was not only me that was ... crying out for some help at the time ... She just seemed so open about it.'

Many of the participants seemed to be living lives that were touched by physical and/or emotional isolation on a day-to-day basis. This isolation appeared to be compounded by their self-injury, and knowing someone else who self-injured held the potential for some participants to feel less alone and, as one participant put it, *'At least I know that I'm not the odd one out'*. For most of the participants concerned, knowing someone else who self-injured was on a one-to-one or group basis. However, one participant found a TV 'soap' storyline about self-injury supportive:

'There was a character on Hollyoaks who self-injured ... And I can remember that quite clearly because that helped me a bit ... that was quite helpful.'

Another reason for participants finding it helpful to know someone else who had self-injured was because it helped them to get their own problems in perspective. Exchanging views with someone who had gone through similar circumstances made participants feel that their own problems were more 'ordinary' and less overwhelming. One participant commented:

'It made your situation look far less a problem, if you know what I mean, when you heard somebody else's. It made you feel that wee bit better.'

Another participant said:

'There's people all round the world does it. I'm not only one, it's just life.'

The receipt of *'good support'* from their peers also made it attractive for some participants to know someone else who self-injured. They appreciated knowing that someone else was willing to listen in a non-judgemental and supportive manner. And they found it helpful learning about how other people coped with emotions similar to their own, and how others had stopped themselves from self-injuring. As one participant commented:

'The other people, some of them have cracked it and they may say how they did it and stuff like that.'

The positive gains that some participants had received from knowing others who self-injured were tempered by two participants who spoke of when this had become tipped over into becoming unhelpful for them. It seemed that there was a fine line to be drawn between peer support, and peer demand. Where people genuinely supported each other in a give and take relationship and a spirit of mutual assistance knowing others who self-injured seemed to be helpful. However, when comparisons started to be made between what one person was 'allowed' to do or have compared with another, and when one person took on another's problems and went too much 'in depth', then knowing someone else who self-injured was thought to be unhelpful. One participant warned:

'[If] it gets too close and you take on other people's problems you'll become ill and it just goes poof!'

The qualities or attitudes of supporters which are valued most

When the research participants related what they found to be most helpful from those supporting them, the majority commented on one or more personal qualities or attitudes of the support person. The 'Top Six' qualities or attitudes that participants found most helpful in a support worker were, in order of frequency:

- being easy to talk to and a good listener
- being non-judgemental, accepting and respectful
- being trustworthy and honest
- being caring, generally kind and nice
- being understanding and perceptive
- the support worker's own sense of calmness, and their ability to help others calm down.

Table 7 (over-page) illustrates some of the comments that were made by participants about the helpful personal qualities or attitudes of a support worker. Whilst the 'Top Six' outlined in Table 7 were mentioned with the most frequency, other attributes and qualities that were mentioned by a few participants each included the support worker having a sense of fun, of being friendly, of the participant and the support worker having shared interests, and of the participant feeling comfortable with the support worker.

Therapeutic input and/or longer term strategies for addressing self-injury

Nine of the 25 participants mentioned receiving therapeutic support aimed at addressing their self-injury. Most described this as 'counselling', although other therapies mentioned included art and drama therapy and behavioural interventions, such as anger management or cognitive behavioural approaches. It may have been the case that others had received such interventions but had forgotten about them, or had not understood them to be as such.

Comments on the effectiveness of therapeutic support aimed at addressing their self-injury varied, but the main theme that emerged from participants' accounts was the importance to the participants of longer-term, rather than short-term, therapeutic interventions. On the whole, participants felt dissatisfied with short-term interventions because it took them time to explain their thoughts or feelings, or because they forgot the techniques they had learned. One participant spoke about feeling let down when short-term counselling came to an end:

'It's like they build us up for that period deep down I still want to see them and six to eight weeks is not enough time. And then when it stops I think to myself that they've let me down and that's when I go into me own little world of me own....I just can't be bothered then'.

Others mentioned that counselling was helpful, but that 'you forget what they've told ya'. Participants said that they needed reminding about what was being talked about and time to practice strategies that they were learning. Throughout this time, the same person needed to be in the counselling role. It seemed to be that when the therapeutic input ended, the tendency was for participants to no longer be able to relate to their previous learning. For example, one participant found a relaxation tape that her psychiatrist had given her to be helpful, but no longer used it once her psychiatrist moved on.

Table 7: Helpful personal qualities and attributes of support workers according to participants

Quality/Attribute	What participants said about this
Being easy to talk to and a good listener	<p><i>'Well it was somebody you could talk to, and she would listen. But she wouldn't do all the talking, she would let you talk.'</i></p> <p>P: <i>I'd probably ring Mary.</i> I: <i>Why would you ring Mary particularly?</i> P: <i>She listens</i></p>
Being non-judgemental, accepting and respectful	<p><i>'Just people not judging, yeah people not judging you for it.'</i></p> <p><i>'If you judge people it actually makes them feel worser. If you say, 'Oh well you're stupid for doing it' it makes them 20 times worse than what they already are.'</i></p>
Being trustworthy and honest	<p>P: <i>I find it very very hard to trust them.</i> I: <i>So what helps you trust people?</i> P: <i>That they don't miss things out when they are telling me things.</i></p> <p><i>'not just pretend they know what I mean, and if they don't, tell me they don't'.</i></p>
Being caring, generally kind and nice	<p><i>'Like now I mean she's absolutely brilliant with us, she's so caring.'</i></p> <p>I: (Showing the participant symbols) <i>And this one – someone being kind?</i> P: <i>That means nice?</i> I: <i>Yeah. That means somebody being nice. Where would that go? What pile is that?</i> P: <i>That one.</i> I: <i>That one – the 'good' pile you're pointing to. OK.</i></p>
Being understanding and perceptive	<p>I: <i>So when people see you with your coat on in the house or your clothes on in bed they should realise that you might be getting sick because that's something that you do when you're not feeling too good. Is that right?</i> P: <i>Mm</i></p> <p><i>d understand me I suppose'.</i></p>
The support worker's own sense of calmness, and their ability to help others calm down.	<p><i>'If somebody flaps then I'll flap because I think there's something to flap about'.</i></p> <p><i>'Some people, some of the staff...are just like chilled all the time so then that helped chill me'.</i></p>

Another participant spoke about how difficult it was to change her ways of thinking and behaving even with the support of her therapist, let alone when her therapist had left:

'They see you for so long, they give you the information and they expect you to go out and do that, but it's not as straightforward, it's not as easy as that'.

Two of the participants with learning disabilities spoke about longer-term, focused interventions that they had experienced with a view to helping them address their self-injury. Both had received cognitive behavioural approaches and spoke highly about them and the difference they had made.

One participant had attended an 'emotional literacy' course *'to try and work out what feelings were'*. Prior to that, she said: *'I didn't know whether I was angry, happy, sad or anything else....[at most] I could say that I've had a bad day and it's all gone wrong'*. She found this *'the majorist help'* because once she could recognise her feelings she could then do a number of other helpful activities. These included writing diary cards to record what had happened each day and how that had made her feel, assessing whether she had grounds for feeling that way and planning what she could do about it.

As she explained:

'If I'm stressed and anxious then I sit down and think, well what am I stressed and anxious about? Then I'll write a list, and then I think, well I need to sort this, this and this out, then I sort it out and that gets rid of it. So it's so simple, but sometimes you don't always think about doing it'.

The second participant had completed a 'mood chart' as part of her work with a psychologist:

'There was a sheet and it had like mood thoughts, and when I used to cut myself I had to write down when I did it and where it was and what I feel...I used to draw a smiley face or a happy face...It was quite a good sheet to write on, but I used to have help writing it 'cause I couldn't write it myself... it just helps you how you're doing and how you're feeling'.

She particularly valued looking back through her entries to remind her of how far she had come since those early days, and how much she had achieved.

What people with learning disabilities thought in general about their own, or others', self-injury

The interviews provided opportunities for the participants to comment in general terms, about their own or others' self-injury. A wide range of comments were given, but what was overwhelmingly apparent was the harsh and negative way in which participants spoke about self-injury in general. This was in contrast to the way participants spoke about individual incidences of self-injury, which were frequently reported to have made them feel 'better' or more able to cope with difficult emotions.

When speaking about self-injury in general, only two of the participants were in any way accepting about it. One commented *'it's just life'* and the other said *'it's alright for me I'm used to it'*. Almost all of the other participants spoke about self-injury in general in harsh and negative ways.

The most frequent way in which participants spoke about self-injury in general was within the framework of it being a 'good' or 'bad' thing to do and that they had been 'good' if they had not self-injured. A fairly typical comment made to the researchers was this, when the participant was telling the researcher whether she had self-injured since they had last met:

'I've still been good and not self-harmed or anything.'

Another participant told the researcher that she was trying hard to be good, which the researcher explored further:

'I: And you say you're trying to be good, what do you mean by being good?'

'P: Well not harming myself.'

'I: OK. So you think if you hurt yourself that's being not good?'

'P: It's being bad.'

The second most frequent way in which participants spoke about self-injury in general was that it was 'stupid', or that they were 'stupid' to behave in such a way. *'It was stupidity', 'if I was stupid enough to do it', and 'I think it's stupid'* were all typical comments. One participant admitted that:

'I thought everybody that hurt themselves were stupid'.

The third most frequent way in which participants spoke about self-injury in general was that it was 'wrong' for them to self-injure, that self-injury wasn't the answer and that they shouldn't do it. Fieldwork notes from an interview with one participant who didn't use much verbal conversation illustrates this:

'Amber was very engaged with the pictures [showing different types of self-injury] and was generally very clear about what she does or doesn't do. At times she identified herself with the pictures saying 'That's me'. Sometimes she was judgemental about the pictures saying 'Ohh', 'Cut that out!' 'Don't do that.'

Other participants said that they thought it was wrong because *'you're not meant to hurt yourself', 'it's not normal behaviour'* and *'I could get an infection there and have me arms chopped off or something'*. One participant considered that self-injury *'causes more issues, more problems for yourself'* and another said:

'It's just not right, because at the end of the day you're scarring your whole body and it doesn't look nice'.

Chapter 4:

Research Findings: The views of family members and professionals

Family members taking part in the study

Fifteen family members took part in twelve interviews.

Seven of the family members were 'linked' to a person with learning disabilities who self-injured and who was taking part in the study. All seven family members were individually interviewed with the person with learning disabilities' consent. All of the 'linked' family members were parents or siblings of the key participants.

In addition, five interviews were conducted with eight 'family informants' not linked to any of the research participants. Each of the family informants had particular views and experiences to relate to the research team about supporting a family member with learning disabilities who self-injures. Seven of the eight family informants were parents of people with severe learning disabilities who self-injured and who were unable to give informed consent to being interviewed in their own right. The eighth family informant was also a parent. Their daughter had chosen not to take part in the research study herself, but had agreed for her parent to be interviewed by the research team.

Professionals taking part in the study

Thirty-three professionals were interviewed for the research study.

Twenty-two of these were 'linked' to a person with learning disabilities who self-injured and who was taking part in the study. All of the professionals were interviewed on their own with the person with learning disabilities' consent. Table 8 shows the different roles that the professionals undertook in relation to the participants with learning disabilities in the study. As Table 8 shows, the professionals who were interviewed came from social service, health and voluntary sector backgrounds.

