

## Hidden Pain? People with learning disabilities who self-injure

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## What do we already know?

- **People without learning disabilities**
  - Research considering their views exists
  - Self-injury has a clear function
  - It is largely used as a coping strategy for dealing with intense emotional distress
  - Interventions: counselling or therapies, to enhance self-esteem / develop a repertoire of coping skills.
- **People with learning disabilities**
  - Little or no research considering their views
  - Self-injury understood within a biological framework
  - Regarded as 'challenging behaviour'
  - Interventions: behavioural responses and medication.

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## The purpose of the research

- 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, which would enable them to get the positive support they need in this area.

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## Research methodology

- Contacting participants
- First visits
- Research interviews
  - People with learning disabilities
  - Family members (linked and unlinked)
  - Professionals (linked and unlinked)
- Post-interview support

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## Research participants

### 24 people with learning disabilities (104 visits)

- Men and women
- Ages 14 – 65 (mean age = 34 years old)
- England, Scotland, Wales and N. Ireland
- Range of types of self-injury
- Range of circumstances (own home – secure unit)

### Family members

7 linked to participants, 5 non-linked

### Professionals

21 linked to participants, 9 non-linked

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## What people say about why they self-injure

1. The circumstances leading up to self-injury
2. The feelings a person has before they self-injure
3. The particular functions that self-injury serves.



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## The circumstances leading up to self-injury: External factors

### Being in disempowering circumstances

- Not feeling listened to
- Being told off
- Being told what to do
- Too many demands and not enough support
- Being treated like a child
- People talking about you



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## The circumstances leading up to self-injury: External factors

### Lack of control within living environment

- Other residents
- Noise/too much going on
- Lack of autonomy
- Not much to do
- Systems!



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## The circumstances leading up to self-injury: External factors

### Having the opportunity to do so

- Find something
- Break something
- Store something
- Importance of being on your own



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**The circumstances leading up to self-injury: Interpersonal factors**



**Being bullied**

- Physically
- Picked on
- Name calling
- Making fun of person
- Being laughed at

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**The circumstances leading up to self-injury: Interpersonal factors**

**Arguments**

- Arguing with someone else
- Overhearing other arguments



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**The circumstances leading up to self-injury: Internal factors**

**Physical health issues**

- Physical illness
- Mobility impairment
- Tiredness, exhaustion
- Under the influence of alcohol



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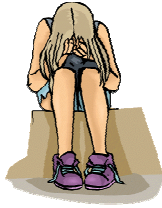
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## The circumstances leading up to self-injury: Internal factors

### Memories of difficult experiences in the past

- Abuse
- Bereavement



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## The feelings a person has before they self-injure

- Circumstances that were difficult to deal with led onto the development of quite intense feelings
- Most commonly reported feelings leading directly to self-injury:
  - Feeling angry
  - Feeling frustrated, wound up
  - Feeling sad, depressed, low
  - Feeling upset

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## The function or meaning of self-injury

### An expression of emotional pain

- Because actions speak louder than words
- Because people are not listening
- Because talking about feelings is difficult
- Because verbal communication is difficult



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## The function or meaning of self-injury

### Suicidal actions or thoughts

- Positive action with the intent to end own life
- Active suicidal thoughts
- Inconsistent/occasional suicidal thoughts
- Ambivalence

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## The function or meaning of self-injury

### A legacy of difficult experiences in the past

- That's made me who I am
- Memories that are always there
- Memories that resurface at various times
- Current difficulties rekindling memories of old traumas

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## The function or meaning of self-injury



### Control

- Not being in control of self
- Not being in control of circumstances
- Wanting control or more control of something

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## Summary

- What people with learning disabilities say about why they self-injure is similar to what people without learning disabilities say
- We found little credence for the assumption that people with learning disabilities self-injure because they have learning disabilities
- At root of self-injury seems to be intense emotional distress that is largely unacknowledged

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## Future plans for the project....

- Writing up the research
- Designing resources for :
  - People with learning disabilities (DVD, workbook, information)
  - Family carers (written information)
  - Professionals (training pack)

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## For further information...

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