Commentary on ‘Supporting people with learning disabilities who self-injure’

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Within the field of learning disability there has been extensive research on the epidemiology, assessment and treatment of what has been termed “self injurious behaviour” (SIB). Oliver et al (1987) identified 596 people with learning disabilities in one region of England who displayed SIB. 40% had a profound disability (IQ below 20), 49% a severe disability (IQ between 20 and 50) and 12% a mild disability (IQ between 50 and 70). The majority (58%) was male and the modal age range was 10-20 years. Many in the sample showed multiple topographies of SIB, the most common being skin picking (39%), self biting (38%) and head punching (36%). More generally, there has also been extensive interest, mainly outside of learning disability, in the notion of “self harm” (SH). Gunnell et al (2004) identified over 4000 episodes of SH seen by Accident & Emergency Departments over an 8 week period in a stratified random sample of 31 general hospitals in England. The majority (55%) of episodes involved females and the modal age range was 18-24 (this was a study of adults). 79% of episodes were of overdose/self-poisoning, 11% self-cutting, 5% both and 4% other kinds of SH.

It seems clear from the above studies that SIB and SH are rather different phenomena involving different behaviours shown by different kinds of people. Of course, there may well be an overlap. It is noted, for example, that 2% of the people in Oliver et al’s (1987) survey engaged in “tool cutting” (possibly similar to self-cutting) and Hawton et al (2007) (in findings otherwise very similar to Gunnell et al (2004)) reported “head banging” in a very small number of individuals. Similarly, there may be some overlap in the age distributions with both SIB and SH being particularly prevalent in young people. The overlap, however, is likely to be rather small and this is reinforced by the quite different understandings of the aetiologies of SIB and SH. Increasingly, SIB is understood to arise from the complex interaction of biological and environmental events in the lives of children and adults with learning disabilities (e.g., Langthorne & McGill, 2008) while, SH is understood to arise from difficulties coping with the short and long-term effects of trauma, especially in childhood (e.g., Lovell, 2007).

In the light of the above it will be clear that I disagree with Pauline Heslop’s assertion that SIB and SH are essentially equivalent. Heslop has written a good paper about one thing (SH) but makes the unsupportable claim that the paper is about (or also about) another thing (SIB). In so doing the paper is (unintentionally, I am sure) rather disrespectful of the experiences both of people who display SIB and the many people who have done research and tried to help people who display SIB over many years. It is suggested, for example, that previous research has ignored “the perspectives of people with learning disabilities themselves”. This may well be true of people who display SH. The problem is, and surely Heslop must realize this, that we have all been unable to access the perspectives of the vast majority of those with whom SIB research has been carried out because they are simply too severely disabled. Heslop notes that, in the current study, 3 individuals used AAC but provides no information about the severity of learning disability of these 3 or the rest of the sample. I would be very surprised to find that any had the kind of severe/profound learning disability most characteristic of people who display SIB (Oliver, et al., 1987). Indeed, the definition used, in describing SH as “usually hidden” would exclude virtually all SIB as displayed by people with severe or profound learning disabilities.

The problem manifests again when the findings are presented. I have worked with many people who display SIB – I have never worked with one who “disclosed” or was able to disclose or it would even occur to to disclose (or not disclose for that matter) their SIB. This and other themes (e.g. “feeling” like self injuring) are specifically situated in the context of a group of people with particular characteristics, they simply have no recognizable meaning for the people with whom I have worked. It seems to me a real shame that Heslop over-extends her argument in this way. This seems a perfectly good piece of research with people with particular characteristics. Why not just report that research, carefully noting with whom it has been carried out, and carefully noting the limitations on its generalization to people with other characteristics. Paradoxically, taking an approach like this would have allowed interesting discussion of the apparent overlaps between a modern behavioural understanding of SIB (resting as it does on purpose, function and communication) and at least some of the themes arising from Heslop’s own participants.

Of course, Heslop’s article is not the first to propose that SIB in people with learning disabilities and SH in the general population are more closely related than had previously been considered. Since the general population includes people with learning disabilities it seems highly likely that some people with learning disabilities will display SH. Heslop may well be right in her implication that SH has sometimes been responded to as if it were SIB. Interpreting SH as SIB or vice versa, given their different aetiologies and the different treatments used, is clearly a mistake and Heslop’s article may contribute to the better identification of people with learning disabilities who display SH. This would be a positive outcome and would be consistent with broader improvements in our understanding of the commonalities between the lives and experiences of people with, and people without, learning disabilities. However, it is valuable to recognize the differences (as well as the commonalities) between the lives and experiences of people with, and without, learning disabilities. Recognizing these differences – in biology, learning and other patterns of behaviour – may turn out to be just as important as recognizing commonalities if we are to deliver truly personalized support.

References

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