Table 8: The different roles of the professionals in relation to the participants with learning disabilities

Role	Number	Percent
Current key-worker	6	27
Past key-worker	3	14
Service manager	3	14
Support worker	2	9
Community Learning Disability Team	2	9
Psychiatrist	2	9
Psychologist	1	4.5
Social Worker	1	4.5
Occupational Therapist	1	4.5
Voluntary sector worker	1	4.5
Total	22	100

In addition, eleven interviews were conducted with professionals not linked to any of the research participants. Each of these professionals had particular views and experiences to relate to the research team about supporting people with learning disabilities who self-injure. Table 9 shows the variety of backgrounds that these professionals came from. As Table 9 shows, the non-linked professionals also undertook diverse roles. They included people from education, social care, health, the voluntary sector and academia.

Table 9: The different backgrounds of professionals interviewed who were not directly linked to any research participants

Role	Number	Percent
Service managers/deputy managers (housing services, day service, 'Challenging Behaviour service)	4	36
College staff (teaching; care staff)	2	18
Support workers (older people; men)	2	18
Transition worker	1	9
Voluntary sector organisation supporting people who self-injure	1	9
Academic	1	9
Total	11	100*

* the total does not add up to 100% due to rounding

The shortest length of time that any of the professionals had been supporting the participants with learning disabilities was four months; the longest time was 14 years. The mean (average) length of time that the professionals had supported the people with learning disabilities was four years and six months.

Terminology used

The views of family members

There was considerable reluctance on the part of family members to use the terms 'self-injury' or 'self-harm'. The majority preferred to use a description of the behaviour of their relative, such as '*her scratching*', '*her banging*' or '*when she bites herself*'. When asked, most families struggled to define 'self-injury' or 'self-harm', either because they had not heard these terms used in relation to their relative before, or because they disputed the use of these terms. One family member said:

'I don't think it's self-harm as such, is it, it's just frustration; she beats herself, she doesn't cut herself on an instrument or ever use an instrument to hurt herself, she just beats herself in frustration basically...and her face, she hits her face... 'cause she wants something'.

Another explained:

'She bites herself, they used to say she bites herself...she uses her elbow to [bang something]. No they haven't named it, given it a different name, no, not really...Self-injury is an individual thing really. It's very individual because some do it in some other

ways and some do it in that way. I mean Carly has never ever done that. Carly only arms [uses her elbow to bang things] and hands biting [bites her hands].

One family member only thought of self-injury or self-harm in relation to people without learning disabilities:

'I don't [hear the terms self-harm or self-injury being used]. I used to think it was people trying to get, you know, attention seekers, especially young teenage girls if they couldn't have what they wanted... I didn't know anything about Ali, why she does it and why she'd want to really hurt herself the way that she does.'

At only four of the twelve interviews – a third – did family members said that they had heard the terms 'self-injury' or 'self-harm' used in relation to their relative, or used these terms themselves. In general, the terms were used interchangeably with no semantic difference between them. Where one term was used more than another it was a matter of preference only, not because of any specific meaning ascribed to that term. In addition, one family member used the term 'self-abuse' interchangeably with 'self-injury'. Only one family member gave a clear definition of what they meant by self-injury or self-harm, describing it as *'anything that inflicts pain on ones self'*.

The views of professionals

There was a considerable degree of confusion about the preferred terminology that professionals used, and the reasons for this. Most used the terms self-injury and self-harm interchangeably. One professional asked: *'Is there any difference between the two [terms]?' Others struggled and gave comments such as: 'I've never really come across self-injury being different to self-harm' or 'It's roughly the same I suppose'. A smaller group of professionals did, however, differentiate between the terms 'self-injury' and 'self-harm'. In these cases the preferred terminology depended on:*

- *how self-injury was generally referred to within that service: 'We always just use the term 'self-harm' at Hinton Park'*
- *whether the person had learning disabilities or not: 'I'd use self-injury to them [people with learning disabilities] and people without a learning disability more say self-harm'*
- *the type of injuries that result: 'Self-injury could certainly be everything that shows in a physical way, that is from head-banging, or cutting, scratching, injuries causing a physical injury. Whereas self-harm might also include, to me, exposing yourself to something that has a psychological impact on you which is not immediately visible'*
- *the intention of the behaviour: 'Self-harm sounds like it is deliberate, the person's deliberately self-harming, whereas self-injury could be accidental'.*

Clearly, with no generally agreed terminology, situations arose in which behaviour that was identified as self-injury in one service would go unreported as such in another. For some of the professionals, taking part in the research interview gave them a chance to clarify their own views and think through some of the issues and implications. One professional commented:

'To be honest, when [manager] approached me...I thought 'God, does she self-harm actually?' And I think: 'Well, she does scratch her legs. Is that classed as self-harming?' And well, it is, isn't it? Because she's hurting herself. And I know everyone else thought the same thing really'.

Another said:

'I never thought of slapping and getting deliberate bruising and things like that – I never really thought that was self-harming...you were thinking of knives and slashing themselves and things like that – that was my thought of self-harming'.

Other terminology that was used less frequently included:

- Self-injurious behaviour: *'in learning disabilities SIB or self-injurious behaviour's more common than self-harm'*
- Challenging behaviour: *'We see self-injury as challenging behaviour, it presents as part of challenging behaviour. It's not just that in isolation, that's not the only thing they do. It's one of a number of behaviours that may crop up'.*
- DSH - deliberate self-harm: *'I don't hear that word anymore really. When I was a trainee say nine years back that was quite common'.*

Communication between family members and services regarding self-injury

Most of the linked family members (six out of seven) lived apart from their relative. Two out of five of the 'family informants' also lived apart from their relative. Generally, most family members expressed some dissatisfaction about the communication between themselves and the services that their relatives used, with regards to communicating about their self-injury. As was mentioned on page 72 above, at only a third of the interviews did family members say that they had heard the terms 'self-injury' or 'self-harm' used in relation to their relative. Most conversations – when they did occur - were conducted about the person's behaviour or their moods. Even so, many of the family members felt that they would have valued more openness in the communication. Comments made included:

'They don't say a lot to me, they don't say what they've done or what they've said. They just say, 'Oh, we've had to take her down to the medical or the walk-in centre, or the doctors'.

'They usually tell me, 'No, no that's fine, we haven't had that problem'. And sometimes when I go to fetch her for the weekend she's clearly very high and so I ask if anything's happened, 'Oh no, no, nothing has happened', but then you subsequently find out that actually something did happen'.

'I wish they'd let me know. I never know when he comes home if I'm going to be - his face whole or his face scratched'.

Family members stressed the importance of good communication regarding their relative's self-injury for a number of reasons. As the family member above explained, they would like to know what to expect. Other reasons given included: so they do not misjudge a situation, so they can look for patterns or identify triggers, so they can gain an overall perspective of the type and degree of their relative's behaviours, so they can determine if there is anything more they can do to support their relative, and so they don't feel quite so isolated. One family member commented:

'It [good communication between themselves and the service that their relative used] was helpful..., because you do feel very isolated, you're dealing with this tempestuous behaviour and you don't really know what to do'.

Two family members said that rather than themselves be the recipient of information or advice from services, they were the provider of advice to services about the best ways to

manage their relative's behaviour. Sometimes this advice was requested; in others it was offered unsolicited:

'I've told [the staff], because they said nothing they do calms her down. I said 'you're best just leaving her alone, make sure that she's not going to injure anybody or anything''.

'We've told them these things, and say maybe visit and check on her, see how she is, the reaction and her voice and things. How she replies to them they should watch out for'.

Circumstances associated with the start of a person's self-injury

The approximate age at which the participants' self-injury had started has been considered on page 33. Many of the family members, however, remembered in greater detail than the participants the particular circumstances that were associated with the start of the participants' self-injury. For some of the family members, these memories were very vivid, even though they had happened many years ago:

'We were in the car taking her back to school and I happened to turn round. I was driving and we were at the traffic lights, and I turned round and her whole hands were all bloodied. So I pulled up and my husband got out and went and got some saline and cotton wool from the chemist'.

'When she went to the first school ... she was in a baby walker at that time when she would scoot herself around like most youngsters, but she would go over to something like the radiator and go to headbutt it'.

'When we went to the training centre I noticed that her little ornaments were gone that my mother had given to her. I thought, 'Well what's she doing with them, then?' In the bottom of the wardrobe I found this carrier bag and about that deep at the bottom was broken bits of pot, glass, ornaments, pebbles. So I went down to the Centre and said, 'Are you doing anything with mosaics or anything, is that what she's breaking them up for?' 'No, no'. They didn't want anything like that. And then she started really cutting herself then'.

'He never started doing that until he was about seven years old, he'd just scream all the time and just constantly cry but not actually hurting himself...and then all of a sudden when he went to about seven that's when he started. At seven he started twirling round but keeping his eyes that way all the time and just constantly going, and you had to keep stopping him all the time, and then he'd get himself worked up because you were stopping him...then that's when the hitting started'.

In contrast, 'linked' professionals only had very hazy knowledge (if any) of when the person they supported had started self-injuring. Over half of the 'linked' professionals believed the self-injury to have started 'many years ago' but could be no more specific than this. Typical comments included:

'I think it's long standing but I don't know when and how it started.'

'It's something that she's always done, even when at home when she was younger, she's always self-harmed. She's got, well when she came to us, scars up her arms from where she'd just pick until she bled and hit herself – she's always done it'.

Most of the remaining professionals did not know when the person they supported had started self-injuring, or what circumstances they were facing at the time. It seemed to be the case that when a person moved into a new service, knowledge of their previous life history did not. For most professionals this did not seem to be an issue:

'It wasn't really the focus of the work that I did with him'.

'It's just what's happened over the last few years and I guess really that's all we need to know about, so we don't tend to ask about what's happened before that'.

'Most of them don't come with information from that far away'.

From the accounts of family members, the first time that participants self-injured was associated with the following circumstances:

- the person's care being provided by two different carers – 2 cases
- being in circumstances that the person doesn't seem to like – 2 cases
- doing what the person doesn't seem to want to do
- living in an environment that is apparently disliked
- at transition from school
- at puberty
- being in one's cot as a baby
- being in the bath as a baby
- at a time of parental illness
- following a previous injury to self.

Two professionals associated the start of a person's self-injury with particular events going on in their lives at the time. For one it was associated with an increase in the amount of free time that the person had; for the second it was when a foster child moved into the family home.

Whether all or some of these circumstances should be considered to be risk factors associated with self-injury requires a larger study. However, they do provide a clue as to what some of the circumstances might be that can trigger a first incident of self-injury in a person.

Circumstances that family members and professionals perceive to be associated with a person's self-injury

All of the family members, and about half of the professionals, were able to identify one, and more usually several, circumstances that they associated with the lead-up, or to an increase or exacerbation of self-injury by a person.

In Chapter 3 (page 38), participants described three main categories of circumstances that they felt led up to their self-injury. These were:

- External factors
 - being in disempowering circumstances
 - having a lack of control within their living environment
 - having the opportunity to do so

- Interpersonal factors
 - being bullied
 - arguments – either having an argument with someone else, or overhearing an argument
- Internal factors
 - physical health issues
 - having particular thoughts or memories.

Here, we have taken as the starting point the views of the participants with learning disabilities, and have analysed the data obtained from family members and professionals to assess whether what the participants with learning disabilities have said about the circumstances leading up to their self-injury has been corroborated by the family members and professionals. We then go on to explore what other circumstances family members and professionals associate with a person's self-injury.

