hidden pain?

Self-injury and people with learning disabilities

bristol crisis service for women

norah fry research centre

Summary of Findings

This summary reports the findings from a three-year research project that was conducted by Bristol Crisis Service for Women and the Norah Fry Research Centre at the University of Bristol from 2006-2009. The aim of the study was to obtain the views of people with learning disabilities about their self-injury. 25 people with learning disabilities and personal experience of self-injury took part in up to four research interviews each. In addition, 15 family members and 33 professionals were interviewed for the research study. Most were 'linked' to the participants with learning disabilities taking part in the study.

All of the participants with learning disabilities lived in the UK in a variety of different living arrangements. Their ages ranged from 14 to 65 (mean age 33). Six were male and 19 were female. Three had particularly limited verbal communication and relied on augmentative and alternative communication (using gestures, signing, symbols and word boards) to relate their thoughts and experiences.

The most frequently reported types of self-injury were scratching, cutting their skin, hitting themselves, self-biting, taking an overdose and hitting out at something else such as a wall or hard object. All but five of the participants engaged in more than one type of self-injury. The maximum number of different types was seven; the mean number was three.

Key findings:

1. Self-injury is a very individual affair

The common feature of all participants' self-injury was that it had periods of exacerbation and abeyance that could be generally understood within the context of the person's life. Most participants injured themselves privately and this was corroborated by family members and professionals. 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 supporter to disclose what they had done.

2. Self-injury is largely used in response to difficult circumstances and emotions

Participants described three key factors leading up to their self-injury:

- external factors (those that involved what was going on around the participant, but the participant generally had little or no control over them)
    - Being in disempowering circumstances (such as not feeling listened to; being told off; being told what to do, or what not to do; being treated like a child)
    - Having a lack of control within their living environment (such as having little or no choice about where they lived, who they lived with, and who supported them, what went on in their home, and some of the 'systems' they had to cope with)

- interpersonal factors (those involving relationships between two or more people)
    - Being bullied
    - Arguments (either 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
    - Having particular thoughts or memories (such as about past traumatic events, persistent thoughts of wanting or needing to self-injure, a more general internal dialogue relating to anxiety, lack of self-confidence or self-esteem).

3. Hidden distress

There was considerable past trauma in the lives of the participants. For some, thinking about those difficult times was directly related to their self-injury. This was 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 usually an antecedent to self-injury. All of the participants 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. The most frequently reported feelings immediately before self-injuring were: feeling angry; feeling sad, depressed or low; and feeling frustrated or wound up. 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. A third of all participants described incidents of self-injury at which they intended to take their own lives. Most of these were serious incidents: three had required resuscitation. 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 <u>rarely</u> 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
- being in the company of a particular person who was generally, but not always, the person providing one-to-one attention, or engaging them in pleasurable activities.

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. These included:

- 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, some 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
- 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
- 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, who best to talk to, how they could best be encouraged to talk, the topic of the conversation itself, and the particular qualities and type of approaches taken by those they spoke with. 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. Many 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; help to change their ways of thinking, not their ways of behaving; and knowing that they were not alone and/or having contact with someone else who self-injured.

Looking to the future

This study 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: we suggest that self-injury is something that can be understood, and that for these people its roots lie in the social, psychological and environmental milieu of their lives, rather than in their biological make-up. We propose a number of recommendations, based on the research findings, as summarised 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
2. Address self-injury in people with learning disabilities as it is addressed in anyone else
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
4. Work with people with learning disabilities to help them understand, clarify and manage their emotions
5. Start with the strategies that people are already using to manage their own self-injury and build on these
6. Work individually and creatively with individuals in a person-centred way
7. Consistency is key
8. Put systems in place to help people with learning disabilities explore past experiences
9. Consider support groups for people with learning disabilities who self-injure
10. Practice listening skills, and be mindful of always being non-judgemental, accepting and respectful

Further information

For further information about the *Hidden Pain?* research project contact:

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Copies of this summary, the full report and an easy-read summary are available from both addresses and 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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