External factors

Family members and professionals were far more likely to identify external factors leading up to the participants with learning disabilities' self-injury than the research participants did themselves.

Being in disempowering circumstances

The disempowering circumstances that participants described as leading up to their self-injury included: not feeling listened to, being told off, being told what to do (or what not to do), having too many demands placed on them without enough support, being treated like a child, or other people talking about them. Clearly, a number of these are based on the perceptions of the individual. However, at a third of the interviews with family members, and a small number of interviews with professionals, interviewees outlined circumstances that could be considered to be disempowering for the person concerned. These were mainly concerning the person trying to do something but not being able to do so, not being included in activities, not understanding what someone was talking about or not understanding how to do something. Comments made included:

'The early morning is sometimes a time when things go wrong – she can dress herself but if things get on back to front or ever so slightly crooked she gets in that kind of mood, very upset' (family member).

'It gets to that point where she's either cut off because her concentration period's come to an end, or she doesn't understand what people are saying because she follows maybe one point, maybe two points but after that it's lost' (family member).

'He just doesn't like things that he doesn't understand and that scares the hell out of him' (family member).

'She gets frustrated because she hasn't really listened, she hasn't got the whole of the conversation and that. She seems to pick out key words and doesn't hear about anything else...that's when you could get her self-harming' (professional).

Having a lack of control within their living environment

Having a lack of control within ones own living environment was a key issue for many of the participants with learning disabilities. It was the most frequently reported circumstance leading up to a person's self-injury as reported by family members, with two-thirds of the

family carers' interviews mentioning aspects of this in association with their relatives' self-injury. It was also mentioned by about a quarter of professionals. Particular aspects of having a lack of control within one's living environment that were highlighted by family members and professionals included: being moved from one placement to another with little or no involvement; a key support person going away; friction between residents; not having enough to do; rules and regulations within the living environment; there being too much noise; a lack of autonomy; and deviations from routine.

'Then again, I mean it was a change of accommodation again, she was removed from her care home to a hostel and the hostel then was closing down and all the girls, everybody there, all the other residents had to find alternative accommodation...it was a very anxious time and anxiety definitely causes her to pick, causes her to self-harm' (family member).

'I think when she was at St Mary's Road, the one before this one. I think she used to do it quite a bit there...I think it was because of the manager there who brought in all sorts of rules and regulations. They were advised that every client should have their room locked, you know the bedrooms so people can't go into it and all that sort of thing...and Kim wants her space, she knows what her space is... I think that was her worst time, the last few years she was there' (family member).

'I think it's always when we stop doing what she is liking, or we're not doing what she wants us to do...another thing is if you take too long doing something and she wants to move onto something else she'll start' (family member).

'I think the setting didn't suit her. There were just too many people to compete with wanting to be heard, too many activities going on, too many choices to be made for her and she needed an individualised service I felt' (professional).

Having the opportunity to do so

Although a number of the participants with learning disabilities spoke about having the opportunity to self-injure as being an issue leading up to their self-injury, this was rarely mentioned by family members or professionals. One family member mentioned that their relative's self-injury seemed to increase when she was on her own; another said that their relative's self-injury most often happened in bed at night. Whether these are related to having the opportunity to do so, however, is unclear. One family member did hint that their relative controlled their self-injury to the extent that it mainly occurred when she was with close family members. As they explained:

'But it's always me, he always plays up for me all the time...It's as if he can do it in front of me or anybody like us, but he's got to watch himself when he's with certain other people. People that are close to him like relatives and things, oh he'll just go on one and doesn't care, but when it's people he doesn't know...'

Interpersonal factors

Few family members or professionals mentioned interpersonal factors leading up to the participants with learning disabilities' self-injury. One family member commented that their relative's self-injury increased when she was being bullied by her peers:

'I know when she will [self-injure] more and that is if somebody laughs at her for doing something like that. And they do torment one another, they do. And if one can read or

count or do this or that and the other can't, they will sometimes let the other person who is less able know about it. This is other residents I'm talking about or other clients at the day centre, and that does upset her... It is [bullying] yes'.

Another family member explained the impact that arguments could have on their relative:

'[If] she thinks that there's going to be an argument then she'll start hitting herself... And if you're having a conversation where it's a bit heated, not an argument, just that someone's annoyed about somebody outside and that can set her off as well... even somebody on the television. Coronation Street, they could be having a big argument and she's sat there and you can see her, and you have to turn the television over, but by then it's too late because she's got herself up to that state where she won't stop and then she'll get up and start. And you can't watch the programme then because she's [self-injuring], and that will last for quite a while again until she's calmed down'.

Getting involved in arguments or friction with others was also mentioned by three professionals as being a circumstance that could lead up to a person's self-injury.

'She reacts poorly when she gets into a relationship problem with a fellow peer. So that is one area she can't handle very well... Unfortunately she has been subject to physical aggression...on at least a couple of occasions – she hasn't retaliated but I think during these occasions she has self-harmed'.

Other interpersonal factors mentioned by family members included their relative being with a particular person and there appearing to be some friction between the two, and when their relative felt threatened by another person. Both of these circumstances were associated with increases in self-injuring behaviours.

Internal factors

Few family carers or professionals mentioned internal factors leading up to, increasing or exacerbating a person's self-injury. Two family members mentioned aspects of physical health that they felt were important factors: one was the presence of allergies that made their relative itch and scratch herself more in the heat – either after a bath or in the spring and summer months; the other associated their relatives' self-injury with epilepsy, and noted an increase in self-injury when there was an increase in epileptic 'turns'. Three professionals mentioned epilepsy as being a condition that exacerbated a person's self-injury. Another thought that being tired or physically unwell was associated with an increase in a person's self-injury.

Whereas half of the participants with learning disabilities were preoccupied by particular thoughts or memories that were at the fore of their minds in the lead up to their self-injury, few professionals or family members gave any indication of being aware of these. One family member considered that thoughts or memories relating to a past traumatic event in the life of their relative might be connected with their self-injury. No family members or professionals spoke about being aware of the person having persistent thoughts of wanting or needing to self-injure. The third group of thoughts identified by participants with learning disabilities was characterised by a more general internal dialogue relating to anxiety or worry, lack of self-confidence or self-esteem. This was mentioned as being factors leading up to self-injury in interviews with two family members and two professionals. One said family member:

'There was a period where Mona had a phrase, 'I'm worried about my future.' Now she did [self-injure] a lot during that stage'.

The second family member explained how the break-up of a relationship between their relative and her boyfriend had led to an increase in self-injury. At core, however, seemed to be the impact that the break-up had had on their relative's self-esteem:

'I think that will have affected Nutan's self-image because other people had boyfriends, she had a boyfriend at last sort of thing and then suddenly that's no longer there. She's never spoken about it but it would hit anyone hard and I imagine it must have hit her fairly hard. And that's quite recent, that might in fact have been why she has been [self-injuring] rather more in recent months than previously'.

Other circumstances that family members and professionals associated with a person's self-injury.

There were a number of other circumstances that family members and professionals associated with the lead up to, or an increase in, or exacerbation of a person's self-injury, that were not mentioned by the people with learning disabilities themselves.

Professionals were more likely than people with learning disabilities or family members to associate self-injury with change. Several mentioned transitions, changes and periods of uncertainty as being important in this respect. One professional explained how they had noticed an increase in self-injury when the service was relocated to a new building:

'The environment can be a big factor. ..We came from the old building which was just over the road. And for a lot of people we saw some behaviours come out that we possibly wouldn't have done, and you think...that person's never done that, they weren't ever likely to do that, and it was only for a short period while they were settling in so it was understandable. But yeah, I think big changes in an environment can possibly be a contributing factor'.

It wasn't only major changes such as this, however, that were thought to be associated with an increase in self-injury. Other professionals spoke about how changes of staff, routines or activities could impact on a person:

'I went to pick her up from one of her meetings. And she knew I was going to pick her up. And I had another girl training, shadowing me and I pulled up outside and I opened up the van and the other person went in first, and she was 'argh' on her hands so hard that she broke the skin on her fingers and everything. And it was purely because this other girl had turned up and she thought I hadn't'.

Professionals were also more likely than people with learning disabilities or family members to associate self-injury with circumstances in which the person had little concept of time. Looking forward to significant events, yet being unable to comprehend the timescales involved was thought by professionals to result in self-injury for some people with learning disabilities:

'She'll ask you, 'Is it time to go home yet?' And we'll say, 'No you've got another three sleeps, four sleeps, five sleeps' however many, and she just doesn't get it. And she wants to go home, she's desperate to go home, of course she is because it's her mum

and dad, you know? But she doesn't understand the concept of time and she finds it difficult'.

There were a number of other circumstances that individual family members and professionals associated with a person's self-injury. One family member thought that their relative's self-injury had increased in frequency and intensity as she had got older; others mentioned particular times of the day, or particular places where self-injury was more likely to occur. A fourth family member mentioned that if they noticed their relative's self-injury to be worse, they could be sure that something was upsetting her, although they would not always be sure what. A professional mentioned noticing that a person's self-injury increased when there were stresses within the family, such as illness.

As instructive as it is to look at circumstances that participants with learning disabilities, family members and professionals associated with leading up to, increasing or exacerbating self-injury, it is also helpful to consider the circumstances that family members and professionals said were rarely associated with a person's self-injury, or those times when their self-injury was of least intensity or frequency. Generally, family members were more likely than professionals to comment on circumstances that were rarely associated with self-injury. The circumstances mentioned focused on three key, possibly inter-related factors:

- having positive one-to-one attention available
- being occupied and engaged in pleasurable activities
- being in the company of a particular person.

The first factor identified by family members and professionals as being connected with the person rarely self-injuring, or their self-injury being of least intensity or frequency was when they had positive one-to-one attention available. One family member recalled that their relative's self-injury stopped on those evenings when she was supported by a carer providing *'fulltime attention'* for a few hours *'just to look after Mel and amuse her'*. A professional recalled how a person's self-injury had diminished when an additional support worker was employed to accompany her to hospital appointments which she found stressful. However, direct attention did not always seem to be needed; what was of importance was that it was available if required. One family member explained that their relative's calmest times were:

'Just with me, in the house...when it's just me and her. And she gets her book, sits down or she puts the music on and she dances to the music...And I could be ironing, she could be reading her books, or she could be upstairs listening to her music, or in here, or drawing, or whatever she's doing, and the minute the phone rings and I answer the phone, she comes in, she's telling me to put the phone down, and then she'll start [self-injuring], and I'm saying 'I'm only on the phone, I'm on the phone'. But no... it's one-to-one all the time'.

As has already been mentioned, being bored, and not having enough to do were mentioned by participants with learning disabilities and family members as being circumstances leading up to self-injury. In contrast, family members (but not professionals) considered that when their relative was occupied and engaged in pleasurable activities their self-injury was likely to be of least intensity or frequency. As one family member summarised:

'I think the more she is occupied in something she likes doing, then the less self-injury you will get'.

One family member thought the decrease in their relative's self-injury was because '*her mind is busy now*' with various activities and always having something to do. Favoured activities mentioned by family members that had a positive effect in reducing their relative's self-injury included listening to music, watching television, being out and about, going for a drive in the car, playing with toys, doing voluntary work, going to the cinema or being in water. Other family members identified that when their relative was engaged in activities at a social club or was on holiday their self-injury was noticeably absent.

The third key factor identified by family members (but not professionals) as being connected with their relative rarely self-injuring, or their self-injury being of least intensity or frequency was when their relative was in the company of a particular person. One family member said that their relative never self-injured when at home with them; another said that their relative never self-injured when with her boyfriend. A third said that their relative never self-injured when their father was in the house. The connecting factor seemed to be that the particular person was generally, but not always, the person providing positive one-to-one attention, or engaging them in pleasurable activities that they liked.

Feelings that family members and professionals associated with a person's self-injury

Most of family members and professionals identified one or more feelings that they thought people experienced before self-injuring. The most frequently mentioned feeling was that of frustration. This was mentioned by over half of the family carers and professionals. Other feelings that they thought people might be experiencing before self-injuring were mentioned far less frequently. These included feeling unhappy, agitated, angry, anxious, distressed, stressed, depressed, powerless, highly strung and having '*churned up emotion*'.

Three of the family members, however, thought that their relative would have difficulty in identifying these feelings themselves. One thought that their relative '*hasn't really got words to express emotions*' and another said:

'Feelings and things he can't express. He doesn't really understand feelings or maybe he does but he understands them differently to you and me.'

The third family member commented:

'Where emotions and things are involved, he's completely illiterate.'

All of these participants with learning disabilities had, in fact, expressed some of the feelings that they experienced before self-injuring to the researchers, either verbally or using pictures and signs.

Professionals too, commented on some of the difficulties that the people with learning disabilities they supported might have in recognising and reporting emotions. One professional said that when they had first started working with a person '*she was getting confused on how she was feeling, she couldn't tell us that she was happy or she was very anxious*'. In part, she considered, this was because the person would report how she wanted the professional to view her, and not what her real feelings were. A second professional commented:

'The difficulty with Alison, she also kind of muddles up emotions, 'cause she'll start crying but it's like she's just putting it on, and then something bad will happen but she'll laugh. If somebody hurts themselves she'll laugh, but then when she's happy she'll pretend that she's crying, so it's like she mixes up what's appropriate.'

For this person it seemed to be genuine confusion as to what the different emotions were.

Trying to stop a person's self-injury

All of the family members, and most of the professionals spoke about strategies they had used to try and stop the person from self-injuring. The two most frequently reported strategies were physically restraining the person, and talking to them.

Physical restraint

Many of the professionals interviewed explained that they were not allowed to use any form of restraint in their work. However, fourteen of the 33 professionals interviewed (42%) did acknowledge that they had used some form of physical restraint on a person with learning disabilities in an attempt to stop them self-injuring. For five of these professionals it had involved gently placing their hands over those of the person with learning disabilities or holding their hands so that they were prevented from harming themselves. All five of these professionals thought that such an intervention was effective:

'You're not allowed to pull her hand away, but you do maybe place your hand over and say, 'Oh Janie, you'll hurt your hand, don't do that.' It's only natural.'

'I just put my hand here and just put a little bit of pressure on, but you can't really push it down, you just put a bit of pressure on and slowly she'll relax and her hand will go down.'

Six of the professionals, however, reported using Control and Restraint (C&R) techniques in an attempt to stop someone self-injuring. Generally, this was used as a last resort, if professionals felt that they had tried other strategies without success, the self-injury was severe and the person was 'a danger to themselves' or their self-injury wasn't diminishing. One professional explained:

'The physical intervention that we have to use is restrictive, so we don't like to do it, we don't do it willy-nilly, we'll try everything first and that is the last resort.'

This professional also, however, gave graphic accounts of restraining a number of service users:

'He is supined two, three times a day in order just to stop him from hurting himself... if he's in that state of mind and we have to do our best to protect him and stop him from hurting himself, so a supine is him lying on his back, one person on each shoulder holding the arms and one person across the legs. And we've asked, 'Shall we let you go?' 'No'. Because he knows that if we let him go he's going to do it again.'

'When he first came to us it was quite horrendous really; we'd got staff running all over the place in order to try and stop him from doing it really. And everybody's on tenterhooks, because in a supine normally it's three people, but we've had up to five with him before and two on the legs, and I'm only a small chap and I've been on his legs before and he's just thrown me off, he is very, very strong. And I think the strength

comes from the frustration and the anger that he's feeling, because like I say, I've seen big blokes across his legs not being able to hold on to him asking for help. So yeah it could go on for five minutes or all day, it depends on how anxious he is I think'.

A number of professionals who did use restraint discussed the dilemma of doing so, having to balance on the one hand the autonomy of the individual, against on the other hand their duty of care to keep the person safe. One professional commented:

'I think there are points...where you have to just intervene and stop someone from coming to serious harm. On the whole if in doubt I think we would take that approach to prevent harm from occurring. And then once we learn more about a person we might adopt a slightly different approach, but the bottom line is always that, to prevent harm from occurring....it's very much a balancing act, how much autonomy can one give someone who will self-harm? On the whole I think the basic mantra is to prevent harm from occurring....If that [restraint] was necessary that is what we would have to use. We don't like to use it, but in an acute situation it's very difficult to make that sophisticated judgement call and if in doubt I think the baseline is to prevent harm from occurring'.

At five of the twelve interviews with family members (42%), family members said that they had physically restrained their relative to stop them from self-injuring – a similar proportion to the number of professionals who said that they had restrained people. For four of these family members, restraint had always made matters worse. The general view was summed up by one family member who commented:

'It doesn't matter how much one tries to stop her doing it, she will ultimately do it whatever'.

One of the family members said that they had been shown how to restrain their relative, but trying to stop her from self-injuring had made her *'ten times worse'* and that their relative then became like a *'raging bull'*.

At two of the interviews, the family members said that they used physical restraint with care, and only when they felt that their relative's self-injury was becoming too dangerous. One family member explained:

'If she banged her throat I used to just pull her hands down because it was so dangerous. If you tried to, I mean you can't restrain Freya at all, if you try to pull her hands away from her face, or her head, or her ears it just made her worse. So it was easier to put the blanket over her and just calm her with that, but with the throat because it's so dangerous we used to put her hands down...you didn't hold, you just pulled her hands down...If she did it again, sometimes we just stood there pulling her hand down, pulling her hand down and telling her, 'No, not to do that'.

The other family carer made it clear that they would hold their relative *'gently'* and in a particular way to prevent serious self-injury, whilst paying as much attention to their own feelings and responses as to those of their relative. They explained:

'Once she is up there you've got to try to bring her down and you can't do that with force no matter ... handling her or shouting at her that's no good at all. You need to really make an effort to calm yourself down, although you're worried because you haven't fulfilled something yourself, you've got to step down. And it works, it takes a long time but it works'.

At the fifth of the interviews with family members, the family members said that the only time that their relative was not physically restrained was when she was in bed. Even then, she would sometimes have been given a 'sleeping draught' and she was monitored with a close circuit television. If she was having a disturbed night she would be put in her chair and restrained for the remainder of the night. Somewhat despairingly this relative commented:

'Even at her calmest moment if she did not have the ties on her hands she would punch herself'.

At a further four of the twelve interviews, family members said that they had not, and would not physically restrain their relative to stop them from self-injuring. One thought that this was 'wrong'; another commented that their relative's self-injury 'comes from inside and I can't reach the inside'. All had used alternative strategies to physical restraint.

Talking

The second most frequently reported strategy engaged by family members and professionals aimed at trying to stop a person's self-injury was talking to them. For some, this involved telling the person to stop doing it. One family member said that when they and their relative's carers took the same approach to this, the self-injury had seemed to improve:

'Us constantly telling her 'don't bite your hand, don't bite your hand' and we do that together, the [carers] and I, and she takes notice of it, she really has. It's a lot, lot better. I wish I had taken a photograph of it now'.

Family carers also said that they found it helpful to remind their relatives about the consequences of their self-injury. Whilst this may or may not contribute to stopping their self-injury, it did seem to encourage some people to be more honest about their self-injury and more open in seeking help for their injuries. As one family carer said:

'Tell[ing] her that it wasn't a good idea to get her skin infected because it could cause her to be very ill, yes, I've told her that... I think she did take it on board and I think at one point I think she may even have been a little frightened by it, which probably wasn't good either because I don't think that fear is positive, I wouldn't imagine in that context... That might encourage her to tell the staff, that may be why she tells the staff, she may know now that it's not a good thing'.

Other strategies mentioned by professionals and family members that were aimed at trying to stop their relatives' self-injury were: using medication, using cushioning, removing items that might be used to self-injure, keeping the person busy, using sanctions and rewards to encourage particular behaviours, ensuring safety in self-injury, using 'redirection' to distract the person from their feelings, and using 'shock tactics'. All were considered to have varying degrees of effectiveness.

The reasons why people with learning disabilities self-injure – according to their family members and professionals

Although professionals and family members were able to relate circumstances and feelings that they perceived to be associated with the person's self-injury, many also provided explanations as to why they thought the person self-injured. Such rationales as to why someone else self-injures should, of course, be viewed in the light of being

perceptions only. It could be argued that only the person themselves could really know the reason or meaning of self-injury for themselves. However, many of the professionals and family members were able to consider the totality of feelings and experiences of a person in a way that the people with learning disabilities were not always able to do or to verbalise, and their views are therefore particularly important in this respect.

When asked about the reasons why they thought a person with learning disabilities self-injured, the majority of professionals and family members identified two key reasons. These were: a release of emotions and as a means of communication. Two further reasons were also identified by a large minority of professionals and family members. These were: to appropriate a reaction from someone and there being a physical cause. A large minority of family members also considered low self-worth/self-efficacy, and the need to obtain something tangible to be key reasons for a person self-injuring. A large minority of professionals considered a lack of choice and control as being a key reason.

A release of emotions

We have already seen on page 81 that most of the professionals and family members interviewed identified one or more feelings that they thought the person experienced before self-injuring. When exploring with them why a person might self-injure, more than half of the professionals and family members thought that emotional reasons were involved. On the whole, self-injury was thought to bring about a 'release' of emotional tension or frustration, brought about by various reasons. Professionals and family members spoke about people not being able to cope with or 'handle' their emotions, getting 'beyond' themselves, or 'out of control'. One family member reflected on her own feelings when she felt overwhelmed with emotions:

'I can get feelings sometimes when I'm really wound up and I think, god I've got to get myself out of this, I feel like chewing the carpet. I mean I don't know whether everybody feels that way, but I mean that kind of intensity of emotion...'

For the person with learning disabilities, self-injury could be an outlet for their feelings, a way of easing tension and regaining control: a suggestion that accords with the views of many of the people with learning disabilities themselves.

As a means of communication

The need to communicate one's needs and feelings was thought by professionals and family members to be an important reason why a person self-injured. Over half of the professionals and family members considered that a person might use self-injury as a means of communication. 'That's the way in which she communicates to us' was what one family member said. Another described it as 'one way of expressing herself'. A professional commented: 'they're choosing to communicate by means of self-harm because it usually involves strong response'. For some professionals and family members, self-injury was thought to take the place of verbal communication, where verbal communication skills had not been developed. For others, however, self-injury was thought to be used in addition to verbal communication when they couldn't or wouldn't vocalise their distress.

As with any form of communication, what is being 'said' needs to be appropriately interpreted by another person before communication could be regarded as effective. Communication is, after all, two-way. If self-injury was being used as a 'distress signal' as one family member considered being the case, the person in receipt of that communication needs to be able to interpret and understand it as such. On the whole,

professionals and family members who thought that the person's self-injury may be a form of communication did seem to be trying their best to interpret and understand what the person was trying to communicate. As one family member said:

'I think it's because she can't communicate and she understands so much, well a lot, but she can't communicate back. You can't understand her signings... It's like if she wants crisps or ice cream, you have to go through everything and it gets her worked up, and in the end she'll get you up and show you what she wants or she'll get up and start hitting herself because she's thinking, 'are you stupid?' This is what she must be thinking, 'can you not understand me?'

To appropriate a reaction from someone

A large minority (slightly fewer than half of the professionals and family members interviewed) considered that the person self-injured in order to appropriate a reaction from them. Professionals and family members said that they associated the self-injury with a demand for attention, or that the person wanted some intervention or reaction at the time. It was *'one way of getting a reaction'* according to one family member. Another said:

'Sometimes you might be sat somewhere and all of a sudden she'll just bang her head, just one time, as if to say, 'I'm here, pay attention.' It's most peculiar. No reason and it won't happen again perhaps, but she'll just give herself a thump'.

One professional commented: *'I suppose she thinks if she does these things she will get more attention'*. Another said:

'Some people it's attention and it really is to get who they want down, because as I say, if the alarms go you have quite a lot of people comes running in and they maybe would be hitting themselves and then they manage to stop to see if who they want to see came down. There's that with a few'.

Some family carers spoke about more personal reactions that were elicited, such as feeling upset or frustrated oneself. It seemed as though their relatives with learning disabilities were in some way trying to elicit in their family members some of the feelings that they themselves were experiencing but were unable to communicate. One family carer explained:

'Sometimes I think she does it deliberately to make me upset... I find it very upsetting and she knows I find it very upsetting because it's so difficult to understand...very puzzling to me. [Sibling] thinks it's just her getting at me, that's what she says'.

There being a physical cause.

The final key reason given by both professionals and family members about why a person might self-injure was related to physical causes. About a third of professionals and slightly less than half of family members interviewed thought this might be the case, although there was considerably more scepticism about this by family members than about other reasons that had been given.

Three family members thought that their relatives' self-injury may be connected with epileptic activity. Another two thought that it might be connected with the particular condition with which their relative had been diagnosed. However most expressed some discomfort at these explanations, suggesting that although they could understand that

different people with the same syndrome or condition could share similar behavioural characteristics, these didn't explain why they engaged in those behaviours in the first place. They were associations, therefore, not causes. One family carer said:

'They said it's all down to the syndrome. Because all [people with that particular syndrome] they're all very bad tempered, and if you go to the specialist at the hospital the first thing they'll say to you, 'Has she got a temper?' And we say, 'Yeah she has got a temper when she wants something.' And he said, 'Oh yeah, well they're well known for it'. But nobody's actually said why they're bad tempered, anything like that, so we're still none the wiser'.

The majority of professionals, and small numbers of family members thought the reason for the person's self-injury could be related to other physical causes. Professionals predominantly mentioned pain and considered self-injury to be a response to physical pain or being unwell. This was mentioned by very few family members. Other reasons, mentioned by both professionals and family members included: being tired; sensory impairments; it being an automatic response mechanism; a habit that was impossible to change; hormones; drug reactions; and because the person had learning disabilities (which will be returned to in the next Chapter). Whilst it was fewer than half of professionals and family members who considered the cause of the person's self-injury as being physical, it is important because it would suggest that these professionals and family carers would not see self-injury as being amenable to behavioural interventions or support in stopping self-injury.

Low self-worth/self-efficacy

At two-thirds of the interviews with family members, issues to do with the low self-worth or self-efficacy of their relative, particularly in comparison with others, were identified as being a reason for the person with learning disabilities' self-injury. This was mentioned by very few professionals. For some family members, feelings of low self-worth were possibly imprinted on the person by those in society around them. One family member explained:

'I think mentally handicapped people - I'm using that word 'cause I don't like learning disability - people don't reward them for achievement, they're just sort of lumped together as mentally handicapped people and I think to a degree they're not seen as individuals, they're not seen as people... And I think you have to feel yourself, that you're a person who means something and I don't think they do... I think that might contribute in some way to this view, 'I'm not worth anything, I'm just somebody who can't think'.

Within this, bullying was also mentioned as being a cause of destroying a person's self-confidence and sense of self-worth:

'There were people at the day centre who tormented her or annoyed her or she couldn't cope with that'.

One family member reflected on their own possible contribution to a reduced sense of self-worth in their relative. They expressed how they had tried to steer the decisions made by their relative in the direction that they thought would be most helpful for the person, not really realising the impact that this could have on their relative's own sense of self-worth and self-efficacy:

'When she had choices at the day centre, maybe I interfered too much, because I'd try to make sure that she got the right choices for her. And maybe she'd already made a decision and maybe, as I say, that was too much interference, because I'd maybe then suggest that perhaps it should be this, and this and this because you like that more. So that's me being controlling, isn't it?...I don't think she liked that... she wanted to make up her mind all by herself'.

A third family member reflected on the impact the constant ignoring of the needs of a person might lead to. This family member suggested that if practical needs are ignored and not met, it would be likely to send a message to that person that their emotional needs are also not worth considering. This could then have a detrimental impact on their sense of self-esteem and self-confidence:

'Ellen actually tells them the light's gone, the DVD is broken, the television doesn't work. She tells them but nobody does anything about it. That's her life, she doesn't have many [pleasures]... she tells them but they don't do anything about it, so it's a terribly bad message to send to anybody. So perhaps she feels now that what's the point in telling them I'm unhappy...What is the point because they don't do anything about it even if I do?'

For other family members, however, the person with learning disabilities' feelings of low self worth or self-efficacy were thought to come from within, and from a conscious or unconscious process of comparison with others. Two family members considered the impact of their relative growing up in a family with siblings without learning disabilities, and the feelings that this constant comparison might engender:

'I think that somebody with a leaning difficulty, particularly somebody with siblings who have much wider, more interesting lives, the frustrations of that must be very hard to bear'.

'All her sisters went off and got married or had partners or whatever, and Mary was always at home and how frustrating was that? I don't know. It must be very frustrating, it must be very frustrating to know that all your sisters have got jobs and you haven't and that's one of her main ambitions now, to get some paid work. She wants to be as like someone who hasn't got learning difficulties as she possibly can be'.

To obtain something tangible

More than half of the family members felt that a reason why their relative with learning disabilities self-injured was in order to obtain something tangible. Again, this was only mentioned by very few professionals. Family members suggested that if their relative could have all they wanted when they wanted it, they would be unlikely to self-injure. That this wasn't always possible, nor desirable, was a key problem. The sorts of things that family members thought their relatives wanted varied from particular toys or objects, to being engaged with particular activities or with particular people.

Most commonly, family members described their relative wanting something tangible, the person needing to communicate this, it giving rise to strong emotions such as frustration, and then the resulting self-injury. It is difficult, therefore, to completely separate the desire for something, or to do something, from the person's feelings about this and their need to communicate about it. There was a closeness and symmetry that was difficult to untangle by many of the family members.

A lack of choice and control

Approximately a quarter of professionals, but very few family members, considered that a person might self-injure because of a lack of choice and control in their lives, or as a means of taking control. One professional commented:

'Generally I think people with learning difficulties are a minority group who don't have a lot of control over their lives'.

In situations where a person lacks control, it was understood that self-injury may be an attempt by the person to wrest some degree of control over the situation, either consciously or unconsciously. One professional explained:

'You're doing it to yourself, it's a bit like starving yourself, isn't it? You can do it, and it's something that you're in charge of'.

Another tried to understand this and empathise by commenting:

'It's not like going home where you can just switch off and have nobody around you. They'll have somebody in their lives all the time'.

The impact on family members own lives of supporting a person with learning disabilities who self-injures

At most of the interviews with family members, family members spoke about the impact on their own lives of supporting their relative. For the majority, the impact had been considerable, and had resulted in a narrowing of horizons, restriction of activities and day-to-day adaptations and stresses over and above those required by other families.

At all but two of the interviews with family carers, the family carers spoke about how supporting their relative had led to a narrowing of their own horizons and a restriction of activities of their own. Some of them spoke about no longer having holidays, or if they did, only going away for short periods at a time. One family member said that it had been eight to ten years since they'd been away on holiday; another said that they couldn't go away for more than four days at a time. For some this was because of a lack of suitable care for their relative when they were away; for others it was because their relative couldn't deal with the change in going away from their familiar environment. One family member said that they felt like *'a prisoner in your own house'* because they couldn't go anywhere without their relative, but that their relative became extremely distressed and started self-injuring when in an unfamiliar environment. Another family member commented wryly: *'We could clear a hospital waiting room in about five minutes'*. A third said:

'My grandchildren's parties are a definite 'no' now, because if they've got balloons or these cracker things it's just horrendous, she can't handle it at all. She would just scream and be continually wanting to bite. So you have to avoid situations with her that you know are going to upset her'.

Another family member summed it up in this way:

'You've got to have lived the dream to really understand it. I cannot explain to someone who goes home at night and thinks, 'What are we going to do tonight dear; shall we go on holiday this year?...None of those things are available to me and never have

been...Do we go on holiday? Hardly ever. Do we have a full night's sleep? Hardly ever. Do we go out to the cinema? No. Do we have a social life? No.'

A number of family members spoke about being distanced by, and purposefully distancing themselves from friends and relatives.

'It frightens people when they come in' said one family member. 'Nobody will come round and visit, only the brave ones'. They continued:

'My brother he hardly, well he comes round every now and then, and when they see him biting himself, they don't like their kids, when they bring Jim and Joe, they don't like them seeing it, so they don't come because it's not a nice thing for other kids to see. And they're asking questions, 'Why are they doing that?' And you try to explain to them, they know there's something wrong with her but they don't, if you know what I mean? They want to know why, 'Well why is she biting herself when we're only laughing or playing?'

Another family member explained why they had purposefully distanced themselves from relatives of their own:

'You distance yourself from the rest of your family. My sister...she'd say, 'Ooh I'll have her for the weekend.' And she'd say to Joan, 'Are you coming with us for the weekend?' and she'd say, 'Oh yes.' She liked [my sister]...And then she'd ring up and say, 'Oh I've decided I can't really cope with that.' Never, ever, ever tried, only ever visited us. And I said to her, 'Please don't tell Joan that you're going to do a thing you're not gonna do, 'cause she's geared up to coming'... There was always that feeling of let down for her'.

The impact of their relatives' self-injury was felt in a very personal way by some family carers too. One said that she used to feel embarrassed when out and about with their relative because people would stare; another family member said that they had lost confidence in themselves when out socially:

'It gets you that way that you can't communicate with anybody neither, and that's what I've found now, you can't express yourself and you can't say what you want to say because it doesn't come out right, because I'm still talking at Kate's level. It's weird, it's like I can't communicate with an adult... It's like whenever we go out, if we go to dos...I stand there just nodding, because... my world's in here, it's not outside...I've got nothing in common with any of them. And I talk about Linda all the time and they're, 'Oh yeah' and they sort of waltz off on to something else'.

Other family members spoke about eating a poor diet because they are under stress all the time, about receiving physical injuries from their relative, and about the impact that a lack of sleep and being permanently tired had on them. One family member said that they felt as though they experienced '*tremendous turmoil*'; others spoke about '*heartache*' and '*heartbreak*'; another said they felt as if they were '*treading on eggshells all the time*' and that they couldn't really relax, even in their own home. Indeed, some family members spoke about putting additional locks or padlocks on doors or cupboards to prevent free access to items in their home by their relative:

'We bolt the kitchen door and then we lock this one...and take the key out, because of her wandering round, isn't it? You don't know what she's doing [at night]... You don't know, do you, no and we don't take any chances...'

Another family member locked rooms and cupboards because:

'she could take something up the stairs and in a temper could stab herself with it, like where she's pinching, or stab herself in the head'.

The impact on family carers own lives of supporting a person with learning disabilities who self-injures was summed up by one of the family carers interviewed for the research:

'65 years of age, nearly 66 years of age and I'm working longer hours now than I've ever worked in my life'.

Whilst this was very much the majority view, there were a small minority of family carers who felt that their lives had been enhanced by supporting their relative with learning disabilities who self-injured. Both had become involved with voluntary sector organisations supporting disabled people and family carers. Talking to other family carers had helped them to think about different ways of responding to situations and different ways of coping with difficulties. It had also given them an important role that they appreciated and was valued by others. One of these family members commented:

'That's just the way my life's gone and I lay it all down to Nikki...there's been a lot of positives come out of having Nikki'.

The impact on professionals' own lives of supporting a person with learning disabilities who self-injures

Few professionals spoke about the impact on their own lives of supporting a person with learning disabilities who self-injures, but all of those who did spoke about the impact in relation to stress. One admitted:

'I come home sometimes and my wife's like, 'Crikey, I don't know how you do it.' And I need a good fag and a drink and go 'Phew, blimey!''

Another explained their love of dangerous sports as being driven by the need to clear their head of the stresses of work:

'That's why I have to do adrenalin weekends away and do daft things like bungee jumping. That's what it is for me, I need that big release...I guess it is taking risks, but it allows me to totally disconnect from everything in my head and just focus on what I'm doing and it's quite a powerful thing – it works for me'.

Other professionals spoke about *'having to get on with it'* and deal with the stresses of the job as they arose, remembering that their clients were clients for a reason.

As with the small number of family members, a small number of professionals felt that their lives were enhanced by supporting people with learning disabilities who self-injured. One said that they felt *'privileged'* and that their life was *'enriched'*. Another commented about wanting *'to put some good back in the world'*.

What family members thought in general about their relatives' self-injury

In general, the interviews with family members revealed a group of individuals who were despondent about their relatives' self-injury and feeling as though they and those supporting their relative lacked the expertise to fully address it. This had seemed to result in a situation of stalemate for many of the family members: much as they hated it, they had come to accept self-injury as being a part of their relatives' life and held little hope for improvement.

Feelings of despondency were common amongst the family members interviewed. Many spoke about their feelings of hurt, sadness, upset and distress when their relative self-injured. For some, those feelings were because of the effect on the person with learning disabilities themselves:

'It distresses me to see her when she does that because sometimes there's been deep gouging, and I feel sad that she has to do it for some reason'.

For others, the feelings of upset and distress were reflected inwards, and family members talked about feelings of guilt and failure at being unable to prevent or stop their relatives' self-injury:

'Well it does disturb me because I immediately turn round and question myself: what have I done? Or why don't I do more? Or I should have prevented it? Immediately I question myself, it's not just that I deal with her problem, I put myself on the line and question myself. But that's sometimes very hard because I can't find an answer. It spills over to me very much because she's part of me and I'm part of her'.

What was apparent from the interviews with family members was that despondency seemed to arise out of the lack of hope for there being any improvement in their relatives' frequency or degree of self-injury. Family members had acquired the message that *'it doesn't seem to be ameliorable'*, or that *'they're never going to cure it'*. One family member said:

'That's what they've said in the hospital, 'She'll always do it, there won't be any cure, there's no cure for it'.

Some felt as though the professionals they were in contact with didn't understand the problem, let alone were able to deal with it, and that this contributed to their lack of optimism. They were left feeling that they didn't know what to do for the best.

Coupled with their feelings of hurt, sadness, upset and distress, the lack of hope seemed to have led to a degree of acceptance for many family members. They talked about self-injury being *'part of the course'*, and that *'wherever she's been living it's always been accepted as the kind of thing that women with learning difficulties do'*. Overwhelmingly, the sense was that family carers disliked and were distressed by their relatives' self-injury, but over time had come to accept it. As one family member summed up:

'When you're out and she's doing people say, 'Oh I suppose you're used to it.' Yeah alright, how do you get used to something like that? You don't, you know? I mean it's as raw now as the day she first did it, it's horrible, it's awful. And it's the single thing about her that causes us the most distress...If we could just stop that but we can't, so you have to accept it'.

There were occasional glimpses of optimism from a small minority of family members. One family member was hopeful that their relative's self-injury was *'just a stage'* that they would *'get through'*. They reflected on the *'amazing strides'* that their relative had already made in her life and held a degree of optimism that self-injury, too, could be overcome. A second family member also hoped that their relative would *'get out of'* their self-injury over time. Two further family members were adamant that they could not accept the status quo. One commented:

'Although you think you've tried everything in the world you obviously haven't. And I haven't given up, I can't say 'Oh I've given up, she'll always be doing it''.

The second said:

'I think to a degree they [professionals] just accept it happens: this person's mentally handicapped and they self abuse. Well I don't feel that that's acceptable, because everything's done for a reason, whatever it is everything is for a reason'.

What professionals thought in general about a person's self-injury

Professionals own feelings

Three quarters of the professionals interviewed spoke about their own feelings regarding a person's self-injury. They described a wide range of largely uncomfortable feelings that they experienced when addressing a person's self-injury. Table 10 shows the feelings that were mentioned.

Table 10: The feelings that professionals described themselves as experiencing when addressing a person's self-injury.

Frustrated	Feeling horrible
Upset	Feeling challenged
Distressed	Disappointed
Feeling it is difficult	Troubled
Shocked	Feeling you hate to see it
Annoyed	Surprised
Feeling it is a struggle	Confused
Cross	Worried
Angry	Horrified
Sad	Feeling as though 'between a rock and a hard place'
Can understand	Can sympathise

Two professionals mentioned less uncomfortable feelings, saying that they tried to understand and sympathise with people with learning disabilities who self-injured. Another three professionals described not having any particular feelings. One commented:

'I don't think I really get any emotions about it anymore because you're just so used to seeing it. I think if it was a different environment, different people – if it was someone I was really close to and they were doing it, it would be quite different, but because it's here and it's work and it's just everyday life you just get used to it and you don't really

feel anything. Which sounds horrible, but I guess it's a coping way isn't it...it's work, you know, work is work and you keep it quite separate so - I guess we're all quite detached at work from our feelings'.

About a third of the professionals did, however, comment on the uncomfortable feelings experienced by other staff members at having to address self-injury. Words used to describe these feelings are shown in Table 11. None of the professionals mentioned any less uncomfortable feelings that were experienced by other staff members.

Table 11: The feelings that professionals described other staff members as experiencing when addressing a person's self-injury.

Feeling as though it is difficult	Repulsed
Frustrated	Feeling guilty
Feeling it is traumatic	Feeling as though you can't understand
Worried	Feeling it is hard to cope with
Shocked	Feeling it is scary

As well as describing their feelings in general about a person's self-injury, some professionals described their feelings towards the person concerned. They spoke about how upsetting and painful it must be for the person self-injuring, how they could understand their suffering, and that they tried to sympathise and empathise with them. One said that they wouldn't *'hold it against anybody'* for self-injuring; another highlighted how everyone is different and the reasons behind their self-injury are different.

Professional's confidence in their own knowledge

Some of the feelings of professionals were underpinned by a lack of confidence or knowledge about supporting a person who self-injured. One professional commented:

'It's like if somebody was trashing a room then I'd think, yeah, yeah I could understand that. And maybe the self-injury is something, if I'm being totally honest, that I wouldn't quite know, wouldn't understand the same'.

Another professional explained that because self-injury was such a difficult issue to address, it tended to be pushed aside and left unaddressed, often for many years:

'I think across all learning disability services people are aware of it, but again, it's kind of one of them things you meet and think, 'don't know much about that', so you think, 'Oh there's all them problems, let me deal with all of them first and we'll leave that'. I think it does get left till last because we don't know much about it and it's the uncertainty of not knowing about it and not knowing where to go with it or what to do with it'.

There was certainly some evidence from professionals that self-injury in people with learning disabilities was not always addressed very promptly:

'I've often thought if she'd had counselling when she actually needed it, it might have actually stopped at least some of this behaviour; if she'd just had someone to listen to her. And I just wonder when that should be flagged up, who should instigate it, all this type of thing....I just can't help feeling that more should have been done initially. I think,

like all of the people here, we should be listening to what they're saying and trying to respond as quickly as we can, instead of leaving it for years and years down the line when people are doing all sorts of things to themselves'.

There was also evidence of professionals not always being clear about what to do for the best:

'We did try and reduce her medication for a while, but we had to re-establish it again because we found that the self-harm increased. So if there was going to be a decrease in medication then we'd certainly need something like a psychologist to come in, at least on a weekly basis to fill in the void...And, as I say, it's almost like the argument in psychology, whether be it cognitive therapy, or behaviour therapy or psycho analysis and they'll all say that they're all beneficial, but what would suit her? This is the question. And if we go down the wrong road then we may not get the results we want and things could be actually worse, so we have to be sure'.

'We don't have any training in it, we're not really given a great deal of advice on what to do, so it is just trial and error. And then you've kind of got to have the guts to try it and hope that it might work, because sometimes if we try things without knowing that it's going to definitely work and it all goes wrong you're in a worse situation. So that is all we do really... I think we're a bit scared to try it and it all go wrong to be honest'.

Overall therefore, there was a lack of confidence in the minds of some professionals about how they responded to self-injury. For a minority of professionals, this was not the case, and they considered that they (and their colleagues) worked in positive and supportive ways with people who self-injured, and frequently reflected on the actions of the person self-injuring and their own responses to it.

When ideologies clash

Over a half of the professional interviewed related circumstances in which ideologies clashed over the best way to support someone with learning disabilities who self-injured. In the main, these were disagreements that were resolved at team meetings or in conversation and recorded in support plans and guidelines. One professional recalled *'heated discussions'* with colleagues and would say *'Steady on, let's discuss'*. Another recalled disagreements:

'Only in the sense that they might say, 'Well this was the response I gave'. And I'll go, 'Nooo! Don't ever say that again!' but then that's about learning, isn't it, and about saying, well that's a good practice and that's not a good practice'.

For one team, learning took place through modelled responses. As the professional explained:

'We would model basically what it is that we would expect the other staff members to do'.

Not all professionals, however, considered different views and opinions about how to respond to self-injury problematic. One professional said:

'We're all of the view that actually multiple perspectives are more useful than single perspectives so that it doesn't have to be a clash, it can be two angles on the same thing'.

Another described different opinions between two members of staff which had resulted in a greater degree of choice and control for the service user concerned:

'The only thing I can think of is with one of the service users, it's not even a clash, just maybe different opinions on how we deal with that service user when they say, 'Oh I've cut myself.' One particular staff member does find it works better for her when she doesn't dwell on it, so the whole support session isn't taken up with, 'Oh let's have a look at your cuts. Oh wow, that's really bad you must've really felt low.' If she says, 'Oh yeah right, OK let's go to town.' or something, she finds that works and she has told us that that works. And some members of staff are like, 'Well I actually prefer to sit down and find out why they self-harmed and...' So there may be a bit of a clash there...It wasn't really resolved. I think all we agreed to do was to have an open mind, and again, it's about asking the question, 'Well you've told me you've self-harmed, why have you told me? Do you need to talk about it, or do you need medical advice, or would you like me to distract you?' And if she says, 'Oh I really need to talk about it' then we can do that. If she says 'distract', just like, 'Come on then, get your coat we're off to Tesco's.' So it's just about valuing other people's opinions really, but using what's best for you at that specific time'.

This was an approach echoed by another professional:

'There is always, if people be honest, there is also conflict in every team. There are very few teams that don't have conflict, and I believe personally conflict is very healthy because out of conflict grows some brilliant ideas'.

Professional's views about the relationship between self-injury and learning disabilities

Over three quarters of the professionals commented on whether they felt that self-injury was associated with the person's learning disability. There were three groups of responses: professionals who thought that a person's self-injury was not at all connected to their learning disabilities; professionals who thought that a person's self-injury might be exacerbated by issues relating to having a learning disability, but that it was not due to having learning disabilities *per se*; and professionals who understood self-injury to be due to the person having learning disabilities.

Professionals who did not think that a person's self-injury was at all connected to their learning disabilities considered that environmental and social influences were more closely related to why a person self-injured. Many drew on experiences that they had from working with, or hearing about people without learning disabilities who self-injured, and considered many of the issues to be the same. One professional commented:

'I think the self-harm, like every other person out there, is to do maybe with the personal struggle that person's facing in their life'.

Another, when asked if they thought self-injury was related to having a learning disability, said:

'No, personally not - because of experiences that we've had. I mean not all of our students have severe learning disabilities, we have a huge range that are doing accredited courses, NVQs, going to the local sector college to access things. And I have known some of those to self-injure or threaten to commit suicide or whatever, so it isn't necessarily due just to a learning disability. And the media says that, or in your

experience you read about other cases and stuff, so it's not just linked to learning disability'.

Some professionals also questioned why, if a particular impairment or condition was associated with self-injury, were all people who experienced this impairment or condition not affected. One professional said that they had attended a conference where the names of particular syndromes had been mentioned as being closely associated with self-injury. This had surprised her, as she was supporting a person with Cri du Chat syndrome, and as she related:

'As far as I'm aware she doesn't self injure typically in the way that I've heard that Cri du Chat children can. Because I was quite surprised that that came up [at the conference], and I was thinking, oh but she's not like that, she doesn't do that'.

A second group of professionals – a similar proportion to the group above - thought that a person's self-injury might be exacerbated by issues relating to having a learning disability, but that it was not due to having learning disabilities *per se*. Most felt that underlying issues of communication difficulties, lack of self-esteem, a lack of recognition of different emotions and a narrow range of coping strategies which are likely to be common experiences for people with learning disabilities, all contributed to why a person might self-injure. One professional explained:

'The experiences that she'd experienced as a result of having a learning disability I think were the things that were important in her life; the difference, the I'm not like my sister, I want to be normal, I want to have kids, I want to get married and I can't – it's crushing, it's awful. And that level of insight that she had meant that she was constantly feeling it with the low self esteem and it was sad, very sad to see it, and I'm sure that certainly effected every behaviour that she ever exhibited'.

Other professionals picked up on different aspects of the contribution that having a learning disability might make:

'I think on the whole a person with a learning disability is slightly disadvantaged in that maybe their cognitive resources to reflect, to process what's going on can be more limited for a person who has a learning disability'.

'I do think from my own experiences it has a relationship with communication issues and poor problem solving, effective problem solving and low tolerance to frustration. And I think all those sorts of issues, and certainly self esteem as well. The issues around having a learning disability per se and the fact that actually that provides you with a number of failure experiences along the way, actually does relate to people that then end up injuring themselves in some way'.

A third group of professionals – about half as many as in each of the two preceding groups - understood self-injury to be due to the person having learning disabilities. These professionals mainly named particular genetic conditions or impairments as being causative of the person's self-injury:

'Yes, it is definitely his autism. An inability to cope with unexpected things or things that he expected or wanted or whatever and built up'.

'That's part of their syndrome, that's it, that's part of what they do, it's part of their learning disability yeah. Whereas, like I say, it's different for me or you...I think that is the attitude, that it's part of their syndrome, it's part of the way they are, it's what they've always done'.

Whatever beliefs a person had about a person with learning disabilities' self-injury, a number of professionals expressed their dissatisfaction at the way in which it was addressed. Many commented on the widespread occurrence of self-injury and the dangers of becoming complacent or blasé about it; self-injury was often considered to be accepted in people with learning disabilities in ways that it would not be in people without learning disabilities:

'I think because it is so common place, I think we should be paying an awful lot more attention...I can't help thinking that within the centres it's almost expected and it's not unusual, and therefore it doesn't really seem to have that level of importance'.

'I get quite annoyed that it takes so long before these things are addressed, and that we are in more acceptance of them because they've got learning disabilities than we would if they didn't. I find that quite annoying'.

'I think a lot of us work with people who self-injure and accept it, we just accept it. I don't see any change in the people I've known for over 12 years who self injure I have to say'.

What family members and professionals think will improve the circumstances of people with learning disabilities who self-injure

Most family members and a small number of professionals suggested what might improve the circumstances of people with learning disabilities who self-injure. A variety of improvements were mentioned. Some were generic, and others specifically related to self-injury.

Of the generic improvements mentioned, family members wanted their views to be taken into consideration more than they felt was happening at present. They also wanted a greater provision of short-break (respite) support. Family members and professionals also spoke about the need for attitudes to change towards people with learning disabilities – both by society at large, and within services. In the main, this was about respecting the person with learning disabilities more, listening to them, following their wishes and treating them as an adult.

A number of improvements specific to self-injury were also mentioned. Family members and professionals stressed the importance of *'not to get to that point in the first place'* (professional) and the importance of prevention. If there were early indications of self-injury, the need for accurate assessment at an early stage was emphasised, with either greater access to Functional Assessments or within specialised assessment centres where strategies to prevent or ameliorate self-injury could also be trialled. Some family members talked about improved awareness of, and attitudes towards, self-injury, so that self-injury is not viewed as *'something reproachable'* and that it isn't *'something for which [people] should be reprimanded'*. They also suggested support groups so that:

'you don't feel so alone, you can take ideas and it doesn't become so burdensome...it helps parents and by helping parents you're actually helping the person who's doing it as well'.

Both professionals and family members suggested improved training, particularly in self-injury awareness, distraction techniques and the use of communication tools such as mood boards. One professional stressed the importance of staff using skilled communication techniques. They suggested that instead of asking unhelpful questions, staff would do better by improving their listening skills:

'I think they sometimes have to continue to say something, when in actual fact, silence is much better'.

Chapter 5:

Conclusions and Recommendations

Conclusions

This report presents the findings from a three-year research project conducted by Bristol Crisis Service for Women and the Norah Fry Research Centre at the University of Bristol. It is based on the views of twenty-five people with learning disabilities and personal experience of self-injury who took part in one or more research interviews between 2007 - 2009. All of the people with learning disabilities lived in England, Wales, Scotland or N. Ireland in a variety of different living arrangements. Their ages ranged from 14 to 65, the mean (average) age was 33. Six of the 25 participants were male and 19 were female. Three of the participants had particularly limited verbal communication and relied on augmentative and alternative communication (AAC) to relate their thoughts and experiences. For these participants, this involved the use of gesture, signing, symbols and word boards.

In addition to the interviews with people with learning disabilities, interviews were also conducted with family members and professionals supporting people with learning disabilities who self-injured:

- Fifteen family members took part in twelve interviews. Seven family members were parents or siblings 'linked' to a person with learning disabilities who self-injured and who was taking part in the study. Eight were not linked to any of the research participants, but had particular views and experiences to relate to the research team about supporting a family member with learning disabilities who self-injures.
- Thirty-three professionals were interviewed for the research study. Twenty-two of these were 'linked' to a person with learning disabilities who self-injured and who was taking part in the study. They came from social service, health and voluntary sector backgrounds. In addition, eleven interviews were conducted with professionals not linked to any of the research participants. Each of these professionals had particular views and experiences to relate to the research team about supporting people with learning disabilities who self-injure. These professionals came from education, social care, health, the voluntary sector and academia.

For the people with learning disabilities taking part in the study, the three most common types of self-injury were scratching, cutting their skin and hitting themselves. Half of the 25 participants reported engaging in these behaviours. The next most frequently reported types of self-injury were self-biting, taking an overdose and hitting out at something else such as a wall or hard object. A quarter of the participants reported engaging in these behaviours. However, all but five of the participants (80%) engaged in more than one type of self-injury. The maximum number of different types of self-injury was seven; the mean (average) number was three. Fourteen of the 25 participants also engaged in behaviours, other than self-injury, that might be considered to 'challenge' those supporting them. For most, this involved hitting out at, hurting or being aggressive towards another person.

1. Self-injury is a very individual affair

There was little evidence from the participants, nor the family members or professionals they were linked with, to suggest that self-injury was a static behaviour that was entirely

predictable or inevitable over long periods of time. Rather, the common feature of all participants' self-injury was that it was a very individual affair, with periods of exacerbation and abeyance that could be generally understood within the context of the person's life. Three-quarters of the participants injured themselves privately, usually waiting until they were in a place where they knew they wouldn't be disturbed. The privacy of the act of self-injury was corroborated by most family members and professionals. However, once someone had self-injured, the degree to which their self-injury was able to remain hidden varied considerably, according to the environment in which they were in, the availability of support staff, the attitudes of those present, and the skill of the person with learning disabilities in caring for and concealing an injury. Reasons for not telling anyone included feeling ashamed, being worried about the consequences, and not feeling comfortable enough with the staff to disclose what they had done. Some of the participants suggested that they would only tell someone about their self-injury when they knew the person well, and felt comfortable with them. They needed some sort of knowledge about the person so that they could anticipate their reaction, and to have a good enough relationship with them upon which trust could be built.

2. Self-injury is largely used in response to difficult emotions and circumstances

Participants described three main categories of circumstances leading up to their self-injury:

- external factors (those in which the participant was not central; they involved what was going on around the participant, but the participant generally had little or no control over them)
 - Being in disempowering circumstances (not feeling listened to; being told off; being told what to do, or what not to do; having too many demands placed on them without enough support; being treated like a child; other people talking about them).
 - Having a lack of control within their living environment (having little or no choice about where they lived, who they lived with, and who supported them; having little or no choice over what went on in their home, what they did during the day and the living environment itself, such as being irritated by other residents, not having enough personal space, there being too much noise, not being able to go out when or where they wanted, some of the 'systems' they had to cope with)
- interpersonal factors (those involving relationships between two or more people)
 - Being bullied (being hit or punched, being picked on, called names, made fun of or laughed at)
 - Arguments (either having an argument with someone else, or overhearing an argument)
- internal factors (those to do with the person themselves, irrespective of what was going on in their current environment, or the people with whom they were interacting)
 - Physical health issues (physical illness, mobility impairment, tiredness/exhaustion, over-consumption of alcohol)
 - Having particular thoughts or memories (about past traumatic events in their lives, persistent thoughts of wanting or needing to self-injure, a more general internal dialogue relating to anxiety or worry, lack of self-confidence or self-esteem and being under pressure)

3. Hidden distress

There was a huge amount of past trauma in the lives of the participants. For some of the participants, thinking about those difficult times was directly related to their self-injury. Such memories or thoughts were largely in relation to abuse and bereavement. Participants who considered their thoughts of previous abuse to be a circumstance in

leading up to their self-injury often mentioned that these were memories that they could not put aside. In contrast, memories of the death of someone close tended to be triggered by certain events, rather than being present all the time or appearing 'out of the blue'. It was when one of these triggers had been encountered that was most likely to lead up to self-injury. Few family members or professionals mentioned being aware of this.

4. Understanding and dealing with difficult feelings seemed to be problematic

Circumstances that were difficult to deal with led to the development of quite intense feelings that were often an antecedent to self-injury. All of the participants in the study were able to identify some of the feelings that they experienced before self-injuring, although many had difficulties recognising a wide range of feelings or of discerning between them. Even so, three-quarters of the participants reported having one and sometimes a combination of three feelings immediately before self-injuring. These were:

- feeling angry
- feeling sad, depressed or low
- feeling frustrated or wound up.

Other feelings reported included feeling upset, stressed; cross or annoyed, and scared. For half of the participants, feeling sad, depressed or low had become extreme and they talked about feeling as though they wanted to end their life. For some, this was a feeling they had that they would not act on. A third of all participants, however, described incidents of self-injury from which they intended to take their own lives. Most of these were serious incidents: three had required the resuscitation of the participant. The intensity of feelings of these participants was such that professional support would have been expected, but this was not the case for all.

5. Self-injury is of least frequency or intensity when people are contented

Many family members and (comparatively fewer) professionals identified circumstances that they thought were rarely associated with a person's self-injury, or times when they felt the person's self-injury was of least intensity or frequency. The circumstances mentioned focused on three key, possibly inter-related factors:

- having positive one-to-one attention available - direct attention did not always seem to be needed: what was of importance was that it was available if required
- being occupied and engaged in pleasurable activities (such as listening to music, watching television, being out and about, going for a drive in the car, playing with toys, doing voluntary work, going to the cinema, being in water, being engaged in activities at a social club, being on holiday).
- being in the company of a particular person who was generally, but not always, the person providing positive one-to-one attention, or engaging them in pleasurable activities that they liked.

6. People are already taking action to limit or stop their own self-injury

Three-quarters of the respondents were already using strategies of their own to try and delay or stop themselves from self-injuring.

- Talking to someone.
Participants stressed the importance of the ready availability of someone to talk to at this time, as most did not seek out someone to talk to lightly – they had to get to a certain pitch, or pass an invisible and very individual threshold before they could approach someone with a view to talking to them. Once in contact with someone, a number of participants, particularly those with limited verbal communication, needed encouragement, time and space to speak as they did not find it easy, when distressed, to start talking about how they were feeling.
- Distraction

Distraction served as a way of breaking the pattern of thinking that the person had got into, and many participants mentioned a wide variety of ways in which they tried to distract themselves.

- Internal thoughts/dialogue
Talking to oneself – aloud or in their head – was used as a strategy by many participants. For this to be effective for participants, considerable practice and a degree of self-confidence was required.
- Trying to calm oneself down
Participants used a variety of strategies to consciously try and calm themselves down included when feelings as though they wanted to self-injure.
- Being in company, or being alone
It was a very individual preference as to whether people who felt like self-injuring wanted to be alone or in company. This depended upon the circumstances they were in, the people who might be available to support them, and the environment that they were in.

7. There is dissonance between what people with learning disabilities thought was helpful support in relation to stopping their self-injury and what others provided them with

As mentioned above, most participants were already using strategies of their own to try and delay or stop themselves from self-injuring. When others intervened, however, these strategies did not seem to be supported or reinforced; rather a different range of strategies was introduced that most participants found unhelpful. These included being restrained at a range of different levels, and being talked *to* (rather than *with*), such as by being told to stop what they were doing, or being told off.

8. Self-injury can make people feel better and worse

Most participants expressed a range of mixed feelings after self-injuring. However, the positive feelings that were felt after self-injury were those that originated from the act of self-injury itself - self-injury sometimes gave participants additional 'good' feelings that they were not experiencing before they self-injured. This was in contrast to the more negative feelings that participants were largely already experiencing when they self-injured and subsequently continued to feel.

9. Understanding the complexities of what people find most helpful is important

Most participants valued having someone to talk with, and/or someone to listen to them as being particularly helpful to them. In order for this to be the case, however, supporters needed to understand the person with learning disabilities individual preferences within this, including:

- how to access someone to talk to (either ad hoc or it being timetabled in, before self-injuring or afterwards)
- who best to talk to (someone trusted and familiar, a particular person, or anyone with the 'right' qualities)
- how they could best be encouraged to talk (by being given 'permission', by being sought out and given an opportunity to talk, or by being reminded to talk to someone at regular intervals)
- the topic of the conversation itself (the problems they faced, day-to-day issues, their feelings, or general conversation to serve as distraction)
- the particular qualities and type of approaches taken by those they spoke with (a supporter who is assertive or someone to be calm and laid-back).

The participants who had particularly limited verbal communication also expressed that what helped them most was communication-related, and what they found helpful was also of an individual nature. Generally they valued physical, rather than verbal communication, and wanted someone to spend time with them to specifically help them to communicate how they were feeling.

10. What participants with learning disabilities considered to be helpful support regarding their self-injury is no different from what people without learning disabilities consider helpful support

As mentioned above, most participants valued having someone to talk with, and/or someone to listen to them as being particularly helpful to them. They also expressed another three key features of helpful support regarding their self-injury. These were:

- the provision of sensitive support in looking after their injuries, such as practical help with cleaning their wounds and accessing dressing materials. This was particularly important as some of the participants were ambivalent about caring for themselves or had multiple and complex reasons for finding it helpful to have a dressing over their injury when others might not think it necessary
- being told or encouraged not to self-injure when this was said by someone for whom the participants felt their well-being genuinely mattered, someone who knew them well, and someone with whom there was mutual respect. This did not include the use of sanctions or rewards to encourage a person not to self-injure. What participants found most helpful was help to change their ways of thinking, not their ways of behaving.
- knowing that they were not alone and/or having contact with someone else who self-injured. This was so that participants could: identify with others and not feel so isolated, help get their own problems in perspective, and obtain general support from their peers.

Looking to the future - recommendations

This study of the experiences of people with learning disabilities who self-injure has provided considerable insights into the circumstances, thoughts and feelings of twenty-five people. In many ways it challenges existing practice in the learning disability field, as we suggest that self-injury is something that can be understood, and that for many people its roots lie in the social, psychological and environmental milieu of their lives, rather than in their biological make-up. We therefore propose a number of recommendations, based on the research findings, as outlined below. We trust that when the recommendations are implemented, we will at least be starting to address self-injury in people with learning disabilities with the care and concern that they deserve, and not 'sweeping it under the carpet' as if there were nothing that we can do about it.

1. Acknowledge self-injury as an issue in its own right and take it seriously

Self-injury is commonly referred to as a form of 'challenging behaviour' and not always addressed as an issue of concern in its own right. We recommend identifying and acknowledging self-injury as a discrete behaviour that is accompanied by particular feelings and meanings for the person concerned. Each incident of self-injury should be taken seriously and understood as having its own particular meaning. This is particularly vital as some incidents may be associated with intense feelings of wanting to end the person's own life.

2. Address self-injury in people with learning disabilities as it is addressed in anyone else

Our evidence suggests that self-injury in people with learning disabilities is far more similar to self-injury in people without learning disabilities than it is different to it. Guidelines and best practice pertaining to the understanding and management of self-injury in people without learning disabilities is therefore highly relevant to many people with learning disabilities and should be adopted as a matter of course.

3. Acknowledge the importance of choice and control in people's lives, and strive to create conditions in which people can be in control as much as possible

A clear effect of the lack of choice and control and of conditions of empowerment can be the desire or drive to self-injure. Creating conditions in which people with learning disabilities can have as much choice and control over their lives as possible is essential to addressing the issue of self-injury. This will mean adopting the personalisation agenda and working in truly person-centred ways with people.

4. Work with people with learning disabilities to help them understand, clarify and manage their emotions

Emotional literacy is skill to be learnt, and people with learning disabilities are no exception. Learning to understand, clarify and manage one's emotions can be complex and difficult at times, but role modelling, discussion, reflection and 'trial and error' all have their place.

5. Start with the strategies that people are already using to manage their own self-injury and build on these.

People with learning disabilities are likely to be already using some strategies to manage or limit their own self-injury, such as self-talk, distraction or seeking help. Use these existing strategies as a starting point in finding out what might work best for a person. Practicing strategies when self-injury is 'least' will provide confidence and a sense of achievement.

6. Work individually and creatively with individuals in a person-centred way

There are no commonly agreed strategies or treatments for self-injury that work for everyone. The key is to work creatively and individually in a proactive way with people to support them to plan and use alternative, but as effective, coping strategies that will ultimately help them limit or stop their self-injury.

7. Consistency is key

Consistency of approach, both within and between supporters of people who self-injure, is important. Agree with the person concerned what would work best for them and consider the use of tools such as Advance Directives, Crisis Plans and/or Wellness Recovery Action Plans (WRAP) so that a consistent approach can be maintained.

8. Put systems in place to help people with learning disabilities explore past experiences

People with learning disabilities gained considerable benefit from having someone to talk to about their experiences, feelings and fears. This included those who related traumatic experiences that had happened to them in the past. People with learning disabilities who self-injure should have access to skilled, therapeutic interventions that can help them address past experiences that continue to affect their well-being. The risks of not addressing this appeared to be far greater than would be any risks associated with engaging in therapies.

9. Consider the establishment of support groups for people with learning disabilities who self-injure

Knowing someone else in a similar circumstance to you can be encouraging and helpful. Carefully managed support groups can provide space and safety for people to explore their thoughts and actions in relation to those of others.

10. Practice listening skills, and be mindful of always being non-judgemental, accepting and respectful

People with learning disabilities who self-injured were clear about the qualities of the support workers that they valued most. Being a good listener was crucial. This means taking account of not only the person's words, but also their body language and other non-verbal communication. Active listening is a communication skill that is vital for professionals and support staff working with people who self-injure, and particularly people with learning disabilities who may not have the vocabulary or the verbal communication to let others know their feelings and thoughts as effectively as others might. Being non-judgemental, accepting and respectful of the person with learning disabilities is more likely to help them manage or reduce their self-injury than being harsh or critical.

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Back cover

The evidence base for the management of self-injury in people with learning disabilities is weak. Most interventions, at best, are based on good practice statements and at worst, are based on individual assumptions of what might help most in any given situation.

The voice of people with learning disabilities who self-injure has been notably lacking. Until now, we have known little or nothing about what they think about their self-injury, how they try and manage it themselves and the support that they feel they need.

Hidden Pain gives practitioners, commissioners, carers, family members and researchers an insight into these and many other complex areas related to self-injury in people with learning disabilities.

The report is based on multiple in-depth interviews with 25 people with learning disabilities who self-injure, plus interviews with family members and professionals supporting them and other key informants. All participants live in England, Scotland, Wales or Northern Ireland.

The report covers:

- People with learning disabilities' experiences of self-injury
- Circumstances leading up to their self-injury
- Their feelings before self-injuring
- How they try and delay or stop themselves self-injuring
- The circumstances for people with learning disabilities after self-injuring
- What they consider to be helpful and less helpful forms of support
- Family members and professionals' views about self-injury
- The impact on family members and professionals of supporting a person with learning disabilities who self-injures.

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